Measuring the Influence of Chronic Diseases on Health-Related Major Life Changing Decisions and Development of a Patient-Based Novel Instrument for its Measurement

A thesis submitted in accordance with the conditions governing candidature

for the degree of

DOCTOR OF PHILOSOPHY

In the

Cardiff University

Presented by

ZAHEER UDDIN BHATTI

Welsh School of Pharmacy
Cardiff University
Cardiff

Department of Dermatology and Wound Healing
School of Medicine
Cardiff University, Cardiff

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

August 2011

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

CONTENTS

Chapter Three: Development of a new instrument for measuring the impact of chronic diseases on major life changing decisions: Conceptualisation and item generation 61

DEDICATION

To my father Abdul Ghaffar, mother Shareefan Khatoon and to my six Big Brothers

ACKNOWLEDGMENTS

I am thankful to Allah for his blessings and for giving me this opportunity to meet and work with truly wonderful people of Cardiff University and Cardiff and Vale University Hospital Health Board.

I am heartily thankful to my excellent, friendly yet highly professional supervisors Professor Sam Salek and Professor Andrew Finlay for their constant encouragement, guidance, support and sharing their vast academic experience from the beginning of this project to the final stages, enabled me to develop appropriate academic skills and understanding of the subject. Thank you very much Professor Salek and Professor Finlay.

I wish to express my sincere gratitude to Professor Julian Halcox (Welsh Heart Research Institute, Cardiff University), Dr Linsay George (Department of Diabetes and Endocrinology, University Hospital Llandough, Cardiff), Dr Ian Ketchell (Adult Cystic Fibrosis Services, University Hospital Llandough, Cardiff), Dr Sharon Jones (Department of Rheumatology, Cardiff and Vale University Health Board, Cardiff), Dr Charlotte Bolton and Dr Ramsey Sabit (Department of Respiratory Medicine, University Hospital Llandough, Cardiff) and Dr Richard Moore (Department of Nephrology and Transplantation, Cardiff and Vale University Health Board, Cardiff) for actively taking part in this project, for their advice and support.

I would like to thank Professor Vincent Piguet (Head of the Dermatology Department, Cardiff and Vale University Health Board, Cardiff) and Dr Maria Gonzalez (Reader in Dermatology and Director of Postgraduate Dermatology Courses) for their support.

I am grateful for the help of all patients of Cardiff and Vale UHHB and University Hospital Llandough who took time to take part in this study and shared their moving and extraordinary life experiences. Many thanks also to Dr N Massani (Welsh Heart Research Institute, Cardiff University), Dr Steven Riley and Sister Jean Jenkins (Department of Nephrology and Transplantation, Cardiff and Vale University Health Board, Cardiff), Sister Glenys Morgan (Rheumatology), Sister Jayne Blumberg (Diabetes Centre), Ms Helen Harron (School of Pharmacy), Ms Erica Swain (Arts and Social Sciences Library), Mr Paul McGeoghan (Inserve Connect), Sister Linda Edmunds (Cardiology), Sister Carol Davis (Adult Cystic Fibrosis Services), Dr M Chowdhury, Sister Ann Thomas, Dr Basra, Ms Susan Williams, Ms Joy Hayes (Dermatology) for their help in this project.

All my gratitude to my parents, to my brothers for their love, support, blessings and prayers for my success.

Finally, special thanks to my brother and friend Fayyaz Uddin.

LIST OF ABBREVIATIONS

ADDQoL	Audit of Diabetes-Dependent Quality of Life
ADS	Appraisal of Diabetes Scale
AF	Atrial Fibrillation
AS	Aortic Stenosis
BSV	Between-subject variation
CAD	Coronary Artery Disease
CDLQI	Childrens Dermatology Life Quality Index
CESD	Centre for Epidemiologic Studies Depression
CFA	Confirmatory Factor Analysis
CI	Confidence Interval
CKD	Chronic Kidney Disease
CLCI	Cumulative Life Course Impairment
CoL	Course of Life
COPD	Chronic Obstructive Pulmonary Disease
CF	Cystic Fibrosis
DDEB	Dominant Dystrophic EB
DFI	Dermatitis Family Impact
DLQI	Dermatology Life Quality Index
DQOL	Diabetes Quality of Life Measure
DQLCTQ-R	Quality of Life Clinical Trial Questionnaire-Revised
DSQOLS	Diabetes Specific Quality of Life Scale
DU	Discounted Utility
EB	Epidermolysis Bullosa
EEG	Electroencephalography
EFA	Exploratory Factor Analysis
EPP	Expert Patent Programme
FACT-G	Functional Aspect of Cancer Therapy – General
FCO	Foreign and Commonwealth Office
FG	Focus Group
fMRI	Functional Magnetic Resonance Tomography
GCSE	General Certificate of Secondary Education
GP	General Practitioner
HIV	Human Immunodeficiency Virus
HRQoL	Health-Related Quality of Life
HRMLCDs	Health-Related Major Life Changing Decisions
HV	Hydroa Vacciniforme
ICC	Interclass Correlation Coefficient
ICF	International Classification of Functioning, Disability and Health
ICF-CY	Children and Youth version of the International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicap
IPSO	Impacts of Psoriasis Questionnaire
IVF	In Vitro Fertilization
JEB	Junctional Epidermolysis Bullosa
JSTOR	Journal Storage
KMO	Kaiser-Meyer-Olkin

MEG	Magneto-encephalography
MI	Myocardial Infarction
MLCD	Major Life Changing Decision
MLCDs	Major Life Changing Decisions
MLCDP	Major Life Changing Decisions Profile
MS	Multiple Sclerosis
NHS	National Health System
NICE	National Institute for Health and Clinical Excellence
NYHA	New York Heart Association
PET	Positron Emission Tomography
PMS	Patient Management System
PULSES	Physical condition, Upper limb function, Lower limb function, Sensory functions, Excretory functions, Support factor
QDAS	Qualitative Data Analysis Software
QoL	Quality of Life
QSD-R	Questionnaire on Stress in Patients with Diabetes-Revised
RA	Rheumatoid Arthritis
RDEB	Recessive Dystrophic Epidermolysis Bullosa
RPDR	Research Patient Data Repository
SF	Short Form
SPSS	Statistical Package for Social Sciences
SRRS	Social Readjustment Rating Scale
UHW	University Hospital of Wales
UK	United Kingdome
USA	United States of America
VAS	Visual Analogue Scale
WHO	World Health Organisation
WHOQOL	World Health Organisation Quality of Life

GLOSSARY OF TERMS

Applicability	Describes the content and emphasis of an instrument in terms of appropriateness of wording, clarity and simplicity of language.
Construct validity	Describes the extent to which a measure behaves in a manner consistent with its reference theoretical or logical properties by comparison with other measures and population characteristics.
Content validity	Describes how adequately the items sampled represent the range of each domain assessed by an instrument.
Comprehensiveness	Describes how thoroughly the domain(s) of interest in a measure are sampled by the items or questions included in that measure.
Face validity	Describes the extent to which the items, on the face of it appear to be measuring the variables they claim to measure.
Factor analysis	Factor analysis is a statistical technique to analyse relationships between a set of variables (items) measured or observed. Factor analysis is widely used to reduce a large number of correlated variables to a more manageable number, and therefore can be used to reduce the number of items in a questionnaire.
Internal consistency	Describes the average degree of association of homogeneity between the items in the test.
Inter-rater reliability	Describes the degree of concordance between two or more raters.
Practicality	Describes the feasibility of using an instrument in its intended population and clinical setting.
Sensitivity	Describes an instrument's sensitivity to small clinically important changes.
Test-retest reliability	Describes the stability of an instrument over time by assessing the extent to which a score can be replicated under constant conditions or equivalent testing situations.

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

The permanent nature of chronic disease may impair patients' psycho-social and physical well being, may change their attitude towards life goals and influence major life changing decisions (MLCDs) over time. Very little information is available in the literature about the long term impact of chronic diseases, particularly their influence on MLCDs. The aim of this study was to investigate the influence of chronic diseases on MLCDs and to develop a standardised tool for use across all chronic conditions to assess the impact of disease on MLCDs.

675 patients (100 from 6 specialties: cardiovascular, rheumatoid, diabetes, cystic fibrosis, chronic obstructive pulmonary disease, nephrology and 75 from dermatology) from the University Hospital of Wales, Cardiff and University Hospital Llandough, Llandough were invited to take part. The data was obtained through surveys, interviews and focus group discussions and this was reduced to core items through "content analysis". In a further study, 225 patients from the seven specialties were asked to complete the MLCDP (version 1a) and, factor analysis was applied to confirm the breadth and depth of the allocated domains and to determine construct validity of the MLCDP.

385 (57%) patients of 675 took part in the first phase of the study. Themes and statements generated from 316 (82%) evaluable responses (postal survey=258, individual interviews=50, focus group=8) were used for the development of the MLCD Profile. The most frequently reported MLCDs concerned early retirement, having children, job, career choice, relationships, housing, moving abroad and education. The correlation between the patients' age and the total number of reported MLCDs was significant (rs = -0.46, p=<0.001, n=308) showing negative relationship. In total, 41 affected MLCD themes were identified and grouped into 15 core MLCD categories. The working definition of health-related "Major Life Changing Decision" was also developed. The 45-item draft profile was grouped into six MLCD domains. 19 clinicians took part in the "content validation" stage and there was good agreement among the panel members for their ratings of language clarity, relevance, completeness and scaling. (Interclass correlation coefficient=0.71, p=<0.0001, CI=0.61-0.78, kappa coefficient=0.81, p=<0.0001, CI=0.69-0.93). This led to a new 41-item version of the MLCDP (version 1a), covering five MLCD domains: education, job/career, family/relationships, social and physical. 210 patients (30 from each of the seven specialties) were recruited into the second phase completed the MLCDP and data were analysed using factor analysis. The Cronbach's alpha value of 0.8 indicated good reliability. Several items were made redundant as a result of factor analysis; this analysis supported the evidence of construct validity. Item prevalence ranking helped to retain conceptually important items at this stage. This profile was easy to complete for most patients (n=131, 97%) and mean completion time was 5.7 minutes. A 32-item version of the MLCDP (version 2) was finally developed, which requires future examination of its other psychometric properties.

The MLCDP is potentially of benefit in alerting clinicians to the long term impact of a chronic disease on patients, and as a tool to assess the true burden of chronic diseases on individuals' long term quality of life. Clinicians' knowledge about the influence of chronic diseases on MLCDs is important to provide better and timely guidance to patients, to support better treatment decisions and eventually to lead to better health outcomes. This study also proposed strategies for patients to consider when taking MLCDs. Such support might result in more appropriate decision-taking and improved health outcomes.

CHAPTER 1

General Introduction

BACKGROUND

Disease is one of the major factors that has a great effect on an individual's QoL. There has been a focus on the evaluation of disease impact and patients' resulting concerns in the area of HRQoL research. The medical world uses its own term "Health-Related Quality of Life" (HRQoL) to describe the specific dimensions only related to health status (Halioua et al. 2000). Knowledge about the concept of HRQoL is vital (Flanagan 1982) for the scientific evaluation of disease impact on patients' lives and response to treatment.

"Human life is our life, it is not an external but internal, not an impersonal but personal, not an objective but subjective process" (Kroner 1936, p. 205).

Kroner's quote is very simple and precise and also supports the view that QoL means different things to different people according to their circumstances and needs. This personal predilection is the key to individuals' emotional well-being, their happiness or sadness. Important priorities in life for some people might be career, family, job, education, children and even the "small things" such as for example fishing, dancing, travelling, driving, sports, eating out or going clubbing. For others, house keeping, taking care of the family, gardening, charitable work, music and cooking might be more important. The majority of these elements reflect life style and individuality, and people try to find peace and happiness in these activities. A majority of people might consider strong economy, financial stability, services (health, education, and transport), high standard of living, good health, cultural activities, and quality time with family as components of better QoL. Having a good balance between work and leisure for a better life might be more important to the younger generation than to the more elderly. Moral values and security based on observance of rules and regulations, security, religion and spirituality might be more important to an older generation.

Therefore, individual perspectives and circumstances determine an individual's QoL, such as, health, education, job, financial status, and standard of living. However, there is no fixed rule or universally accepted concept of QoL that could be applicable to all people. For example, giving up a highly paid job for less stressful work might be the most likely choice for the majority of people as a first reaction. However, giving up a well paid but stressful job is not easy as there may be other benefits attached to it, such as financial advantage to the family, children and their future. Therefore, the decision is difficult; some might prefer less money to have better family relationships but some might prefer to sacrifice quality in their personal life to provide a better standard of living for their family members. Even for a single person, a change of job means change and adaptation in life style. It is clear that what we value is most important and having a good life style and being mentally healthy might be more valuable than having financial stability. In all circumstances happiness seems relevant to a good QoL. However, to achieve a good QoL it is necessary to take into account that individual preferences are most important.

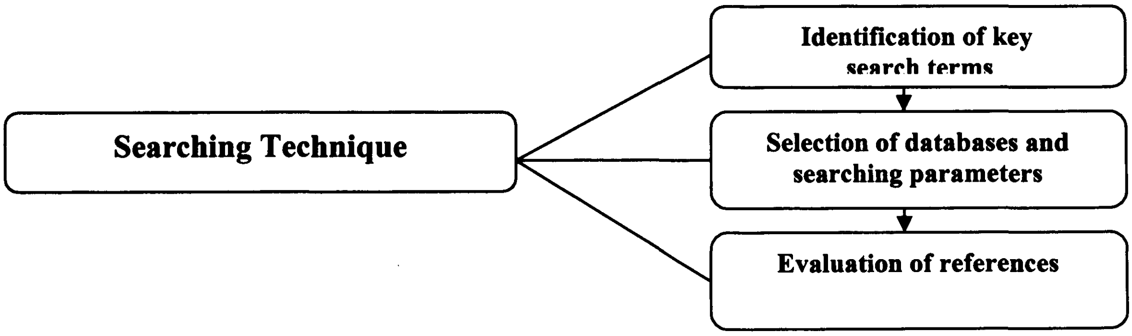
The concept of QoL consisting of both subjective (personal appraisal) and objective (life conditions) dimensions (Felce 1997) has been seen by many as a "perceived" (WHOQOL Group 1998), or "subjective" concept (Sullivan 1992; Revicki et al. 2000). Hunt (1988) stated that subjective or perceived health perception is based upon an individual's experience of mental, physical and social events as they impinge upon feelings of wellbeing. Therefore, any factor outside traditional QoL dimensions (physical, psychological and social) such as family effects or major life changing decisions, which could impact on the quality of a patients' life, should also be considered for evaluation and targeted for improvement. This argument supports the concept of "what things are important in people's lives?" highlighted by Bowling in her survey (Bowling 1995). The evaluation of fixed traditional psychological, physical and social domains may not reflect overall subjective well-being. Certain elements and influential factors in life can help develop the specific character of an individual and create a unique human attitude towards life, such as health, education, job, finance, religion, spirituality, family, parents/child relationship, divorce, daily hard work and quality time, politics, social attitude, culture, language, war, occupation, imprisonment, stress and the environment. Quality of life is therefore influenced not only by what we do but the way in which we perform life activities and take important decisions in different circumstances. This behaviour gives a specific character to our life that is unique to each individual. HRQoL concerns the state of an individual, affected by disease, illness or injury, and any change to their daily living, choices/preferences, important life decision or their disease impact over time should be evaluated from a broader health-related perspective. Knowledge about how patients live their lives and take important life decisions under the influence of different circumstances and life events is vital. In particular, knowledge about the influence of chronic diseases on major life changing decisions is important to achieve better patient health outcomes. Therefore the first step towards this investigation was to carry out a detailed literature review particularly encompassing patients' whole lives.

REVIEW OF THE LITERATURE

The main purpose of this review was to see whether or not there is any relevant information available in the literature regarding the influence of chronic disease on MLCDs, to what extent this problem exists and how patients take their MLCDs while suffering from long term health problems. Therefore, search terms (Table 1.1) were carefully discussed and selected in order to make sure that the broader health perspective of patients related to coping, social support and adaptation to chronic illness should be included for initial conceptualisation of the research area. For example, search terms "living with disease", coping with disease", "patient adaptation" and "influence on quality of life" were specifically included. At the review planning stage the area related to "clinical decision making" was also discussed as a search term but this search term was not included because this area is directly related to clinicians and their decisions for better management for patients and nothing to do with the patients' life decisions while suffering from chronic diseases.

The search strategy was carefully formulated to retrieve appropriate publications and to reduce the chances of missing important relevant information related to the research area. The literature search involved three stages: Identification of key search terms, selection of databases and searching parameters and evaluation of references (Figure 1.1).

Figure 1.1: Searching strategy



The key search terms were selected to gain a broad perspective and to ensure a wide coverage of the literature. The terms included Quality of Life, life changing decision, and long term impact. The Wolter Kulwar, OvidSP MEDLINE(R) (1950 to April Week 4 2008) database (formerly known as Ovid) was selected for the initial comprehensive literature search. A literature search using Google Scholar and the Cardiff University Library Voyager and electronic journals portal was also carried out. This portal includes Adis Online, Alpha Med Press, American Association for Cancer Research, American Medical Association Journals and the JSTOR database for old literature. Another Meta Search was carried out in Cardiff University Electronic Resources-Metalib on 28 January 2010 for the term "life changing decisions". Metalib resources, in a medicine search, include Cochrane Library (Wiely), Embase: Excerpta Medica (Ovid), PubMed, Web of Science and Zetoc. A separate questionnaire and item search was also carried out in February and March 2010 of the "Compendium of Quality of Life instruments" (Salek 1998, 2007). This compendium describes over 150 questionnaires, profiles and inventories and covers general, disease specific, group specific and economic specific instruments.

A review of published studies and articles was conducted. The aim and methodology given in the abstract of the articles of each study identified was read to determine its relevance. Important and relevant articles were then retrieved from the main database. From the OvidSP MEDLINE(R) database, 4251 articles were retrieved for close inspection to identify any study with potential relevance to our research concept. Articles were obtained with a number of combinations of different selected key terms (Table 1.1). Those articles which cover areas close to our key search terms were selected to be included in the review of the research topic "influence of chronic diseases on major life changing decisions". 3397 articles were identified from a separate search using a combination of "Quality of Life" and other descriptors such as "prospective study", "long-term study", "qualitative study", "longitudinal study", "cohort study" and "follow-up study". When the term "life changing decisions" was entered in the Cardiff University Metalib (Medicine) resource (Figure 1.2) 1941 articles were retrieved. The instrument search revealed that the majority of the selected instruments covered the core QoL domains of physical, psychological, social and emotional aspects. Other identified domains were personal care, support, outlook, symptoms' status, level of independence, environment, spiritual/religious/personal beliefs, pain, sleep and energy level. In a detailed review of widely used and well validated questionnaires (Table 1.2) and within the vast variety of other health-related instruments that were reviewed, we identified no domain, indicator or item specifically covered the impact of disease on major life changing decisions.

Only two articles matched the term "major life changing decisions". One article was related to psychology (Bauer et al. 2005) and the second article was related to neuroeconomics (Berns et al. 2007). The searching techniques used were also useful for the retrieval of other articles relevant to different aspects of the review such as Quality of Life and health assessment domains, Quality of Life indicators, chronic diseases and patient perceptions, philosophical concepts and qualitative assessment techniques. Studies were excluded if they were not published in the English language.

Table 1.1: Search results of different individual and combined terms

Single or combined terms used in searches	Number of retrieved references
Life changing decisions	2
Patient decisions	93
Personal decisions	45
Family decisions	52
Change in life style	115
Patient fear	95
Patient opinions	73
Patient suggestions	12
Patient views	133
Patient recommendations	39
Patient experiences	480
Patient account	249
Patient perceptions	711
Patient feelings	19
Patient adaptations	1
Patient diary	93
Influence on Quality of Life	368
Long illness	44
Living with disease	95
Coping with disease	74
Quality of Life over time	70
Long term impact	1255
Quality of Life, long-term impact and disease: combined search	60
Disease, influence, impact, family and decisions: combined search	73

Figure 1.2: Metalib resource result for the term "life changing decisions"

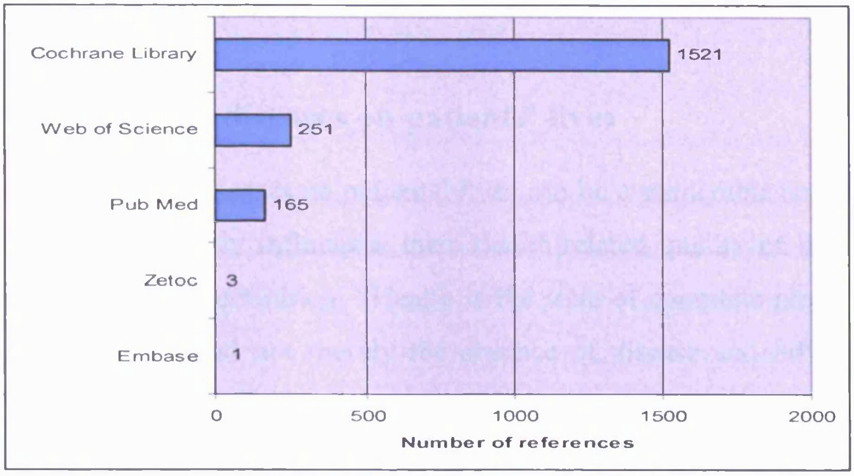


Table 1.2: Major QoL instruments and their domains

Instruments	Items	Domains
The PULSES profile (Moskowitz and McCann 1957)	6	Physical functioning, Social and mental status
Barthel Index (Mahoney and Barthel 1965)	10	Functional independence, Personal care, Mobility
Index of Activity of Daily Living (Katz et al. 1963)	6	Physical functioning
The Rapid Disability Rating Scale (Linn and Linn 1982)	18	Functional capacity, Mental status
The General Health Questionnaire (Goldberg 1972)	60	Somatic symptoms, Anxiety and insomnia, Social dysfunction, Severe depression
The Functional Aspect of Cancer Therapy - General (FACT-G) (Cella et al. 1993)	22	Physical well-being, Social and family well-being, Emotional well-being, Functional well-being
QoL Index (Spitzer et al. 1981)	5	Activity, Daily living, Health, Support, Outlook
The Functional Status Questionnaire (Jette et al. 1986)	34	Physical function, Psychological function, Work performance, Social activity, Quality of social interaction
The Duke Health Profile (Parkerson et al. 1990)	17	Symptoms status, Physical function, Emotional function, Social function
The MacMaster Health Index Questionnaire (Chambers et al. 1976)	59	Physical, Emotional, Social function
The World Health Organization QoL Scale (WHOQOL Group 1994)	100	Physical health, Psychological, Level of independence, Social relation, Environment, Spiritual/religion/ personal beliefs
The Sickness Impact Profile (Bergner et al. 1976)	136	Physical, Psychosocial, Independent categories
The Nottingham Health Profile (Hunt et al. 1981)	45	Part I: Physical ability, Pain, Sleep, Social isolation, Emotional reactions, Energy level Part II: 7 item handicap indicators
The Short-Form-36 Health Survey (Ware et al. 2000)	36	Physical functioning, Role limitations due to physical health problem, Bodily pain, Social functioning, General mental health, Role limitation due to emotional problems, Vitality, Energy or fatigue, General health perception
The EuroQoL EQ-5D Quality of Life Scale (EuroQoL Group 1990)	5	Mobility, Self-care, Usual activities, Pain/discomfort, Anxiety/depression

CHRONIC DISEASES AND MAJOR LIFE CHANGING DECISIONS

Influence of chronic diseases on patients' lives

The impact of chronic diseases on patients' lives can be considerable and the severity of patients' health directly influences their Health-related quality of life (HRQoL). According to the WHO definition, "Health is the state of complete physical, mental and social well-being and not merely the absence of disease and infirmity"(WHO 1946, p. 2, 1958, p. 495). This definition has been a subject of wide criticism and has been scrutinised from positive and negative health and illness perspectives (Downie et al. 1996). The definition of Sigerist (1941, p. 100) "Health is therefore, not simply the absence of disease: it is something positive, a joyful attitude towards life, and a cheerful acceptance of the responsibilities that life puts on the individual" seems similar but has a clear subjective approach, including life satisfaction within a broader perspective. Barnett (1991, p. 41C) described illness as a "subjective perception by a patient of an unusual/unpleasant feeling that may lead to differential behaviour patterns". The WHO definition is very simple and has more positive elements of health, yet it is very effective and provides an initial platform for the creation of a more comprehensive definition. The earlier part of the WHO definition, that is "complete physical, mental and social well being" has a direct association with impairment, disability and handicap, but it is possible to argue about what constitutes physical, mental and social well being, and that is why it has become a debatable definition for many researchers. HRQoL is more than the evaluation of these traditional dimensions. Patients' behaviour, perceptions and experiences are equally important for the complete assessment of HRQoL.

Chronic diseases can cause serious impairment, disability and handicap and affect the lives of patients over considerable periods of time. The WHO first published the International Classification of Impairment, Disability and handicap (ICIDH) in 1980. In the ICIDH manual, these terms were described as consequences of disease (WHO 1980). The WHO described the concepts of these important terms in order to clarify terminology and to use them in the ICIDH model:

Impairment: In the context of health experience impairment is any loss or abnormality of psychological, physiological and anatomical structure or function.

Disability: In the context of health experience a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: In the context of health experience a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

In the light of the above classification if as an example we apply these terms to patients who are suffering from severe psoriasis, scaling will be the impairment, palm involvement (unable to use the hand) will be the disability and the effect of this on the patient's social setting will result in handicap (Chren and Weinstock 2004). These terms are interconnected to each other and technically the assessment of disability cannot be carried out without the assessment of disease impairment. Similarly, handicap results from an impairment and disability. Therefore, the evaluation of impairment and disability is necessary for the assessment of handicap.

Growing criticism lead to a process of revision of the ICIDH. The new classification ICIDH-2 has been developed to eliminate the conceptual deficiencies within the original ICIDH. Inclusion of activity, participation and contextual factors (environmental and personal) in ICIDH-2 improved the classification (WHO 1999). The ICIDH-2 has now been superseded by the new WHO International Classification of Functioning, Disability and Health (ICF). This classification was approved by the World Health Assembly on 22 May 2001 (WHO 2001). In September 2007, WHO published the Children and Youth version of the International Classification of Functioning, Disability and Health (ICF-CY) (WHO 2007).

The literature concerning HRQoL is mainly focused on the current impact of chronic disease on patients' QoL and the disease burden on health system. The following brief review of chronic diseases and their impact on patients' lives will provide us with an initial platform for in-depth discussion and will be helpful for background understanding of "the influence of chronic diseases on major life changing decisions".

Rheumatoid Arthritis

Living with rheumatoid arthritis (RA) is a "tightrope between freedom and a life sentence"(Ryan 2006, p. 193).

Rheumatoid arthritis is a serious disabling disease and the single largest cause of disability in the UK (Badley and Tenant 1993). RA affects around 1% of the adult population all over the world (WHO Technical Report Series 919 2003). Its financial burden to healthcare systems and on patients is immense (Meenan et al. 1978; Stone 1984; Cooper 2000). The most obvious impact of RA is physical disability but challenges with daily living also result in a psychological and social impact on patients' HRQoL (Yelin et al. 1987a). Similarly, loss of sexual satisfaction (Blake et al. 1987) may result in the break up of a relationship. It has been reported (Yelin et al. 1987a; Yelin et al. 1987b) that patients with RA experience more losses in functional ability than people without arthritis in every domain of life activities, such as work, leisure and social activities. Loss of ability to work has been the worst affected area among working people because of the obvious functional disability caused by RA (Yelin et al. 1987a; Yelin et al. 1987b).

Cardiovascular Disorders

Cardiovascular diseases such as congestive heart failure (Juenger et al. 2002), myocardial infarction (Roebuck et al. 2001), hypertension (Fletcher and Bulpitt 1993) and angina (VandenBurg 1993) have significant impact on patients' HRQoL. Psychological distress caused by heart problems affects sexual activity. Impaired sexual functioning limits the QoL of up to 75% of post-myocardial infarct patients. Depression and anxiety among cardiac patients is also associated with poor health (Javadi et al. 2004). In a study carried out by Juenger et al (2002) comparisons were carried out between congestive heart failure and other chronic diseases (hepatitis C, chronic haemodialysis and major depression). Levels of heart failure were evaluated with the New York Heart Association (NYHA) Functional Classification and HRQoL assessment with the SF-36 (German version). The congestive heart failure patients showed a global reduction in QoL in all the SF-36 scales compared with the general population. Physical and emotional role functioning were the most affected areas. Patients with congestive heart failure showed the same pattern of reduced QoL as patients on chronic haemodialysis. Patients with chronic hepatitis C had higher scores in physical functioning, role functioning physical and general health than the heart failure population. Patients with more advanced congestive heart failure (NYHA class III) had similar scores to patients with major depression on the mental health scales (Juenger et al. 2002). Heart failure not only impaired patients' physical, role and social functioning (Carels 2004) but also affects the QoL of partners (Luttik et al. 2007). Health-related problems and difficult life issues faced by chronic heart failure patients, such as debilitating physical symptoms, role changes, frequent hospitalisations, forced retirement and financial stress can lead to depression and ultimately reduction in the QoL of patients and their partners (Martensson et al. 2003).

Angina pectoris affects 2-3% of the population. It is one of the most common and costly health problems in the UK and consumed over 1% of all NHS expenditure in the year 2000 (Stewart et al. 2003). Patients with angina also experience reductions in their functional role and poor QoL (Lyons et al. 1994; Gandjour and Lauterbach 1999; Lewin 1999; Stewart et al. 2003). In patients with hypertension, antihypertensive treatment and associated side effects may contribute towards poor QoL (Hill et al. 1985; Fletcher et al. 1989).

Diabetes

Diabetes significantly reduces the QoL of patients, in particular the burden of psychosocial issues may have a major impact on self care behaviour. Diabetes management demands many decisions being taken on a daily basis, making such self management very challenging for patients. Evidence concerning a possible link between increased disease duration and decreased QoL is conflicting and arguments concerning such a relationship have not yet been resolved (Rubin and Peyrot 1999). Due to the demanding nature of the disease and its significant burden on the lives of patients, Rubin (2000) described it as "diabetes overwhelmus". Diabetes can significantly compromise physical, psychological and social functioning. Disease complications and resulting change in life style significantly contribute towards impaired physical functioning and hence impaired QoL. For example, advanced systemic involvement, chronic pain, amputation and a complete change in routine activities due to the diabetes regimen may all affect QoL. The chronic nature of the disease, constant treatment demands and the onset of multiple complications may result in patients feeling hopeless and emotionally depressed. Even hypo and hyperglycaemic episodes may contribute to a constant depressive mood. Patients have to adopt a new life style to overcome their management problems and to improve daily self care. Change in life style and daily habits can increase pressure on the person and family which in turn may cause serious effects on relationships resulting in patients feeling socially isolated (Polonsky 2000). Improved social support may help patients with diabetes to manage metabolic control, to better self care and to adjust to their altered psychosocial status (Goz et al. 2007).

The Diabetes Quality of Life Measure (DQOL) (Jacobson 1994), the Diabetes Specific Quality of Life Scale (DSQOLS) (Bott et al. 1998), the Quality of Life Clinical Trial Questionnaire-Revised (DQLCTQ-R) (Shen et al. 1999), the Appraisal of Diabetes Scale (ADS) (Carey et al. 1991), the Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R) (Herschbach et al. 1997) and the Audit of Diabetes-Dependent Quality of Life (ADDQoL) (Bradley et al. 1999) have all been used in studies to assess different aspects and domains related to the QoL of patients with diabetes.

Cystic Fibrosis

Cystic Fibrosis (CF) is one of the commonest life-threatening diseases affecting 8,000 children in the UK (Cystic Fibrosis Trust 2008) and 30,000 in the United States (Cystic Fibrosis Foundation 2008). Each week in the UK, five children are born with CF and three young people die due to CF (Cystic Fibrosis Trust 2008). In 1938, 80% of babies born with CF died within the first week of life (Congleton et al. 1996). In the 1950s, few babies lived to attend elementary school (Cystic Fibrosis Foundation 2008). Nowadays, due to advances in management and proper care, the majority of CF patients survive into adulthood (Abbott et al. 1997). It was reported in 1998 on the basis of epidemiological analysis that of children born in 1990 with CF, more then 90% will reach adulthood and have a life expectancy of 40 years (Staab et al. 1998). Despite improved management techniques and longer life expectancey, progressive lung involvement and chronic airway limitation have a major impact on the QoL of patients with CF (de-Jong et al. 1997). Health-related quality of life perception and behaviour (Brown et al. 1994; Gee et al. 2003), depression (Riekert et al. 2007), clinical assessment trials (Abbott and Hart 2005) and impact of lung transplantation

(Busschbach et al. 1994; Vermeulen et al. 2004) have been studied in CF patients to determine the impacts of CF on patients' lives.

Respiratory Disorders

Chronic obstructive pulmonary disease (COPD) is a common long-term chronic condition. Nearly three million adults die each year of COPD. COPD causes a substantial amount of financial burden to healthcare systems (Soriano et al. 2000). In 2004 in England and Wales 23,204 patients died due to COPD. In the United Kingdom the cost of lost productivity due to COPD is estimated at between £600 million and £1.5 billion per year (Halpin and Miravitlles 2006). The burden of COPD on HRQoL is immense (Guyatt et al. 1987). Severe disease symptoms and reduced lung function (Fletcher and Peto 1977), frequent treatment and hospital admission (Halpin and Miravitlles 2006) and reduced physical functioning can cause considerable impact on patients' QoL (Gosselink and Decramer 1998) and ultimately may lead to social isolation and depression (van-Ede et al. 1999). In one study, it was reported that even mild COPD can cause significant impairment in HRQoL (Ferrer et al. 1997).

Asthma is another common chronic conditions; it affects approximately 4 to 11 % of the population and its worldwide prevalence has risen during the last decade (Braido et al. 2007). Asthma is associated with significant morbidity (Mannino et al. 2002) whereby, chronicity, severity and sudden attacks can severely affect patients' QoL (Schier et al. 1998). Relief of symptoms and strategies to improve patients' QoL may help in successful management (Jones 1995). However, psychosocial factors can influence health outcomes (Janson et al. 1994).

Chronic Kidney Disease

Chronic kidney disease (CKD) is an important cause of morbidity and mortality worldwide. Very little information is available concerning impairment of QoL in CKD patients (Perlman et al. 2005). Maintenance of QoL at different stages of CKD is very important (Kalender et al. 2007). Chronic kidney disease with complications caused by co-morbid conditions can affect the functioning and well-being of patients significantly and those on dialysis may have more impairment of QoL which may lead to an impact on the family (Fowler and Bass 2006).

Psoriasis

Psoriasis is a chronic inflammatory skin disorder and around 2 to 3 % of the world population are affected by this disabling condition (Finlay and Ortonne 2004; Kormeili et al. 2004). The financial implications of psoriasis are very high and in the USA alone approximately $1.6 billion to $3.2 billion is the amount estimated that is required for out-patient treatment alone (Feldman et al. 1997). Jayaprakasam et al (2002) concluded in one study comparing disease severity and QoL that the impact of common skin diseases on HRQoL may not correlate with severity. In another study, Heydendael et al (2004) suggested that there was no significant correlation between disease severity and QoL. However, they found a significant correlation between disease visibility and QoL impairment (Heydendael et al. 2004).

Mental stress has negative impacts on psoriasis. In the majority of cases, psoriasis patients have noted stressful incidents before a recurrence or exacerbation of their psoriasis, for example, family stress, death in the family, an accident, hospitalisation, exams or sexual assault (Gupta and Gupta 2003). In the opinion of Sulzberger and Zaidens (1948) there is a relationship between traumatic emotional events and early outbreak of psoriasis; similarly, in a large number of patients, stress is associated with exacerbation of psoriasis (Sulzberger and Zaidens 1948). A constantly stressful life with high emotions, anxiety and embarrassment along with physical and social impairment may lead to serious depression. In a few patients, the catalogue of psychological stressors is serious enough to push patients towards suicidal thinking. In severely disabling disorders, such as psoriasis, a complete assessment of the overall disability is very important because psychiatric co-morbidity may correlate with the risks of a psychiatric emergency such as suicide. Intervention may help reduce the progression and recurrence of such psychological problems (Gupta and Gupta 2003). Physical impacts are mainly related to signs, symptoms and daily activities. The most common functional activity related problems which may be affected are walking, carrying, climbing stairs and daily routine work (Korte et al. 2004). In a National Psoriasis Foundation patient-membership survey (Krueger et al. 2001) a considerable number of patients reported problems performing daily activities. In particular, older patients faced more problems performing daily functional activities, such as using hands (19%) and walking (14%) (Krueger et al. 2001). Finlay and Coles (1995) found that out of 369 psoriasis patients, 46% patients were working and of these 59% lost time at work (20 days per annum) simply because of their psoriasis. 34% of patients, among those not working or retired, reported psoriasis as one of the main factors resulting in their inability to work. Concerning the impacts on the social lives of patients, the main affected activities involve skin exposure (different choice of clothes, beach and swimwear), sports, socialising in public, sexual behaviour and going to the hairdresser. Psoriasis can cause serious damage to relationships with family, friends, partner and neighbours and in terms of personal contact at work (Korte et al. 2004). Furthermore, 30% to 70% of psoriatic patients encounter serious sexual problems (Gupta and Gupta 1997) which in turn may lead to mental distress in some patients. Gupta and Gupta (1997) noted that 49 out of 120 patients reported reduced sexual activity regardless of age, sex, marital status or duration of psoriasis. When measured, psychological problems scored high, in the range of clinical depression, suggesting that psoriasis can have a devastating impact on QoL.

Atopic Eczema

Atopic eczema is a chronic skin disorder which affects 10% of children in early childhood. It is more common in children under 5 years of age (Daud et al. 1993). In adults, prevalence and incidence is not completely established but a life-time prevalence of around 1% to 5.1% has been reported (Schafer 2006). Atopic eczema severely affects the QoL of patients and their family members (Lawson et al. 1998). The psychological impacts are very high in patients suffering from eczema. It has been reported that approximately 70% of patients are living a stressful life (Gupta and Gupta 2003). Atopic eczema in children could result in severe depression in the mother which could harm the mother and child relationship, whereas in adults, atopic eczema is related to anxiety and anger. Pruritus plays a major role in eczema and is directly related to the mental distress (Gupta and Gupta 2003). In 1998, Lawson et al (1998) prepared a 10-item Dermatitis Family Impact (DFI) questionnaire to assess the QoL of families affected by childhood atopic dermatitis. In the initial study, 74% parents felt a burden of extra care, 71% parents reported mental distress (psychological pressure, feelings of guilt, frustration, resentment and helplessness), 66% reported a change in their normal life (no pets, diet, and restricted use of household products), and 63% of siblings were losing sleep. Other negative impacts on the families were because of an affected child facing bullying at school, a change in child behaviour, reduced leisure activities and the financial burden. Foo and

Schofield (2000) also used the DFI to assess the family impact and found that severity of eczema in newly referred patients was related to family impact and that the family impact was reduced by effective treatment. They also suggested that the family impact might be higher in young children.

Acne

Acne is a very common skin disorder. It is so common that almost every person has acne at some stage and most of the time it is easily ignored. Teenagers are the most affected by acne with a recorded highest incidence of acne at the age of 16 to 18 years (Finlay 1992). Goulden et al (1997) noticed an increasing number of acne cases in adults over the age of 25 years. In a study in Leeds (Goulden et al. 1997) 300 adults (129 men and 171 women) over the age of 25 were interviewed and the acne severity grading with scaring was recorded. Fifty eight percent of women and 47% of men were affected by acne and the highest incidence was between the ages of 25 and 34 years. Acne occurs on highly visible areas of the body and so can cause extremely high psychological distress to sufferers (Finlay 1992). Mental distress is significantly increased with exacerbation and scaring. It has been reported that the psychological impacts of acne are similar to the psychological impacts of asthma, seizures, diabetes and arthritis (Gupta and Gupta 2003). According to Cotterill and Cunliffe (1997), continuous long term suffering may lead to a long term psychological impact such as depression. Depressive syndromes, alcoholism and personality disorders in patients with poor socio-economic status may lead to suicidal thoughts or actual suicide (Cotterill and Cunliffe 1997). The most serious social impact of acne is on employment and on patients' careers. Application to join the army might be refused because acne may be exacerbated in tropical areas. Employers may not offer a job to a candidate because of his or her appearance due to acne. Acne can seriously damage relationships and social activities, such as family life, sports, hobbies and leisure activities. Because of its visibility, its appearance and the resulting lack of confidence, acne patients may face difficulty making new friends and building relationships (Finlay 1992).

Vitiligo

Vitiligo is one of the most visibly debilitating skin disorders, particularly in people with darker skin. Approximately 1% to 4% of the world's population is affected by vitiligo. In India, it has been ranked as the third major health problem after leprosy and malaria and is regarded as "white leprosy" (Parsad et al. 2003). The estimated prevalence of vitiligo in the United States is around 1% (Kovacs 1998). Vitiligo has severe social consequences and patients feel embarrassed, depressed and stigmatized. Women with vitiligo have less chance of getting married and married women might even face divorce in India because of vitiligo (Parsad et al. 2003). Vitiligo has a serious impact on patients' QoL. One patient described vitiligo as "worse than having diabetes" (Austin 2004).

Hair Loss

Hair loss and alopecia areata can have as severe as impact on QoL as psoriasis and atopic eczema (Williamson et al. 1997). Williamson et al (1997) carried out a study to assess the level of handicap in patients with hair loss. Seventy adult patients completed the DLQI and a depression questionnaire (CESD-10) along with utility questions. For the purpose of long term assessment, the time frame for questions in the DLQI was modified from the "previous week" "to the previous year". The previous week mean DLQI was 8.3, whereas, the "previous year" DLQI mean score was 12.5, which suggested a significant variation in disability over a one-year time span. The main reported areas were self-consciousness and problems with social and leisure activities. The CESD-10 score was 12.7 (range 0-25) suggesting considerable mental distress (Williamson et al. 1997). Hay et al (2000) found that women with alopecia areata rated their condition extremely embarrassing. They also concluded that the range of impacts of alopecia areata on QoL is similar to other chronic skin disorders.

Other Chronic Debilitating Skin Disorders

The visibility of any skin disorder can cause some degree of disability. However, in some conditions, skin related disability is more severe than others. Chronic skin disorders, such as Darier's disease, Hailey-Hailey disease, port wine stains and Behcet's disease can also cause serious impairment of QoL. Harris et al (1995; 1996) and Burge and Wilkinson (1992) reported that most patients with Darier's disease and Hailey-Hailey disease live normal lives. Lanigan and Cotterill (1989) found a significant psychological morbidity in port wine stain patients. The majority of the patients experienced stigmatisation, difficulty in relationships, embarrassment, anxiety and depression. Blackford et al (1997) conducted the first large survey (335 patients) to measure the QoL in patients with Behcet's syndrome. They found a significant level of disability with the most affected aspects being "symptoms and feelings" and "personal relationships".

Conceptualisation of Health-Related Major Life Changing Decisions

In the development of any new concept, initial psychological, social and philosophical conceptualisation is necessary to understand and define the idea. Initial conceptualisation not only provides the basis for the rationale but also unfolds the complex and intricate nature of a subject, allowing for a more specific, realistic and logical approach for future progress. There is a lack of understanding up to now about "Major Life Changing Decisions" (MLCDs) in the area of health, including a lack of knowledge about the influence of patients' personality and attitude, what constitutes long-term impact, and how chronic disease impacts on patients' lives and behaviour. A systematic approach to these areas will help in the understanding of the patients' personality and attitude in different circumstances and situations, particularly at the time of important life events and subsequently the nature of the major life decisions that people make. Along with "human psychology" and "diseases long term impact", the exploration of some wider but interrelated concepts such as "life course, life transitions and life goals concepts in the health realm" and "life events and illness concept" will enhance understanding of the conceptualisation of disease influence on major life changing decisions.

Life changing decisions and human psychology

Psychologists have gained considerable knowledge about human behaviour under difficult conditions (Seligman 2000), but their understanding of illness related human behaviour is at an early stage. Most literature on life change refers to life events and related change, and psychologists find it hard to get reliable information on life change (Heatherton and Nichols 1994). "Life changing decisions" has been studied in psychology as "crystallization of desire and discontent" (Bauer et al. 2005) but very limited information is available in the health realm. This concept might have a different implication in a health and illness paradigm but may help the understanding of the relationships between illness and life changing decisions.

Life changing decisions are complex and may lead to a different life course. It is obvious that the life decisions that people make are normally intended to gain the desirable outcome of a better life. However, not every life decision turns out to be a positive or a correct decision. It has been suggested that the reasons for making life decisions are connected to the life path that a person is following and the broader concepts of personality and well being (Bauer et al. 2005). "Crystallization of desire" is a style of life changing decision making in which people give more emphasis to the future rather than to the present or past. Whereas an escape from an undesirable past is observed as a "crystallization of discontent". It has been suggested that people have to face crystallization of discontent before making any life changing decision (Bauer et al. 2005). This means there is a realisation that the past was undesirable but a desirable future is still possible. This seems very close to formulating a coping or future strategy after any negative life event. For example, clinicians are aware that after the diagnosis of a chronic or life threatening condition, acceptance is always a great challenge for patients. They search all available avenues for a cure and may take a considerable time to realise that they might have to live with the condition for the rest of their lives. Subsequently patients go through a process of denial, depression/anger, acceptance and adjustment (Lee 2005). A change in attitude to acceptance may give a patient motivation for the future but life changing decisions and related choices may remain very limited due to the constant illness and related factors (severity, depression, treatment etc). Therefore, the desired future outcome may not be as successful as for disease free individuals. In human psychology, it has been recognised that people with a positive attitude and who are happy have many goals and purposes in life (Emmons 1986). Therefore, it is possible that the specific individual circumstances and personality of an individual may influence the nature and approach to life changing decisions. This theory is supported by the factual observation of Baumeister et al (2001) that "bad is stronger than good". They suggested that bad (negative) life events have a greater and more intense impact on individuals than good (positive) life events. People always react strongly to negative events. The intensity of response may differ due to the type of negative life events that people face. For example, the response to imminent death will be immediate, whereas the reaction to the diagnosis of a chronic disease will be long term and the response may be reflected in subsequent life changing decisions. In psychology, task method, life narratives and memories were used to understand personal striving, personality and behaviour in chance situations, adaptations to death or in crises (Langer and Roth 1975; Emmons 1986; Moffitt and Singer 1994; McAdams 1995; Bauer and Bonanno 2001a, b). Life change has also been studied as regret about early adult life choices as motivation for life changes in later life (Stewart and Vandewater 1999). It is difficult to understand what constitutes regret as people take their decisions according to their own circumstances and available opportunities. It is very difficult to analyse the contribution or regret as a motivation for future change when important life decisions are based on health grounds.

Disease Long Term Impact

It is important to understand the long term impacts of chronic disease as these impacts may change over a period of time. The first step towards this quest is to be able to define chronicity or long term impact. Most dictionaries and websites do not specify a particular time span to these terms. The reason is obvious, as diseases may have different time frames for acuteness or chronicity. For example, in acute urticaria, an urticarial reaction and recurrence may occur for a few hours to several weeks, but for usually less than 30 days and in chronic urticaria hives appeared daily for more than 30 days (Wolff et al. 2005). The Japanese Respiratory Society published guidelines to define "acute" and "chronic" cough to improve diagnosis and treatment. According to this guideline, an acute cough lasts less than 3 weeks. A prolonged cough lasts 3 to 8 weeks and a chronic cough lasts more than 8 weeks (The Japanese Respiratory Society 2006).

There is however no fixed definition of the duration of acute and chronic disease. The definition of chronic disease by the U.S. National Centre for Health Statistics, "chronic diseases generally cannot be prevented by vaccines or cured by medication, nor do they just disappear" (U.S. Department of Health and Human Services 2004). It is generally considered that diseases with a history of more than three months and have no complete cure, or diseases that persist for a long period of time, fall under the term of long term or chronic disease. Permanent impact or an impact which affects patients for many years or throughout their lives due to illness could be described as a long term impact. Several studies have assessed the QoL impact on patients who had suffered from chronic diseases for a long period of time. These include: the assessment of the impacts of psoriasis on 369 patients by Finlay and Coles (1995), a survey by Rapp et al (1999), The National Psoriasis Foundation Patients Membership Survey (Krueger et al. 2001), the Nordic Psoriasis Association Survey (Zachariae et al. 2004), the International Quality of Life Assessment Project in eight countries (Alonso et al. 2004), the impact of asthma in the Australian population study (Ampon et al. 2005), 29 chronic conditions general health population survey in Finland (Saarni et al. 2006), chronic obstructive pulmonary disease patients' experience (Barnett 2005), and maintenance haemodialysis: patients' experience (Hagren et al. 2005). However, these studies were not specifically designed to assess the long term impact.

Generally when a disease progresses, immediate or short term impacts may lead to more serious impacts, which may affect patients throughout their lives. Therefore, small frequent impacts caused by chronic diseases could be viewed as long term impacts. For example, psychologically, anxiety may turn into depression or suicidal thinking. Physically, impacts related to signs and symptoms (itch and pain) may lead to constant sleep disturbance and hence lack of fitness and loss of days from work. Socially, constant illness and reduced sexual drive may cause a break up of a friendship or marriage; also, absence of leisure activities may lead to complete isolation and serious mental distress. On the other hand, some initial impacts may affect patients throughout their lives. Rudolph et al (2008) measured the long term functional status in 42 patients with Guillain–Barré syndrome at a median of six years after disease onset and compared this group with 50 healthy individuals. There was decreased physical functioning in patients and no difference between patients with < 6 years and >6 years follow up.

At the moment, we have more understanding of specific psychological, physical and social impacts associated with chronic disorders. These impacts cause patients impairment, disability and handicap, captured fortuitously thorough several similar studies primarily evaluating current impact. Similarly, in follow up studies the assessment of disease impact mainly concerns current impacts, and the changes which have occurred in that over a period of time (Huurre and Aro 2002; Beattie et al. 2003; Heald et al. 2004; Sillanpaa et al. 2004; Chen et al. 2006; Kuriya et al. 2008; Husser and Roberto 2009; Saha et al. 2009). For example, if the impact of a disease were measured at the time of diagnosis and then 20 years later patients are asked how their illness has affected their lives; this would be a record of two sets of current impact on two different occasions. Even if patients are asked how the disease has affected them over the previous year, this may not reflect the type of impact that the patient has faced over the 20 years course of the disease. Patients might have experienced different disease impacts after 5, 10 or 15 years. To more appropriately record the long term impact, it might be better to ask patients how their illness has affected them over the last 20 years. Such a holistic exploratory retrospective approach may provide a completely new insight into the different nature of the long term impacts faced by patients during different stages of their life and might reveal new domains in which life is affected.

Unaeze et al (2006) published an 11-year prospective study in which they evaluated the long term impacts of psoriasis on HRQoL. A total of 484 patients were interviewed in 1993 and then again in 2004. The Impacts of Psoriasis questionnaire (IPSO) was used for the assessment. This study showed that the impacts of psoriasis on HRQoL decreased over time. Social impacts were stable or slightly improved (social activity, travel and making new friends). Unattractiveness, embarrassment, and the feeling of being outcast were the most affected areas. After 11 years, these areas were improved considerably, particularly the feeling of unattractiveness. The question concerning "Not enjoying activities" scored very low a decade ago, but the score increased several fold by 2004. "Not feeling better after treatment" and "Causes family friction" scored high, which indicates the increased severity of impact in these areas (Unaeze et al. 2006).

This study (Unaeze et al. 2006) was designed to evaluate the long term impacts of psoriasis and provides a foundation for future research. However, identification of pitfalls may be helpful in future studies. For example, the sample size of 484 subjects represents a high drop out rate. Initially, 867 patients entered the study and completed the IPSO but by 2004, 221 patients had died (25%) and 171 patients were not able to be followed up. This is a genuine problem in long-term follow-up studies. Furthermore, most of the patients were between 45 and 55 years of age. This might be an influential factor contributing to a decreased score in some impacts, as older people might adjust to the situation more easily than younger people. Severity, intervention and gender data in such studies could yield more information. The IPSO items mainly assess current impacts at the time of administration. The questionnaire asks patients to report current impacts or disease impacts during the past month and assess the psychosocial impact of psoriasis on a patient's life (Nijsten et al. 2006). In this study researchers recorded the change in known impact at a particular time (2004) after 11 years, but did not record the overall impact over the intervening 11 years and in what ways the disease impacted on patients' lives over that period. Therefore, along with a follow up or prospective research strategy, a novel, refined holistic and exploratory retrospective approach is necessary for the assessment of the true nature of the long term impact of disease on patients' lives.

The long-term influence of eczema on patients' QoL over the past few years was assessed in a study by Finlay (1996). Ninety-two eczema patients were evaluated and 80% of the patients reported effects on their family life. Working patients lost around £5000 (estimated median) over the previous year. Other impacts identified were effects on sexual relationships (57%), choice of career (51%) and 52% reported effects on long term personal friendships/relationships (Finlay 1996).

Childhood disorders and level of long term impacts

The impacts of chronic disorders, particularly those of genetic disorders or of childhood conditions, have two dimensions, one related to the child and the other related to the parents. For example in atopic dermatitis, it is difficult to establish the level of psychological, physical and social impacts in preschool children. Before school age children have little understanding or ability to express how their skin condition has affected them. Children begin to understand when they start school; and over time, they try to understand what is wrong with their skin, why their skin is different from others and why they have to use moisturisers or protective clothing. This continuous thinking about their skin condition may cause a great deal of confusion, distress and problems with learning. Confusion and lack of concentration are clearly short term impacts. However, these problems may lead to long term impacts of poor academic performance and hence inability of affected children to reach their full potential in their life and career. This is because by high school age children normally fully understand about their illnesses, and as children grow up, long term impacts start appearing, such as they may feel depressed due to a lack of physical and social activities, difficulty in making new friends, bullying at school, avoiding sports or swimming because of physical disability or due to their appearance. Growth retardation and learning disability could be considered to be long term impacts.

Treatment related long term impact

Chronic illnesses require continuous long term treatment in order to control the disease and reduce the patients' disability to a reasonable level so that patients are able to perform normal day-to-day activities. To achieve this goal requires constant active treatment, monitoring and follow up. However, long term treatment has its own disadvantages, which may cause further adverse impacts on patients' QoL. There have been advances in pharmacological as well as surgical treatments in recent years. It is possible to assess the long term impact of these new approaches on patients' lives. It is even possible to measure the long term impact of cancer and the impact of advanced therapy on functioning and the psychosocial aspects of patients' lives (Redd and Jacobsen 1988). A large amount of information is available about the long term impact of management (medical/surgical) on patients HRQoL and its long term impact on patients' lives (Terrell et al. 1998; Svedlund et al. 1999; Sin et al. 2002; Halonen et al. 2003; Engel et al. 2004; Vartanian et al. 2004; Constantinides et al. 2006; Dornhoffer et al. 2008; Koivunen and Lukkarinen 2008; Lundberg et al. 2008).

Life course, life transitions, life goals, life events and the concept of health

These concepts are widely discussed and studied in the fields of psychology, sociology and in the epidemiology of personality and behaviour. Knowledge of these concepts is also essential from a health perspective and may provide a better understanding concerning the concept of health and life decisions. However, there is very little information concerning these areas in the health-related literature.

Life course: The "Life course" concept is not a new concept in behavioural research. It concerns different aspects of life studied in psychology, health, sociology and in personality and attitude related subjects (Kuh et al. 2003). In the health sciences, this concept has been studied in relation to chronic disease epidemiology, a discipline which explores the relationship between the timing of disease exposure and outcome within the life course of individuals (Lynch and Smith 2005). Ben-Shlome and Kuh (2002, p. 258) defined life course approach to chronic disease related epidemiological approach as "the study of long term effects on chronic disease risk of physical and social exposure during gestation, childhood, adolescence, young adulthood and later adult life". During the course of life, the risk of developing chronic diseases may increase due to negative social circumstances (Mishra et al. 2009) and an accumulation of disadvantages may have an influence on QoL in early old age (Blane et al. 2004). A Course of Life (CoL) questionnaire (Brenninkmeijer et al. 2009) has been described to assess the timing of developmental milestones in young adults (aged=18-30 years) who have grown up with chronic or life threatening diseases and the CoL has been used to compare this group with a control group of healthy individuals. Items of questionnaires of such nature are largely grouped into three scales (development of autonomy, psychosexual development and social development) and two risk behaviour scales (antisocial behaviour, and substance use and gambling). These questionnaire items have been used along with quality of life questionnaires to assess the life development and achievement of patients suffering from various conditions, such as atopic eczema (Brenninkmeijer et al. 2009), phenylketonuria (Bosch et al. 2007), congenital hyperthyroidism (Veer et al. 2008), and survivors of childhood cancer, patients with anorectal malformations, Hirschsprung's disease, patients with oesophageal atresia and patients with end-stage renal disease (Stam et al. 2006) and childhood vitiligo (Homan et al. 2008).

Recently, Kimball et al (2010) reviewed the long term impact of psoriasis and proposed the concept of "Cumulative Life Course Impairment" (CLCI). This speciality specific modified concept of health and life course epidemiology results from an interaction between "(a) the burden of stigmatization and physical and psychological co-morbidities and (b) coping strategies and external factors" (Kimball et al. 2010). The concept of CLCI appears to be relevant concerning long term impact of psoriasis but may not be generalisable across other medical specialities. In particular, stigmatisation which overlaps with psychological co-morbidities is more relevant to skin conditions for aesthetic reasons. Stigmatisation may not be relevant to patients who are suffering from non dermatological chronic conditions. The concept of CLCI as described by Kimball et al (2010) does not specifically address the impact of psoriasis on MLCDs. However, if a MLCD is influenced by psoriasis, this may contribute to CLCI, and indeed it may be that influences on MLCD are of equal or greater importance than stigmatisation and coping strategies in contributing to CLCI.

Life transition: People go through many transitions in their lifetime (Heatherton and Nichols 1994). "Life transition" is a delicate concept of self-reflection and concerns realising the potential and creative opportunity for development. It is not necessary that all life transitions (voluntary or involuntary) guarantee any happiness or meaning to life (Bauer and McAdams 2004b). A transition in life is the change from one stage of life to another or a shift of life from one situation to another situation; either due to a natural progression of life or due to consequences of life events or the important decisions that people make. This change could be from a negative to a positive or from a positive to a negative situation. Life stages and changes in role (son, daughter, husband, wife, parents, grand-parents) are clearly example of life transition. However in addition any major change in life due to an individual's circumstances and life events can be a part of life transition. When undergoing a life transition, it is often difficult to forget about the previous stage or phase of life and both good and bad memories may re-emerge time and time again. In particular, in a phase where someone is having a bad time, that person normally finds it difficult to forget previous happy memories. The life transition concept also provides insight in to the concept of a new beginning. For example, the diagnosis of a chronic disease results in an undesirable negative life transition from a disease free life stage to a life phase living with disease, and long term illness can make it more difficult for patients to forget about their previous good life and to move forward (Bridges 1980). Another area of interest concerns the origin of a life transition, whether it is related to a specific life event, circumstance or situation.

Life goals: Elliot and Sheldon (1998) defined personal goals as the "consciously articulated, personally meaningful objectives that individuals pursue in their daily lives and operationalise in terms of personal projects, personal strivings and life tasks". At an early stage of life people normally set different life goals, objectives and priorities according to what they want to achieve in the future and setting out goals to which a person aspires gives a sense of purpose to life (Elliot and Sheldon 1998). Bauer and McAdams (2004a) reached a more or less similar understanding, and stated that goals reveal what people want and how they want to achieve them in life, but they more specifically linked goals to "personal growth" and coined the term "growth goals". This term describes life goals that are normally connected to life stages and roles and denote a positive attitude towards life and positive behaviour. Education, career, relationships and family (marriage, having children), travelling, life style change (weight loss, quit smoking and alcohol habits) and gaining financial stability are examples of different aspects of life where people set personal life goals and positive targets to achieve a better QoL in the future. It is a matter for each individual what sort of objectives they want to set for their life. However, circumstances and life events such as death of a partner, accidents, onset of chronic disease or financial instability may change personal goals and individuals' priorities. For example, changes in a desirable career pathway or a decision not to move abroad due to disability or ill health are undesirable deviations from pre-defined life goals. Whereas job promotion may change life goals overnight and provide an opportunity to set new life goals, directly linked to financial stability.

Life events and Illness concept

There has been much research to assess the impact of stressful life events and depression, covering a vast array of social and psychological subjects. Life events and associated stress may cause serious health problems (Graham and Stevenson 1963; Rahe et al. 1964). The concept of "Life event" has a different conceptual meaning from life stages, life transitions and life goals. Life events can occur at any stage of life. The timing of life events, as suggested in the epidemiology literature concerning life course (Lynch and Smith 2005), is also important and may have several implications for individuals' lives. Lief's (1948) work, related to life events and health, was probably the first in this area.

In 1967, Holmes and Rahe (1967) developed the Social Readjustment Rating Scale (SRRS) to measure the association between stressful life events and the onset of illness and their ground breaking work set the standard for future research (Lin et al. 1979; Tausig 1982). They described 43 important life events and established arbitrary "Life Changing Units" as scoring units for each stressful life event that occurred. The subjects were asked to assign an arbitrary scale value (weighting) to life events according to an event occurrence and its severity. The highest value of 100 units was given to "Death of a spouse", 73 to "Divorce", 65 to "Marital separation", 63 to "Jail term", 53 to "Personal injury or illness" and to "Death of close family member", 20 to "Change in working hours" and "Change in residence". Lower scores of 16, 13, 12 and 11 were given to "Change in eating habits", "Vocation", "Christmas" and "Minor violation of law", respectively. In the SRRS not all events included are related to negative aspects of life. For example, "Marital reconciliation" (45), "Gain of a new family member" (39) and "Outstanding personal achievement" (28) are not stressful events but may require some social readjustment. A score of <150 indicates a 30 percent chance or low probability of developing a stress-related illness, a score 150 to 299 indicates a 50 percent chance and a score of >300 indicates an 80 percent chance of illness. This scale provides a list of important life events which may cause stress related illness. Our study however is examining the reverse of this, whether illness can result in major life events or influence major life changing decisions.

Psycho-social stressors are sources of life events and several aspects, such as the relationship between life events and illness, life events and stressor, social support, life adjustment and association with physical and mental symptomatology, have been explored in detail (Paykel et al. 1969; Myers et al. 1972; Rahe 1975; Paykel 1979; Brown and Harris 1987). Important life events can alter people's lives forever in both negative and positive ways and can be defined as "negative life events" (death, divorce, separation, abortion, bankruptcy, prison sentence, chronic illness) and "positive life events" (marriage, birth, job, higher education) (Table 1.3).

Life events and chronic strain such as barriers to achieving life goals, inequitable rewards from roles, excessive or insufficient demands from the environment, frustration of role expectation and economic deprivation are defined as stressors. Life events can lead to chronic strain and vice versa (Kiecolt 1994). Some life events, such as divorce or separation appear to be negative in nature but might turn out to be positive events and may result in happiness in someone's life.

Kiecolt (1994) explained that life events do not always produce psychological distress, particularly if relief can be obtained from a negative life event such as divorce after marital conflict. Conversely, apparently positive life events such as moving house or moving to another country or change of employment might be disastrous for some people. Therefore, the positive or negative natures of some life events are also connected to the individual's special circumstances and their perceived value.

Table 1.3: Important negative and positive life events

Negative Life Events	Positive Life Events
Death Chronic illness Limb amputation Loss of an organ or part of a body (eye, tongue etc) Lost job Bankruptcy Addiction Crime Prison sentence Environmental disaster War Divorce Separation Miscarriage	Marriage Birth Cure (from disease, addiction) Employment Education Moving house (to a better house) Moving to another country (for a better future)

The diagnosis of a chronic condition, such as cancer, is not only a life-changing event for the patient but also for the family. Similarly, a life event can also have an affect on an individual's health and health behaviour (Clark et al. 2004; McFarland et al. 2006). Disease and the concept of "life event" has also been studied in relation to disability in rheumatoid arthritis (Guillemin et al. 1995; Smedstad et al. 1995), psoriasis (Poikolainen et al. 1994), chronic urticaria (Malhotra and Mehta 2008), alopecia areata (Perini et al. 1984), hospital admissions for asthma (Wainwright et al. 2007) and schizophrenia (Norman and Malla 1993).

People always need support in their difficult times and because of life changing events people may turn to spirituality for comfort, hope and relief. Activities such as music therapy, touch, humour, guided imagery, story telling, aromatherapy and prayer are regarded as part of spiritual care and are included in complementary and alternative medicine (Elkins and Cavendish 2004). People's behaviour after a life event is a psycho-reactionary action but Paykel et al (1969) suggested that personality, coping strategies and previous experience may influence this reactionary action. Most studies in this area are related to understanding the role of life events as triggering factors of illness and to exploring the long term influence of stressful life events and associated illnesses.

Minor life decisions

Minor or routine decisions are those decisions which people normally take on a daily basis. The majority of these decisions are of little individual importance but they are required on a day to day basis to allow life to run smoothly. The consequences and implication of the majority of the minor decisions are generally short term and may not alter life significantly. Minor decisions could be seen as decisions which might lead to a short-term change in life. Routine daily decisions such as selection of transport (bus, train or airplane), selection of coffee, sandwich or wine from a long list of menu choices, decisions about which restaurant to go to or the venue selection for a marriage or christening of a child could have an impact on daily life for a short period of time and may have some financial and time implications. However, it is important to understand that these decisions are subjective in nature and have perceived value. Therefore some decisions which may be viewed as minor to some people, may be more important and life changing to others, particularly for those who are facing a negative life event such as suffering from a chronic condition.

Major life changing decisions

The diagnosis of a chronic disease is a life changing event in physical, psychological and social terms (Nussbaum et al. 2003; Barnack and Chrisler 2007; Sawka et al. 2009) and the initial news of a life threatening condition is often devastating for patients (Stevens and Hildebrandt 2006). Very little information is available over what constitutes a major life changing decision or how chronic disease can influence life changing decisions. King et al (2000, p. 509-10) suggested that "Major life changes, by definition, require individuals to come to terms with a new set of life circumstances. Some life changes involve irrevocable alterations in our lives, requiring us to redefine the very meaning of our existence, to seek out new sources of purpose, and to reassess our priorities". From the perspective of life events, life stage, life course, life transition and life goals, a general idea can be formulated about the importance of major life changing decisions.

Life is about choices where decisions play an important role. Life choices may become limited and undesirable due to negative stressful life events, and in this situation any decision could be life changing. In their daily routine people might flip a coin to make some decisions because in both cases (head or tail) the impact of the decision may not alter their life significantly. However, this may not be an option for people who are suffering from chronic illnesses for a very long period of time. People do not make major life decisions on a daily basis. Major life decisions are directly connected with life events, life stages, life goals and priorities and are so important that they affect the whole course of a person's life. For example, decisions to move abroad or which career to select would have life long consequences and normally determine an individuals' future life. Therefore, people usually give thoughtful consideration to every aspect of a life change which may have major implications, because their choice, right or wrong, may potentially change their life forever. Patients' priorities in life change in different/difficult life situations, such as after important life events, after the onset of chronic disease or after life threatening illness (Heatherton and Nichols 1994; Carr and Higginson 2001). From a health perspective, an individual's behaviour, personality and choices might be influenced by long term illness and illness may itself make it harder for patients to make appropriate life changing decisions. Long term poor health may even drag patients towards the ultimate life changing decision of suicide (Koivumaa-Honkanen et al. 2001). Making a major life changing decision in itself seems a major event in life because any wrong or right decision may change life for a considerable period of time and possibly the impacts of the decision may persist forever.

Some life changing decisions are age and gender related and timing is crucial for these decisions. For example, decisions at the right time about higher education and early career development or having children are important as part of the natural course of life and at different life stages, but the continuous long term impact of chronic disease on patients' lives may influence these decisions. Patients might either decide differently or might delay their decision waiting for the right time or situation (complete cure or disease at a manageable level).

It is important to understand that major life change may occur in both negative and positive life events and/or as a result of decisions we make in important life situations. However, the influence of negative impact may remain for a long time and may affect the nature of subsequent life changing decisions. The diagnosis of a chronic disease or of a long term health condition, such as physical or mental disability due to a traffic accident, is a negative life event. The impact of a particular negative life event may remain with individuals for the rest of their lives and may change their life goals, priorities amd role/identity at different life stages. Moreover, one negative life event, such as onset of a chronic disease, limb amputation, death of a family member, imprisonment, addiction or divorce may affect other forthcoming positive life events, part of an expected normal life course, such as education, career choice, employment, marriage, housing, having children and moving abroad. All of these positive events are sources of happiness in life and of well-being, all of which could be affected by a single previous negative life event.

Ballas and Dorling (2007) used life event and happiness data from the British Household Survey. They identified that being married, having a new relationship, employment-related gains, being parents, educational achievement and buying a house were associated with individuals' happiness. In contrast, the end of a relationship, death of parents, poor health of parents and employment loss have negative impacts on happiness. Younger people were concerned about education related events whereas older people were more concerned about health. Ballas and Dorling also noted that the end of a relationship may become a positive life event (reason for celebration) for some people and "pregnancy and birth" are associated with both happiness and unhappiness. This emphasises the subjective nature of response to life events and supports the argument that the reactions to some life events are associated with people's individual circumstances which could lead to different life decisions.

It appears obvious that negative and stressful life events may trigger unhappiness and depression. The resulting persistently dejected attitude may turn into severe depression and may adversely influence people's thinking and behaviour towards life changing decision making. People may change their predefined life goals because of ill health and set new priorities for the future, such as not to have a child, to change career or retire. Decisions, taken at the time of any major life event should be regarded as major life changing decisions. There is no specific definition of what constitutes a major life changing decision particularly a health-related life changing decision. In general, a major life changing decision (MLCD) could be defined as an important decision which could change or alter life forever or an important decision which has a long-term consequence or implication in life. For the development of a preliminary carefully considered definition, an in-depth insight into and knowledge of patients' lives is crucial.

What can be learnt from the available literature?

In a literature search, only two articles matched the term "major life changing decisions". These were related to psychology (Bauer et al. 2005) and to neuroeconomics (Berns et al. 2007). Other articles were not specific to disease impact on life changing decisions but contained some information related to disease and its influence on patients' lives and were useful for conceptualisation.

Bauer et al (2005) examined the personal stories of life changing decisions in relation to personality and well being and discussed the concepts of "crystallization of desire (approaching to a desired future) and crystallization of discontent (escaping an undesired past)". People make major life changing decisions either in an unbearable situation (crystallisation of discontent) or when they experience positivity in life and are eager to make changes (crystallization of desire). These studies seem to be a continuation of Baumeister's (1994) work, in which he identified a phenomenon called "crystallization of discontent", a period of distress which leads to major life change. To this effect, Bauer et al (2005) carried out two studies. In the first study, the data came from a larger study of life stories. Adults were asked to write down one to two pages about life changing decisions that they had made in their lives and were asked to complete other measures related to well-being, striving and traits. They tested two hypotheses: "Hypothesis 1: that crystallization of desire would be part of a constellation of personality characteristics that corresponds to well-being. Hypothesis 2: that crystallization of desire would continue to predict well-being when controlling for striving and traits". In the second study adult participants who had recently changed their career or religion were recruited and asked to write about their decisions to change. They tested hypotheses one and two from the first study and tested two new hypotheses. "Hypothesis 3: that participant emphasizing a crystallization of desire rather than discontent would be more likely to report that their decisions turned out well. Hypothesis 4: that crystallization of desire would be independent of how well the decision turned out in predicting well-being". In summary, participants reported a higher level of life satisfaction and better decision outcomes when they had made decisions based on desire. This study suggested that motivation for new ideas in life may bring better decisions and well being as an outcome. However, more research is required to analyse how people take life changing decisions in negative life events, particularly in health-related situations. How to become motivated (internal or external) during a stressful negative life event is another area of concern, particularly in health-related life situations.

The subject of neuroeconomics measures human behaviour and related brain functioning. A combination of approaches from psychology, economics and neurosciences are combined to study and evaluate the role of the brain when people make decisions, decide preferences, take risks, seek rewards, learn, use their memory and knowledge and make economic decisions. To aid this research, neuroscientific tools such as electromagnetic recordings including electroencephalography (EEG), magneto-encephalography (MEG) and methods measuring metabolic or hemodynamic responses to neural activity such as positron emission tomography (PET) and functional magnetic resonance tomography (fMRI) are used to compare localised brain activities in different situations. Experiments normally use the techniques of assessing response to different choices/preferences, risk, reward, gambling and may use utility trade off methods (Kenning and Plassmann 2005).

In the second article Berns et al (2007) explained life changing decisions as an example of intertemporal choice. Intertemporal choice is a study of preferences, value allocation and decisions with consequences that play out over time. Life changing decisions related to education, marriage, fertility and how much food to eat, spending, investment, relationships and crime are some examples of intertemporal choices which contain tradeoffs. Berns et al (2007) discussed these choices from the perspective of neuroeconomics (psychology, economics and neurosciences) and highlighted the Discounted Utility (DU) model which has been used in economics to evaluate how people make decisions (intertemporal choices) and as a tool for public policy (decisions related to spending, development, health and education in the public domain). The DU model is based on weighing the positive and negative aspects of decisions by means of a loss and gain ratio (Berns et al. 2007). This is another approach to documenting and understanding life changing decisions. Detailed knowledge is required to apply this concept in the context of stressful, undesirable negative life events and subsequent major life changing decisions making, particularly in long term health-related situations.

Concerning broader aspects of the subject of life decision making, it is worth mentioning here that neuroscientists have also studied brain chemicals and their relationship to human behaviour. It is considered that neuromodulators (dopamine, acetylcholine and noradrenaline) are not only involved in every mental function and several psychiatric problems but also have more specific functions in learning, the decision making process and in regulating the balance between exploitation and exploration (Cohen and Jones 2005).

The extensive literature review of health, illness and patient centred issues, has not revealed any specific research evaluating health-related life changing decisions. Several studies (Robinson-Smith 2002; Smith 2002; Cassidy et al. 2004; Fisher et al. 2007a; Fisher et al. 2007b; Miller and Askew 2007) referred to disease as "life changing" or as a "major life changing event or experience" but remained focused on disease evaluation, treatment, patient education and QoL. Some level of understanding can be obtained from the few available studies that show how chronic disease might impact on important life decisions.

Breast cancer is a life threatening condition and deciding to have children after breast cancer is an important life changing decision for mothers. Dow (1994) carried out a study to identify the reasons why young women decided to become pregnant after breast cancer, to describe helpful behaviours in decision-making and to explore the meaning of having children after breast cancer. In this qualitative research, 16 women took part in semi-structured interviews. The participants were asked to share their experiences following an open ended question about breast cancer and subsequent pregnancy. Three main themes were identified influencing having children after breast cancer treatment: having children as a cherished goal; a desire for sense of normalcy; and reconnection with others. In this study, the participants were interviewed after breast cancer treatment. Even in this situation, participants did mention concerns about pregnancy (having a normal pregnancy, having a healthy infant, disease recurrence and concerns related to breast feeding) and having children (recurrence and death, being hypervigilant, restructured living one day at a time, maternal concern). This research also highlighted the point that a longstanding desire for having children was interrupted by the diagnosis of breast cancer. Before the diagnosis, breast cancer participants were in control; however, after breast cancer, they lost control of their lives. Experiences about specific behaviour of their spouse and family, healthcare providers and other breast cancer survivors were identified as critical factors in decision-making. Behaviours recorded resulting in the decision to have a subsequent pregnancy are given in Table 1.4 (Dow 1994).

Dow's research findings, particularly those given in Table 1.4, suggest that a patient's personal efforts, professional help and the process of sharing experiences could be helpful to the person in making important decisions in life. This area was also discussed in another study, where patients with HIV chose not to become pregnant following learning about their diagnosis (Craft et al. 2007).

Anderson and Martin (2003) presented as a single case study the narratives of one couple (a cancer survivor and her husband), who lived through the life-changing events following a cancer diagnosis. The narratives are very moving and give insight into how a chronic life threatening condition can change a patients' life. It is also evident that after the diagnosis, all of a sudden the patient's priorities changed and the patient was preparing herself for the future. It is not clear whether the patient took any life changing decision, but words used by the patient in her story, such as, "I thought I was dying", "I had no control over what was happening to me", "I was still worried about my future" and "It was dehumanizing and very lonely" indicate that the disease and its treatment have a physical impact and result in emotional fluctuation, fear and uncertainty which may influence a patient's priorities in life and may also change their family and social role and identity.

Physical health and marital dissatisfaction have a direct effect on each other (Ganong and Coleman 1991). Ill health, mental well-being and its associations with marriage, relationships and family have been widely discussed in the literature, and any change in circumstances due to health may impact on the QoL of family members and relationships. For example, if poor health causes a breakup in a relationship then divorce (as a stressful life event) may lead to poor health (Renne 1977; Albrecht et al. 1983; Gove et al. 1983; Ross et al. 1990). Wilson and Waddoups (2002) carried out a study to investigate how poor health impacts on the breakup of marriages. The data were used from the four waves of the Health and Retirement Study (1992, 1994, 1996 and 1998).

Table 1.4: Behavioural pattern in decision making to have a subsequent pregnancy (Adopted from Dow 1994)

The individual and spouse	Developing a realistic view on disease and decisions about one's future Learning to live with uncertainty over time Needing the love and support of one's spouse Finding an obstetrician who is sensitive to their cancer history
The individual and the healthcare team	Having frank discussion about the "worst case scenario" Having an oncology team available to answer questions about survivorship Learning practical information on physiologic late effects (e.g. infertility, breastfeeding, fatigue) Delineating personal versus medical decision making
The individual and the family	Knowing that family and friends may express apprehension and be less supportive
Individual and other cancer survivors	Meeting other women or learning about others who made similar decisions

In 1992 4,241 couples aged 51-61 entered into this study. The health mismatch hypothesis was tested by using different spousal health combinations and separation used as an indicator of marital dissolution. They did not observe marital dissolution from a life course perspective or from the perspective of influence of poor health on separation. However, the study still suggests that the poor health of a spouse at a young age may cause marriage dissolution over time. There is information concerning the impact of disease on marriage, marital adjustment and marital quality (Burman and Margolin 1992; Roth-Roemer and Kurpius 1996; Goodwin 1997; Cannon et al. 1998); however, it is not clear whether chronic disease influences patient's decisions to get married or prevents them becoming involved in any relationship.

Seidler and Kimball (2009) suggest that patients with chronic skin disease may learn to cope over time but their important decisions early in life may have long-lasting impact on their QoL. They used the Research Patient Data Repository (RPDR) database and cross-sectional analysis to determine any link between key ages or age ranges and social disconnection. Religious non-affiliation (for loss of social network), divorce (for loss of interpersonal connection) and use of Medicaid (for disconnection in the work place) were used as surrogate evaluative measures for the assessment of social connectivity among psoriasis patients. They found that divorce rates in psoriasis patients compared to the general population were higher in the age groups 29-31 years (1.3% vs. 1.7; $p < 0.05$) and 32-34 years (2.3 vs. 1.1; $p < 0.001$). Seidler and Kimball (2009) highlighted the importance of the association of disease and age groups with the important life decision to divorce, but it is not clear whether psoriasis specifically had an influence on the patients' decision to get divorced or whether psoriasis contributed to the partners' decision to get divorced.

Chronic disease can also influence the major life changing decisions of other family members. In a cross-sectional study Fine et al (2005) asked a series of questions to parents of children suffering from inherited Epidermolysis Bullosa (EB) about the long term impact of their child's illness on their marital life. A total of 54-64% parents of children with Dominant Dystrophic EB (DDEB) and Recessive Dystrophic EB (RDEB) reported that they had decided not to have additional children. Eighty-eight percent of divorced couples with children affected by Junctional EB (JEB), 50% of divorced couples with children affected by DDEB and 67% of divorced couples with children affected by RDEB reported that their child's disease was a major/primary factor leading to their decision to divorce.

In a 1-year follow-up study, Cvetkovski et al (2006) concluded that occupational hand eczema in later life is associated with poor QoL and lower socioeconomic status and results in patients taking prolonged sick leave, becoming unemployed or changing their job. One year is a relatively short period for follow up to assess these changes, but in this study 50% of patients had changed their jobs during the 12 months, which suggests how chronic illness can change life significantly. The frequency of job change in their study due to hand eczema was higher than when previously assessed by Meding et al (2005) in their 15 year follow-up study (1983-1998). They found that 20 (3%) out of 706 patients from different employment backgrounds (medical and nursing work, cleaners, hairdressers, kitchen workers, painters and mechanics) reported change in their occupations because of their hand eczema, and 15 patients reported improvement after change in occupation. Eight percent of patients had reported change in their occupation before the initial 1983 examination. In terms of job change, both studies focused on occupational risk and did not discuss the nature or the consequences of the decision involved in relation to change in employment. It is obvious from both studies that chronic disease can influence a patient's decision related to selection of jobs or to change in occupation. Long term illness can make it difficult for patients to remain in the same employment if their occupation is one of the major reasons for health deterioration. Choices seem very limited for patients and in some cases change of job might result in financial loss. Patients might remain in the same employment and suffer because of socioeconomic reasons (family, better housing and children's education). Therefore, a change of occupation or the selection of job taking into account a health perspective are clearly major life changing decisions.

In another study, Malcomson et al (2008) conducted two qualitative focus group discussions to explore the impact of multiple sclerosis (MS) (n=13, age=40-67 years, mean disease duration=17 years) on patients' lives. Several patients reported changes to their employment circumstances along with other disease related impacts (interpersonal and social life, stress, unpredictability, fear and impact on daily living). Despite the resulting loss in socioeconomic status, one patient made a decision to change from full time to part time employment and two patients gave up their paid jobs because of the impact (fatigue, lack of energy, decreased mobility and stress) of MS on their lives. The patients indicated that MS influenced their important decisions regarding employment and made them compromise (an undesirable objective) in the best way possible to accommodate their health needs and to take control of their resulting life style changes.

Arnold et al (2008) conducted six focus group (n=48) discussions with women suffering from fibromyalgia to assess its impact on their lives. Participants raised a variety of disease related (cognitive impairment, emotional, functional and QoL impact) and symptoms related (pain, fatigue and sleep) issues. Socially, fibromyalgia patients feel that due to the unpredictable nature of the disease, they are unable to plan any event and are judged by co-workers and friends as unreliable, resulting in loss of friendship and their withdrawal from social engagements. The participants also reported that they failed to properly look after their own children and families. For example, not being able to go for family trips was reported as life changing by patients and lack of participation in household activities and decreased sexual intimacy had caused great strain on their personal relationships. This indicates that not to take part in simple things, such as social activities, could be a life changing decision. Some people might still take part in different activities but embarrassment and humiliation and the long term nature of the disease might drag them towards complete isolation. Similarly, the constant strain of disease on personal relationships may lead to taking more serious life decisions, such as separation or divorce. The participants also reported that their disease not only made them change their job frequently but also reduced their working hours. Half of the patients left their jobs because of their illness, which ultimately resulted in financial instability. Some patients reported that their conditions stopped them from pursuing higher education; this seems to be a very tough life changing decision with resulting consequences of low paid menial hard work and further health deterioration (Arnold et al. 2008). This raised the question whether such patients need more support and appropriate advice at those life stages when they have to take important life decisions regarding employment and education. Indeed, this is another important area of concern and increased patient understanding seems necessary to reduce disease impact on decisions which determine the future course of life.

Choices concerning reproduction are also very important life decisions and disease may influence an individuals' choice to have children. Kadir et al (2000) suggested that the decision to have children is a complex one, even in the absence of disease. They conducted a survey to assess haemophilia women's experiences in pregnancy and their attitudes towards their reproductive choices. They found that age, emotional, social and financial factors were the main influences in planning pregnancy. Twenty-two percent of 160 women reported that their decision about their first pregnancy and 13 of 132 women reported that their decisions about subsequent pregnancies were influenced by counselling and the results of parental diagnostic tests. The following question was also asked to all women, whether they had "ever made a conscious decision not to have children/any more children". Fifty-four percent of the women reported that having haemophilia was a major factor in this decision. Forty-four percent did not want to transfer haemophilia to their child, 6% had previous experience of haemophilia in the family and 27% reported personal, social, financial and medical reasons for this decision (Kadir et al. 2000). This survey indicated an individual's priorities in different life situations, such as the prime example of disease influence on having children. Various studies suggest that the decision to have genetic testing could be a life changing decision and may impact on family planning, interpersonal relationships, social, financial and employment aspects (Lim et al. 2004; Smith et al. 2004; Cameron and Muller 2009). Even the decision of parents about how to proceed after the antenatal diagnosis of congenital problems seems to be important and difficult to make, as the decision may change their lives forever (Rempel et al. 2004). Similarly, other health-related decisions such as the decision over choice of treatment (whether surgery or medication) could be life changing for a patient (Mastaglia and Kristjanson 2001; Warren and Griffiths 2008; McHugh and Luker 2009).

According to the Foreign and Commonwealth Office (FCO), around half of British people (age >55) said they were thinking of moving to another country and to start a new life. It has been emphasised that weather should not be the sole factor influencing the decision to relocate and people should consider the practical aspects of relocating, such as learning a new language, the political situation, currency fluctuations, the availability of long term healthcare and pension issues (Foreign and Commonwealth Office 2010). This FCO survey suggests that moving abroad seems a popular choice later in life among the British population, but their advice clearly indicates that relocating to another country is a life changing decision and any wrong or uncalculated move could be disastrous for individuals and for their families. If this is a big decision for healthy people, then it could be a daunting task for people suffering with chronic conditions.

Life decisions are subjective in nature and have perceived value. Some decisions seem very minor and more related to day to day activities/choices, but individuals' circumstances such as onset of chronic disease could make these daily decisions and choices more important for that individual and life changing. Huggins et al (2009) surveyed young patients suffering from hydroa vacciniforme (HV) and suggested that type of chronic condition and duration of disease (median age at onset 7 years) can influence the quality of life impact. Concerning the Children's Dermatology Life Quality Index (CDLQI) responses: 63.6% patients (n=11, age range=9-17 years) reported impact on going out, playing and hobbies; 54.5% reported impact on choice of clothing; and 36.4% reported impact on swimming and sports activities. On their Dermatology Life Quality Index (DLQI) responses, 75% adult patients (n=4, age =18 and over) reported that their skin condition influenced their choice of clothing. It is understandable that disease related aesthetic reasons and embarrassment (50%) could play an important part in viewing simple decisions such as choice of clothing or swimming as major decisions as they concern change of life style and image, which they feel to be wrongly perceived by others. In another study Hon et al (2008) found that young girls with atopic dermatitis had more problems concerning clothes or shoes than boys, indicating the importance of the relationship between gender and disease influence on specific aspects of patients' lives. Similarly, decisions about life style may have serious consequences on health. For example, smoking, drinking and over eating can cause serious health problems (Wright et al. 2004). Any decision to alter these habits may determine individuals' future health, indicating the significance of life style related decisions.

Conclusion

The nature of subjective directions, life events, life transitions, life course, life stages, life goals and life changing decisions are very complex. Their meaning might be different and hence confusing in sociology, philosophy, psychology and the realm of health. Despite separate descriptors, these concepts seem inter-connected. For example, in one complete course of life, individuals go through different life stages and have to face different life events (negative/positive). They subsequently have to make important life decisions which may change a person's goals and life for ever. In other words, these concepts direct our thoughts towards change in life stages (childhood, adolescent, middle age and old age), identifying social roles/identities (son, daughter, student, employer, employee, husband, wife, parents, grand-parents), facing life events/circumstances (e.g. birth, marriage, separation, divorce, disease, education, career choice, retirement, death) and defining life goals/priorities e.g. to become an engineer, doctor, lawyer, artist, sports professional, traveller or politician). Life priorities and goals may differ from one individual to another due to their personal life circumstances, situations and the nature of the life event they face. Individuals' priorities and goals may influence their attitude, perception of life, their behaviour and the important life decisions they make. The sequence of these concepts encompasses the chronology of one complete course of life.

Important life events, circumstances, or other factors, such as poor health, death, birth, divorce, and marriage can alter people's lives for ever and subsequently may affect their QoL in psychological, social, physical and emotional domain. Therefore, the inclusion of the term "life changing events" and "life changing decisions" in the definition of QoL might to help improve and better reflect the ambiguous broad concept of QoL.

The medical and health sciences literature is replete with information predominantly related to the current impact of different diseases on patients' QoL and mainly focused on traditional HRQoL domains (physical, social and psychological), therapy evaluation, treatment decision-making, utility preferences, impact on families, spirituality, and the implication of health economics, financial burden and healthcare facilities. In contrast, very little is known about the long-term impact of chronic disease on patients' lives, for example the concept of influence of chronic diseases on major life changing decisions has never been studied before. Answers to some important specific questions need proper investigation, such as, what is the definition of life changing decisions from a HRQoL perspective? How do or should patients take their life changing decisions while suffering from long-term health problems? To what extent do chronic diseases influence major life changing decisions? What sorts of influential factors are involved in life changing decision? How capable are patients to take appropriate life changing decisions in life? Are there any guidelines or strategies available for patients and for healthcare providers to assist patients to take appropriate decisions allowing them to maximise their control over their lives? Lastly, does the exploration of major life changing decisions really matter to patients, their families or health providers? Thus, how people take life changing decisions and what factors influence their particular decisions, requires proper understanding.

The lack of knowledge in this area suggests a new research possibility. Along with both follow up and prospective research techniques, exploratory retrospective research methodology is essential to understand the magnitude of the influence of chronic diseases on life changing decisions. This critical analysis of the literature points to a completely new dimension to health-related outcome research and encompassing this concept might change the way researchers evaluate HRQoL. There is clearly a need for a new multidisciplinary comprehensive research and measuring techniques to capture fundamental information for further conceptualisation, to determine the definition of health-related major life changing decisions, to assess the feasibility of its measurement as a new dimension and to determine its possible implications on patients' lives and the healthcare resources.

AIMS AND OBJECTIVES OF THE STUDY

Aims

- To identify the influence of chronic diseases on major life changing decisions.
- To develop a standardised questionnaire to capture information related to health-related major life changing decisions.

Objectives

- To create a standard definition of health-related "Major Life Changing Decisions" for future research.
- To investigate the level and the type of affected MLCDs between different chronic disease areas.
- To identify key factors influencing major life changing decisions and its correlation with the disease.
- To determine the link between gender and type of influenced MLCDs
- To identify correlation between patients' age and the number of MLCDs affected.
- To evaluate the psychometric properties of the newly developed instrument such as content validity, factor analysis and practicality.
- To define the possible use of this newly developed tool.
- To develop strategies for patients to facilitate better life decision-making.
- To record patients' feedback about the study

CHAPTER 2

Study rationale and methodological framework

INTRODUCTION

This was a cross-sectional prospective study and was carried out to investigate the influence of chronic diseases on major life changing decisions. Data was generated by asking patients to record the impact of their disease over the course of their life. This chapter provides detailed information related to study rationale, objectives, ethical considerations, inclusion and exclusion criteria, study design and data processing techniques, and analysis.

STUDY RATIONALE

Chronic diseases such as psoriasis, eczema, heart failure, rheumatoid arthritis, chronic obstructive pulmonary disease (COPD), chronic kidney disease (CKD), cystic fibrosis (CF) and diabetes are very common chronic conditions which may affect patients over many years and cause serious impacts on their HRQoL. Chronic skin conditions not only affect a considerable portion of the population but also have strong financial implications (Phillips and Dover 1991; Finlay 1992; Poon et al. 1999; Parsad et al. 2003; Stern et al. 2004; Schafer 2006). Psychologically, physically and socially, skin disorders are very debilitating and may cause serious QoL impairment, disability and handicap. Similarly, other common chronic diseases, such as rheumatoid arthritis (Katz 1995), osteoarthritis (de-Bock et al. 1995), hypertension (Wei et al. 2005), congestive heart failure (Carels 2004), angina (Melsop et al. 2003), asthma (Meszaros et al. 2003) and COPD (Garrido et al. 2006), CKD (Perlman et al. 2005), CF (de-Jong et al. 1997) and diabetes (Rubin 2000) also have a severe impact on patients' lives. The severity of impact related to different QoL domains may vary from disease to disease. For example, in patients with arthritis physical functioning is the most obviously affected area. Several research surveys have been carried out to assess the impacts of chronic diseases on QoL. However, these studies have not addressed the long term impact of chronic disorders on critical life decisions taken by patients.

The concept of life changing decisions has been discussed in the field of psychology as "crystallisation of desire and crystallisation of discontent" (Bauer et al. 2005) and in neuroeconomics as intertemporal choices (Berns et al. 2007). However, this concept has never been studied from the perspective of health, illness and patients. Despite the current impact of disease on patients' lives being assessed in details, from several studies it is only possible to form a vague idea of how the resulting impaired QoL might influence major life changing decisions.

Decisions about the most important issues in life, particularly, marriage or relationships, divorce or separation, having a child, higher education, job and career, change of profession or early retirement, relocating to another city or country, are not easy. Even for a completely healthy person, such decisions are often difficult to make and people often seek advice from relatives, friends and professionals. This common human behaviour generates another important question: how do people with chronic disease take such decisions? One could easily imagine that the nature and duration of chronic disease may influence patients' life changing decisions and prevent them from achieving their desired objectives and goals. For example, occupational limitations resulting from psoriasis may have a negative influence on choice of career or profession; genetic concern about psoriasis may change a patient's approach towards having a child in the future. The visibility of psoriasis, acne and vitiligo may prevent younger patients' from pursuing higher education, relationships and the type of work they might have wanted to select as a career. Rheumatoid arthritis and osteoarthritis have severe impacts on patients' physical activities. Patients might take early retirement and some possibilities such as moving house or shifting to another country may no longer be an option because of the disease. Asthma, chronic obstructive pulmonary disease, hypertension and renal disease could restrict patients' options of job opportunities. The effects of the disease on daily living and the need for constant care might disturb a patient's marriage or a patient might decide not to engage in any relationship. Therefore, the long-term nature of debilitating disorders and resulting psychological, physical, social and financial impacts may change patients' thinking and approach towards life and force them to adjust their life objectives according to their health and resulting circumstances.

It is clear from the above that making decisions about important issues in life, while at the same time living with chronic disorders, is a very difficult task. However, this aspect of the lives of patients and the magnitude of the impact of chronic diseases on life decisions has not yet been studied. But, from the practical experience in the routine clinics, it has been observed on many occasions that patients had taken different life decisions only because of their chronic skin condition. Based on observation a question posed: "can chronic diseases influence major life changing decisions?" Following an in-depth critical review of the literature, we have concluded that there is an evident gap in research in this area. A comprehensive study will therefore be carried out in order to identify the health-related life decisions issues that affect patients over time to inform the development of a questionnaire for assessment of such phenomenon. In addition, to develop strategies to meet patients' decision support needs and to contribute to a better health outcome.

METHODOLOGICAL FRAMEWORK

Study population

This study was a cross-sectional prospective study of patients who were treated at the University Hospital of Wales (UHW), Cardiff and University Hospital Llandough, Llandough (Cardiff and Vale NHS Trust) with chronic diseases (dermatology, cardiology, rheumatology, nephrology, diabetes and respiratory disorders) aged 16 years or above for >1 year. Young patients (16 to 20 years) were specifically recruited because at this age, young people normally try to set their life goals and objectives for the future. For example, they might set their education targets and work hard to achieve professional qualifications to enter into a specific career.

Inclusion criteria

- Patients suffering from chronic disease (dermatological, cardio-vascular, rheumatologic, renal, diabetes or respiratory) for more than one year
- Patients aged 16 years or above
- Male or female
- Belong to any ethnic group
- Patients who can read and write in English
- Agree to protect the confidentiality of other focus group participants
- Are willing to share personal experiences in a tape recorded interview or group discussion

Exclusion criteria

- Patients with comorbidity
- Patients under 16 years of age

- Patients who have been suffering from chronic disease (dermatological, cardio-vascular, rheumatologic, renal, diabetes or respiratory) for less than one year
- Patients unable to read and/or write in English or who have special communication needs
- Patients who have disability from any other cause (physical or mental)

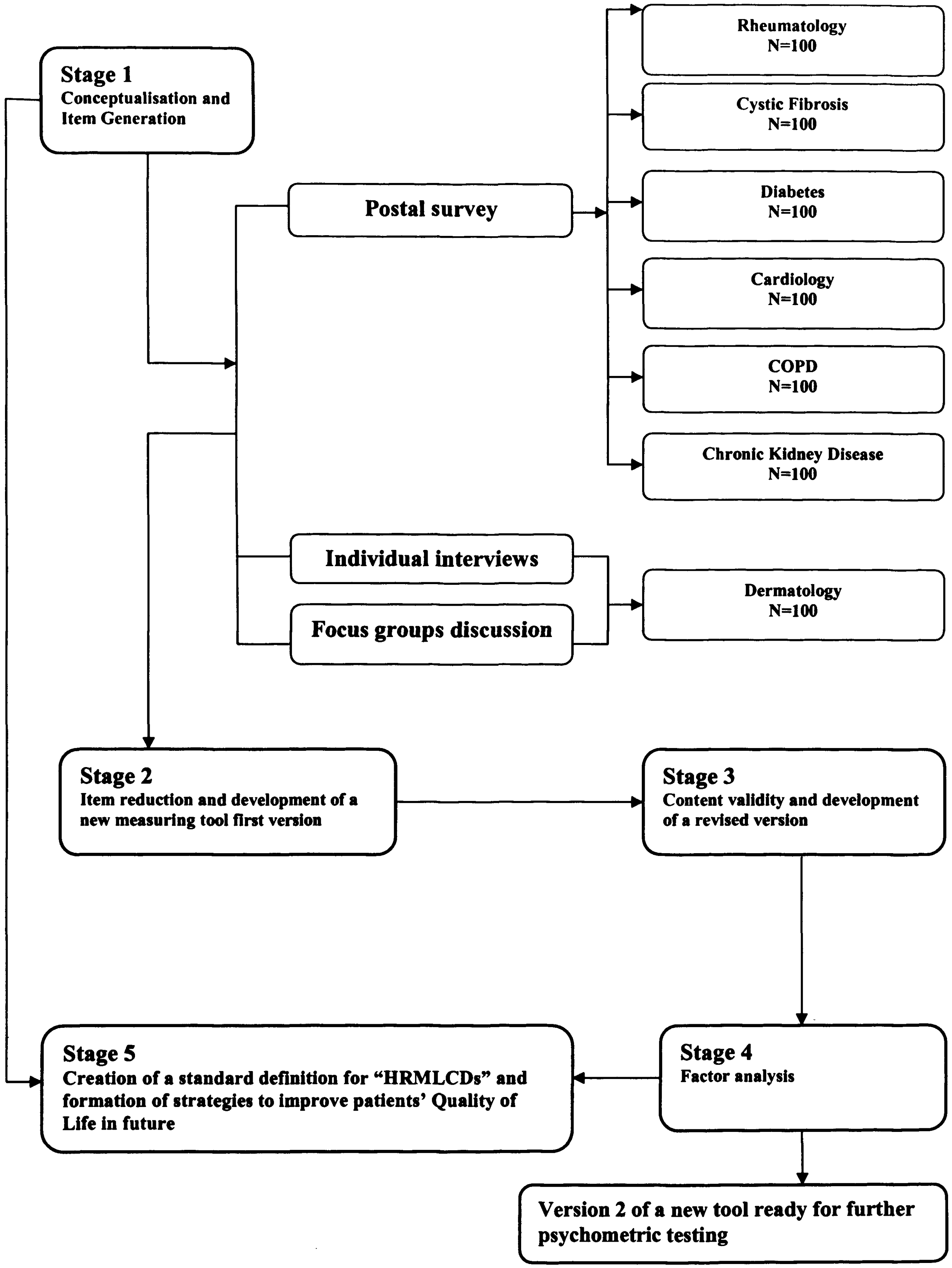
Ethical considerations

Due to the large scale of this project, to optimise the study results, to aid the smooth running of the project, to ensure good coordination among participating specialties and to minimise the cost and time, long and thoughtful consideration were given to the research plan before seeking ethical approval. Only one application for ethical permission was filed covering all study stages in order to increase the efficiency of the study and to aid its smooth running. Ethical permission to conduct this study was obtained from the South East Wales Research Ethics Committee in 2 June 2008 (Appendix 1). Permission was also obtained from UHW Research and Development (R&D) department on 18 June 2008 (Appendix 2). Appropriate information about the study and patients rights was given to all identified patients using a "Patient Information Sheet". Approved consent forms were used to record participants' consent. Participants who took part in focus group discussions were specifically asked to agree to protect the confidentiality of other focus group participants. Every patient was allotted a "code number" for identification. Records of the digital recording of individual interviews/focus groups and written postal replies were kept in a secure place in the Department of Dermatology, University Hospital of Wales. Data were transferred to a Cardiff University secured computer without any personal details for analysis. Access to the Cardiff University computer is protected and only the participating researchers have the access to the data collected from study participants.

Study Design

This cross-sectional prospective study was carefully designed before its commencement in order to capture the most appropriate information to its maximum capacity in the allocated time frame. This study was carried out in the following five stages (Figure 2.1).

Figure 2.1: Study Flow Chart



Stage 1: Conceptualisation and item generation
Stage 2: Item reduction and development of the first version of a new tool
Stage 3: Content validity and development of a revised version of the tool
Stage 4: Factor analysis and development of the final version
Stage 5: Formation of strategies for appropriate decision taking

Stage 1: Conceptualisation and item generation

Initial data was collected through (a) a postal questionnaire survey (b) individual interviews and (c) focus groups discussion to identify the influence of chronic diseases on major life changing decisions. A working definition of "Health-Related Major Life Changing Decisions" (HRMLCDs) was formulated during this stage. After collection of all the data from the postal survey, the individual interviews and the focus group meetings, main themes and categories were identified using qualitative analysis. This information was used for the development of a generic major life changing decision questionnaire "Major Life Changing Decisions Profile" (MLCDP).

Stage 2: Item reduction and development of the first version of a new tool

The items generated in Stage 1 were analysed using qualitative techniques to reduce them to the core items identified by the participants and yet retain population and gender specific items. After qualitative analysis, in three lengthy brain storming sessions, appropriate taxonomy and rephrasing of items were used to fit categories or domains. Standard scientific techniques in terms of language, reading age and item length were applied for the developmental version of the new tool MLCDP (version 1).

Stage 3: Content validity and development of revised version of the tool

This stage was important to examine the new measure for its focus and emphasis for the intended population using a panel of judges consisting of consultant physicians and nurses from different disciplines. The panel rated each item for its language clarity, completeness, relevance and scaling. Agreement among the panel members was statistically measured using interclass correlation and kappa coefficient. The suggested changes by the panel were implemented to produce the revised version of the new tool MLCDP (version 1a).

Stage 4: Factor analysis and development of the final version

The purpose of this exercise was further validation of the new tool seeking confirmation of the breadth and depth of the allocated domains through the application of the statistical technique of factor analysis. 210 patients (30 from each of the 7 medical specialities) were recruited and were asked to complete the revised (MLCDP- version 1a) tool. Internal consistency reliability of items within a factor were also tested using the reliability coefficient, namely Cronbach's coefficient alpha. Face value and practicality of the new tool was also measured by using a separate questions sheet, mainly recording patients' views on different aspects of the new tool. The end result of this phase was the final version of the new tool MLCDP (version 2) which will be examined for its other psychometric properties such as clinical validity, reliability and responsiveness in future work.

Stage 5: Formation of strategies for appropriate decision taking

Data collected from patients at stage 1 and stage 4 were meticulously scrutinized in detail for the creation of strategies to help patients develop more appropriate long-term decision taking, hopefully allowing patients to develop their full and appropriate potentials in life. The information gathered through the newly developed tool may further inform clinicians, care teams and policy makers in their planning over how to deliver care, how to plan resources and how to develop strategies for patients to minimise the impact of chronic disease on major life changing decisions. Correct strategies would enable patients to make optimal decisions. Data collected during the stage 4 was used to create a more universally acceptable definition of "Health-Related Major Life Changing Decisions" (HRMLCDs).

Data collection techniques

At the study design stage, in addition to dermatology six other major specialities (nephrology, cardiology, cystic fibrosis services, respiratory medicine, diabetes clinic and rheumatology) were selected in order to capture a broad range of information from patients who were suffering from different types of the most prevalent chronic conditions. Specialities such as dermatology, cardiology and rheumatology cover a number of different chronic conditions. A consultant physician in each speciality was contacted and invited to take part in this study.

The study protocol with speciality specific sections was presented to all collaborators for their consideration and to seek their cooperation. After ethical approval was given by the South East Wales Research Ethics Committee, participating consultant physicians were invited for detailed briefing about the methods of each stage of the study and the step by step role of each member. The name "MLCD-study group" was given to this research collaboration. Several MLCD-study group meetings were carried out for research updates, particularly about patient recruitment, publications, study time frame and the smooth running of this large project in general.

Initial data was collected through (a) postal survey (b) individual interviews and (c) focus group discussions.

Postal survey

A total of 600 patients suffering from chronic diseases (i.e. cardio-vascular, rheumatology, cystic fibrosis, chronic obstructive pulmonary disease, diabetes and chronic kidney disease) for more than one year and who fulfilled the study inclusion/exclusion criteria, were invited to complete the postal survey (100 patients from each medical speciality). Patients suffering from chronic obstructive pulmonary disease (COPD), cystic fibrosis (CF) and diabetes were recruited from University Hospital Llandough, Llandough (Cardiff and Vale NHS Trust). Patient selection for each disease area was carried out by the responsible consultant physician and then a list of eligible patients was compiled for assigning identification code. A proforma was used (Appendix 3) to keep a record tracking all the posted survey packs and reminder responses. For example, the date of posting, date of response received and date of first reminder to non-responders. Survey packs were posted to patients who fulfilled the study inclusion/exclusion criteria with a covering letter signed by the responsible consultant physician caring for the patient. Patients were asked to read and try to understand the participant information sheet, sign the consent form, complete the requested sections and return them in the enclosed pre-paid self addressed envelope (Appendix A). One follow up request (Appendix B) was carried out to improve the response rate.

The postal questionnaire survey pack consisted of four sections, and this was sent to all identified patients accompanied by a covering letter from respective consultant physician (Appendix C): each pack consisted of four sections: Section 1 consisted of the general "Participant Information Sheet" (Appendix D), which provided information about the purpose and the procedure of the study, recording, storage of data, data protection and anonymity of personal information. Patients were informed about their rights in this information sheet, emphasising that they had no obligation to take part, and could withdraw at any stage. Contact details with a several telephone numbers were specified in the participant's information sheet for any queries. Section 2 consisted of the "Participant Consent Form" (for postal survey) (Appendix E). Section 3 consisted of the "Participant Personal Details" sheet and was used for demographic data collection (Appendix F), such as age, gender, education, occupation, marital status and disease duration, Section 4 consisted of an "Exploratory Qualitative Assessment Sheet" (Appendix G). In this section, patients were asked to write down their experiences in response to one exploratory question "Please write down any ways in which your long-term disease has had a major influence on major life decisions". In this section, examples of important life decisions were given to participant's such as marriage or relationship, divorce or separation, having a child, higher education, job and career, change of profession or early retirement, relocating to another city or country. Common themes were identified from the returned responses and later were used for qualitative analysis.

Individual interviews

Fifty-five patients under the care of the Department of Dermatology, University Hospital of Wales, were contacted for individual interviews. They all had been suffering from chronic skin disease for more than one year and fulfilled the study inclusion criteria. For individual interviews, patients were identified through the hospital clinical record system (Patient Management System). The patients' medical records were thoroughly searched to ensure the eligibility of the selected patients. Identified patients were contacted by the respective consultant physician directly in the dermatology out-patient department or via post.

Patients approached in the out-patient clinic were given an interview information pack. Sufficient time was given to patients to read and understand the different sections of the individual interview pack. A choice was given to patients who were still interested in possibly participating either to take part in this study on the same day or to later inform the researchers using the dedicated telephone numbers whether or not they wished to participate.

For patients contacted by post, invitation letters with an information pack were sent out to eligible patients two weeks prior to their expected out-patient appointment so they would carefully read and understand the participant information sheet. The patients were asked to inform the researchers using the dedicated telephone numbers if they were willing to take part in the study or, alternatively, participants were asked to complete and tear off the bottom part of the clinician's invitation letter and send it to the Department of Dermatology using a pre-paid self addressed envelope within four working days.

Interviews were carried out in the Welsh Institute of Dermatology, in a dedicated room either in the academic department or in the dermatology out-patient department. Those who indicated their interest by telephone or post were later contacted to schedule an interview at a convenient time for the patient.

Along with the clinicians' invitation letter (Appendix H) each individual interview pack consisted of 3 sections; Section 1, general "Participant Information Sheet" (Appendix I), Section 2, "Patient Consent Form" (For individual interviews) (Appendix J), Section 3, "Participant Personal Details" sheet (Appendix K). In-depth one-to-one semi-structured interviews were carried out by Z U B and were recorded using a digital recorder. A semi-structured checklist was designed for conducting the individual interviews. After a brief introduction and obtaining informed written consent, the same open ended exploratory question which was used for the postal survey was asked to the patients (i.e. Could you please share your experiences about any ways in which your long-term disease has had a major influence on major life decisions). Patients were given sufficient time to think about the life and reflect on the ways they think their disease had influenced life decisions. Later, patients were asked to consider more specific aspects of life such as marriage or relationship, divorce or separation, having a child, higher education, job and career, change of profession or early retirement, relocating to another city or country and encouraged by the interviewer to speak freely about their experiences. Patients were asked to give examples in this more detailed discussion. Any new area reported by patients during interview was later included in the remaining interviews. The same guideline was used for all interviews. Digitally recorded interviews were downloaded later that day to a secure dedicated computer. Verbatim word by word transcriptions of all the interviews were carried out for in-depth qualitative analysis and to reduce interviewer bias. At the end of the each interview two additional questions were asked in relation to secondary objectives of this study: 1) How can we help patients to take appropriate MLCDs in a similar situation to you? 2) What do you think about this study?

Focus Groups

Twenty patients suffering from chronic skin disease for more than one year and fulfilled the study inclusion/exclusion criteria were invited from the Department of Dermatology, University Hospital of Wales to contribute to focus group discussions. The patients were contacted by their respective consultant physician and the same method for recruiting patients for individual interviews (described above) was used for the focus groups. Patients were invited to attend focus group discussions in the dermatology out-patient department either by post or at their visit to the dermatology out-patient department. After confirmation, participants were informed at least two weeks before about the venue (a specific allocated room in the Dermatology Department, University Hospital of Wales), time and duration of a particular focus group discussion. Dedicated telephone numbers were established so that participants could inform the researchers directly if they were unable to attend a focus group meeting.

Each focus group was organised in the same way and consisted of participants who were unknown to each other. A semi-structured checklist was used for each discussion, which was developed from information revealed by the postal survey and individual interviews experiences. Along with the clinicians' invitation letter (Appendix L) the patients' focus group information pack consisted of four sections. Section 1 consisted of the general "Participant Information Sheet" (Appendix M), Section 2 consisted of a separate "Additional Information Sheet for Focus Groups" (Appendix N). This section was completely different from the general participant information sheet and was created to provide more specific information about the formation of focus groups and to explain the systematic procedure of conducting the discussion. Section 3 consisted of "Participant Consent Form" (for focus group) (Appendix P). Section 4 consisted of "Participant Personal Details" sheet (Appendix Q). All focus groups discussions were moderated by Z U B and were recorded using a digital recorder.

The initial plan was to contact 50 patients to form five focus groups with 10 patients in each group. However, after completing two focus groups, it was clear that no new information was being obtained and so further recruitment for the remaining three focus groups was discontinued.

Researcher role as a moderator: The moderator's role is crucial to the success of a focus group meeting. It is important to understand that participants generate the data and the moderator collects it. This basic understanding sets the tone of the role of a moderator. During each focus group discussion, the moderator's main role was defined as follows (Krueger 1997):

- To create a relaxed environment
- To facilitate free and open discussion
- To maintain a focus on the topic areas (by skipping areas which have already been covered and directing participants to new areas)
- To make sure all participants take part in the discussion
- To move things forward and provide a smooth transition from one topic area to another
- To discourage direct conversation
- To demonstrate respect to every participant regardless of their social and educational background

Discussion formation guide: The focus group discussions were structured (Morgan 1997). Participants were asked one question at a time, specific to the topic area selected by the moderator. As part of a structured plan, the moderator directed participants from general to more specific areas of the selected subject to facilitate more appropriate and specific discussion. A similar structured plan was used for both group discussions. During the discussion, participants were seated, facing each other around a round table to encourage all to freely take part in the discussion and respond more easily to any comments from other participants. The "Funnelling question technique" was used to direct discussion from general to more specific topics (Khan and Manderson 1992; Morgan 1997). The following pattern suggested by Krueger (1997) was used for opening the discussion: Welcome remarks; Overview of topic; Guidelines or ground rules; and Opening question.

After a brief welcome and the moderator-participant's self-introduction (Morgan 1997), the moderator opened the discussion by introducing a topic and by asking the same open ended question used for the postal survey and for individual interviews. The participants were asked "Could you please share your experiences about any ways in which your long-term disease has had a major influence on major life decisions". After an initial response from all the participants, they were systematically directed towards more specific aspects of life such as marriage or relationship, divorce or separation, having a child, higher education, job and career, change of profession or early retirement, relocating to another city or country. The moderator did not ask any specific question to any participants. The moderator helped participants to freely share their views, experiences, attitude, behaviour and any influence of their skin condition on their lives. The patients were asked to share their views one by one for recording purposes. All conversation was digitally recorded. The moderator thanked all participants for their time and participation.

Setting: Focus group meetings were carried out in the Department of Dermatology, University Hospital of Wales. The participants were reimbursed for their travel expenses incurred attending a focus group meeting.

The complete lists of documents used in three qualitative methods are listed in Table 2.1.

Data processing and analysis

Verbatim transcriptions of the individual interviews and focus group meeting were carried out from the digital recordings. These transcripts and those of the written responses from the postal survey were saved on to a secure computer. NVivo 8 qualitative software was used for analysis. Data was examined line by line and sentence by sentence.

Table 2.1: List of sections related to each method used in this study

Method	List of sections
Postal questionnaire survey pack	Section 1: Participant Information Sheet Section 2: Participant Consent Form Section 3: Participant Personal Details Section 4: Exploratory Qualitative Assessment Sheet
Individual interview invitation pack	Section 1: Participant Information Sheet Section 2: Participant Consent Form Section 3: Participant Personal Details
Focus group invitation pack	Section 1: Participant Information Sheet Section 2: Additional Information for Focus Groups Section 3: Participant Consent Form Section 4: Participant Personal Details

The common themes were identified from the text, grouped into major life decisions and later used to develop the first version of the new questionnaire MLCDP (version 1). Further confirmation of content validity of the initial version of MLCDP was carried out by a group of experts (consultant physicians and nurses from different disciplines). Agreement among the panel members was tested statistically using the ICC and kappa coefficient technique. On the basis of this analysis and suggestions from experts, changes were made to the MLCDP creating version 1a. Finally, exploratory factor analysis was carried out. Internal consistency reliability of items within a factor was also measured, using the Cronbach's coefficient alpha to show the relationship of each item within a factor. The applicability and practicality of the use of this new tool was also assessed using a short 4-item questionnaire. The end result of this phase was the creation of version 2 of the new tool MLCDP. SPSS 12 and 16 statistical software was used for all analysis.

CHAPTER 3

Development of a new instrument for measuring the impact of chronic diseases on major life changing decisions: Conceptualisation and item generation

INTRODUCTION

Conceptualisation of MLCDs and item generation was the first stage of the study. Due to lack of related information in the literature, detailed consideration was given at this stage for better understanding. Several meetings of the research team were carried out. The study question, methods, sample size, patient recruitment and data processing were discussed with research collaborators in order to obtain maximum information from patients. The detailed content analysis produced vital information for the conceptualisation of a novel concept of health and MLCDs. On the basis of the initial information, a working definition of "HRMLCDs" was formulated. Identified themes from patients comments were later used for items generation in a way that each item should represent each affected MLCD area reported by patients.

METHODS

Initial data collection

Initial data was gathered through (1) a postal questionnaire survey (2) individual interviews and (3) focus groups discussion to identify the influence of chronic diseases on major life changing decisions. The information obtained by these three main qualitative techniques was qualitatively coded into nodes, major categories and domains. Thereafter, it was analysed, summarised and quantified in the form of numbers and percentages to provide statistical meaning to the data.

Data processing and analysis

After collecting the initial data using the above mentioned three main qualitative techniques, the data were meticulously and systematically analysed word by word and line by line using NVivo 8 qualitative software. Main emerging themes and categories were carefully identified and grouped into main areas of patients' reported and affected life changing decisions. This information was later used for the development of the initial version of a generic measure the "Major Life Changing Decisions Profile" (MLCDP). At first, postal survey data were qualitatively analysed using NVivo 8 qualitative software (described later in this chapter). In this "content analysis" 38 affected "MLCDs themes" were identified and grouped into 14 "core MLCDs categories". These themes and core decision categories were later quantified in terms of frequencies and percentages using SPSS 16 statistical software to ascertain the magnitude of the impact of chronic diseases on MLCDs. Initially, in-depth data analysis was carried out separately for each individual speciality. The results were then combined to produce overall collective survey results.

All interviews were recorded using a digital recorder (interviews (n=50) total recording time=30 hours 52 min and 36 seconds, mean interviews duration=37.7 minutes, range=6.4 to 118.4 minutes). Word by word verbatim transcripts of the individual interviews were carried out by Z U B. Data was qualitatively analysed using the specific technique known as "content analysis" employing Nvivio8 qualitative software. Thirty-three affected "MLCDs themes" were identified and grouped into 13 "core MLCD categories". All identified themes and core categories were quantified as frequencies and percentages using SPSS 16 statistical software to determine the level of influence of chronic skin diseases on patients MLCDs. The correlation between the patients' age and the total number of influenced MLCDs reported by patients was calculated using the Spearman correlation coefficient.

Both focus group discussions were recorded using a digital recorder (FG1=57 minutes, FG2=60 minutes. Word by word verbatim transcripts of the focus groups were made from the digital recordings. Data were analysed using the specific technique known as "content analysis" using NVivo 8 qualitative software. Nine affected "MLCDs themes" were identified and grouped into 6 "core MLCD categories".

PROCEDURE

Postal survey: Participants were identified by the healthcare providers who were taking part in this study as collaborating researchers (consultant physicians). A total of 600 survey packs were posted or given to patients in the outpatient departments at the University Hospital of Wales and the University Hospital Llandough, Cardiff. These patients were adult (age 16 and over) from six medical specialities (cardiology, diabetes clinic, cystic fibrosis (CF) services, rheumatology, respiratory medicine and nephrology) who had been suffering from a chronic disease for more than one year (Table 3.1).

Individual interviews: fifty-five patients suffering from chronic skin diseases were identified through the hospital clinical record via the "Patient Management System (PMS). Patients' medical records were thoroughly searched to ensure that the strict inclusion/exclusion criteria were met. Identified patients were contacted by the clinician (dermatologist) either directly in the dermatology out-patient department or via post. After obtaining informed written consent, one to one in-depth interviews were carried out in the Welsh Institute of Dermatology, University Hospital of Wales, Cardiff.

Table 3.1: Total number of survey packs (total=600) posted to patients from each speciality

Participating medical speciality	Number of survey packs posted
Cardiovascular diseases	100
Rheumatology	100
Nephrology: Chronic Kidney Disease (CKD)	100
Diabetes	100
Cystic Fibrosis Services	100
Respiratory Medicine: Chronic Obstructive Pulmonary Disease (COPD)	100

Focus groups: Twenty patients suffering from chronic skin diseases were identified from the hospital clinical records via the "Patient Management System (PMS)". Patient's medical records were thoroughly searched to ensure that the strict inclusion/exclusion criteria were met. Identified patients were contacted either directly in the dermatology out-patient department or via post. After obtaining informed written consent, focus group discussions were carried out in the Welsh Institute of Dermatology, University Hospital of Wales, Cardiff.

Sample size and response rate consideration: Postal surveys are normally received as "cold" mail and because there has been no previous contact with the research team people may not respond. This may ultimately result in a response rate as low as 20% (Kelley et al. 2003). Similarly, the length, type and the nature of the survey may also influence the response rate (Zelnio 1980). In this study, the response rate was >50 % (n=310) (mean response rate= 51.6%, range= 36% to 61%), indicating a satisfactory level of response from six participating medical specialities (n=600) (Table 3.2).

Reminders were sent out to non respondents with a personalised covering letter, which also increased the response rate.

The general rule on sample size for interviews, for ensuring that all relevant information is revealed, is that when no additional information is emerging from subsequent interviews, then a sufficient sample size has been reached. Glaser and Strauss (1967) discussed the concept of "data saturation point" in detail and refer saturation as a point in data collection in which

> *"no additional data are being found whereby the (researcher) can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated...when one category is saturated, nothing remains but to go on to new groups for data on other categories, and attempt to saturate these categories also". (p. 65)*

This saturation point was reached at 28th interview when no new information was emerging. Another 22 interviews were carried out which yielded no new information; hence a satisfactory level of confidence had been achieved for initial data collection.

RESULTS

For the purpose of clarity the results will be presented in five parts: Part I, postal survey; Part II, individual interviews; Part III, focus groups; Part IV, content analysis and Part V, formation of definition of MLCD.

Part I. Postal Survey

Demographic characteristics of the study participants

A total of 258 (83.2%) responses were evaluable. There were 145 (56.2%) male and 113 (43.8%) female participants with the mean age of 53.7 years (median=58 years; range=18-92 years) (Table 3.3). of these 129 (50%) only had school education, 81 (31.4%) patients had college level and 48 (18.6%) had university education. More than a half of the participants (n=145, 56.2%) were married, 53 (20.5%) were single and 29 (11%) were divorced. In terms of employment status, 64 (24.8%) were employed, 29 (11.2%) were unemployed, 50 (19.4 %) were retired and 105 (40.7%) patients had retired early due to long term disease (Table 3.3).

Patients had been suffering from one of 20 different chronic conditions. The overall mean disease duration was 17 years (range 2 to 58 years). Participants from cardiology had been suffering from heart failure (13), coronary artery diseases (11), congenital heart problems (7), atrial fibrillation (3), cardiomyopathy (2), aortic stenosis (2) and myocardial infarction (2). Participants from nephrology had been suffering from chronic kidney diseases (CKD) (CKD Stage IV: 19, CKD Stage V: 3). Participants from respiratory medicine had been suffering from COPD (38) and CF (53). Forty participants were suffering from diabetes (diabetes type I: 12, diabetes type 2: 38). In rheumatology there were 20 patients with rheumatoid arthritis, 15 with ankylosing spondylitis, 7 with psoriatic arthritis, 4 with osteoarthritis, 3 with polymaylgia rheumatica, 2 with systemic lupus erythematosus, 2 with Sjorgen's syndrome, 1 with reflex sympathetic dystrophy and 1 with myositis (Table 3.4). The mean age and mean disease duration of participants are listed by speciality in Table 3.5.

Results: 310 (51.6%) of 600 patients returned their survey packs. 46 (7.6%) patients declined to take part and 6 (1%) patients had died (informed by relatives). 258 (83.2%) patients (male=145, female=113; mean age=53.7 years, range=18-92 years; mean disease duration=17 years, range=2-58 years; Rheumatology=55, CF=53, Diabetes=50, Cardiology=40, COPD=38, Chronic Kidney Disease=22) reported whether their chronic disease had had any influence on MLCDs or not. 207 (80.2%) patients reported their chronic disease had influenced at least one MLCD (core life decisions areas affected=14; mean MLCDs affected=2.1, range=1-9) and 51 (19.7%) patients reported no influence (Table 3.2).

The total numbers of affected core life decision areas with mean MLCDs are listed in table 3.6 by individual medical specialty. The mean number (4.3) of affected MLCDs was higher in CF patients then patients from any other speciality. As compared to other specialities, nephrology patients reported influence on less core life decisions areas (10) with a low mean (1.1) and a lower range of affected MLCDs (1-4). Whereas, diabetes patients reported more affected core life decisions areas (13) than patients from other specialities. A total of 119 patients reported influence on 1 to 2 MLCDs, 57 patients reported 3 to 4 and 13 patients reported influence on 6 MLCDs (Figure 3.1). One patient reported influence on 9 MLCDs with an overall median of 2.

Table 3.2: Postal survey response (%) by speciality

Participating medical speciality	Total survey packs posted or given to patients (N=600)	Survey response rate (N=310, 51.6%)	Declined (N=46, 7.6%)	Patients had died (informed by relatives) (N=6, 1 %)	Nature of responses and level of disease influence on MLCDs		
					Evaluable responses (N=258, 83.2%)	Influence on MLCDs (N=207, 80.2%)	No Influence on MLCDs (N=51, 19.7%)
Rheumatology	100	58 (58%)	3 (5%)	-	55 (94.8%)	45 (82%)	10 (18%)
Cystic Fibrosis Services (CF)	100	61 (61%)	8 (13.1%)	-	53 (86.8%)	50 (94.4%)	3 (5.6%)
Diabetes Clinic	100	60 (60%)	10 (16.6%)	-	50 (83.3%)	37 (74%)	13 (26%)
Cardiology	100	46 (46%)	4 (8.6%)	2 (4.3%)	40 (86.9%)	28 (70%)	12 (30%)
Respiratory Medicine (COPD)	100	49 (49%)	9 (18.3%)	2 (4%)	38 (77.5%)	31 (81.5%)	7 (18.4%)
Nephrology (CKD)	100	36 (36%)	12 (33.3%)	2 (5.5%)	22 (61.1%)	16 (72.7%)	6 (27.3%)

The MLCDs affected by chronic disease were related to early retirement (105, 40.6%), job (76, 29.4%), having children (64, 24.8%), career choice (58, 22.4%), relationships (divorce, marriage, separation) (40, 15.5%), moving abroad (35, 13.5%), education (32, 12.4%), housing (30, 11.6%), moving to another city (11, 4.2%), to step down from professional body (3. 1.1%), to quit professional sports (3, 1.1%) and major treatment decisions (dialysis, transplant, surgery) (3, 1.1%). Decisions related to holidays and travelling abroad (39, 15.1%) and life style change (18, 6.9%) were also regarded as life changing decisions by a considerable number of patients (Figure 3.2).

Table 3.3: Demographic characteristics of the study participants (n=258)

Variables	Number (%)
Age (years)	
Range	18-92
Median	58
Mean	53.7
Gender	
Female	113 (43.8)
Male	145 (56.2)
Education	
School	129 (50)
College	81 (31.4)
University	48 (18.6)
Marital status	
Single	53 (20.5)
Married	145 (56.2)
Divorced	29 (11.2)
Separated	1 (0.4)
Living with partner	8 (3.1)
Widowed	22 (8.5)
Employment status	
Employed	64 (24.8)
Unemployed	29 (11.2)
Retired	50 (19.4)
Early retirement	105 (40.7)
Part time employment	7 (2.7)
Student	3 (1.2)

Table 3.4: Frequencies of disease states for the six study groups

Specialities/diseases	N	Percent
1. Cardiology		
Heart Failure	13	5.0
Coronary Artery Disease (CAD)	11	4.3
Congenital Heart Problems	7	2.7
Atrial Fibrillation (AF)	3	1.2
Cardiomyopathy	2	.8
Aortic Stenosis (AS)	2	.8
Myocardial Infarction (MI)	2	.8
2. Nephrology		
CKD IV	19	7.4
CKD V	3	1.2
3. Respiratory Medicine		
COPD	38	14.7
4. Cystic Fibrosis (CF)	53	20.5
5. Diabetes		
Diabetes Type 2	38	14.7
Diabetes Type 1	12	4.7
6. Rheumatology		
Rheumatoid Arthritis	20	7.8
Ankylosing Spondylitis	15	5.8
Psoriatic Arthritis	7	2.7
Osteoarthritis	4	1.6
Polymyalgia Rheumatica	3	1.2
Systemic Lupus Erythematosus	2	.8
Sjorgen's Syndrome	2	.8
Reflex Sympathetic Dystrophy	1	.4
Myositis	1	.4
Total	258	100.0

Table 3.5: Patients' mean age and disease duration by medical speciality

Medical Speciality		Number of patients	Patient Age (years)		Disease Duration (years)	
			Mean	**Range**	**Mean**	**Range**
Rheumatology		55	55.1	28-82	17.0	2-47
Diabetes Clinic		50	59.4	27-84	17.1	2-56
Cardiology		40	59.5	19-81	15.5	2-58
Respiratory Medicine	CF	53	27.7	18-53	25.6	7-53
	COPD	38	65.8	53-84	9.1	2-50
Nephrology		22	68.3	46-92	12.4	2-33

Table 3.6: Total major life changing decisions areas with mean MLCDs affected by the six medical specialities

Medical speciality	Number of patients	Total number of major life changing decision areas affected	Affected MLCDs per patient		
			Mean	Median	Range
Rheumatology	55	12	1.9	2.0	1-6
Diabetes clinic	50	13	1.8	2.0	1-7
Cardiology	40	12	1.6	1.0	1-8
CF	53	12	4.3	4.0	1-9
COPD	38	11	1.3	1.0	1-6
Nephrology	22	10	1.1	1.0	1-4

Figure 3.1: Distribution of affected MLCDs among postal survey patients (n=258)

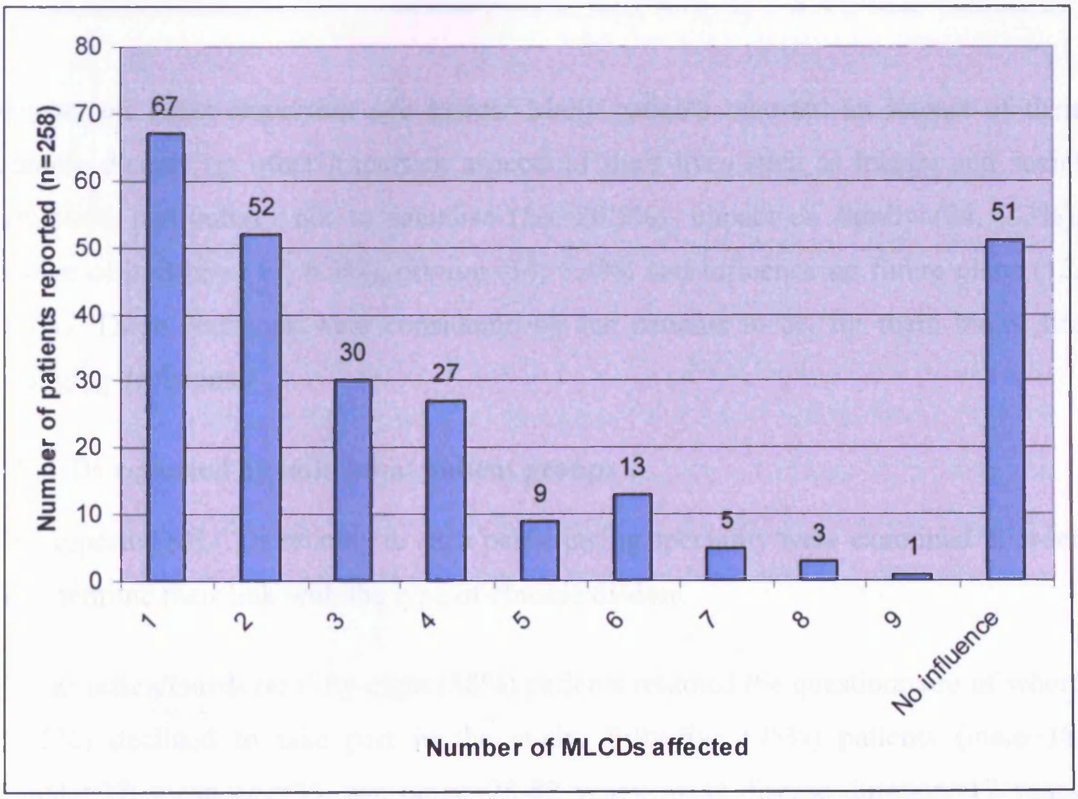
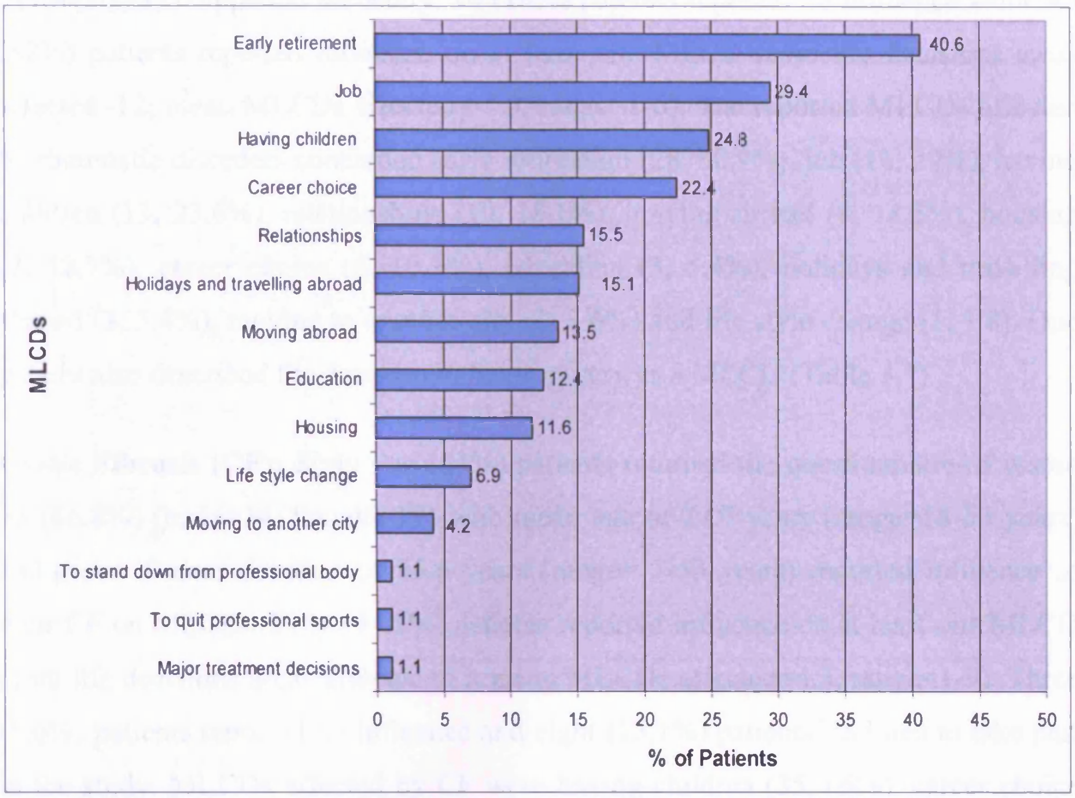


Figure 3.2: MLCDs influenced by chronic diseases for the postal survey participants



Impact on other important life issues: Many patients reported an impact of their chronic disease on other important aspects of their lives such as leisure and social activities, particularly not to socialise (53, 20.5%), impact on family (24, 9.3%), choice of holidays (17, 6.5%), driving (14, 5.4%) and influence on future plans (12, 4.6%). These decisions were considered by the patients to be, for them major life changing decisions.

MLCDs reported by individual patient groups

The reported MLCDs relating to each participating speciality were examined in order to determine their link with the type of chronic disease.

Rheumatic disorders: Fifty-eight (58%) patients returned the questionnaire of whom 3 (5%) declined to take part in the study. Fifty-five (95%) patients (male=18, female=37; mean age=55, age range=28-82 years; mean disease duration=17 years, range=2-47 years; Rheumatoid arthritis=20, Ankylosing spondylitis=15, Psoriatic arthritis=7, Osteoarthritis=4, Polymyalgia rheumatica=3, Systemic lupus erythematosus=2, Sjogren's syndrome=2, Myositis=1, Reflex sympathetic dystrophy=1) completed the study. 10 (18%) patients reported no influence while 45 (82%) patients reported influence on at least one MLCD (core life decisions areas affected=12; mean MLCDs affected= 1.9, range=1-6). The reported MLCDs affected by rheumatic disorders concerned early retirement (28, 50.9%), job (16, 29%), having children (13, 23.6%), relationships (10, 18.1%), moving abroad (8, 14.5%), housing (7, 12.7%), career choice (6, 10.9%), education (3, 5.4%), holidays and travelling abroad (3, 5.4%), moving to another city (2, 3.6%) and life style change (1, 1.8). One patient also described the decision to have surgery as a MLCD (Table 3.7).

Cystic Fibrosis (CF): Sixty-one (61%) patients returned the questionnaire of whom 53 (86.8%) (male=34, female=19) with mean age of 27.7 years (range=18-53 years) and mean disease duration of 25.6 years (range= 7-53 years) reported influence of their CF on MLCDs. Fifty (94.3%) patients reported influence on at least one MLCD (core life decisions areas affected=12; mean MLCDs affected=4.3, range=1-9). Three (5.6%) patients reported no influence and eight (13.1%) patients declined to take part in the study. MLCDs affected by CF were having children (35, 66%), career choice (31, 58.4%), job (31, 58.4%), education (24, 45.2%), relationships (19, 35.8%), moving abroad (13, 24.5%), early retirement (12, 22.6%), housing (9, 16.9%), moving to another city (3, 5.6%) and major treatment decisions (1, 1.8%) (Table 3.7). Decisions related to holidays and travel abroad (12, 22.6%), and life style change (2, 3.7%) were also regarded as life changing.

Chronic Obstructive Pulmonary Disease (COPD): Forty-nine (49%) questionnaire were returned of which 9 (18.3%) were not completed and 2 had deceased (informed by relatives). The remaining 38 (77.5%) patients (male= 23, female= 15) with mean age of 65.8 years (range= 53-84 years) and mean disease duration 9.1 years (range=2-50 years) reported influence of their COPD on MLCD. Thirty-one (81.5%) patients reported influence on at least one MLCD (core life decisions areas affected=11; mean MLCDs affected=1.3, range=1-6) and 7 (18.4%) patients reported no influence. The MLCDs affected by COPD were early retirement (20, 52.6%), job (8, 21%), housing (3, 7.8%), career choice (2, 5.2%), moving abroad (2, 5.2%), to quit professional sport

(2, 5.2%), decision to change life style (2, 5.2%), stand down from professional bodies (1, 2.6%), moving to another city (1, 2.6%) and having children (1, 2.6%) (Table 3.7). Nine (23.6%) patients reported decision about holidays and travelling abroad as MLCD and this was the second most frequently reported area reported by COPD patients.

Diabetes: Sixty (60%) patients returned their questionnaire of whom 10 (16.6%) declined to take part, and therefore there were 50 (type1=12, type2=38; male=30, female=20) with mean age of 59.4 years (range=27-84 years) and mean disease duration of 17.1 years (range=2-56 years) evaluable patients. Thirty-seven (74%) patients reported influence on at least one MLCD (core life decisions areas affected=13; mean MLCDs affected=1.8, range=1-7) and 13 (26%) patients reported no influence. The MLCDs affected by diabetes were early retirement (20, 40%), career choice (13, 26%), job (12, 24%), decision to change life style (11, 22%), having children (7, 14%), relationships (7, 14%), moving abroad (6, 12%), housing (3, 6%), education (2, 4%), moving to another city (2, 4%), to stand down from professional bodies (1, 2%) and to quite professional sports (1, 2%) (Table 3.7). Decisions related to holidays and travelling abroad (7, 14%) were also regarded as life changing.

Cardiovascular disorders: Forty-six (46%) patients returned their questionnaire of whom 4 (8.6 %) declined to take part in the study and 2 (4.3%) had died as informed by the relatives. Forty patients (male=27, female=13) with mean age of 59.5 years (range=19-81 years) and mean disease duration of 15.5 years (range=2-58 years) reported whether or not their disease had had any influence on MLCDs. Twenty-eight (70%) patients reported that their disease influenced at least one MLCD (core life decisions areas affected=12; mean MLCDs affected=1.6, range=1-8) and 12 (30%) reported no influence. The reported MLCDs concerned early retirement (15, 37.5%), having children (7, 17.5%), job (7, 17.5%), career choice (5, 12.5%), relationships (5, 12.5%), housing (4, 10%), moving abroad (4, 10%), education (3, 7.5%), moving to another city (2, 5%), decision to change life style (2, 5%) and to stand down from a professional body (1, 2.5%) (Table 3.7). Decisions related to holidays and travelling abroad (6, 15%) were also regarded as MLCDs.

Chronic Kidney Disease (CKD): Thirty-six (36%) out of 100 patients returned their questionnaire of whom 12 (33%) declined to take part in the study. The remaining 22 patients (male=13, female=9; mean age=68 years, range=46-92 years; CKD-IV=19, CKD-V=3; mean disease duration=12 years, range=2-33 years) were evaluable. Sixteen (78%) patients reported influence on at least one MLCD (core life decisions areas affected=10, mean MLCDs affected=1.1, range=1-4) and 6 (27%) reported no influence on MLCDs. The affected MLCDs were early retirement (10, 45.4%), housing (4, 18.1%), job (2, 9%), moving abroad (2, 9%), relationships (1, 4.5%), moving to another city (1, 4.5%), career choice (1, 4.5%), having children (1, 4.5%) and major treatment decisions (1, 4.5%) (Table 3.7). 2 (9%) patients reported the decisions to go for holiday and travelling abroad as MLCDs.

Table 3.7: Summary of MLCDs influenced by chronic diseases by the six disease areas

MLCDs n=207	Rheum* n=45	CF* n=50	COPD* n=31	DM* n=37	Cardio* n=28	CKD* n=16
Early retirement	✓	✓	✓	✓	✓	✓
Job	✓	✓	✓	✓	✓	
Having children	✓	✓	✓	✓	✓	✓
Career choice	✓	✓	✓	✓	✓	✓
Relationships	✓	✓	✗	✓	✓	✓
Holidays and travelling abroad	✓	✓	✓	✓	✓	✓
Moving abroad	✓	✓	✓	✓	✓	✓
Education	✓	✓	✗	✓	✓	✗
Housing	✓	✓	✓	✓	✓	✓
Lifestyle change	✓	✓	✓	✓	✓	✗
Moving to another city	✓	✓	✓	✓	✓	✓
To stand down from professional body	✗	✗	✓	✓	✓	✗
To quit professional sports	✗	✗	✓	✓	✗	✗
Major treatment decisions	✓	✓	✗	✗	✗	✓

*Rheum=Rheumatic disorders, CF=Cystic Fibrosis, COPD=Chronic Obstructive Pulmonary Disease, DM=Diabetes Mellitus, Cardio=Cardiovascular disorders, CKD=Chronic Kidney Disease

Part II. Individual interviews

Demographic characteristics of the study participants

Fifty-five patients were invited for interviews of whom 5 (9%) declined to take part. Fifty (91%) patients, (male=25, female=25), mean age=42.3 years (median=44.5 years; range=17-67 years), who were suffering from one of 8 chronic skin diseases (Figure 3.3) with mean disease duration of 29 years (range=2-61 years), participated in the study. Eighteen (36%) patients were single, 17 (34%) married and 7 (14%) divorced. Nineteen (38%) patients had school education, 16 (32%) college and 15 (30%) patients had university education. More than half of the patients (27, 54%) were employed and 10 (20%) patients had taken early retirement. Patients' detailed demographics are shown in Table 3.8.

Figure 3.3: Distribution of skin diseases in the study participants (n=50)

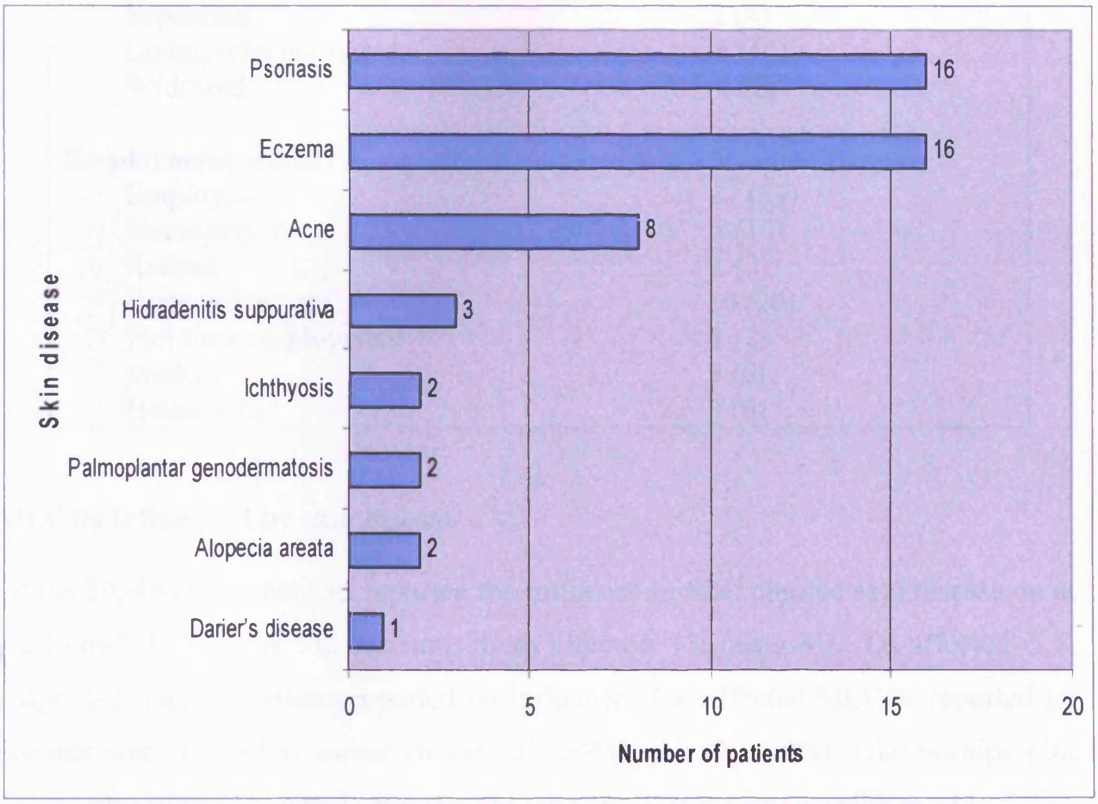


Table 3.8: Demographic characteristics of the study participants (n=50)

Variables	Number (%)
Age (years)	
Range	17-67
Median	44.5
Mean	42.3
Gender	
Female	25 (50)
Male	25 (50)
Education	
School	19 (38)
College	16 (32)
University	15 (30)
Marital status	
Single	18 (36)
Married	17 (34)
Divorced	7 (14)
Separated	2 (4)
Living with partner	5 (10)
Widowed	1 (2)
Employment status	
Employed	27 (54)
Unemployed	5 (10)
Retired	1 (2)
Early retirement	10 (20)
Part time employment	1 (2)
Student	3 (6)
Housewife	3 (6)

MLCDs influenced by skin disease

Of the 50, 45 (90%) patients reported the influence of their chronic skin disease on at least one MLCD (core life decisions areas affected=13; mean MLCDs affected=5.5, range=1-12) and 5 patients reported no influence. The affected MLCDs reported by patients were related to career choice (33, 66%), job (29, 58%), relationships (26, 52%), education (22, 44%), moving abroad (16, 32%), having children (11, 22%), early retirement (10, 20%), housing (7, 14%), moving to another city (6, 12%), holidays and travelling abroad (5, 10%), decision to change life style (2, 4%) and to quit professional sports (2, 4%). Several "lifestyle related decisions" were also regarded as MLCDs by a large number of patients, such as choice of clothing (27, 54%), stopped swimming (17, 34%), not to socialise (11, 22%) and wearing make up (11, 22%) (Figure 3.4). These were the only new themes that emerged during the interviews that had not been identified from the postal study. Decisions related to major treatment and to stand down from a professional body were reported in the postal surveys, but were not reported by patients during interviews.

The distribution of the number of affected MLCDs reported by 50 patients is shown in Figure 3.5. The distribution indicates the magnitude of affected MLCDs. More than half of the patients (n=26) reported that their disease influenced between 5 to 7 MLCDs. Four patients reported influence on nine MLCDs, two patients on 10 MLCDs and two patients reported influence on 11 and 12 types of MLCDs respectively.

Figure 3.4: MLCDs influenced by chronic skin diseases identified from interviews

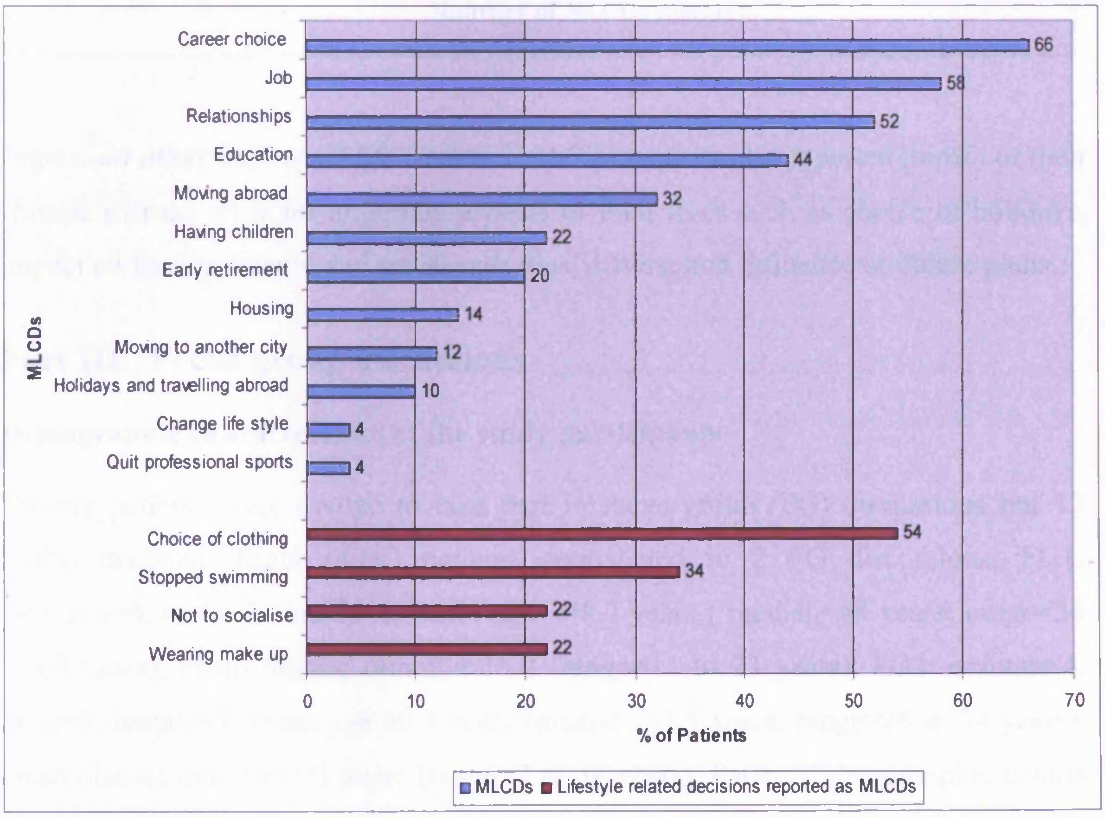
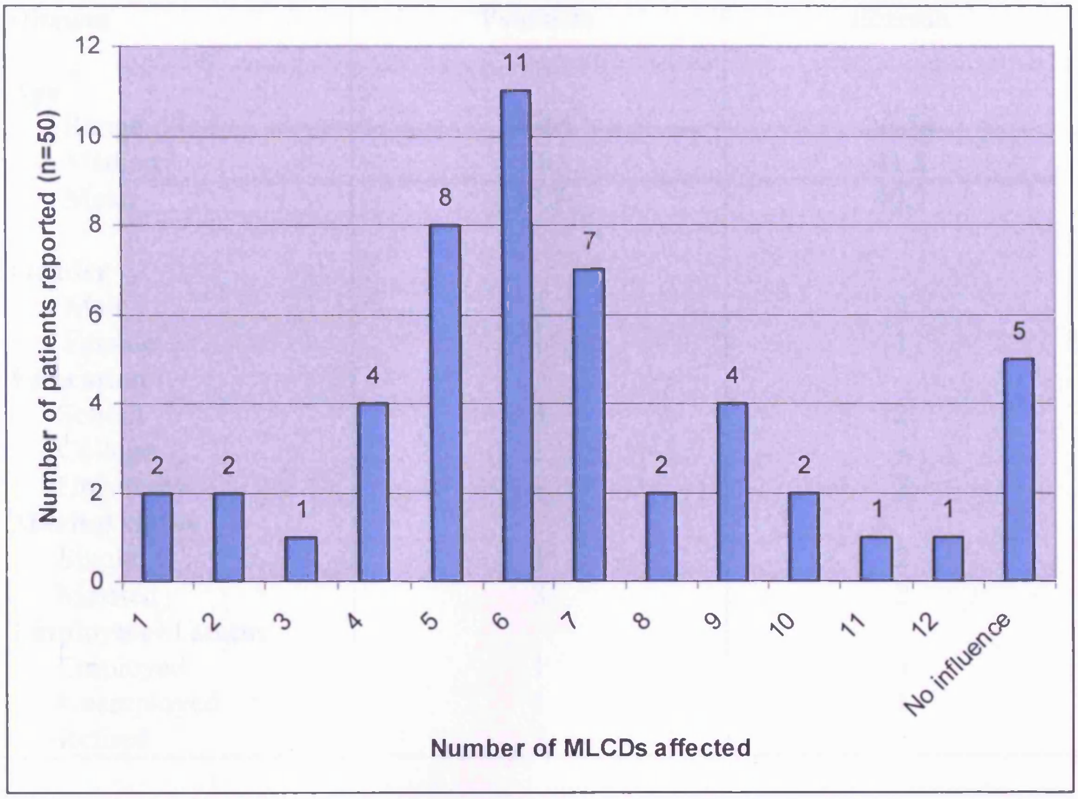


Figure 3.5: Number of affected MLCDs reported by patients with skin diseases (n=50)



Impact on other important life issues: 33 (66%) patients also reported impact of their chronic disease on other important aspects of their lives such as choice of holidays, impact on family, leisure and social activities, driving and influence on future plans.

Part III. Focus group discussions

Demographic characteristics of the study participants

Twenty patients were invited to take part in focus group (FG) discussions but 12 (60%) declined. Eight (40%) patients contributed to 2 FG discussions; FG1, psoriasis=4, male=3, female=1, mean age= 48.7 years (median=48 years; range=34 to 65 years), mean disease duration 15.2 (range=11 to 23 years); FG2, eczema=4, male=3, female=1, mean age 40.7 years (median=41.5 years; range=26 to 54 years), mean disease duration=31 years (range=7 to 54 years). Patients' demographic details are shown in Table 3.9.

Table 3.9: Demographic characteristics of the study participants

Patient demographics	FG1 (n=4)	FG2 (n=4)
Disease	Psoriasis	Eczema
Age		
Range	34-65	26-54
Median	48	41.5
Mean	48.7	40.7
Gender		
Male	3	3
Female	1	1
Education		
School	3	2
College	1	-
University	-	2
Marital status		
Single	1	2
Married	3	2
Employment status		
Employed	1	3
Unemployed	1	1
Retired	2	-

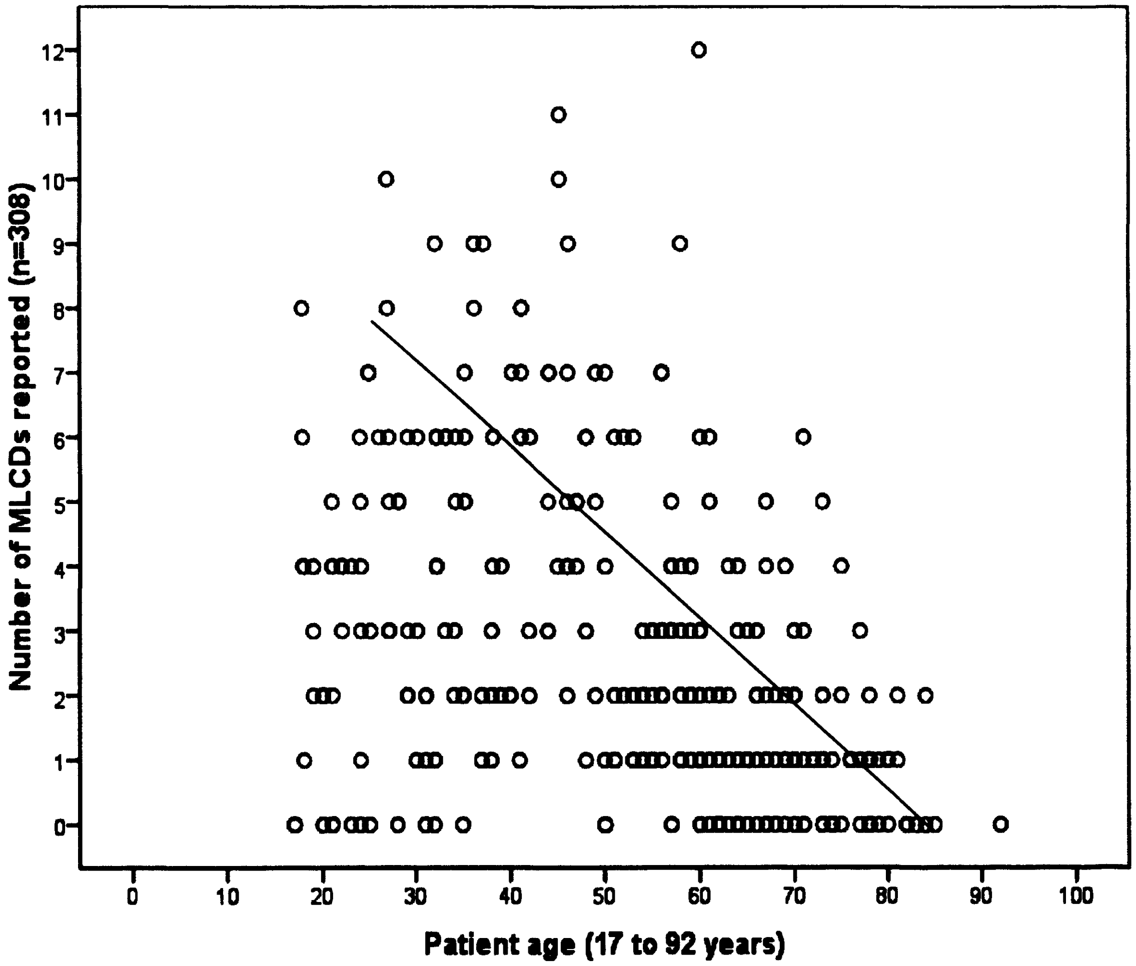
MLCDs influenced by skin diseases

Initially, five FGs (n=50, 10 patients in each group) were planned but due to repetition and emergence of the same information, and difficulty in recruitment, further recruitment was stopped after two FG meetings. The information obtained was similar to the information gathered through the postal survey and the individual interviews, and no new information was gained. The MLCDs reported as being affected by patients during FG discussions were career choice, early retirement, job, housing, holidays and travelling abroad and life style related decisions such as choice of clothing, not to go swimming, and wearing make up. This provided reassurance that no major themes were being overlooked and confirmed the rigour of the earlier interview process.

Relationships between the patients' age and their reported MLCDs

It was of interest to understand whether there was any link between the patients' age and their number of affected MLCDs. There was a wide scatter, but showed a trend towards decreasing total number of influenced MLCDs with increasing age of the patients (Figure 3.6) and this was statistically significant (rs = -0.46, p=<0.001, n=308). This suggests that younger patients need more help at an early stage of their disease to take control over their MLCDs and lives. It is clear that most of the MLCDs taken by patients are related to early life stages and many of these MLCDs may not be relevant at a later stage of life, such as having children, career and job. The total number of new MLCDs affected is therefore naturally less in older patients.

Figure 3.6: Scatter plot showing the relationship between patient age and the total number of MLCDs affected as reported by patients (n=308)



Comparison of MLCDs for gender

Postal survey: The percentage of male participants (145, 56.2%) was slightly higher than females (113, 43.8%). Chronic disease influences on MLCDs related to career choice and early retirement were reported more frequently by male patients and influences on the decision to have children was reported more frequently by female participants. Otherwise, there were no significant differences between males and female regarding the type and the level of MLCDs affected (Figure 3.7).

Individual interviews (Dermatology): The numbers of male (n=25) and female (n=25) participants were equal and no significant difference was found between them in the way they reported the influence of their chronic disease on MLCDs and the number and the type of affected MLCDs. However, a higher number of male (n=11) than female (n=5) patients reported an influence of their chronic disease on their decision to move abroad. Similarly, important decisions related to housing were affected in more female (n=7) than male (n=1) patients. In addition, the decision to wear make up because of their chronic disease was only reported by female patients (n=11) reflecting the gender specific nature of this MLCD (Figure 3.8).

Figure 3.7: Comparison of MLCDs between males and females (Postal survey)

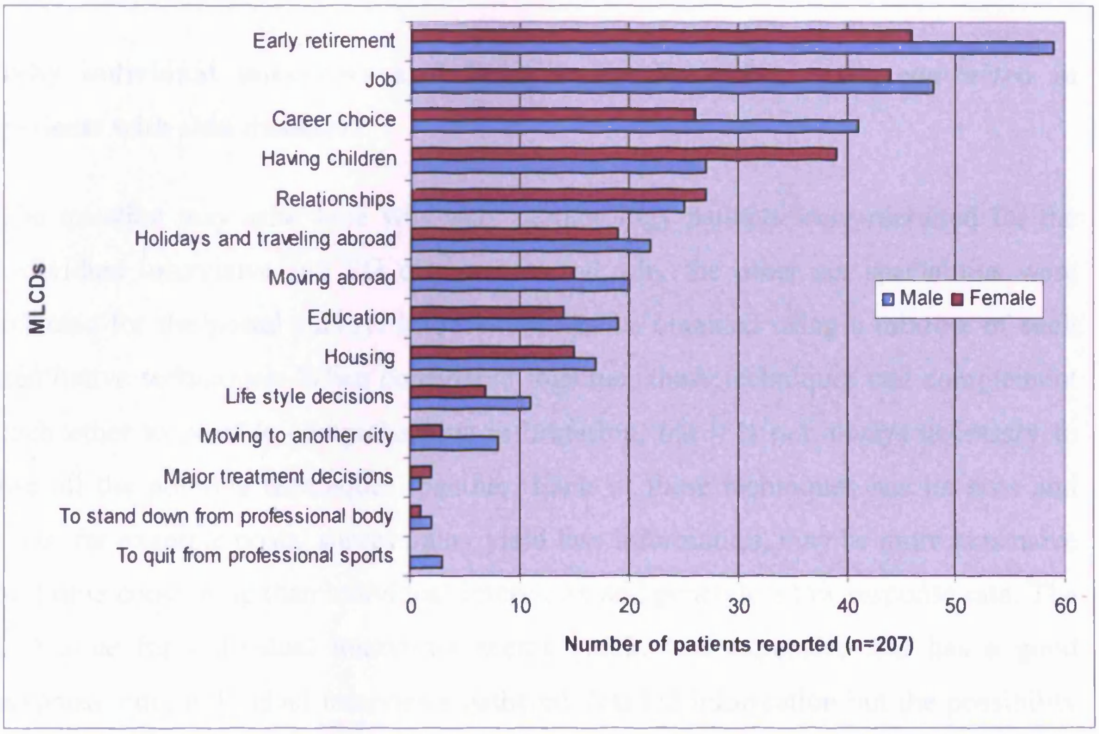
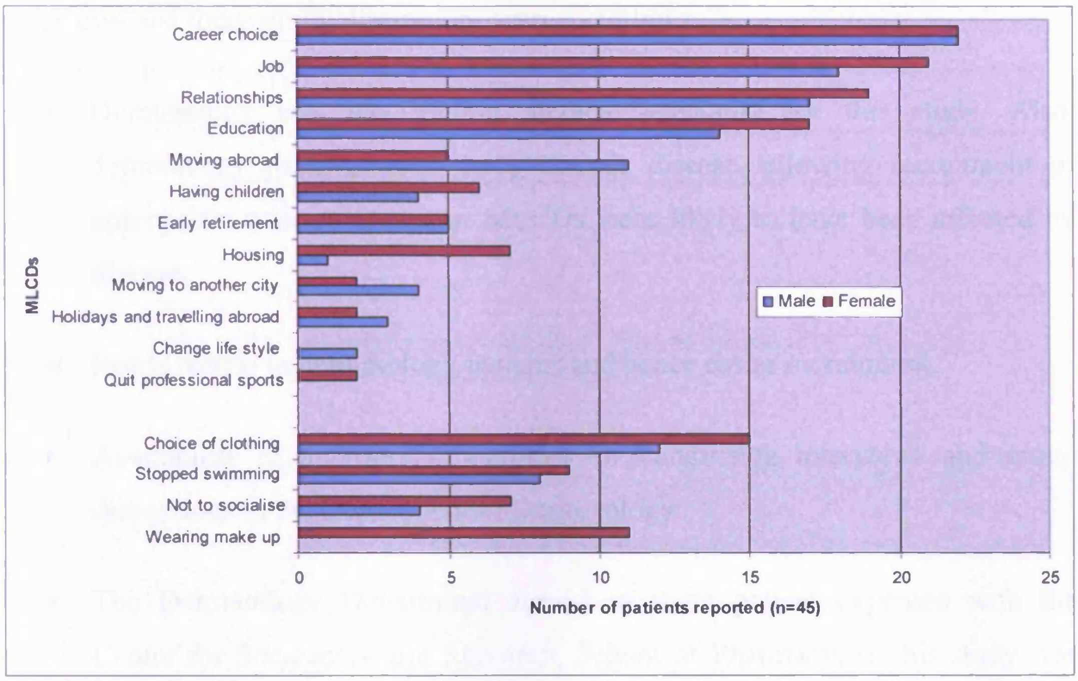


Figure 3.8: Comparison of MLCDs between males and females (Individual interviews)



Why individual interviews and focus group discussions were conducted in patients with skin diseases?

The question may arise here why only dermatology patients were recruited for the individual interviews and FG discussions and why the other six specialities were selected for the postal survey. Information can be obtained using a mixture of such qualitative techniques. When considered together, these techniques can complement each other to provide comprehensive information, but it is not always necessary to use all the possible techniques together. Each of these techniques has its pros and cons; for example postal surveys may yield less information, may be more expensive and time consuming than individual interviews and generate a low response rate. The technique for individual interviews seems quick, less expensive and has a good response rate. Individual interviews gathered detailed information but the possibility may exist of an interviewer's bias. In focus groups, patients may avoid sharing sensitive issues due to the presence of other participants and due to time restrictions which may not allow detailed discussion by all participants. On the other hand, the time available, the cost of patients attending interviews, the potential major costs of group discussions for >500 patients and the availability of appropriate facilities are also important practical considerations for selecting a specific information gathering strategy. The reasons why only dermatology patients were recruited for individual interviews and focus group discussions were as follows:

- Dermatology was the leading medical speciality for this study. Also, dermatology patients often have chronic disease, allowing recruitment of appropriate patients in whom MLCDs were likely to have been affected by disease.
- Ready access to dermatology patients and hence easier recruitment.
- Availability of appropriate facilities for conducting interviews and group discussions in the Department of Dermatology.
- The Dermatology Department agreed to share patient expenses with the Centre for Socioeconomic Research, School of Pharmacy, as this study was jointly supervised between these two units.

It was decided at the protocol stage that only dermatology patients would be recruited for individual interviews and for focus group discussion.

Factors influencing MLCDs

Of the 258 evaluable replies, 207 (80.2%) patients reported an influence of their chronic disease on various MLCDs. The patients also reported various "factors" correlated to their chronic disease that had influenced their MLCDs and explained why they took MLCDs differently.

Twenty-five factors influencing MLCDs were identified. Ill health and severity of disease, reported by 71% of respondents, frequent hospital visits and treatment (30.4%), physical disability (30.4%) and stress, fear and anxiety (29.9%) were the most frequently reported factors (Figure 3.9). Life expectancy (1.4%), discrimination (1.4%) and job insecurity (0.9%) were the least frequently reported disease associated factors that influenced patients' MLCDs. Details of all factors influencing MLCDs are shown in Table 3.10.

Similar key factors were also indentified during individual interviews (n=45) (Figure 3.10) and were also discussed during focus group sessions. These factors included ill health and severity of disease, appearance, public attitude and bullying, physical disability, lack of confidence, self esteem and self consciousness, embarrassment, working conditions and risk to health. These factors can be classed under "patient's comments" which will be further described later in this chapter.

Figure 3.9: Key disease related factors that influenced MLCDs (Postal survey, n=207)

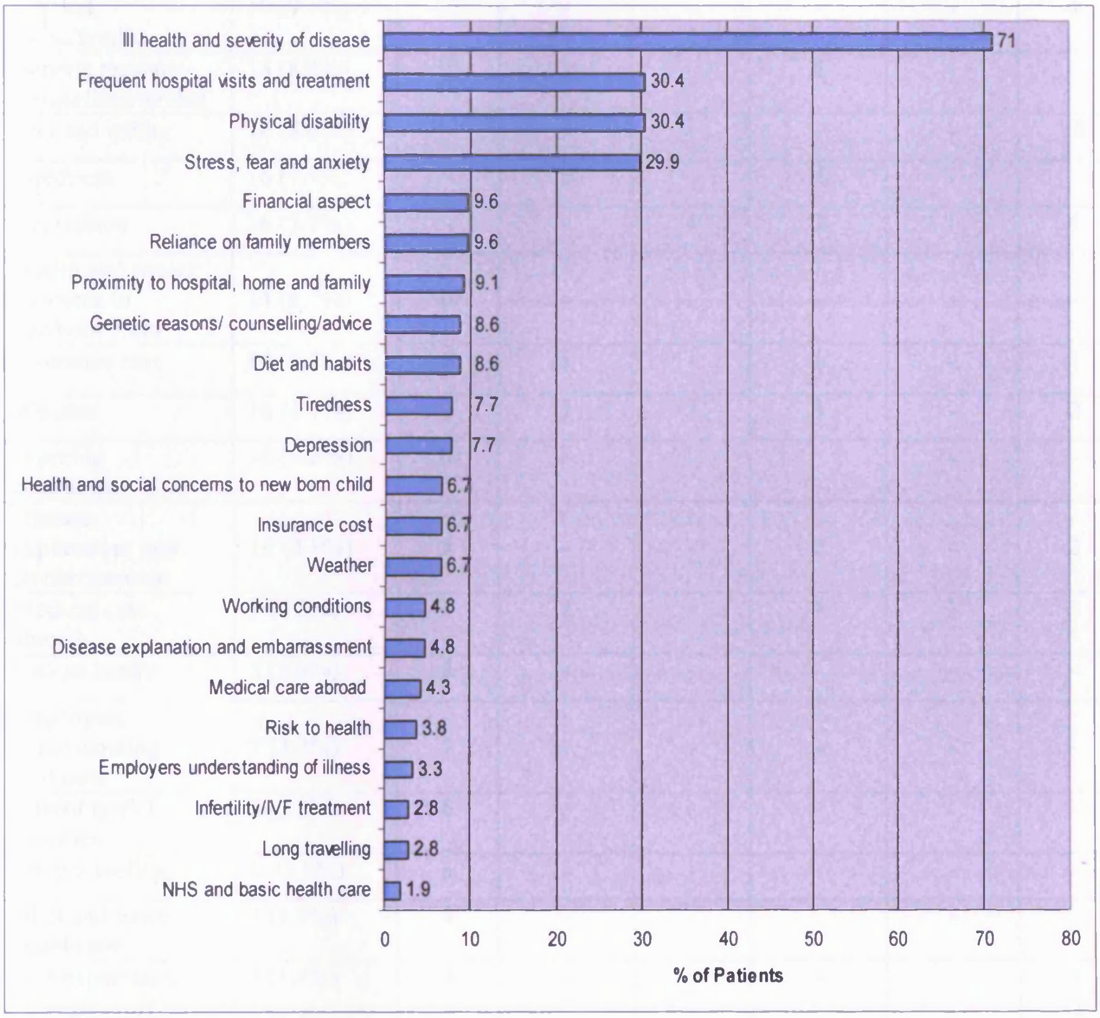
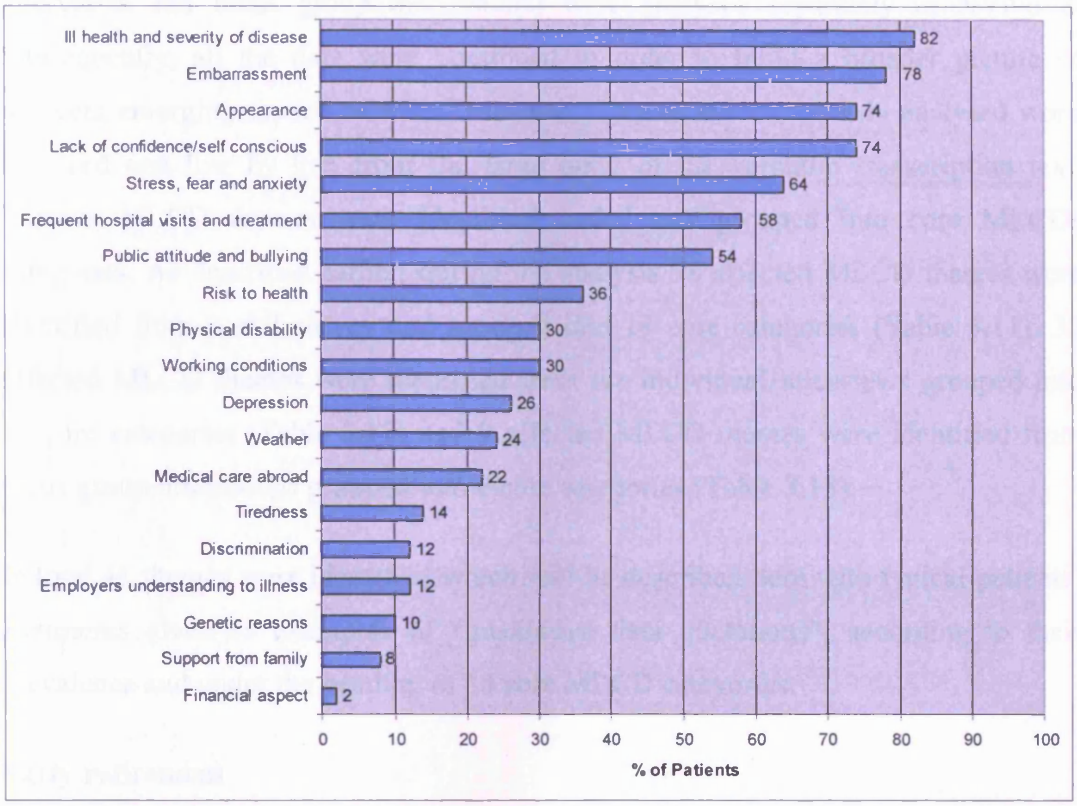


Table 3.10: Factors influencing MLCDs

Factors influencing MLCDs (n=207)	N	CF* N=50	Cardio* N=28	COPD* N=31	Rheum* N=45	Nephro* N=16	DM* N=37
Ill health and severity of disease	147 (71%)	34	16	27	32	11	27
Frequent hospital visits/treatment	63 (30.4%)	17	10	7	17	1	11
Physical disability	63 (30.4%)	6		16	30		11
Stress, fear and anxiety	62 (29.9%)	18	5	12	12	2	13
Financial aspect	20 (9.6%)	6	2	-	8	-	4
Reliance on family members	20 (9.6%)	3	1	8	4	2	2
Proximity to hospital, home/family	19 (9.1%)	15	-	-	-	-	4
Genetic reasons/ counselling/advice	18 (8.6%)	10	3	-	5	-	-
Diet and habits	18 (8.6%)	-	-	-	-	-	18
Tiredness	16 (7.7%)	-	5		10	1	
Depression	16 (7.7%)	-	-	4	7	1	4
Health and social concerns to newborn child	14 (6.7%)	14	-	-	-	-	-
Insurance cost	14 (6.7%)	8	1	-	1	-	4
Weather	14 (6.7%)	3	1	5	3	-	2
Working conditions	10 (4.8%)	10	-	-		-	-
Disease explanation and embarrassment	10 (4.8%)	8	-	-	2	-	2
Medical care abroad	9 (4.3%)	-	2	-	4	1	3
Risk to health	8 (3.8%)	8	-	-	-	-	-
Employers understanding of illness	7 (3.3%)	7	-	-	-	-	-
Infertility/IVF treatment	6 (2.8%)	6	-	-	-	-	-
Long travelling	6 (2.8%)	6	-	-	-	-	-
NHS and basic healthcare	4 (1.9%)	4	-	-	-	-	-
Life expectancy	3 (1.4%)	3	-	-	-	-	-
Discrimination	3 (1.4%)	-	-	-	-	-	3
Job insecurity	2 (0.9%)	2	-	-	-	-	-

* CF=Cystic Fibrosis, Cardio=Cardiology, COPD=Chronic Obstructive Pulmonary Disease, Rheum=Rheumatology, Nephro=Nephrology, DM=Diabetes Mellitus

Figure 3.10: Key disease related influential factors that influenced MLCDs (Individual interviews, n=45)



Part IV. Content analysis

Content analysis is a systematic way of identifying and organising relevant segments of qualitative data into more meaningful information. Similar segments from the text were coded (thematic coding) and grouped into core categories for their meanings, easy identification, retrieval, comparison and quantification (frequencies). Strauss and Corbin (1990) described each core category as a "sun" and its associated themes as "planets".

The detailed content analysis of qualitative data was carried out using NVivo 8 "Qualitative Data Analysis Software" (QDAS) produced by QSR International Pt Ltd. This software provides a "tree branch", a hierarchal coding system for emerging themes and links to their main category, or in other words, to their conceptual core domain. A colour coding system in this software makes a large amount of text data much easier to organise, aiding analysis. A "Memo" option allows researchers to note down their own thoughts while analysing data, which can later be linked to its original source.

Initially, data obtained through three qualitative methods (postal survey, individual interviews and focus group discussions) were analysed separately in NVivo 8. Subsequently, all the data were combined in order to build a broader picture of different emerging aspects of MLCD themes. Data were meticulously analysed word by word and line by line from the large body of the verbatim transcription text. Various MLCD themes were identified coded and grouped into core MLCDs categories. As described earlier, during the analysis 38 affected MLCD themes were identified from postal survey and grouped into 14 core categories (Table 3.11), 33 affected MLCD themes were identified from the individual interviews grouped into 13 core categories (Table 3.12) and 9 affected MLCD themes were identified from focus group discussions grouped into 6 core categories (Table 3.13).

In total 41 themes were identified which will be described here with typical patients' comments given as examples of "qualitative data quotations", according to their prevalence and under the heading of 15 core MLCD categories.

Early retirement

The decision to take "early retirement" was the most prevalent affected MLCD reported by patients (postal survey: n=105, 40.6%; individual interviews: n=10, 20%; focus groups discussion=Yes). The unremitting nature of the impact of chronic diseases on patients' lives was so immense that with time it had diminished some patients' ability or desire to work. The majority of patients reported their desire to work until retirement age but the long-term nature of their illness prevented them from undertaking normal employment activities and eventually made it impossible for them to continue.

"I retired from work in December 2004, much earlier then I had always planned as my illness caused me to be unreliable. My employer did not want me to retire but I felt unable to carry on as my input was essential for the running of a small business"

<Internals\Rheumatology\RHEU-692>

"Due to bad health I can not carry on working and I have to take early retirement. It is all due to diabetes and related complications and I was classified as disabled"

<Internals\Diabetes\DIAB-549>

"As the direct result of this long term disease, I had no alternatives other then to take early retirement last May 2008, I should have continued to work for at least another five years"

<Internals\Nephrology\NEPH-283>

Table 3.11: Main MLCD themes identified from the content analysis of the postal survey (n=207)

Core MLCD categories	MLCD themes
Career choice	Abandoned career plan Career selection Change of profession
Decision to change life style	Change in life style
Major treatment decision	Decision to have dialysis Decision to have organ transplant Decision to have surgery
Early retirement	Decision to take early retirement
Education	Higher education Left education Selection of an educational institute
Having children	Delayed plans for having children Having children through IVF Not to have children Not to have more children
Holidays and travelling abroad	Holidays abroad Travelling abroad
Housing	Buying a house Moving to another house
Job	Flexible working hours employment Gave up job Job selection Not to mention illness on job application Not to progress further in job Not to seek employment Part time employment Self employment To stay in same employment Unemployed or remain unemployed
Moving abroad	Decision to move to another country
Moving to another city	Decision to move to another city
Relationships	Divorce Marriage Not to become involved in relationships Separation
Stand down from professional bodies	Decision to leave professional body
To quit professional sports	Decision to quit sports

Table 3.12: Main MLCD themes identified from content analysis of individual interviews (n=45)

Core MLCD categories	MLCD themes
Career choice	Abandoned career plan Career selection Change of profession
Decision to change life style	Change in life style
Early retirement	Decision to take early retirement
Education	Higher education Left education Selection of an educational institute
Having children	Delayed plans for having children Not to have children Not to have more children
Holidays and travelling abroad	Holidays abroad
Housing	Buying a house Moving to another house
Job	Flexible working hours employment Gave up job Job selection Not to progress further in job Part time employment Self employment To stay in same employment Unemployed or remain unemployed
Life style decisions reported as MLCDs	Choice of clothing Not to go swimming Not to socialise Wearing make up
Moving abroad	Decision to move to another country
Moving to another city	Decision to move to another city
Relationships	Divorce Marriage Not to become involved in relationships Separation
To quit professional sports	Decision to quit sports

Table 3.13: Main MLCD themes identified from content analysis of focus groups (n=8)

Core MLCDs categories	MLCD themes
Career choice	Career selection
Early retirement	Decision to take early retirement
Holidays and travelling abroad	Holidays abroad
Housing	Moving to another house
Job	Gave up job To stay in same employment
Life style decisions reported as MLCDs	Choice of clothing Not to go swimming Wearing make up

Retirement is generally regarded as one of the major life stages, when people officially stop working for a living. Retirement age is usually at a predefined time, defined by the state or employers (60 or 65 years of age) when people end their working life. It is normally organised with a state pension and other benefits related to pension contributions to allow people to live their remaining life within a reasonable economic standard. It is obvious that the decision to take early retirement for any reason has significant financial implications and in particular may not be an easy option for those who earn a limited income. Despite the huge financial implications of this MLCD, their chronic disease left no choice for many patients other than to take early retirement, in order to look after their health.

"Have had to seriously consider early retirement and subsequently the financial implications on pension options"

<Internals\Rheumatology\RHEU-695>

"My heart condition means that I had to finish my working life early. That caused a problem with a lack of finance"

<Internals\Cardiology\CARD-109>

The financial implications of the decision to retire early should not be underestimated as retirement may lead to various interconnected impacts on patients' health. For example, one diabetes patient reported:

"Early retirement: leading to a loss of self worth resulting in depression leading to mental break down. Break down of family structure"

<Internals\Diabetes\DIAB-533>

Looking after their health may become a full time job for some patients and it may not be possible for them to continue to take part in active employment. One dermatology patient reported:

"My eczema is a full time job apart from anything else. From the time you get up to the time you going to go to bed. Going to bed is not much fun because you are so restless. But it is actually a fulltime job looking after your skin"

<Internals\Interviews\Dermatology-Individual Interviews\II-12>

Being unable to accept the condition and having specific beliefs may also play an important role in a patient's psychological well being, leading to withdrawal from employment. One dermatology patient reported "psoriasis as a curse":

"I have tried but I won't. I wasn't very well. I couldn't stand up behind the till. I couldn't pick things up. I couldn't get out from bed properly and then I was diagnosed with psoriatic arthritis. Then, I thought that I have psoriasis, now I have got this so it seems like it's not letting me go. It is going to be on my face until I die and it is a curse. It is bad, it is horrible. It is like a curse on me"

<Internals\Interviews\Dermatology-Individual Interviews\II-13>

The disease's physical impact played a major role in the decision of some patients to take early retirement.

"I got arthritis from psoriasis and it just became impossible for me to get on and off the buses, walk to the school and stand in the yard so I retired in 2003...I suppose it was a physical part at this point. Because I worked in school for 20 years and I had gone to school with it most of the time and they knew what I had. I think that was the only place where I felt confident in that work but, as I said, I like paid in that summer because I would be covered from head to toe and would have to suffer. It was only an hour and so which again is that the psoriasis. I couldn't have worked any longer any where else. Because, I couldn't have coped with the heat and everything else"

<Internals\Interviews\Dermatology-Individual Interviews\II-21>

On the other hand, working become a way of life for many people and taking retirement so early due to illness may also affect patients emotionally:

"That was the decision (early retirement) but it was an inevitable decision because of the disease and that's influenced my life completely. The way the disease and that ability to work and hold down a job has influenced everything else both emotionally you know, that's a whole other story, how I feel about not working for so long"

<Internals\Interviews\Dermatology-Individual Interviews\II-28>

"Because I had spent a lot of time in the infirmary and the Heath... Yes definitely (it's a major life changing decision) and changed my life in a big way because it is nice to go out and meet people and talk to people. It is being locked away now"

<Internals\Interviews\Dermatology-Individual Interviews\II-49>

Patients' comments

"I stopped working at the age of 52 due to health concerns. I had to take this decision. It was preventing me to do normal life, so due to my ongoing health problem I had to take this decision and not to engage in employment"

<Internals\Cardiology\CARD-149>

"CF caused the premature end of my career, forcing retirement at the age of 37 years"

<Internals\CF\Cystic Fibrosis\CF-404>

"Taking early retirement because I could not continue looking after myself and working"

<Internals\CF\Cystic Fibrosis\CF-431>

"Retired from work at 57 years due to tiredness as I was a nursery nurse"

<Internals\Diabetes\DIAB-530>

"I have had to finish work at 53. This has been hard as I was developing a new career"

<Internals\Diabetes\DIAB-596>

"I have to, I had no options my health wouldn't take the pressure.....I had health problems, it was severe then and it was worse when I finished and still worse now, so from the time I left there to now its just gone down hill, it's up and then goes down but it got worse... of course it had to be (major life changing decision), I had no option...I left because my health wouldn't let me do anymore"

<Internals\Interviews\Dermatology-Individual Interviews\II-47>

"Not being able to drive through lack of confidence after many operations and not able to walk very far and having to rely on my family and friends to look after me. I had to take early retirement"

<Internals\Nephrology\NEPH-203>

"Unable to work for a very long period of time. Then got the job in (employer name) but again due to my health I have decided to take early retirement"

<Internals\Respiratory Medicine\RESP-314>

"I worked until 1994 but found that I took early retirement on the grounds of ill health because of rheumatoid arthritis...That decision was life changing for me as I loved my job, but I realised that I could no longer cope with trying to work and hold down a job"

<Internals\Rheumatology\RHEU-615>

"Unable to return to employment and my profession hairdressing due to joint pain and deformity of my hands- took early retirement"

<Internals\Rheumatology\RHEU-619>

"Have decided to give up work, have worked all my life, but have no quality of life, so have taken ill health retirement"

<Internals\Rheumatology\RHEU-660>

"I have also got psoriatic arthritis. I had to finish work when I was 47 and found that quiet hard to cope with at that time. Still do really because it makes you feel a bit useless. As you are not contributing, not doing anything, you know what I mean...At the time, I was too ill anyway, so I was far too ill at that time to look for further employment" (FG1FP1)

"Well the only thing that happened to me was when I had this psoriatic arthritis and psoriasis, they offered me alternative employment such as office work and stuff like that, such as I was on the safety committee. They wanted me to be the safety officer but at that time with all that was going on. I just wanted to finish anyway. It was too much for me to do anyway...It was just getting to a stage where I couldn't do the work. When I actually stopped, before I finished they employed another chap, right to work alongside me and I was to tell him what to do. But in the end it is one of those things that you can't work and say to a chap pick up that and lift that, in the end you try to do it yourself and it was just too much...I had already served 33 years there and I had to finish 10 years early. I am sure at the end of it I could have more, I wouldn't say money, but more security if I had done it another ten years"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG1MP2>

Job

The major life changing decisions related to "Job" or employment was the second most prevalent affected MLCD reported by patients (postal survey: n=76, 29.4%; individual interviews: n=29, 58%; focus groups discussion=Yes). In this core MLCD domain, 10 major categories were identified: Gave up job, unemployment, part time employment, to stay in same employment and self employment were the most prevalent affected aspects of MLCDs. Less frequently reported MLCDs were related to: not to seek employment, not to progress, not to mention illness in job application and job selection.

Gave up job: Most patients reported that giving up an established job was not an easy decision but certainly was life changing in respect to their daily routine, finance, family, life style and future plans. Particular working environments also made it harder for patients to continue their chosen employment. Similarly, giving up such a job where patients might have opportunities to develop their career in the future made it more difficult for patients to take this important MLCD. The aesthetic nature of chronic skin diseases was the most obvious reason for several patients to take this decision, and to avoid continuous embarrassment. The physical nature of the employment had also contributed towards some patients' decisions to give up their job.

Patients' comments

"I was a long distance lorry driver. I had to give up my job. For five years, I didn't accept this; I was the bread winner of my family"

<Internals\Diabetes\DIAB-572>

"When going on to insulin I was working in the Middle East and decided to give up my position there which was highly paid, 50+k per annum"

<Internals\Diabetes\DIAB-576>

"I was working in a soldering factory, developed asthma. Also missing a lot of work and the boss complained I was spending too much time off line in the toilet. Decided to leave the job, since then I have not worked due to ill health"

<Internals\CF\Cystic Fibrosis\CF-499>

"Had to give up a job after becoming ill, a job I enjoyed very much and hoped would move into a career"

<Internals\CF\Cystic Fibrosis\CF-479>

"Initially after ventricular tachycardia in my early 20s had to resign my job and career as a field scientist (environmental)"

<Internals\Cardiology\CARD-116>

"The main thing that influences you if it's become apparent not to just yourself but for other people, and then you react the way the other people perceive you. Now in my particular case, I used to work as a teacher and with that I felt that I was in the eyes of my students throughout the day. Now with my particular skin condition with the sort of dry skin, it is a very severe dryness which sometimes comes on even after I put medication on. So I found sometimes, teaching first thing in the morning after having prepared myself, you know like shower and then cream and then an hour later I find that my skin was sort of dry again and of course the pupils then wouldn't waste any time pointing that out, sort of laughing and saying "oh sir…this is happening, this is happening"…So therefore, as a reaction to that I certainly felt very self-conscious about putting myself in that situation and it was certainly a factor in me deciding to leave the teaching profession…I didn't feel I was able to give 100% sort of with it if the pupils were then going to be distracted through my appearance so that did cause me to think long and hard whether I wanted to carry on in the classroom and perform in front of children without my condition being under control, so that is the way it's affected me regarding the sort of work situation"

<Internals\Interviews\Dermatology-Individual Interviews\II-07>

"I was a shopkeeper and then I got married. I worked for a children's school for eight years, I looked after partially sighted children, which I felt protected from them because they didn't judge me, in fact they couldn't see me properly which helped. They never judged me. I worked for them for 8 years. That was the reason behind the change of job. I don't want to take it on my face again. People bring it to your face again when you've got psoriasis. I used to scrub myself with the scrubbing brush because I grew up thinking because I was dirty"

<Internals\Interviews\Dermatology-Individual Interviews\II-13>

"Because I couldn't just physically couldn't do the job anymore. My hands were so cracked and bleeding all the time, my face was permanently purple and so itchy and so I didn't have much hair left...yes because I couldn't cope with the dirt on the shop floor and things like that and I can't cope with paper, the dirt of paper and things. So I can't touch a lot of dust"

<Internals\Interviews\Dermatology-Individual Interviews\II-19>

"Giving up work I think was obviously a directly influenced decision really. We were living away from our home area, our home area is here, we were living away and we got to the point, I was never really at work, so the decision was to leave work and return home. I was with my partner then, I wasn't single. We decided really because of that to return home partly because of the treatment available here and also you have support from family and things like that...I was always on the waiting list for the surgery so that was always quite difficult. You are constantly sort of in limbo, which explains why I haven't worked for a long time. Once I gave up work, never intended to stop working for good. I moved back here and wanted to get another job but I just never had that sort of reliability I can offer to an employer you know. I could be off regularly. I could never say when I was going to have surgery... yea, that was my personal decision, they never asked me to leave or anything like that...I mean it was physical a lot of it, the nature of the condition mostly on my buttocks, I had an office job and it's very difficult, just physically"

<Internals\Interviews\Dermatology-Individual Interviews\II-28>

"So yes my illness then definitely made me make a choice to change my lifestyle which meant giving up my job because hidradenitis is triggered by many things including sweat, stress, friction...oh very big decision. I mean you know it's your livelihood your career, I mean the main reasons I had to stop, I had an operation, surgery around my bottom and everything. I had a fistula which came out I couldn't do the job, I couldn't stand for anything, and I am like sit upright...the decision to give up my job was because of hidradenitis"

<Internals\Interviews\Dermatology-Individual Interviews\II-30>

"I went for catering because I knew that you could wear long sleeves and ever thing. So I did catering for two years, it wasn't a very good profession to go in, to be honest with you. It's really low paid and long hours, dreadful when you have a skin condition. When you are doing things like Dithro creams you have got to spend time and if you are working split shifts or steady shifts it didn't suit, so I gave up because it didn't suit"

<Internals\Interviews\Dermatology-Individual Interviews\II-41>

"I did mobile hairdressing at that time...I used to wear a wig, I used to be conscious about it and then people used to think that they noticed and then (left this job) I did eventually, I was most embarrassed at one stage because I was doing mobile hair

dressing I went to this lady's house and she had a hanging basket when she opened the door. I knocked my head on that hanging basket and it flew off and that was so embarrassing you know, but she was alright about it but that really I thought what am I doing with this job…I left that job and went to work in an office for a conservatory company. (have to leave this job) it was just such hard work and my husband"

<Internals\Interviews\Dermatology-Individual Interviews\II-46>

"I joined the nursing home, I was there for a good few years, and then I left it because I was picking up quite a lot of infections from people who had leg ulcers, different things and…it was very hard when you leave work, you know, stayed on for bit longer but my skin got out of control so then I went for something else, tried something else …yea, because I left the job…upsetting really because you go through all that much work and effort and you know and then you got to leave because of your health".

<Internals\Interviews\Dermatology-Individual Interviews\II-49>

"Finished fire services as my health deteriorated"

<Internals\Respiratory Medicine\RESP-314>

"I had just started my own dress-making business making bridal gowns when I developed rheumatoid arthritis so I had to give it up straight away"

<Internals\Rheumatology\RHEU-686>

"The main one you know is been affected by is the ability to work at the moment…well it is preventing me from working…at the moment it seems impossible. I just can't. I was working in a laboratory which obviously makes things even worse because you are wearing gloves and washing your hands all day long and it completely flares up"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG-2MP3>

Unemployed or remain unemployed: Generally, long term unemployment refers to a situation where people want to work but are unable to find work either through lack of employment opportunities or lack of suitable work for the employee (health and disability). People cannot afford to be unemployed or remain unemployed for a very long period of time because of their financial commitments and because of the impact of unemployment on their family lifestyle. However, despite a delicate balance between employment and health, many patients decided to be unemployed in order to be in a position where they could look after their health properly. This important major life changing decision also had an emotional, psychological, financial and social bearing on their family and was mainly based on the patients' previous unpleasant employment experiences associated with suffering from their chronic condition. The lack of understanding from employers, job suitability (unable to find a job suitable for their health) and unpredictability (remission and recurrence) of the chronic condition were also contributing factors.

On the other hand, if a patient had had chronic disease since childhood, then it made it more complicated and difficult for them to be in employment. Their chronic illness negatively contributed towards their lack of education and work skills and made it harder for them to find any suitable job. Because of the constant unpredictability of their chronic condition, patients preferred to remain unemployed as they didn't know when and how long they would be in hospital. In some cases due to consultant intervention, patients stopped working and remained unemployed in order to get proper treatment and gain enough mental and physical strength to return later to suitable work. Some critics might argue that patients becoming unemployed or remaining unemployed may not be by choice but by need; they had to take this life changing decision. It is a genuine argument, but patients have to decide and the willingness of patients to work demonstrates their desire to take control over their chronic disease as part of their long term coping strategy.

Patients' comments

"Jobless at home, if there wasn't any eczema I could have had a nicer better education and with a decent job...well not too happy, sort of depressed you can imagine, my confidence is ok but I still feel down because I am not working and living with parents"

<Internals\Interviews\Dermatology-Individual Interviews\II-45>

"I was suspended from my job last year because I was told I was lazy and didn't work as hard as my colleagues. This has left me low and under confident and worried about further employment... Unemployed due to long term health problem"

<Internals\Cardiology\CARD-103>

"Decided not to get employed because of appointments, IV's, hospital admissions...Always wanted to work but due to health decided not to"

<Internals\CF\Cystic Fibrosis\CF-460>

"Because I left school early, I was worried about being rebutted from work, as I had no GCSE or working skills"

<Internals\CF\Cystic Fibrosis\CF-409>

"Yea because I was, I am still not dealing with it very well but I just couldn't visualise myself in any work and dealing with it and dealing with my son and home and now

obviously since July the other major situation (physical aspect/aesthetic reason)... confidence I think is my huge thing"

<Internals\Interviews\Dermatology-Individual Interviews\II-23>

"Unemployed because of a long term health problem and decided to look after my health. Lack of finances so living with parents"

<Internals\CF\Cystic Fibrosis\CF-486>

"I have worked in every job, had until being stopped by my GP, because I am down too much"

<Internals\CF\Cystic Fibrosis\CF-489>

"A friend of mine offered me a job. Stripping asbestos and when you strip asbestos from old buildings you got to have two full suits on. They call it double suiting. I was struggling to pay my mortgage. I still am. I couldn't take the job because when I'm perspiring the itching is intense, it intensifies so much and I knew that I couldn't do a job so that's another way that it affected my life in a big way...from taking that employment yea, whereas 6 years ago I would have taken it without a thought...definitely yea (major life changing decision), because I'm still seeking employment. Now I am in arrears with my mortgage it has really affected me in a big way"

<Internals\Interviews\Dermatology-Individual Interviews\II-25>

"Over many years I have made around 10 job applications and have not been offered ONE job"

<Internals\CF\Cystic Fibrosis\CF-492>

"Following a redundancy situation I felt that I could not continue to my maximum in new employment, therefore long term employment becomes scary to me"

<Internals\Respiratory Medicine\RESP-324>

"Because I am not working it's affected my personal life, and not being independent, money and physically wise"

<Internals\Respiratory Medicine\RESP-399>

Part time employment: Part time employment refers to working for fewer working hours than normal full time working hours. Working fewer hours was part of some patients coping strategy to remain employed, and at the same time look after their health. However, financial worry was the prime concern for patients and made this decision crucial and life changing. Despite their chronic illness this way of working allowed patients to make themselves available for work with less responsibility and stress, to get out of isolation, to socialise, meet people and contribute to society without putting too much strain on their health. Sometimes the nature of treatment made it difficult for patients to work full time. However, changing to part time employment remains a critical decision that becomes necessary because of the nature and severity of their health condition. In other words, their health left no choice but to take this life changing decision to work part time.

Patients' comments

"Had to cut hours in work due to bad health, resulting in less money"

<Internals\CF\Cystic Fibrosis\CF-408>

"Job: after complications and operations I now work only part time as a teacher"

<Internals\Cardiology\CARD-115>

"I do a part time job because it gives me time to do exercise to look after my heath"

<Internals\CF\Cystic Fibrosis\CF-434>

"Recently I have had to go part time in work because of my condition"

<Internals\CF\Cystic Fibrosis\CF-458>

"I have had to decrease the hours that I worked from full time to part time, because of the effects from my diabetes"

<Internals\Diabetes\DIAB-554>

"Because of the pills, potions and the creams and stuff I did used to get very tired and very sore and my hands are very susceptible to being cracked and everything. So part time was better than doing the full time job and getting really really bad...financially yes, horrifically difficult because we needed the money, then you have to do what you can do"

<Internals\Interviews\Dermatology-Individual Interviews\II-19>

"As a teacher of French at secondary level, I chose to work part time for 12 years for several reasons, one of which was my reduced saliva/dry mouth which made it uncomfortable for me to teach classes (approximately 30 students) for 4/5/6 hours a day, five days a week"

<Internals\Rheumatology\RHEU-636>

To stay in the same employment: This is one of the very interesting decisions patients made. Patients were comfortable where they were working with regard to their illness and job requirements. Other factors were: employers understanding of their illness, environment suitable for their health, less contact with the public, less work, less stress, fear of being unable to get another job, limited education or skills, and in some cases the aesthetic nature of their chronic illness. For example, if an employer understands their illness, then it is very easy for patients to explain why they are off from work today or why they need an urgent hospital visit or admission. At least this attitude gives patients a little freedom to think about their treatment rather then worrying about losing their job all the time, which itself may cause stress and further deterioration to their health. Having less promotion chances, less money, being afraid of not getting another job and the understanding of employers make this decision more life changing for patients.

Patients' comments

"Stay with current employers due to them being very understanding with regard to my health requirements"

<Internals\CF\Cystic Fibrosis\CF-410>

"I decided to stay in the same work place and never looked anywhere else as my employer understands my illness"

<Internals\CF\Cystic Fibrosis\CF-413>

"I stayed at my last job for 11 years because I felt safe there, the managers understand my illness and numerous hospital appointments, and not many places would be so understanding"

<Internals\CF\Cystic Fibrosis\CF-418>

"I am too worried about changing my job in case the place I change to is not as understanding as my current employers"

<Internals\CF\Cystic Fibrosis\CF-440>

"I have had a lot of support from my friends in work so the thought of getting a new job was scary. It was very hard to go back to my current job. It scared me what may happen"

<Internals\Diabetes\DIAB-514>

"Yes it was definitely (major life changing decision)...because I lost my self esteem, my confidence and that I was like my own boss in a way, so it give me the self confidence back, the independence...oh, definitely yea, it helped me so much...it did change my life definitely and made me feel whole again as a person, brought my confidence back, my self esteem and my trust in people...oh yea, major influence on my life, yea. I mean it has been a hard climb up this road and falling back all the time and all of a sudden it's falling a part"

<Internals\Interviews\Dermatology-Individual Interviews\II-46>

"Oh, yes (kept me in the same job) I couldn't get on because of my health, it was only as I said when I finished I might finish the driving. It just, it got the pressure that my body couldn't take it you see. It takes every time I put pressure on it... deliberately took the decision to stay in the same job...because of limited education which was one, and the skin, you see when you, how can I explain, you see when you, you got to keep going back younger because that's where the problem started you see, in a younger age right when you were smart you lost your education, so you going to lose it right the way through the years"

<Internals\Interviews\Dermatology-Individual Interviews\II-47>

"Being working with same employer (different department) since leaving school as I feel there have been limitations on career opportunities"

<Internals\Rheumatology\RHEU-645>

Self employment: The decision to be or remain self employed is a great example of a coping strategy to live with a long term health problem. Several patients took this life changing decision as a planned strategy in order to be in charge of their employment, treatment, health and better quality of life. Being self employed they could work whenever they wanted (flexible hours and shorter hours) and also look after their health.

Patients' comments

"At age 27 I went into further education to allow me to be self-employed as I become unemployed by companies due to my health"

<Internals\Cardiology\CARD-108>

"Had to leave full-time job due to health deterioration. Decided to go self-employed so I can choose my own hours according to my health"

<Internals\CF\Cystic Fibrosis\CF-438>

"Because I can work my own hours. The difference is now I do not feel guilty. I can work around it, if it's bad, much more flexibility. I can go home and shower whenever I want. I am not tied, you know just go and put some cream on and moisturise. Something I wanted to do, which I had to do really because the last two years is definitely a change in treatment"

<Internals\Interviews\Dermatology-Individual Interviews\II-08>

"I was self-employed. That did not affect my skin at all. Because when you are self employed you can do things that were fine. I could accommodate them no problem...so I could come, I think it was like three days in a week, because I was self employed and they were quite accommodating, they just say come in the morning and have your UV light...I could manage my time better, I could manage my treatment, I had UV light and of course when you are in employment you don't want to be leaving a couple of times a week, so I did that. The first time it was very successful and it was quite clear and I really appreciated it"

<Internals\Interviews\Dermatology-Individual Interviews\II-41>

"I am currently self-employed. I have found it more and more difficult to carry out this as it makes changes in my walking/shortness of breath"

<Internals\Respiratory Medicine\RESP-316>

"Decision to become self-employed and worked flexible hours, difficult to manage financially. Wanted to be productive and work but not able to take on full time employment in demanding jobs as I had in the past"

<Internals\Rheumatology\RHEU-607>

"It was a fact during my decision to go freelance because it was difficult doing the full time job that I was doing. I went through a particular difficult time and the amount of time I needed to spend in a day sorting my skin out, it was difficult to actually be full time employed. So I went self employed because I had a bit more flexibility in my working day, which allowed me to sort of do the regime I needed to do with my skin at that particular time...you are asking whether I am worse or better off. It's difficult initially but this is a few years ago. I have built up my work now so actually it has ended up being a good decision for me, but at the time it was a difficult decision to make"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG-2FP1>

Not to progress further in job: Not to progress further in a job appeared to be a big life changing decision as patients sacrifice their promotion, possible financial incentives and career development to make sure their health remains in control. It is not an easy decision to make, in terms of keeping a balance between new employment roles, level of stress, increasing responsibilities and looking after their health. Patients also reported fear of deterioration of their health which may have resulted in rapid demotion. In some cases several patients even redefined their duties to allow them to be in a stress free position and thereby deliberately ending their chances of promotion or progression to a higher position. In one case, due to his skin condition, a patient withdrew himself from promotion as he thought that the nature of his skin condition (psoriasis) would make it difficult for him to be in the new and demanding position.

Patients' comments

"Didn't apply for promotion, I was accommodated with reduced working hours at the lower level"

<Internals\Cardiology\CARD-157>

"Decided not to progress further in my job as I felt due to illness, I am always in and out of hospital"

<Internals\CF\Cystic Fibrosis\CF-413>

"HR post, changed to a more clerical role by request"

<Internals\Diabetes\DIAB-569>

"Let me think what sort of jobs in the past I have done, jobs I haven't gone for. There was one recently, there was a job vacancy where I am working and a big part of it was to do with promoting a pension scheme where we are and a big part of it is standing up in front doing seminars, doing presentations in front of lots of people and that sort of thing...could have been a good job, yea more money, yes, yea"

<Internals\Interviews\Dermatology-Individual Interviews\II-03>

"In my job I did have the opportunity to sort of go into an aspect of another job where I was working with chemicals, powders and things like this you know, but I couldn't because of the psoriasis, because it would be major irritations the psoriasis so I couldn't go there and also if I were going into like what we call clean areas you know I wouldn't because of flakiness and things like this wouldn't be able to go in there...I choose to stay what I was doing, I mean what it was, it was a further thing on in the same business but an advancement, so you could say really promotion better job you know, a different side of the business but ...well that is right (life changing) there, yes"

<Internals\Interviews\Dermatology-Individual Interviews\II-44>

Not to seek employment: This important life decision is similar to "unemployment" or to "remain unemployed", but due to the nature of the emerging themes and reasons given by patients, it was justified as a separate category under the core MLCD domain "job".

Patients' comments

"Have stopped applying for jobs as always rejected due to health history"

<Internals\Rheumatology\RHEU-632>

"Difficulties finding work. If you told employers you had SLE because they had not heard of it there was no longer any chance"

<Internals\Rheumatology\RHEU-673>

"Hard to find work because of my illness (CF) not to seek job"

<Internals\CF\Cystic Fibrosis\CF-439>

"I worked in radio but after missing time I lost my weekly slot and I have no intention of trying to return".

<Internals\CF\Cystic Fibrosis\CF-490>

"Inability to gain future employment"

<Internals\Diabetes\DIAB-578>

"Alternative employment was considered but found to be impractical, physically, would not like to let down employer over that...developed my health problems so took that decision not to seek further employment"

<Internals\Diabetes\DIAB-582>

Flexible working hours employment: Instead of routine employment hours, many patients decided to work flexible working hours because of their chronic disease and as a part of their coping strategy. This is completely different from part time employment as it may involve a shift pattern. Although patients felt financially restrained and had poor chances of promotion and career development, this important decision resulting directly from them having chronic condition allowed patients a freedom to manage their health as appropriate (hospital visits, treatment, admissions). Most importantly, this also kept them in employment and earning reasonable money allowing them to get on with their daily lives.

Patients' comments

"I work close to home and on flexible hours to ease my life in terms of commuting and time from home, and having the flexibility to do what I want more or less when I want"

<Internals\CF\Cystic Fibrosis\CF-405>

"I have had to change my role within the police service from an active authorised firearm officer to an office based role with hours to suit my needs i.e. later starts"

<Internals\Rheumatology\RHEU-677>

"I have decided to stay with my dad's company as I think it's a lot easier than having to explain to other employers with regard to why I need time off for my illness"

<Internals\CF\Cystic Fibrosis\CF-470>

"Unable to work a "normal" shift patron as a nurse, I work on a shift, 2 weeks on/2 weeks off to ensure I have 2 weeks off for rest plus catch up on sleep"

<Internals\Rheumatology\RHEU-606>

Job selection: Job selection is a very critical life changing decision. The decision (whether right or wrong for the individual) will determine what to expect in future in terms of health, stress, finance and family life. Decision taking may become more difficult and limited when suffering from a chronic disease. Many patients reported that this decision was certainly life changing and was a very tricky decision to make.

Patients' comments

"Yes in a way (psoriasis), because I suppose all through my life I've been told that I can't do certain things. Then there were physical restrictions that prevented me doing other things. I suppose I've always done things differently. I've never done things conventionally. I decided to give it a go. I applied for it. If I got it I got it if I didn't I didn't but I at least I put my name there...yes, it was a big decision because it meant that from I suppose again the job I was doing was in an environment where I always lived, people I always knew. Whereas doing that training officer's job I would be meeting complete strangers from different creeds, different cultures, different religions etc... yea and it was a lot of travelling because I was doing 1500 to 2000 miles a week. So the travelling side of it could potentially put a lot of pressure on my treatment. And it did but I just evolved the treatment regime to accommodate that"

<Internals\Interviews\Dermatology-Individual Interviews\II-40>

"I explained to them about my skin and obviously what happened and they gave me a selection of jobs, not really physically touching anything, I selected the sales advisor in a cycle department...it is really (life changing), because if I didn't have it I'd probably be still doing music right now, but I have a lot of options open available to me whether I can go with my family business, I can actually do a bit more of (company name) cars"

<Internals\Interviews\Dermatology-Individual Interviews\II-42>

Not to mention illness on job application: This is an unexpected life decision which emerged during content analysis. It may not be important for many but was a life changing decision for one patient following which the patient managed to obtain a job. This honest account from a patient of how he gave false information on a job application indicates how chronic diseases can change a patient's perception, behaviour and attitude to focus on their health and life.

Patient comment

"Decided not to mention CF on job application because of several previous complications that had resulted in me taking the interview more about the CF than the job and my ability to do it, and people with less experience were then given the job. Had to omit information about having Cystic Fibrosis from job applications in order to get a job"

<Internals\CF\Cystic Fibrosis\CF-422>

Career Choice

Patients' major decisions related to career choice were the third most important core MLCD category influenced by chronic diseases (Postal survey: n=58, 22.4%; individual interviews: n=33, 66%; focus group discussions: Yes). In this domain, identified themes were grouped into 3 main categories: abandoned career plans, career selection and change of profession.

Abandoned career plan: Patients had to take this difficult life changing decision in order to select different careers or jobs which would not affect their health. Several patients wrongly selected their careers at the beginning but later discovered that their chronic conditions were preventing them from carrying on doing what they wanted to do as a career in their lives. Several patients abandoned their career plan and left in the middle of their chosen career, indicating the need to highlight this important issue at an early stage of a disease. This would not only save patients' time and money, but also potentially prolong their good state of health.

Patients' comments

"I did not proceed in my career as I thought my health situation would affect future career goals and a full time job"

<Internals\CF\Cystic Fibrosis\CF-403>

"I was due to take part in an IT course in Exeter University but due to my health at the time I didn't go on it. I might be in a different profession"

<Internals\CF\Cystic Fibrosis\CF-424>

"I am now finally qualified as a holistic therapist, I want to be able to work but cannot as my health has seriously decreased which, I have no choice about"

<Internals\Cardiology\CARD-108>

"Career: I am trained as a lawyer but cannot pursue this fully as long hours, stress affects my illness too much and this prevents me from fulfilling my full potential"

<Internals\Diabetes\DIAB-525>

"Influenced my decision not to pursue a high level career as a company director"

<Internals\Diabetes\DIAB-555>

"For example, you know I may have quite liked to, I am not saying I would have, but may have quite liked to have got away from the patient's hospital, that sort of thing, maybe then some rep work or something like that, but I knew that I wouldn't be able to do anything like that if I had eczema all over my face and I was meeting people and...yes, yea, its stops things at a very early stage when you, when the idea comes in you know, you think oh yea that might be quite a nice job, I'd quite like to do that"

<Internals\Interviews\Dermatology-Individual Interviews\II-24>

"Have had to reconsider my commitment to future career development due to the extra mental and physical stress that would cause"

<Internals\Rheumatology\RHEU-695>

Career selection: Career selection is clearly a difficult task, even for healthy individuals. Initial career selection occurs at an early stage of life where young people select specific educational pathways to lead to their chosen career. Career choice is clearly an important major life changing decision. This is not an easy decision for patients who suffer from long standing illness and their decision (appropriate or not) to choose a specific career certainly changes their lives. Those who considered their health and made an informed choice at an early stage reported better outcome.

"Encouraged" by parents to go to university so that I would be able to get a "non-manual job". Chose to study archaeological conservation rather than straight archaeology because would not be required to work outdoors in the British climate. as more likely to work indoors than outdoors"

<Internals\CF\Cystic Fibrosis\CF-422>

Some patients were not aware the possibility any career associated disease aggravating problems such as chemicals, dust, stress or working conditions. Due to lack of advice and awareness, some patients selected their career incorrectly more than once, which they abandoned later on and unfortunately wasted time at an early stage of their life and career development. This also severely impacted on their health, families and finance.

Patients' comments

"I feel Marfan's, particularly the eye problem, influenced my career choice. I completed teacher training but never took a teaching job partly because of the problems poor eyesight caused"

<Internals\Cardiology\CARD-114>

"I left school straight into YTS to become a hairdresser, had to finish before I was fully qualified as the chemicals was affecting my lungs"

<Internals\CF\Cystic Fibrosis\CF-403

"Wanted to be a car mechanic, but due to working conditions this was not a career suitable for my health"

<Internals\CF\Cystic Fibrosis\CF-410>

"Choose to do a business degree to have a career in a stable environment i.e. office work as opposed to working outside"

<Internals\CF\Cystic Fibrosis\CF-412>

"When I was younger (age 12 approximately) I thought about working with horses but was told I could not work with horses because of the germs it carries and CF, so I changed my career plan"

<Internals\CF\Cystic Fibrosis\CF-417>

"In terms of career choice I was to be an interpreter for the deaf community. I developed arthritis, that put a lot of strain on joints and muscle"

<Internals\CF\Cystic Fibrosis\CF-499>

"As a child I wanted to join the army (Action Man and trucks were my favourite toys). Unfortunately could not join the army as I am a diabetic. I wanted to join the

ambulance services as a paramedic. Surprise, surprise, cannot join the paramedic/ambulance service because I am diabetic!"

<Internals\Diabetes\DIAB-502>

"I was a physical education teacher. Changed subject three years into teaching"

<Internals\Diabetes\DIAB-595>

"I would have liked to go on to do cooking and that but I couldn't because I knew I would be discriminated against...I could have gone to medical things but I feel discriminated with my skin...you got to make sure that you carry gloves all the time and that's worse to me because the skin opens"

<Internals\Interviews\Dermatology-Individual Interviews\II-09>

"I wanted to do a degree in English literature and I had to take sort of a completely different direction because of treatment of psoriasis and going in to the construction industry and train and got to be ultimately qualified as a quality surveyor. So that was one of the major effects that disease had on my intentions for further education...well, the opportunity wasn't available to me so I didn't decide not to, I just, because I felt that too much time would have been lost and it was inevitable that I had to choose something else...well it was something that I certainly would have much preferred to study English literature and working in construction was not my first choice. It was a matter of having to earn a living and get a job which would pay you know, so that was the reason for doing it...and by the length of time that I have to spend in hospital"

<Internals\Interviews\Dermatology-Individual Interviews\II-18>

"One of the major decisions that I made as a result of my condition, I had for a long time intended to join the Royal Air Force and having spoken to a number of friends who were applying slightly earlier than I did, fortunately, started to go down that road. They tell me that they leave the medical examination until last and then they tell you if you have a condition such as psoriasis you are not accepted. So I thought, well, save everybody's time, I won't even bother to apply, which I think to a certain extent I can understand the military not wanting to take on people with a medical condition, but I think that the severity and extent should be taken into consideration as well and also the type of job available within the military, not all of them are dependent on 100% physical fitness"

<Internals\Interviews\Dermatology-Individual Interviews\II-32>

"I suppose the other one is my psoriasis that dictated my decisions, for example, I couldn't pursue the career I wanted because I have got psoriasis because at that particular time we were not accepted in the armed forces with chronic disease regardless what it was. I went to university nursing, but the style of nursing I was able to do because I was a clinical risk, was to do psychiatric...so it's really my skin dictated which career I have followed...I had all the qualifications, had the necessary skills they were looking for but when I came for a medical I obviously I had over 95% coverage when I came to the medical so it was highlighted really, I was a clinical risk to do general medicine which I wanted to do... yes, I've not done two years and that was a better choice for me"

<Internals\Interviews\Dermatology-Individual Interviews\II-40>

"When I was thinking about my profession I didn't know what to do, I couldn't decide... Yes, but I will say when I was 13 and you have to make choices of what you intend to do, that's when those consideration come in. Because I decided when a lot of my friends did at that time, it was a secretarial course and I thought I did not know whether I wanted to go in to an office... Because you would be in a skirt and a shirt, and I wanted to be covered up. When you think back about those days when you worked at (company name) they had a uniform, they wore short sleeves and pencil skirts. And I knew that I did not want to be in a pencil skirt and short sleeves top because of my psoriasis. So I did a lot of craft things, I love art, textiles, cooking and I did a lot of those things rather than going down the academic group, I did crafts things because I thought that was what I am going to do, something along those lines then...done secretarial route, with my friends, because all my friends did it, I was the only one who did not...I've gone back to it, haven't I because I went and did business finance later. When you are older you think oh this is all ridiculous...when I was 13 I should have done the secretarial course which then put me in further and I should have done really, then probably I would have done business and finance when I was like 16"

<Internals\Interviews\Dermatology-Individual Interviews\II-41>

"The health stopped me because it's stopped me from my education and it's stopped me doing what I wanted to do, see, it reverses me into another field rather then going from the field that I want, you know, you want to go it's like a tree, you wanted to go straight but you end up you got to be branched off, see, you got to take the branches...my skin always had that, what can I say, it's always taken the forefront, whatever the decision I have made it's been at the forefront"

<Internals\Interviews\Dermatology-Individual Interviews\II-47>

"Yes that was basically my mom said "What do you want to do?" and I said I would like to go into beauty and hairdressing but I can't really because all the chemicals they use; and my friends would go to catering you mean cheffing and at that age you do tend to want to go where my mates are going but I didn't...I suppose in a way it's not right but I wouldn't have been comfortable with having to say to the teacher "I can't touch that, I can't use that, I can't"...definitely for the Army (career choice) because it was eczema and asthma comes together and I was like never get in. I knew I wouldn't be able to get in"

<Internals\Interviews\Dermatology-Individual Interviews\II-48>

"Looking for different avenues of possibly changing my career"

<Internals\Nephrology\NEPH-300>

"Since leaving school, as I feel there have been limitations on career opportunities...Apprehensive of applying for different jobs due to the consciousness of having a disability"

<Internals\Rheumatology\RHEU-645>

"I always wanted to be a police officer and I made my decision back in the days like I am going through at the moment. They wear dark uniforms and they wear short sleeve shirts, and I did make a conscious decision not to go for the police force. Because that

affects me...I knew it was a career thing, I know that I had a problem...It knocks your confidence again, once you have been knocked back like that then it is not just one job, everything it does"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG1MP1>

"Yeah I had a similar experience to that. I went to train as a nurse when I first left school. The type of nursing I wanted to do was people working with mental handicap. So it was not a sort of nursing where I would have been sort of doing washing and things every day but they said because I would be having to get my hands in soap solutions and things they automatically turned anyone down with eczema and at that point I never had eczema on my hands. So I felt it was really unfair that they just didn't really listen to what I said about my condition. They just said we do not take anyone for nurse training who has eczema in this area. And I felt quiet stigmatised. It had a big effect on me at that point you know...yea that's absolutely the eczema that has got me, I passed the interview, I passed everything and the final thing on the day was medical and it was because of the medical that I could not do it...well I think the choice I made was that I was going to stick with the career but I was not going to work in a place where they were going to judge me on that. As I said before they were attaching a stigma to it and I did not really want to work in a hospital that had an attitude"

<Internals\Interviews\Dermatology-FG Discussion\FG2FP1>

Change of profession: When patients realised that their current profession is not suitable for them, then they had to take another life changing decision to change their profession. It can be a brave decision as their career opportunities remained limited but their decision did change their lives in a more positive way. The lesson from this is that taking early informed decisions is not only better for their health, but also better for their finance, family and quality of life.

Patients' comments

"Turned down for nursing course due to health despite academic achievements...Leaving social work practice to lecture in order to prolong career"

<Internals\CF\Cystic Fibrosis\CF-468>

"I started as a carpenter and now I work in an office"

<Internals\CF\Cystic Fibrosis\CF-470>

"I am a trained physiotherapist, but due to cross infection issues I am undertaking another career"

<Internals\CF\Cystic Fibrosis\CF-471>

"I was a builder working 18 hours a day, not eating much, not really looking after my self. Changed then to working in kebabs and pizza house just working evening times.

Then I am working to become a driving instructor to work my own hours, the change of career is to have a better and easier life for me and the family"

<Internals\Diabetes\DIAB-542>

"I used to work in (company name). I worked there for 7 years then I changed my profession to be a motor mechanic because of my health condition"

<Internals\Diabetes\DIAB-549>

"I think what major bearing the psoriasis had on my working life is that I was given the advice by one employer, because I had to take so much time off, that he advised me to go into the public sector where there is more job security and that's what I did...I certainly think I made the right decision to go into the public sector, but that was then when I was, you know, 30 years ago or more...yes...I think the guy was being helpful"

<Internals\Interviews\Dermatology-Individual Interviews\II-18>

"Also I now do work by the internet. So that is a big major life changing thing. Now most of my meetings done in virtual space rather than a real space because travelling is a problem...So my social life is over the internet as is my business life. So there was a big decision I had to make...I am a professional artist by the way that's the work I do now. I also write for 4 or 5 online magazines and publications. I was a psychiatric nurse...I was studying at university. I gave up my job as a nurse a year before. I did 15 years of nursing, psychiatry nursing became too dangerous, so I moved on...yes I studied and then got a degree and then got a teaching qualification because I wanted to move from nursing to teaching"

<Internals\Interviews\Dermatology-Individual Interviews\II-30>

"I wanted to work but later engineering work...but all the chemicals involved I didn't know at the time my skin and I couldn't do the job so it sort of fell through...I didn't start the job I went to college for...and there was no option for me so I thought ...yea, and then I started to go to the job centre for a few years looking for jobs signing on the dole"

<Internals\Interviews\Dermatology-Individual Interviews\II-45>

"I really wanted to work at the (name of hospital) with the babies unit but due to my chest problem I have to go for other jobs"

<Internals\Respiratory Medicine\RESP-314>

"Cannot go back to my trade as a plasterer due to muscle damage and breathing problems in my chest, affected my everyday life"

<Internals\Respiratory Medicine\RESP-399>

"I have pursued a second career/hobby turned career as a horse riding instructor. As the arthritis may progress quickly I have rescheduled various riding exams and riding objectives (I have brought the schedule forward) in case the arthritis affects my ability to ride at a later date"

<Internals\Rheumatology\RHEU-635>

"Applied to train as a nurse but due to ill health I was unable to take the opportunity"

<Internals\Rheumatology\RHEU-645>

Having Children

The decision to have children or not to have children was a life changing decision for patients who had been suffering from a chronic condition for a very long period of time and who had gone through various treatment options over time (Postal survey: n=64, 24.8%; individual interview: n=11, 22%; focus groups discussion: No). Patients' decisions were directly influenced by their health-related circumstances, such as affordability, genetic reasons, their health and coping with their children's health and the long term nature of the treatment. This was the fourth most frequently mentioned MLCD. Identified themes were grouped into 4 main categories of not to have children, delayed plans for having children, not to have more children and having children through IVF treatment.

Not to have children: Not to have children is basically a conscious decision to refuse or not to have a family. This decision changed patients' lives significantly perhaps forever. Patients were clear in their decisions on genetic, social, financial, health and in many cases on moral grounds. For example, to avoid having a baby who may have or develop the same chronic condition and not to put them in the same situation for the rest of their lives.

Patients' comments

"Having a family – the risk of passing on the gene is high"
<Internals\Cardiology\CARD-103>

"Don't want to feel a burden to anyone, as could not have children due to medications and possible complications with children"
<Internals\Cardiology\CARD-108>

"Decided not have children and stay on the contraceptive as I'm worried how it will affect my health in the long term and the baby's health and life"

<Internals\CF\Cystic Fibrosis\CF-417>

"Went for genetic counselling but decided a child would be too much for me if my health deteriorated and it would not be fair on the child if something happened to me"

<Internals\CF\Cystic Fibrosis\CF-418>

"Having a child: making decisions about the moral aspects of the chance the child will have the same disease, then sharing medical issues around having children"

<Internals\CF\Cystic Fibrosis\CF-500>

"At the moment the thought of having children is scary as many things can go wrong. I am very paranoid about getting pregnant but hopefully I will be able to cope one day"

<Internals\Diabetes\DIAB-514>

"Children: I would like to have children, however I feel apprehensive about the effect this would have on my illness and also wonder if I would have enough energy to look after them"

<Internals\Diabetes\DIAB-525>

"No, we have never actually intended for children. One of the reasons, not one, it's certainly isn't one of the major reasons, but one of the reasons being psoriasis, because I didn't want children, any of my children to go through what I had particularly when I was in school. I am not saying that was a right decision or wrong decision but that has always been my decision. I would not criticise anybody for saying that I am wrong because I am certainly not saying that I am right but that is how I see the situation"

<Internals\Interviews\Dermatology-Individual Interviews\II-32>

"First one is about children. I decided at the age of 13 I wouldn't have children. Because I didn't want a child to experience what I experienced in my childhood, if they were bullied because of psoriasis. Although society is a bit more accepting now it wasn't 30 years ago. The same experience is still there so that's the one decision I made and stuck by that. My childhood was horrendous. My parents did the best they could do with the information they had. I got an older brother so they, if I am honest, I don't know how the hell they did it. So it wasn't a fun experience. The actual physical element of it was horrendous and I made that decision at 12...At 12 I was in hospital with a woman who had psoriasis and she was pregnant and she was there for 9 months, her pregnancy flared her skin so badly"

<Internals\Interviews\Dermatology-Individual Interviews\II-40>

"Thought hard prior to having children, I am still not sure if I have the ability to live up with my young son (but does anyone!!)"

<Internals\Rheumatology\RHEU-611>

"Having a child, Can't have a child whilst I am on medication"

<Internals\Rheumatology\RHEU-624>

"In early 20's decided against having children as ankylosing spondylitis is genetic"

<Internals\Rheumatology\RHEU-632>

"Not just being able to just try and start a family. Having to consider the consequences"

<Internals\Rheumatology\RHEU-645>

Delayed plans for having children: Several patients wanted to start their family but they were not sure about the genetic involvement or consequences of their chronic condition on a baby. They consulted their doctors, geneticists, health advisors, went through many tests and delayed their plans to have children for their own safety and for the health of a new born child. In one case the doctor's advice turned out to be wrong and the baby developed the same condition as the mother had.

Patients' comments

"Deciding to have children: took genetic advice on the matter. Throughout my late 20s I was unsure whether to start a family and found genetic counselling put my issues into perspective"

<Internals\Cardiology\CARD-114>

"Discuss genetic science with doctor before having baby"

<Internals\CF\Cystic Fibrosis\CF-461>

"Having a child because of genetics, it took eight and a half years for the test and then having a child, it's a long process. Was told I was fit and well enough to go ahead"

<Internals\CF\Cystic Fibrosis\CF-495>

"I gave serious consideration before having a child. I delayed making a decision about having a child due to diabetes"

<Internals\Diabetes\DIAB-598>

"What happened to us when I was trying for a child before I had Darier's disease, when I got married I was 21 but it took five years. Before I had her I said to the doctor when they first saw my skin problem I said to him if I have children will they have it? he said "99% they wouldn't". If they said to me fifty fifty I wouldn't have... I mean its effects, my daughter is quite different but she is stronger and doesn't need to see the doctor. She doesn't take medication"

<Internals\Interviews\Dermatology-Individual Interviews\II-05>

"I made an appointment with my GP and I told him the situation. There was a possibility that my children will get eczema. I do not know the percentage; the wife went to the family clinic and told them the situation. We read up about it...oh yes, we had to give a big thought about it, big. My wife went to see the midwife...there was a time we thought: well if we end up having a child and it's a girl with eczema as bad as I got we wouldn't cope with it...we are looking at in-between anything from one year to two years or perhaps longer. Because it was going to see different people, what about our chances and different things. We were concerned about coping with a young baby with eczema, severe eczema. My mother must have had a dreadful time. Without the medication"

<Internals\Interviews\Dermatology-Individual Interviews\II-12>

"Having children was a definite major decision, where the disease was considered we always sought advice from geneticist etc, looked into it directly because of the disease. So it was really up to us and then more up to me in a way whether to take the risk. That's how it feels. Obviously, we have decided we would have children...yea that changed my life, well it was the decision whether to have children or not because of this disease and the risk of passing it on to them. Once you make that decision that's it and you live with that but I mean there is nothing you could do about it. I've taken out health insurance for my children"

<Internals\Interviews\Dermatology-Individual Interviews\II-28>

"Yea for ages about having a baby and took me a while to get pregnant and ...I suppose, when it was very bad its about five or six years ago, I think I did because I thought I can't get pregnant not having the creams I am using at the moment, specially in the first trimester I can't take the amount of steroid creams that I am taking and have a baby because I was worried that its going to have effects on the baby"

<Internals\Interviews\Dermatology-Individual Interviews\II-50>

"Will have to plan to start a family if/when the time arrives. I.e. stop taking medication for three months"

<Internals\Rheumatology\RHEU-606>

Not to have more children: The decision to not to have more children was based on patients' experiences with their first pregnancy, the severity of their chronic disease, worries about complications, concerns about looking after their health and baby at the same time, their finances and the potential impact on family life.

Patients' comments

"Having a second child: due to complications after the birth of my second child I will not take the risk of a second pregnancy"

<Internals\Cardiology\CARD-115>

"Restricted family to one child due to difficulties at birth"

<Internals\Diabetes\DIAB-530>

"Yes, I wanted 4 children and I stopped at 3 because I could not cope with anymore. Having had 3 kids together, being so ill after the 3rd one. After the 3rd child a big influence was I had to stop breast feeding. I breast fed my first two children exclusively for 6 months but with the third one my skin was so bad I had to stop. I could only breast-feed her for 6 weeks...yes, I always thought 4 children it was such a perfect number in a family. I would like to have 4 children, after having 3 children I was exhausted I couldn't face; you know we decided not to have another one"

<Internals\Interviews\Dermatology-Individual Interviews\II-06>

"The disease has affected me because it's stopped me working... because you want to fetch your children up the best you can and it's not been. You want to give everything if you can and because we had one child we can manage to give that child everything but if you have more boys you got less money to live on. At the time when I finished work, my wife was part time so she could have gone back full time but there were no jobs around...but years ago we did think about it to have other children but because I was worse than I am now. It was a case of managing a child but trying to pick him up and things like that because my arthritis was quite bad at that time, now we take different drugs and everything It's helped, its managed my arthritis much better...I have decided because I have finished work as well, they finished me off and I couldn't afford to do different things so that has changed completely then, you tend to think more what you going to do, how to get things. When it's two parents working it's always easier then to afford different things, when there is a one wage coming in it's different completely"

<Internals\Interviews\Dermatology-Individual Interviews\II-20>

"Another life changing decision was made in relation to the number of children my husband and I were able to have. In view of my renal failure my husband was advised to have a vasectomy as any further pregnancies would have an adverse effect upon my severely damaged kidneys"

<Internals\Nephrology\NEPH-283>

"Wanted to have more children but decided not to because of ongoing health problems"

<Internals\Respiratory Medicine\RESP-314>

"I had only one child, not being able to cope or wanting to pass on my illness to any of my children"

<Internals\Rheumatology\RHEU-638>

"My long-term prognosis of psoriatic arthritis and the medication I have been prescribed has meant that having any further children may not be an option. I have had to make a decision to not have any more children due to the fact I have mobility difficulties and problems with my hands and wrists which on occasion makes it difficult for me to do things for myself and my children"

<Internals\Rheumatology\RHEU-675>

Having children through IVF (In Vitro Fertilisation): some patients, with cystic fibrosis or rheumatoid arthritis decided to have children through IVF. For some patients IVF wasn't successful but had provided a potential opportunity to start their own family. Some patients found it difficult to explain about their illness, having children and IVF treatment.

Patients' comments

"Decision to have children; due to health problems, children were born via IVF fertility"

<Internals\CF\Cystic Fibrosis\CF-410>

"I have spoken to my current girlfriend about having children. It was hard to explain because I am infertile, but my girlfriend understands everything and in the future I am hoping to have a child"

<Internals\CF\Cystic Fibrosis\CF-427>

"We went through IVF. My husband was afraid it would shorten my life span. I was concerned about the possibility of leaving a child without a mother"

<Internals\CF\Cystic Fibrosis\CF-494>

"Decided to have IVF as I have a very supportive husband, now late 30's"

<Internals\Rheumatology\RHEU-632>

"Have no children. Had IVF, it wasn't successful"

<Internals\Rheumatology\RHEU-655>

Relationships

The area of relationships was the fifth most affected core MLCD (Postal survey: n=40, 15.5%; individual interviews: n=26, 52%; focus groups discussion: No). The most affected MLCDs reported by patients were related to: not to become involved in relationships, separation, marriage and divorce. The illness of patients and its associated physical, social and psychological trauma were the main factors to have a direct impact on patients taking MLCDs differently related to relationships.

Not to become involved in relationships: Patients thought that their treatment routine and hospital visits might put a strain on their relationship with their partner and were afraid that the relationship would end if the partner found out about the implication of their long term health problem. Fear of rejection and lack of self confidence were the other factors. Some patients had concerns over their life expectancy. Some patients had had more than one relationship but their health problems caused separation and due to these bad experiences they decided not to become involved in further relationships. Some patients didn't want their partners to suffer with them. Patients also found it difficult to explain about their disease to their partners, and for that reason alone, they did not want to be judged by their disease. One patient described this approach as a "survival reflex" to exist, indicating that choosing not to become involved in relationships could be a major life changing decision.

Patients' comments

"Scared of involvement in further relationships"

<Internals\CF\Cystic Fibrosis\CF-407>

"Not really ready for a relationship right now because of health, plus I come in hospital often"

<Internals\CF\Cystic Fibrosis\CF-409>

"I decided not to be involved in a relationship due to further health problems"

<Internals\CF\Cystic Fibrosis\CF-424>

"I decided not to get close to anyone because I don't want them to see me suffer and have of the same worries"

<Internals\CF\Cystic Fibrosis\CF-443>

"I found it difficult to start relationships. I hated the thought of explaining diabetes. I didn't want to be judged"

<Internals\Diabetes\DIAB-514>

"Will not or cannot form new relationships i.e. (no partner) by-product loneliness, resignation that it will be what it will be, not what it should be"

<Internals\Diabetes\DIAB-533>

"Only just started seeing someone when my skin cleared up and before that in 4 years being single for 4 years and haven't had a date or any kind of interaction with a man so that was a very tough time... oh of course (difficult decision), everybody is human and everybody wants to be with somebody but 4 years is a long time, but you know it's taken this time... now the last two weeks I was talking to somebody for quite a long time... not being with someone (was a life changing decision) oh yea of course, you feel very lonely, you know, just it's very hard"

<Internals\Interviews\Dermatology-Individual Interviews\II-02>

"I did not at the beginning when I was younger but then I got older, like I said as you get older you sort of...I mean I have sort of boyfriends but I wouldn't sort of, how can I say, it was always at arms length. I wouldn't sort of get too involved with...because you always think, they probably might find somebody prettier then me... "

<Internals\Interviews\Dermatology-Individual Interviews\II-03>

"Similarly with relationships, you know, I do tend to hold back rather than, you know, sort of willingly going out and looking for a partner...It is just how I have to react, what I have had to develop as a way of managing the condition...I have described my approach to that as taking a "survival reflex" in a way doing what I have to do to exist or to continue"

<Internals\Interviews\Dermatology-Individual Interviews\II-07>

"It wasn't a difficult decision because of I was so self-conscious of my condition I thought right, ok, stay in don't go out...I have been involved in a relationship but I noticed that the condition got worse. I think, let's say in the last 10 years or so, I haven't had a proper relationship in about 7 or 8 years"

<Internals\Interviews\Dermatology-Individual Interviews\II-14>

"Mostly with relationships; I have not been in any long term relationships all that much due to when they realise that I am suffering from eczema they don't want to know...they could see on the face and my hands"

<Internals\Interviews\Dermatology-Individual Interviews\II-16>

"I would be extremely worried if I even got the slightest bit involved with somebody because I don't think I could cope with that, because that would take more involvement in somebody just getting to know somebody...yes, because it is not just when somebody you know you, commit to a relationship, you meet somebody else, it's not that simple. Meeting with somebody else, getting to know them, there is another element involved here and because I wanted to tell somebody straightaway but I would also be afraid of putting them off because I don't feel feminine like this at all, not at all"

<Internals\Interviews\Dermatology-Individual Interviews\II-23>

"It stopped me having any further relationship after my marriage had broken up...It's a battle to deal with self-confidence. Massive battle to control your self-confidence... no, I don't think it's fear. I just see it as a very unsettling thing"

<Internals\Interviews\Dermatology-Individual Interviews\II-29>

"Yea in my life, no relationships previously, I don't get close because I don't feel comfortable getting close...yea it was my decision because of my skin condition...yea, I didn't feel confident...it was always, not a proper relationship, no I didn't feel confident...I wouldn't get close enough to people, even at school level, it was kind of always a barrier between me and them"

<Internals\Interviews\Dermatology-Individual Interviews\II-45>

"Relationships: whilst I have no symptoms (thankfully), I worry about getting into a relationship as they would have to know about the problems with my kidneys and may think about me differently"

<Internals\Nephrology\NEPH-231>

"Not in a relationship as I find my arthritis stops me from going out to meet people as I am usually in too much pain or too tired"

<Internals\Rheumatology\RHEU-606>

"Relationships: from meeting with friends to intimate relationships, linked as above to some erosion in confidence (intimate relationships especially due to changing body, part deformity and fear of pain)"

<Internals\Rheumatology\RHEU-656>

Separation: Patients took this decision because their long term illness caused so much stress not only for them but also for their partners. For example, extra hard work related to treatment (creams and lotions), washing, and frequent hospital visits caused a rift in their relationships. In some cases partners were psychologically unable to accept the chronic disease. Patients also faced problems within their families as their chronic disease caused a series of impacts such as not working, less money, problems in the family and life style which than led to a break up in relationships.

Patients' comments

"Relationships: separated due to stress of illness"

<Internals\CF\Cystic Fibrosis\CF-407>

"Separation: first partner was not interested in our relationship being long term because of my illness. He wanted to know if he could catch it"

<Internals\CF\Cystic Fibrosis\CF-429>

"Part of my health was my decision also to end my relationship"

<Internals\CF\Cystic Fibrosis\CF-443>

"Financially was better working as my marriage broke up 8 years ago"

<Internals\CF\Cystic Fibrosis\CF-455>

"Parted from my partner 5 years ago, very upset, deep depression, can't trust men"

<Internals\Diabetes\DIAB-529>

"Reduced working hours, got less money, caused marriage problem (separation)"

<Internals\Diabetes\DIAB-542>

"Oh yes, because I couldn't be natural, you know, couldn't just do the natural thing, it was always a restriction on everything we did, you know. We lived together as a couple but then you know, working around, I can't even work around my bra, or you know, when it comes to physical attraction, you know...it was a breakdown because things just weren't nice and I didn't feel confident and comfortable enough for myself so obviously we couldn't carry on our relationship"

<Internals\Interviews\Dermatology-Individual Interviews\II-02>

"Those were short terms. Some was because of skin, my skin condition you know. People look at you as if you are dirty, that sort of thing. There is a bit of stigma against it you know. It's not you got a bad kidney, it does not show, everything is normal. But this is all outside and people just look. It's first impression, people see you. If you go for a job interview and you have eczema"

<Internals\Interviews\Dermatology-Individual Interviews\II-08>

"Some of it was because of eczema, she was getting fed up having to help to do my treatment, the bed washing, the blood and our daughter had it as well"

<Internals\Interviews\Dermatology-Individual Interviews\II-10>

"I think it would be wrong to blame the condition for all of it. I would say there may be part of it, you know, that affected the relationship; yes...my life is smaller and

more insular. I go to work, come home. I don't go out very much so that is how life changed. Whereas, when I was younger; for example, hoping that the condition will clear up, I was just like everybody else. To go out, have relationships, but as the condition worsened it definitely affected me...it was a factor because at the time I had to use this topical lotion which is not very nice for a girl friend or wife...it was for me, you know, horrible stuff, smelly and it's disgusting. How can anybody want to even come and give you a hug, let alone kiss you, that sort of thing, you know, I opted out for many years, you know, and after a while it begins to build up, so you become very conscious of it"

<Internals\Interviews\Dermatology-Individual Interviews\II-14>

"But it happened after, as I said to you, when I was very upset, trying to deal with it in the early stages last year, he just sat there and totally ignored me or I caught him just looking at me and I felt I could have been so emotional, but I was thinking that he was looking at me in disgust but he never responded to me in any way, shape or form"

<Internals\Interviews\Dermatology-Individual Interviews\II-23>

"Emm probably, to an extent because if you don't feel, if you are never satisfied with your lot because the condition is an inhibiting factor, then I think that is an impact, that has an impact on your decision"

<Internals\Interviews\Dermatology-Individual Interviews\II-33>

"I also think that it affects everything like relationships and how you perceive and how you think people are going to perceive you. I think they are not to be trusted, I think, you think "oh waoo". You might meet somebody and when you tell them, you have got a skin condition; you do not know how they will react. But I met my husband when I was like 15. Because he accepted it I married him when I was 21. But don't think it was the right thing to do because we ended up splitting 10 years later. We were together for 10 years and I've got a son from him but I do not think he was the right person to be with...I think so yes. They wouldn't say that was the reason but I believe it was...I mean one in particular commented on my skin and the fact at the time that problem with my hip and I explained that I could have arthritic psoriasis. As I was getting older, it's a consideration. I still have a problem with it and when I sort of mentioned this and I discussed it with his mother. I could see this almost like this women had got a problem, you know. It wasn't too long after that we split up and I do think it had a bearing"

<Internals\Interviews\Dermatology-Individual Interviews\II-41>

"We had ups and downs, yea definitely, I mean especially when the kiddies were at home. At one stage I did walk out with my youngest daughter you know because there was an argument all the time, my husband was very loud and...yea I had to go...I think it was (hair problem) because I used to think, I used to blame him for it you see and then he didn't used to help because he used to be worrying and get stressed a lot and have effects on me...yes he did have an attitude at first, yea, he did. He couldn't cope with it, he would say oh, you know, he was panicking over it and I said don't worry about it but it started to make me feel worse then, you know...yes, he was very

embarrassed, yea, oh somebody is coming, put your wig on. What are you wearing that scarf for, it looks awful, I said I need to wear it to give me a break for a change"

<Internals\Interviews\Dermatology-Individual Interviews\II-46>

Marriage: Patients either delayed their plans to get married or decided not to get married because of their chronic condition. One patient raised his concern regarding the link between marriage, illness and the level of benefits he/she could get. Patients were also concerned about subsequent life changing decisions, such as having children after the marriage, would this place on extra financial burden on the families having to look after their children. To avoid this situation, or due to previous bad experiences, they simply decided not to get married and denied themselves their right to experience family life. On the other hand, two patients were deliberately married to persons who also had the same chronic disease and found it easier to cope with their health conditions. Patients stated:

"And looking at who I married, I married someone with severe eczema, whom I didn't meet through being in the clinic or anything but I met him socially. It was just something I don't like to talk about really, because we both were being seen in the clinic, perhaps that was, you know, one of the reasons we got to know each other better. Why we have such a good relationship because we can understand...if he scratches I know how he feels, I don't say something that's going to hurt, I don't say just stop scratching and it is the same the other way around. You know occasionally I say oh you wouldn't believe how bad I feel with the itching at the minute and he says yes I do and then I realise that he does, so it takes a lot of pressure off and it really really helps. In the same way if I bleed on something like a cushion or something I get really embarrassed. He would do the same thing why you are getting embarrassed. Obviously, I like him for who he is but it does help a little bit and it makes me feel a bit easier in myself"

<Internals\Interviews\Dermatology-Individual Interviews\II-27>

"Marriage: my chosen partner also had the same diagnosis. We had a lot in common. We both embarked on marriage fairly late on in life"

<Internals\Rheumatology\RHEU-607>

Patients' comments

"Because of CF I am not employed, I am on high rate benefits and would lose my benefit if I got married and my CF would get worse"

<Internals\CF\Cystic Fibrosis\CF441>

"Haven't got married due to health condition"

<Internals\Cardiology\CARD-108>

"Married at the age of 37 after many years deliberately, had seen father die at 42 after heart disease (including VT) worried about dying and leaving family and partner if the condition returned"

<Internals\Cardiology\CARD-116>

"Marriage: decided against marriage due to long term health problem"

<Internals\CF\Cystic Fibrosis\CF-429>

"I mean I have no problem talking to people. But if it goes further and someone wants to get more personal, all these questions come up and its certainly has affected things like relationships, because I am less likely to get involved. I am not ashamed or anything or whatever, I think it has to be someone very very close and then I can describe what is going on and hopefully she would accept the situation. I think, that's what I am hoping. I could imagine a situation where someone may be put off by a situation because they don't understand what is going on"

<Internals\Interviews\Dermatology-Individual Interviews\II-07>

"My wish was that on my wedding day, I would like to be able to walk down the aisle without limping. Since my diagnosis in 2002 a course of sulphasalazine and physio improved my posture significantly. Once I was back walking again, I decided on the year I got married"

<Internals\Rheumatology\RHEU-601>

Divorce: long term chronic disease, inability to have children due to ill health, mood swing and disease impact on partner and family were some of the major factors influencing patients' decision to divorce. In some cases patients' partners had difficulty coping with their illness and the change in the partner/husband's behaviour or attitude led to divorce. One patient reported that the treatment he had, had given him enough confidence to go out, meet people and socialise. Although this was a positive result, it caused an unexpected opposite adverse impact which lead to divorce. The patient stated:

"I think what I was saying, the medication for me it maybe gave me more confidence. The medicine gave me more confidence because the psoriasis is being suppressed by the medication. Whereas, if I hadn't been on medication my personality was more conscious of the fact that people were looking at me, were viewing and seeing the effects of the psoriasis. After the medication I then I suppose I was more confident to enter certain social areas and that then maybe affected that (relationship). What happened with my wife is that we sort of drifted apart a little bit and there were all sorts of background stuff going on. I got involved with a number of people which sort of fuelled the separation...and that then in some respects was part of a number of things affected (created negative impact on my relationship) yes. Because when you have psoriasis and you become trusted by the person you are with and then you feel quite not vulnerable, I suppose. But you know from a physical point of view maybe you don't feel as attracted to people, you tend to stay in close social groups"

<Internals\Interviews\Dermatology-Individual Interviews\II-39>

Patients' comments

"Divorce, results of illness, sterility and earning powers (1993)"

<Internals\Cardiology\CARD-126>

"My ex-husband said I have bad mood swings due to diabetes which resulted in divorce"

<Internals\Diabetes\DIAB-507>

"We have been divorced for 12 years. I waited until my children were grown up and starting their own life before I allowed myself to have a life in a way, I don't know in what way and how it would be and psoriasis will be all over me and everything...I wasn't perfect for him. He stated that he needed a wife with perfect skin and I wasn't like that"

<Internals\Interviews\Dermatology-Individual Interviews\II-13>

"I wouldn't say it is all to do with it but it was some part, yes it was. My wife was agitated with my problem. Although my wife was accepting but I couldn't accept it and I just felt, oh I don't know, I just didn't feel like it anymore. I just didn't want to go to bed...embarrassed in front of my own wife. I just felt this. I just wanted to be my own, you know what I mean. I just put things off. Put blazer on, so all bits on my blazer. I didn't want to go to anything...It was (difficult decision) yea, you know I had a beautiful home, yea, big decision. I left the house. I just said I didn't want to be in the marriage anymore. Bad patch, we were in separate beds"

<Internals\Interviews\Dermatology-Individual Interviews\II-22>

"Divorced: The worry about the outcome of my kidney disease has caused me depression issues. Therapy has cost me 13K and I have been unable to take anti-depressants because of the side-effects on my kidneys. This has impacted on my relationships"

<Internals\Nephrology\NEPH-231>

"Lack of proper sleep due to pain at night leaves me feeling very weary and fatigued during the day. This continual lack of sleep impacts in the way I interact with people especially people close to me, this might have been a contributing factor to my first marriage breakdown"

<Internals\Rheumatology\RHEU-612>

"My marriage ended in divorce after only 5 years. My ex-husband stated my illness as a big strain on our family life"

<Internals\Rheumatology\RHEU-615>

"My marriage failed (divorce) mostly due to this illness and how I dealt with it"

<Internals\Rheumatology\RHEU-638>

Education

Education related MLCDs such as those related to higher education, to leaving education and to the selection of an educational institute were the sixth frequently reported aspects reported by patients (postal survey: n=32, 12.4 %, individual interviews: n=22, 44%, focus groups discussion: No).

Left education: The majority of patients left education (school, college, university) early in order to accommodate their health, or simply because they could not cope with the constant nature of their ill health and increasing educational demands. They felt that their health directly prevented them from continuing their education. Many patients were aware of the consequences of this major life changing decision; however their health problems left no option for them but to take this difficult decision. Several patients wanted to gain some level of education in order to avoid having to do a menial job, and to earn a reasonable income with less stress, which they thought would be helpful in coping with their ongoing health problems. Patients felt they had no choice but to leave further education due to regular hospital visits and admissions for several weeks to months. Because of their ongoing health concerns, some patients developed a negative attitude towards education which led them to withdraw from their educational interests and eventually they discontinued their education. One patient described combining education and coping with ill health as "it was too much", which sums up the whole story. Some patients found it difficult to explain their illnesses to their teachers and class fellows, which directly impacted their life changing decision. Embarrassment, lack of self esteem and confidence also contributed towards this important life changing decision. One patient reported that at an early age he wasn't able to think properly and reported his decision to leave education as the "easy way out" and stated:

"It wasn't wholly because of that but there is a part of it because of your confidence at that age, because I would have been sixteen, seventeen then and you really don't think...well that's how I left school, with just GCSEs. I only know that I had 6 GCSEs and I really didn't know what I wanted to do anyway. I had the GCSEs but I didn't have any sort of A level or degrees or anything like that. I mean had I progressed, I could have done better; I could have had a better career you know and decided what I wanted to do but it's a bit late now...no (not a difficult decision), because it was an easy way out, you know"

<Internals\Interviews\Dermatology-Individual Interviews\II-03>

In a similar situation another patient admitted the importance of education at an early stage and stated:

"The overall experience you know of school with the problem. I wasn't focused I suppose because I felt a certain way so I didn't go to school. I should have. So I didn't finish my education, I left it at fifteen"

<Internals\Interviews\Dermatology-Individual Interviews\II-02>

One patient claimed that psoriasis made him "dyslexic" which also suggested how vital early intervention is. The patient stated:

"Yes, because I was so wrapped up in psoriasis. When I went to high school I still got the bad treatment. Nobody wanted to sit by me. So it affected me so much I couldn't write nothing, I couldn't think too hard, so therefore, I have been dyslexic but I know I could do all these things if psoriasis didn't come first in my life. I like to shut it away so I can get on with my life but it stops you, it really does...the decision I took is that I am so bad with psoriasis I am not allowed to have education. I should know my place in society. So it was a waste of time even learning because I was no good to no one, so gave up with it all...at school (stopped education), I loved to be a typist but I left school and let the psoriasis overtake me and I didn't get the education at that level and that is why I didn't go there"

<Internals\Interviews\Dermatology-Individual Interviews\II-13>

Patients' experiences indicate the need of awareness in this area particularly among young patients and their carers. Parents, clinicians and health providers need to be able to advise patients at an early age, guide them towards better decisions, explore different routes for education and for their career, which will ultimately help patients to take control over their health and life.

Patients' comments

"Education: procedures and operations, tiredness has had an impact which has left me under-confident to begin again at FE or HE level. Started but not complete FE"

<Internals\Cardiology\CARD-103>

"I left school at 16 with no qualifications due to missing most of the final year because of health problems"

<Internals\Cardiology\CARD-108>

"Left school early because of chest problems, coughing a lot mainly, did not particularly like school and decided not to go to school or college"

<Internals\CF\Cystic Fibrosis\CF-409>

"Due to spending time in hospital, off sick from school, I felt I wasn't able to carry on to further education"

<Internals\CF\Cystic Fibrosis\CF-424>

"Decided not to carry on with school because of CF, it was too much"

<Internals\CF\Cystic Fibrosis\CF441>

"Had planed to study fine art in Goldsmith School of Art in London (scored the highest A-level art mark in the country) but stayed in Cardiff as I had just had been diagnosed with CF and was ill in hospital. Had to give up studying at that time as I had a lot to cope with my newly diagnosed illness"

<Internals\CF\Cystic Fibrosis\CF-457>

"Did not do further education as I become more unwell and would not be able to do the work I was applying for"

<Internals\Diabetes\DIAB-507>

"When I was younger I had to come out because my eczema affected my ability to study, so education in one way because eczema wasn't under control when I first went to university. Same reasons of not being able to do studies because of lack of sleep or basically eczema out of control, so last thing I wanted to do was study, because I didn't sleep very well. Maybe I was taking anti-histamines so you got over tired...if say, my degree you know, I got at 22 I'd have been well educated and probably got a better job by now"

<Internals\Interviews\Dermatology-Individual Interviews\II-26>

"This is one of the reasons that I finished school at 16 rather then going on to further education, because mainly of the reaction that I had from my peers to the condition...that's correct, because of the reaction I had, from particularly my peers, while I was in school. To be very honest I had enough of it...at the time I thought it was an easy decision but in hindsight I think probably was a mistake but at the age of 16 I thought I knew best"

<Internals\Interviews\Dermatology-Individual Interviews\II-32>

"I was quite ill most of time, bad when very young and an infant, sort of cleared up in mid teens, early teens, then when I got 'fifteen sort of flared up again, I was sort of bed ridden almost. So started my last schooling, my exams... missed six months of the school year by the time I could go back. It was like pretty much exam ruined...just back and forth to the hospital trying to get treatment, after that I was thinking of just retaking the exam but, I was back and forth. I decided to just completely forget it. I was looking at college later on but then there was nothing really I could sort of go to college for...basically it affected my education and my confidence during school as well...yes, definitely (changed my life)...just a general education, when I was looking for a job, so I didn't have the qualification, the job I could do was factory work but in factory work, you are dealing with chemicals and things that my skin cannot... "

<Internals\Interviews\Dermatology-Individual Interviews\II-45>

Higher education: This area reflects patients' major decisions whether or not to gain a higher education at college, university or at a professional level. Many patients chose and planned their specific career pathways and selected a specific line of education so that they could eventually be in a reasonable employment in a safe environment suitable to managing their health problems. One patient stated:

"Choose to do a business degree to have a career in a stable environment"

<Internals\CF\Cystic Fibrosis\CF-412>

The involvement of the parents is also important in advising children who suffer from chronic illness who are about to take important life changing decisions. In the following quote a patient clearly stated the importance of parental advice:

"Encouraged" by parents to go to university so that I would be able to get a "non-manual job"

<Internals\CF\Cystic Fibrosis\CF-422>

On the other hand, the decision to embark on higher education as an adult was also sometimes tough and a life changing decision. These "late" but important adult decisions were based on patients trying to increase their chances of having a better job from the point of view of their health. One patient stated:

"As a diabetic child I missed school often, which affected my education. I have had to return and undertake education as an adult to seek career opportunities"

<Internals\Diabetes\DIAB-502>

Another patient stated:

"Probably education, I've gone back to education now as I'm currently being on cyclosporine and my eczema improved so back to university, I am pleased to get back to university... Whereas, I am going back to education now, so it's kind of back to where I should have been when I was younger, perhaps"

<Internals\Interviews\Dermatology-Individual Interviews\II-26>

However, it is evident that to start higher education is not a straight forward decision when a severe disease and a constant struggle with the illness are centre stage in someone's life. For example, many patients did not pursue higher education in the first place or left while at university, due to a constant fear of missing lectures if they were to become seriously ill, fear of being at the university away from home, concerns about continuous problems caused by travelling and study related stress.

Patients' comments

"Education: Later in life thought about university but didn't want to stay away from home"

<Internals\CF\Cystic Fibrosis\CF-407>

"My education and decisions on my future have been heavily based on my CF. Such as choosing not to go to university"

<Internals\CF\Cystic Fibrosis\CF-428>

"Left university due to problems travelling and being in university"

<Internals\CF\Cystic Fibrosis\CF-486>

"With my application to my university course I was given advice by the disability adviser and the course leader advised me that the course would be too difficult to manage with my CF. I ignored this and went ahead with the course. In hindsight I think that the advisors were correct as I am having difficulty keeping up"

<Internals\CF\Cystic Fibrosis\CF-492>

"Unfortunately, I was doing well in my course. I was in the top 10, I think, in my course but it flared up and I had to come to hospital for 3 months so I missed the crucial part of the common foundation part of the course. Although I arranged my placements so that I would do that in my summer breaks, the college wouldn't let me at that time. So either I re-sat the entire year, which I wasn't prepared to do to be honest, that was the 2nd year (bloody hard), so I came out. I suppose that my plight was highlighted after I resigned because the principal from the college came to home to see me, to see why I made that decision... Because I couldn't physically re-do the entire year yet again. If I'd been struggling and failed it I could have understood that decision but I passed so well even though I was in hospital. I was only in C1, then, my friends would take the lessons and I was back in that environment that I was in"

<Internals\Interviews\Dermatology-Individual Interviews\II-40>

"Higher education: going to university was a decision made during a temporary remission. I had a major flare up in my second year and was advised by my consultant to take a year out and rest, I did not, very determined to finish and gained a degree"

<Internals\Rheumatology\RHEU-607>

"It is difficult to get further education as you never know how you are from day to day"

<Internals\Rheumatology\RHEU-621>

Selection of an educational institute: Selection of an educational institute was also a major life changing decision for patients. Of course, their main concern was their long term health problem but they had to weigh their decision between getting a better education from a better university or to stay closer to home for family support and to be under the care of familiar hospital/staff they had known from childhood.

Patients' comments

"I originally decided to go to Gloucester University but had to think of my health and choose Swansea as this was closer to home and closer in case if I got ill"

<Internals\CF\Cystic Fibrosis\CF-434>

"Higher education: no relation in terms of course but looked for a university in proximity to CF Unit and family support structures"

<Internals\CF\Cystic Fibrosis\CF-451>

"Chose to move to Chester university from home to study, but decided to keep my hospital in Cardiff as I feel comfortable here"

<Internals\CF\Cystic Fibrosis\CF-417>

"When I was applying for University I wanted to go to Bath but changed my opinion to Cardiff because the hospital had better facilities then Bath/Bristol"

<Internals\CF\Cystic Fibrosis\CF-492>

"Yes. I wanted to be a nurse... no (other choice), I could have gone, I had the grades to wherever I wanted but to be very honest with you UHW is home to me. I've spent more time here than I have in my parent's home...and I chose UHW...because of my psoriasis, because it's safe here. It is an environment I know. Whereas, Swansea was my other option or Bristol...The other choices were Bristol, Swansea and Birmingham. I think it was, it is quite a long time ago now...yes (UHW) and it wasn't that far away from home, it's only 40 miles away from home"

<Internals\Interviews\Dermatology-Individual Interviews\II-40>

Moving abroad

The decision by patients about moving abroad was the seventh most frequently mentioned major life changing decision which was directly influenced by their chronic illnesses (Postal survey: n=35, 13.5%; individual interviews: n=16, 32%; focus groups discussion: No). The decision whether to move or not to move abroad was a life changing decision for patients but they took this decision in a practical way, according to their health, their individual wishes and other circumstances including finance, health facilities, insurance and weather. The attitude of patients and the way they took this important life changing decision (weighing up the pros and cons) gives some insight into how patients develop strategies to help them deal appropriately with difficult but necessary life changing situations. The following comments from several patients indicate that their eyes were on the future consequences of their decision; hence they were very keen to take the right decision for them.

Patients' comments

"I wanted to go to Spain but decided not to go because I was unsure of the health facilities"

<Internals\Cardiology\CARD-106>

"I have always wanted to move to a warmer climate (France-Cyprus) but I feel I would be unable to afford the health insurance or potential medical bills, which has prevented me from doing so"

<Internals\Cardiology\CARD-108>

"We wanted to move to the USA but due to my CF I decided against this. Firstly due to the NHS here and then having to pay for insurance abroad"

<Internals\CF\Cystic Fibrosis\CF-405>

"Country: NHS, Not going for jobs in USA/Canada because I would have to pay healthcare and drugs etc"

<Internals\CF\Cystic Fibrosis\CF-451>

"I wanted to move to Australia but there is no NHS and I couldn't afford the monthly drugs bill. Also I was told I may not get a visa due to diabetes"

<Internals\Diabetes\DIAB-507>

"Preparing to relocate to Florida in the winter months to avoid the cold weather"

<Internals\Diabetes\DIAB-524>

"I have toyed with the idea of emigrating. Even went as far as to look into the diabetic care but decided against it"

<Internals\Diabetes\DIAB-553>

"First thing, in about two months time, I am moving to Spain because I know that's the only place that my skin never causes me any problems. I know because I lived out there previously and worked out there previously and it's always cleared up and never had any problem at all. And then as soon as you return home it starts up again, so it has been in the back of my mind since I was a child. Even when I used to see my normal doctor he was saying "the best place is for you is abroad where the sun is", so from the age of as a teenager I always said to myself one day I will go and we are eventually moving out now next month"

<Internals\Interviews\Dermatology-Individual Interviews\II-48>

"I was planning to live abroad for 6 months of the year after retirement but now I don't choose to do so. This has altered my life"

<Internals\Nephrology\NEPH-270>

"Moving: also considering moving to a more agreeable climate e.g. south of France, Portugal"

<Internals\Respiratory Medicine\RESP-336>

"Was looking at a house in Spain but dropped the idea because of health concerns and health facilities abroad and health insurance"

<Internals\Rheumatology\RHEU-659>

"Have twice considered emigrating abroad to Australia, N Z or Canada, but access to health service here with my history decided against"

<Internals\Rheumatology\RHEU-696>

Holidays and travelling abroad

50 years ago this may not be have been a MLCD but in today's society yearly holidays (sometimes three times a year) are important events in people's lives and any change may become life changing for them. Many patients reported decisions about holiday plans as MLCDs (Postal survey: N=39, 15.1%; individual interviews: n=5 10%; focus groups discussion: Yes). It is obvious that when holidays and travelling abroad becomes a part of a culture and a way of life in a particular society, then any divergence or hindrance in their cultural and life style behaviour and routine could become a life changing situation. In the UK, people normally take at least one holiday per year or travel abroad for various reasons such as to meet friends and family overseas, job, business and for study reasons. The majority of people take this cultural, social or leisure freedom for granted (even though it is a recent cultural phenomenon) which makes it very difficult to deal with when this freedom is taken away by any life event, such as chronic illness.

Holidays abroad: patients were keen to go on holidays abroad but sometimes did not due to the severity of their long standing illness, high insurance costs or inability to get health insurance, fear of deterioration of their illness during holidays, treatment, long flights, weather, appearance, embarrassment and limited holiday choice. Two patients categorised this decision as" life changing" and stated:

"No holidays: life changing because of medication and travel sickness"

<Internals\Diabetes\DIAB-564>

"Not being able to go for holidays for eight years is life changing"

<Internals\Rheumatology\RHEU-659>

Another patient reported inability to holiday abroad as "a sudden change in life" and stated:

A holiday abroad is not possible and was a sudden change in my life, but we had to take this decision because of my insulin injections (5 times a day).

<Internals\Diabetes\DIAB-572>

Patients' comments

"Unable to have holidays and fly abroad"

<Internals\Cardiology\CARD-186>

"It also affected my holidays as I could not fly, down to insurance costs. Airlines were not accepting me so it does affect me in a lot of my outgoing activities with my family holidays"

<Internals\CF\Cystic Fibrosis\CF-403>

"Choice of holidays are only limited due to duration, can't enjoy long holidays because of fear of getting ill"

<Internals\CF\Cystic Fibrosis\CF-407>

"Going on holidays as travel insurance will not cover me"

<Internals\Diabetes\DIAB-507>

"As soon as I board a plane my ankles swell so much I can't get shoes on. They remain this way in hot climates until I arrive home again. Hence no more holidays abroad"

<Internals\Diabetes\DIAB-557>

"Yes, I feel happy to go on holidays in this country because I don't have to get undressed, it's so cool. End of it. If I went to Spain or, I don't think I could possibly do that...yea (major decision)...Oh, yes (influenced by disease), definitely. It's ruined my life, yes. People say it could be worse, could be this and that. It doesn't matter; I have got my own problems. I accept people are going to have problems, but they can hide that problem, but I get up in the morning and look at the bathroom, it reminds me every morning. It reminds me. I try to cover up, bit of makeup on your hands or whatever with moisturiser. That can only you have...yea (difficult decision)...yea, appearance, yes appearance (embarrassment)...yes, that's right, yea, I can't explain it now. When I first had it, it's like psoriasis in different places but all the places joined up so my whole body is more or less one psoriasis"

<Internals\Interviews\Dermatology-Individual Interviews\II-22>

"It probably is yea (life changing decision) because the only holidays we go now, then I am happy, if is we hire a private villa with a private pool... (limitation in holidays choice) oh yes, yea...the only thing because of then, you know, I got private pool we can enjoy the holiday facilities, you know, with the grand children, and because people there know my skin problem so it's no worries for me...well, it is yea (costly), you can go on cheap package holidays, you know, if I wasn't able to do that, I would go on all the holidays but keep my vest on you know...oh yes definitely (life changing decision) you know because it sort of your holiday thing and just sort of closes right down you know all the opportunity or choices you have got and become more restricted"

<Internals\Interviews\Dermatology-Individual Interviews\II-44>

"Being unable to plan holidays abroad has had a major effect"

<Internals\Nephrology\NEPH-236>

"I choose not to holiday abroad because I am afraid in case I am ill when I am away. This has changed my life"

<Internals\Nephrology\NEPH-270>

"About 8 years ago we wanted to do holidays abroad. Due to my health I decided not to go as it was too much effort and I am afraid to fly. It has changed my life"

<Internals\Respiratory Medicine\RESP-314>

"I have found it difficult to consider holidays as it would be complicated if I had an attack while away"

<Internals\Rheumatology\RHEU-629>

"Well I used to go twice a year for holidays. My wife used to come with me twice a year. We are not going now, so that is how it has changed my life...especially abroad, you can't walk around with a long sleeves shirt and trousers. You got to go down with shorts or maybe a vest on top that is it the maximum, and you will be showing whatever is wrong with you"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG1-MP2>

Travelling abroad: The reasons stated by patients who had decided not to go abroad on holidays because of their disease were similar to those stated above. They included for example, fear of travelling with chronic illness, severity of illness, treatment options abroad, high insurance cost or inability to get insurance. The influence of disease on job related travelling had different impacts on patients, such as financial implications making this impact of high importance to patients.

"I cut down going abroad to a minimum when I was working, I travelled to many foreign countries in the period from 1977-1997 with my work"

<Internals\Cardiology\CARD-190>

The inability to visit family members and friends was described as a heart breaking and a difficult life changing decision for patients.

"Not being able to visit family in Australia"

<Internals\CF\Cystic Fibrosis\CF-440>

"Have been unable to visit my sister in South Africa due to high insurance and problems with long distance flights"

<Internals\CF\Cystic Fibrosis\CF-479>

"I would like to travel to visit my friends and family in other countries but cannot sit on a plane for long and would not like to be taken ill or go into hospital abroad"

<Internals\Rheumatology\RHEU-638>

"Unable to visit family members in Malta due to severe pain in my bones"

<Internals\Rheumatology\RHEU-659>

Patients' comments

"Would not contemplate travelling abroad with my condition"

<Internals\Cardiology\CARD-113>

"For many years our hobby has been caravanning and in particular crossing over to Europe several times a year and visiting various countries. This stopped as I am unable to travel any great distance and also not having the strength to do what I wanted to do'

<Internals\Cardiology\CARD-134>

"It has restricted our proposed travel plans – I no longer do long haul flights"

<Internals\Cardiology\CARD-166>

"I wanted to go away travelling for 6 months to 1 year but felt that, being realistic, I couldn't be away for this long for several health reasons. 1. I couldn't carry all the meds 2. I think my health would suffer being away without checkups for that long a period"

<Internals\CF\Cystic Fibrosis\CF-466>

"Location: although I would like to see more of the world, I feel I need to be close to my family in order to receive the support I need. This makes me very resentful of my illness"

<Internals\Diabetes\DIAB-525>

"A change in life style: I developed diabetes 3 years ago and continued my usual life style of travelling abroad for 2 to 3 months twice per year (which we had done for the last 30 years) but in January 2008 I decided this had to stop for me...This change of life style, obviously involves my husband –the real reason why we travelled, and who, until the end of 2008 has paid 2 to 3 trips to US but has now decided to give this up because I will not accompany him anymore, though I have not influenced him on this matter"

<Internals\Diabetes\DIAB-581>

"Travel implication: need oxygen supply when required. Additional cost of portable oxygen supply during travel e.g. flight"

<Internals\Respiratory Medicine\RESP-313>

"Unable to stay away from home for long periods due to nervousness of never knowing how I will be attacked by the condition day to day"

<Internals\Respiratory Medicine\RESP-392>

Housing

Decisions related to housing (buying a house or moving to another house) generally related to individuals' financial situation. However, the nature of the disease and patients' long standing health-related needs influenced this decision significantly

(Postal survey: n=30, 11.6%; individual interviews: n=7, 14%; focus groups discussion=Yes).

Buying a house: Buying a house was a very technical decision for patients. Health uncertainty was directly associated with their job, level of income, insurance and mortgage prospects. This health, job and financial link made house buying a very challenging life changing decision for patients, when they had to consider all the aspects before taking any final decision. Life expectancy was also a big issue for many patients as their prognosis made it hard to get a mortgage. Patients also feared that deterioration in their health or their death would be "unfair" and hard on their partner to deal with it. One patient lost his job due to illness and ultimately lost his mortgage. Patients had to consider their health needs in relation to their choice of size, design and location of the house. Patients also paid more money just to buy a suitable house to accommodate their health needs, such as not buying a house if the garden was overlooked, because of embarrassment related to their appearance, or choosing a bungalow because of difficulty with stairs.

Patients' comments

"When buying a house with my ex-partner I bought a house. It did not stop me but I was unable to get the security because of difficulties related to insurance because of my illness"

<Internals\CF\Cystic Fibrosis\CF-413>

"Getting a house and mortgage is something that is affected by my health as I am unsure about job security and being too ill to work someday, not being able to pay the mortgage off"

<Internals\CF\Cystic Fibrosis\CF-428>

"Don't feel as though I can take out a mortgage. In case I leave my partner in money troubles if anything did happen"

<Internals\CF\Cystic Fibrosis\CF-440>

"Purchasing a house: as I cannot get any life insurance to pay off the mortgage (should I die before my mortgage is paid off) because I am diabetic!! Although I am currently fit and healthy"

<Internals\Diabetes\DIAB-502>

"I tell you what I used to look at when I had psoriasis was whether a house had a nice closed garden, so nobody could see me, so I wouldn't buy a house if it was overlooked... would never pick a house with a garden overlooked. The house I have got now I paid more for that house"

<Internals\Interviews\Dermatology-Individual Interviews\II-41>

"The loss of my job by talking to my manager, this resulted in not only losing my job but I had a mortgage with the company"

<Internals\Rheumatology\RHEU-673>

***Moving to another house*:** The majority of the patients had to downsize their housing because of their health and other health-related factors, such as lack of finance, physical aspects, pollution, dust, mould, carpet, long walk to shops and accessibility to hospital. In some cases, for example if patients had to carry oxygen all the time or suffered from a rheumatological disorder, patients moved to specially adapted houses so that they could move around. Patients also moved house nearer to their families in case there was any health deterioration and they needed immediate assistance. Some patents also wanted to move house because of their illnesses but they were unable to afford it.

Patients' comments

"I am considering selling my house. Downsizing to ensure financial stability"

<Internals\Cardiology\CARD-102>

"The only real change has been moving house. The previous home was too big to manage, garden etc. Also I now live in an apartment with a lift, so no stairs to negotiate. I am reasonably stable now"

<Internals\Cardiology\CARD-117>

"Moved house because of CF because I need more space for my medication, wheelchair and oxygen"

<Internals\CF\Cystic Fibrosis\CF-419>

"Moved house due to living in a damp flat which affected my chest"

<Internals\CF\Cystic Fibrosis\CF-438>

"When I and my mum moved house my health played a big part in the choice of house, location and surrounding area e.g. main road/air quality"

<Internals\CF\Cystic Fibrosis\CF-490>

"Moving house to be closer to my mother because I am having frequent hypos"

<Internals\Diabetes\DIAB-507>

"Moved into sheltered accommodation 10 years ago, I had difficulty looking after my house and garden before moving"

<Internals\Diabetes\DIAB-551>

"Yes, in a round about way, yes (because of psoriasis). We are in a bungalow now. The arthritis I got from psoriasis. It went so bad I had to move...I couldn't climb upstairs and of course we didn't have a mortgage and then pressure was on (name of partner) to move again because we had another mortgage to buy the bungalow which

I could subsidise...10 years ago (took decision)...oh definitely (right decision)... (improved life) yes"

<Internals\Interviews\Dermatology-Individual Interviews\II-21>

"I used to live in an old house and I did find that it just aggravated my skin more, so that my house I am in now, a new house which is only 10 years old, so I suppose that was something and I suppose I wanted to move. I don't know, maybe we had some carpets rather then wood flooring and even it stays more hygienic, I just found my skin much better now in the house I am in. And of course when I was a student in the halls of residence I didn't live there, something to do with my skin at the time being quite bad"

<Internals\Interviews\Dermatology-Individual Interviews\II-50>

"I wanted to move house but the problem with my kidneys made me not move house, as I was warned that I would not be able to get another mortgage"

<Internals\Nephrology\NEPH-231>

"Because of my illness I had to retire early aged 58. This has caused major implications not just health wise but has also influenced my income. Because I cannot earn a living, my spending capacity is greatly affected. We would like to move but cannot afford to"

<Internals\Respiratory Medicine\RESP-356>

"Relocating to an area where stronger network of support i.e. friends. Shared home with my widowed father, mutual support"

<Internals\Rheumatology\RHEU-607>

"Home: need to move to smaller property, can no longer manage because of cleaning, etc for the size of house I currently occupy. My garden has suffered greatly. Unable to do most of the tasks I used to do with ease. Even watering can be just too tiring. Linked to above need to move, but finding it difficult to summon the energy needed for this major task"

<Internals\Rheumatology\RHEU-656>

"I had to move house 6 years ago to a house that had been semi-adapted for the disabled, from a house I owned to a housing association property. As I couldn't afford the adaptations...I am going to have to move to a bungalow in a different area as my condition is worsening and I need to use a wheelchair more, the housing association is building it especially for me and my needs"

<Internals\Rheumatology\RHEU-672>

"We moved house because I used to do the gardening and I couldn't do the garden anymore. So we did move house and bought a flat, so it would be more compact and stuff like that...Oh, it was a big shock; you know my husband was already made redundant and I was the only earner in the house anyway. So then we took the decision to sell the house and get a smaller flat you know. So it was like a downsize type of thing. So that we knew we could afford, do you know what I mean. Denise started to come down to money then"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG1FP1>

Decision to change life style

A decision to change life style usually results from a history of people developing life style habits (such as over eating, smoking, drinking alcohol) which later may develop into addiction and serious health hazards. It has always proved to be very hard for people to change lifetime habits and any change will change their lives forever. For some patients, their health left no choice but to take the tough decision to quit their habits and addictions in order to improve their health and prolong their life (Postal survey: n=18, 6.9%; individual interviews: n=2, 4%; focus group discussions: No). In some cases the advice of doctors led patients to take this crucial decision. For example, patients were either warned by their doctors or they were themselves aware of the demands of their health to do more physical exercise, to avoid junk food and to quit smoking and alcohol. One patient stated:

"Once they diagnosed my diabetes, I decided that I had to lose weight and cut down on smoking and change my diet. It was a fairly hard decision to make"

<Internals\Diabetes\DIAB-538>

In some cases, due to the nature of their illnesses, diet became a complicated issue. For example, patients had to take a certain amount of calories in order to keep at a desirable weight. One patient reported:

"I have had to change my diet and life style, eat lots of high calorie snacks/main meals when naturally I would want to eat a low calorie small diet. This is a daily struggle and frustrating"

<Internals\CF\Cystic Fibrosis\CF-457>

Patients found it even hard to shop when they had to go through every single product label to read the ingredients and calorie values in order to avoid risking any health deterioration;

"Always having to be concerned about how much carbs are in food when I shop...Life style changes to me are important as in smoking, drinking etc"

<Internals\Diabetes\DIAB-507>

Patients' comments

"I live for today not for tomorrow. I don't worry about bills, I just want to enjoy my life with my wife and get the most out of it...I re-thought my life style and changed certain hobbies. I no longer drink and try to stick with a healthy diet'

<Internals\Cardiology\CARD-142>

"Change of life style: adapt to do things differently...Gave up smoking when diagnosed (4 years) approx"

<Internals\Cardiology\CARD-157>

"My lifestyle has changed. The older I get the more exercise I need to do to maintain my health. This will be good in the long term"

<Internals\CF\Cystic Fibrosis\CF-434>

"When I discovered that I had diabetes I realised I had to change my lifestyle, eating and smoking. I was determined to improve my health"

<Internals\Diabetes\DIAB-534>

"Changed life style, social life, eating food, drinking, nights out, sexual life and family life, grand children...I would like to carry on my life style, but not being able to due to lack of energy to change to a healthy life style, I have to"

<Internals\Diabetes\DIAB-542>

"Diabetes has changed my life style. Which I have to do anyway because of the illness and if I don't do that, I will be in trouble. It was very hard to stop smoking, drinking, etc"

<Internals\Diabetes\DIAB-549>

"Being diagnosed this is life changing as I have to plan visits around diabetes instead of travelling, food, medication. Previously I could travel as and when I wanted...Domestic life style changed as diets etc have to change to accommodate the new eating habits of diabetes and meal times are less flexible. Social life changed by the fact that habits have to change to allow me to accommodate the diabetes requirements...Life changing at home, any physical activities e.g. gardening, decorating even playing with grand children to an extent, have to be planned to take into account, the need to take more food for energy"

<Internals\Diabetes\DIAB-560>

"Diabetes will cause anyone to have a change of life style because there are rules to be considered...Life style needs to change because of the illness...Most people when confronted with the reality that they have diabetes, try to deny the fact and try to continue with the regimen as was normal before. The time will come when the illness has to be recognised and life style has to change"

<Internals\Diabetes\DIAB-569>

"Alcohol is bad for eczema so I gave up alcohol at very early age...well I suppose it is (life changing decision) really yea because if I were able to drink alcohol without waking up the next day with a red face and everything else that goes with it, heated the blood it does, it just causes you grief"

<Internals\Interviews\Dermatology-Individual Interviews\II-08>

"So it's changed me what I wear. I decided to lose weight to see if that would help so I changed my diet totally. I am not quite a vegetarian but I haven't eaten red meat for 5 years. I gave up sugar in just about everything, not just only in tea and coffee. I don't have it in food stuffs...I gave up smoking cigarettes...well, can I be honest, sometimes I see it as a blessing as much as a curse because I feel that if I had continued as I

was I would probably be very ill, and the fact was that because of hidradenitis, I gave up alcohol. I was a heavy drinker, very heavy drinker, seven nights a week down the pub. Also I was 22 stone, now I am 17 stone because hidradenitis, when I read about it, loosing weight may help, I lost 5 stone over two years. I am still going down slowly. So those were decisions, in a way maybe hidradenitis saved my life because I think that weight and drinking that amount and I smoked. I smoked 20 -30 cigs a day"

<Internals\Interviews\Dermatology-Individual Interviews\II-30>

"Old age and advanced stage of decline in my lungs has caused me to make major decisions on how I live my life from day to day, as from 2009 forwards'

<Internals\Respiratory Medicine\RESP-329>

"I started running and going to the gym to strengthen my body and help it to support my weight...I also had to reduce my intake of salt to counter the side effect of the prednisolone"

<Internals\Rheumatology\RHEU-646>

Moving to another city

The decision of patients to move or not to another city was also influenced by their long standing health problems. Decisions were taken both to accommodate health issues and to improve health and quality of life in general (Postal survey: n=11, 4.2%; individual interviews: n=6, 12%; focus groups discussion: No). For example, the following statement from a patient indicates the nature and importance of this MLCD:

"Once I have had my transplant I don't know how many quality years I will have left. Therefore I would like to move out of the city and to the sea /coast Cornwall/Devon"

<Internals\Cardiology\CARD-103>

Several patients decided not to move to another city because of the fear of changing hospital and quality of treatment, so they were happy where they were. One patient reported:

"Moving away from home: will need to move to a new clinic and surgeon to allow the condition to be looked after"

<Internals\CF\Cystic Fibrosis\CF-402>

"Avoiding moving from my house to another city because of the excellent GP and hospital and friends"

<Internals\Diabetes\DIAB-534>

Some patients had the chance to move to another city to follow better prospects but decided against it because of their job, treatment, hospital, education, family and support of friends.

Patients' comments

I have had the opportunity to move to England for a job but the hassle of moving doctors and hospital has put me off"

<Internals\CF\Cystic Fibrosis\CF-428>

"Long term illness affected many life decisions, moving to the area where wife worked as the main earner. We have moved from Lancashire to Kent and to South Wales. I had very little choice to move where her work was"

<Internals\Diabetes\DIAB-567>

"Well it has been something that would block a move abroad. For instance, I haven't seriously thought about it. I think other factors have meant that we would stay here in Cardiff anyway, but we thought it would be nice to move to another part of the country to retire, but then you always think of healthcare and how effective it would be wherever I move"

<Internals\Interviews\Dermatology-Individual Interviews\II-18>

"My husband and I had been planning to move from south to mid Wales to purchase a business. However, I was advised by my renal physician to remain close to my family as I might require their support, particularly in respect to my two children. I followed their advice"

<Internals\Nephrology\NEPH-283>

"Reluctant to move away from Cardiff as treatment for my condition is nearby"

<Internals\Rheumatology\RHEU-655>

"My progressive condition played a major part in deciding to move back to Wales after just 40 years living and working in London. Not only nearer to family but a larger more convenient central flat with lift with excellent transport on the doorstep and all aspects of healthcare within reach and accessible"

<Internals\Rheumatology\RHEU-666>

To quit professional sports

Professional sportsmen have a career and a life time hobby following retirement. Several patients were involved in a particular sport that they loved, competed in, travelled for and from which they earned respect and money. They started their favourite sport as a career, but their plans didn't work out, or were interrupted because of their ongoing chronic health problem and they chose to quit professional sports (Postal survey: n=3, 1.1%; individual interviews: n=2, 4%; focus group discussions:

No). They had to decide whether to carry on with their sport and also put a strain on their health or to quit professional sports to look after their health first. Some patients wanted to carry on but they were unable to perform to their usual level of ability due to the severity, unpredictability and the nature of their illness, for example the embarrassment of having a chronic skin disease.

Patients' comments

"I think what it is competition (karate career) then and, it was so much maintenance to get this skin down and keep your personal hygiene as well. It was too difficult because of the training, that was more use of your feet, so that is why, the smell would be more...yea and then I had to stop it, because then it was too extreme... I just stopped it, it had, physical block, mental block is what I mean, when you get older then you don't feel it, people say something just won't say something but when you are younger you don't feel that way, put on a lot of weight, change my life style, mentally and physically...I would have been training other people. I can see myself, you know, training people and be into competition"

<Internals\Interviews\Dermatology-Individual Interviews\II-09>

"I used to swim for Cardiff when I was seventeen but I stopped after a while when the disease progressed and became very noticeable, so it is really embarrassing for me"

<Internals\Interviews\Dermatology-Individual Interviews\II-15>

"I have always played golf to a high level but now I am considering withdrawing from active play, with it would go the social interaction"

<Internals\Respiratory Medicine\RESP-324>

Stand down from professional bodies

Taking part in regular community or association activities is a life long social practice for many people. Patients' chronic diseases prevented them from taking part in these activities or resulted in them surrendering their positions: these were reported as being major life changing decisions (Postal survey: n=3, 1.1%; individual interviews: n=0; focus group discussions: No).

Patients' comments

"Not stand for re-election as a trustee of a charity as it involves meetings away from Cardiff"

<Internals\Cardiology\CARD-194>

"I was a jazz band trainer. We qualified for the world championship, but because I don't have a driving licence I had to give up training. Using other means of transport may deteriorate my condition so I had to give up and it was a life changing decision"

<Internals\Diabetes\DIAB-549>

"I had to stand down from various national committees and bodies on which I represented the local...The major one was acting as Chaplain. I have missed out so much during this last year...The main reason for standing down is not being in a position to plan ahead with a certainty that on a given date I will be well enough to fulfil the promise"

<Internals\Respiratory Medicine\RESP-329>

Major treatment decisions

Some major treatment decisions were also reported as MLCDs by patients (Postal survey: n=3, 1.1%; individual interviews: n=0; focus group discussions: No). For example, the decision to have dialysis, organ transplant or surgery could easily change patients' lives forever or may provide the opportunity and hope of having some better quality years. The fear of major treatment complications was also in the mind of some patients. The impact of their illness on families, and the consideration of treatment timing and its impact were the most interesting aspects of this life changing decision.

Patients' comments

"Going on dialysis is life changing. It will be time consuming and the decision will be made although I am not looking forward to it. I will go whenever it is necessary"

<Internals\Nephrology\NEPH-246>

"Lung transplant, because of my son and husband I would go for it without a thought"

<Internals\CF\Cystic Fibrosis\CF-495>

"Surgery: decision to have both knees replaced when still relatively young is one I don't regret. For me it was about quality of life and made bringing up a family far more manageable"

<Internals\Rheumatology\RHEU-607>

Life style decisions reported as MLCDs

Life style decisions are based on the activities that people do and choices that people make on a daily basis, such as what to wear, where to go and what leisure activities to do. People normally take these activities for granted, and so any change in circumstances, such as the onset of a chronic illness, may change their life style choices for ever. Patients' choices will become limited; health concerns and limitations may make what would normally be an undesirable option a best alternative, which makes it life changing for patients. These life style decisions were reported as MLCDs only during individual interviews and during focus group discussions and were not reported by patients who took part in the postal survey. The life style decisions such as choice of clothing (n=23, 46%), not to go swimming (n=17, 34%), not to socialise (n= 11, 22%) and wearing make up (n=11, 22%) appeared to some patients to be more important and life changing than some of the other more obvious MLCDs reported by patients, such as housing, moving abroad and major treatment decisions.

The patients' main concerns over choice of clothing were about the changes in type of clothing (cotton or nylon), style (short sleeves, long sleeves, skirts, trousers) and colour (light colour or dark colour). Their decision concerning swimming was related to public attitudes and embarrassment: they were unable to enjoy swimming with their children and families and when on holiday. Patients who decided not to socialise stopped their regular visits to the pub or social clubs and decided to stay at home in isolation rather than going to parties and family gatherings. Wearing make up was a gender specific decision, depending on the nature of the patents' condition. Patients either hid their chronic skin condition under make up or they were unable to wear make up because of their chronic skin disease. Being unable to wear makeup shattered their confidence and in their opinion made them psychologically different from other people.

The reason why lifestyle decisions are described at the end of this content analysis is because these decisions are normally perceived as routine daily decisions and not as MLCDs. The type and the magnitude of these reported impacts of chronic disease on patients' lives provide a new insight into this area. The findings clearly suggest that any change in normal life routine due to chronic illness or being unable to perform or take part to their full potential (without restriction) in these activities for a long period of time becomes very important and life changing for patients. Patients who reported these decisions as MLCDs had been suffering from chronic skin disorders for many years. Skin diseases impact on a variety of factors, such as, obvious aesthetic perceptions, embarrassment, self confidence, self-esteem, public attitude, anxiety, depression and treatment. All of these factors contribute to life-style decisions being reported as MLCDs.

The following specific examples of patients' comments grouped under each life style decision explain why these decisions were major life changing decisions for some patients, and how their quality of life and that of their families was subsequently affected.

Patients' comments (Choice of clothing)

"Yes, yea that was quite a big part actually because the acne was on my shoulders, on my back and on front as well, it was quite difficult to buy clothes in summer. In the winter it was fine but in summer and if you're going to a wedding or something like that, you always sort of buy things that covered half way on your arms...I mean choosing clothes was terrible you know (why it is life changing?) because I mean you go to a function, you know a Christmas party or something like that, and it is so hard to buy like a dress or anything, and you turn up and you feel everybody else will be lovely, little dresses, little straps and you be there covering up all your shoulders and everything and just felt again like you didn't fit in, you know, that you are different to everybody else because you're wearing different things, you know, trying to cover yourself...yea, yea definitely (changed my life)"

<Internals\Interviews\Dermatology-Individual Interviews\II-03>

"It's got to be cotton. I cannot wear anything synthetic. If you wear a nice suit, its got to go to the cleaner the following day because of all the grease you carry on your body all the time. You just got to think so much ahead all of the time...oh yes, if your skin is bad you wear long sleeves all the time, even in summer...yes, definitely (life changing decision), yea because I still think there is a stigma attached to it. If you are driving a taxi and you get people in the cab and you have eczema all over your hands, if you are not showing it, people don't know, but if you got a short t-shirt...of course you are (hiding) you know, you just do not want people to know what is wrong with you. You just keep covering them because it is easier to cover them than explain... it is the second glance, it is the looks (public attitude). My kids are fine but when their friends come over and I am wearing shorts and this lad says "oh your dad looks sort of alien". It's all the explanations. You do not want to explain to people what it is. It is not catching and it is not dirty. You do think about yourself. It is just constant because you've had it all your life, that's the way, it's built into you. It is like that's how it is...you do it all the time, you automatically buy long sleeves because you've always done it. Even now my skin is not bad; I always wear long sleeves... (changed my life) 100%, I would say what you wear...if you go to a restaurant, If you've got short sleeves shirt on and your skin is bad at the time and you just feel uncomfortable, you wouldn't enjoy yourself as much as if you covered up. It is psychological, it is really. Maybe no one is looking at you but you feel they are. What you do not see, it does not hurt you"

<Internals\Interviews\Dermatology-Individual Interviews\II-08>

"It's still major now. It is very big; I will not go to the front door if somebody knocks at the door. I have to get the cardigan because in the house I will wear short sleeves...If he wants to go out, sort my clothes I am going to wear and I have to make sure that it is long sleeves. The worst time is summer because, say you go to places you see all these women smartly dressed, I have always got the trousers on and I've always got the long sleeves top and people, say you are working, they say what have you got on? And you can't explain to them why you have got it on. So it is big"

<Internals\Interviews\Dermatology-Individual Interviews\II-21>

"You prefer to hide it because you don't want people to say to you; "Oh what have you got, what is that?" So yea you do try to hide it, or I try and hide it...yes, it is a big thing; it is horrible people saying "What is that? What is that rash you have got?"... at the moment I would try to cover up as much as I could...oh yea, definitely (major decision), yes it was. I never could wear what I wanted...I don't think there is anything specific, it was just I didn't like to wear something where everyone could see my eczema"

<Internals\Interviews\Dermatology-Individual Interviews\II-24>

"Big major decision. Depending on the state of my arms. Some weeks my arms are ok and then I can, mostly I can't...well it is (major decision), you should have a choice over what you want to wear. You shouldn't be governed, you know only work really governs you what you wear...well it can, I really think, one individual thing changes your life. It's everything put from one perspective. It is constant reminders that you've got this disease...yeah, you can't wear long sleeved shirts, and you can't wear dark tops, so you can't wear anything dark on top. It's all them things mixed in that have a psychological effect on you. What an individual thinks will not change your life. It's everything that has a strain and a big effect on your life"

<Internals\Interviews\Dermatology-Individual Interviews\II-25>

"Oh yes, that is something I do all the time (hiding skin). I have a habit of I always pull down my cuffs...no actually it is because what you are doing here is you are making a decision everyday of your life not revealing yourself...yea and it becomes a habit now when it is less relevant but I still do it, it becomes a feature of my life...oh yea (major decision). I have not worn t–shirts since I was 11...how has it changed your life? It means you are obviously more guarded, you are more cautious; you are less open so it changes your personality because that sort of wanting to hide yourself will have an impact generally. You have people who could, if I put it bluntly who could be ugly as sin, fat as lard and here they are wandering around with shorts and you think to yourself, bloody hell if I looked like that I wouldn't do that. They are prepared to not conform to the, you know you got to look beautiful or whatever somebody, with the skin condition because if lets say if you are huge, 20 stones that is normal. I don't think 20 stones is normal. I mean there are big people. If you are a fat a person you are still normal. If you have a skin condition you are not normal. Now you make a decision, you lose weight, you put on weight, whatever it is but with the skin condition, it is imposed upon you (long-term and ongoing), that's abnormal. It is an ongoing thing; it's abnormal just like I said losing a leg is abnormal. You're supposed to have two and most people have got two. In that sense you are hiding something that is abnormal"

<Internals\Interviews\Dermatology-Individual Interviews\II-33>

"Yea, my choice of clothes is because of my psoriasis...it was my life changing decision on my clothes and what colour I wear. I wear trousers and I always cover my arms when I go out"

<Internals\Interviews\Dermatology-Individual Interviews\II-35>

"I always did (for 20 years) because my psoriasis was quite bad...it didn't boost my confidence to keep wearing long sleeves, tops, no, because you are always conscious that people are thinking that she is always in long sleeves too, she never wears short sleeves"

<Internals\Interviews\Dermatology-Individual Interviews\II-41>

"Aaaa that is big one (choice of clothing). Yea I have to, if I am going to wear something, I can't wear anything if it itches, you know, when you are out for shopping you can't buy certain items of clothing...long sleeves is good to hide eczema when its bad, and short sleeves is good for when it's better, because the sun is out there and you want to get sun on your skin...yea (always wear) to cover my skin, if my skin is bad I cover...yea God (life changing) because its just automatic to you because you done it since I was a child, I don't know whether it's like life changing, for me, it is...it would be because straight away you can't wear what you like to wear"

<Internals\Interviews\Dermatology-Individual Interviews\II-48>

"Aa, colour is a major thing...it's everyday, these add up to a major decision, everyday you've got to make a choice of colour, just this is everything, that is the colour of carpet in your house, colour of your car, down to the shirt you are wearing, down to long sleeves, short sleeves, every single thing...It goes on too long. It's over the period of time, it's just so massive. Previously, one of my big decisions was joining the police force where I saw short sleeves, so I deliberately avoided it"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG1MP1>

"Another thing, on a bus they will sit behind you and they see"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG1MP3>

Patients' comments (Stopped swimming)

"Don't go swimming, decided not to go swimming because of eczema and public attitude...my children want to go swimming so I have to rely on my wife to take then. I can't have fun in the pool with them...with arthritis you need to go in the pool. So I can't go in the pool (psoriasis), I miss the enjoyment, and being with the family. It does make things hard that I can't go with them"

<Internals\Interviews\Dermatology-Individual Interviews\II-10>

"From the beginning...in school...yes (major life changing)...I can't swim because of it and I never took games or PT or anything like that in my school years, that was because of eczema, because of embarrassment"

<Internals\Interviews\Dermatology-Individual Interviews\II-16>

"I had psoriasis, I wouldn't be seen with psoriasis (stopped at the age of 16)...oh definitely (major life changing decision). It has spoilt a lot of things like with children

or when we go out on holidays and we go away sometimes with friends and they go into the Jacuzzi and things. As I said, this weekend was a classic example, we went away with grand children, they were in the water, my son, daughter and grand children and I sit at the balcony and watched them"

<Internals\Interviews\Dermatology-Individual Interviews\II-21>

"I used to go to the swimming pool years and years ago when I was young and when the psoriasis was just on my hair then, and I used to have long hair so it wasn't visible really, but for the past 20 odd years no, never...simply because you just see people staring at you and talking and you know it is just not worth it. People are not educated enough about it...oh yes, yea (major life changing decision), that I wouldn't do that. I mean the only thing that upset me as a major life changing thing by that way was when the grandchildren were younger, not going to pool with them...oh, it affected me that way, yes definitely"

<Internals\Interviews\Dermatology-Individual Interviews\II-44>

"I used to go to swimming lessons and thought I would like to go again but I got this problem (skin condition) and it just stopped...oh yea, definitely (major life changing decision), the thing you stopped doing, something you want to do...because you can't do it, you can't do what normal people do. The only way would be to wear a swimming hat which I don't like to. I mean you can still go into the water but then you've got to tape it on"

<Internals\Interviews\Dermatology-Individual Interviews\II-46>

Patients' comments (Not to socialise)

"Very much so (major decision) because I was very outgoing when I was younger. I was always going out, very social and obviously the condition changed that...all kinds of ways. When I was younger I was never at home, always out all the time...my self consciousness about my condition (reason)...yes, I wouldn't say afraid but self conscious, embarrassment, bit of fear"

<Internals\Interviews\Dermatology-Individual Interviews\II-14>

"I suffered with nerves and yea, it is (major decision) I'd rather not bother than feel embarrassed with it...I feel that people are looking at you all the time. They don't know it is eczema they might think it is something else and as people are people they don't understand the situation, they can be nasty...calling names and they call you "spotty", things like that and I'd rather not go"

<Internals\Interviews\Dermatology-Individual Interviews\II-16>

"Well, yes I wouldn't wear the clothes they wore then, you know, the short skirts or whatever it is they wore...: It was (difficult decision) but I think it was just part of growing up and that was it...never did (go out or socialise, clubbing, pub)...I suppose it was (major decision) I just sort of did it. It was just that, that's the way I was and that was the way it's going to stay"

<Internals\Interviews\Dermatology-Individual Interviews\II-19>

"Oh definitely (major life changing), because I was always, like, dancing and going out and between my arthritis and psoriasis... "

<Internals\Interviews\Dermatology-Individual Interviews\II-21>

"I haven't got one (social life)...what it is I got everything, in the last 5-6 years. I've locked myself away (patient crying), because with everything I just couldn't cope with life. My psoriasis was worse and I wouldn't go out and meet people, I wouldn't go and sit in the park and I have a garden and sit in the sun...yes (life changing)...yea, because I find it hard to socialise"

<Internals\Interviews\Dermatology-Individual Interviews\II-35>

"That's yea, that is life changing because I know that because I am going through that now because it's all on my face. The only place I keep getting eczema, it keeps coming up here on my face... I won't go out...I won't go out. There has been a few because I am a dancer and I won't go. There might be social events or something, if my skin is really bad I won't go"

<Internals\Interviews\Dermatology-Individual Interviews\II-48>

"Most of the time I stayed in. I don't go out because people are cruel, very cruel and most of the time I stay in now...my hands are bad and my face, I'd rather stay at home. You are tired because of treatment three times a day, the bandages for 8 months, so you can't plan anything really because of all the treatment and bandages and rest is most important...yea (major life changing decision) because I like meeting people, you know, it is not nice to be on your own. When the children grow up they go and...yea, my eldest does the shopping for me and her husband"

<Internals\Interviews\Dermatology-Individual Interviews\II-49>

Patients' comments (Wearing make up)

"It did, yea, because it changed the social group I was in at school. Lot of people wouldn't talk to me because I didn't want to wear makeup and they said "she is weird"

<Internals\Interviews\Dermatology-Individual Interviews\II-27>

"Spend so much money on make up, it is ridiculous, putting it on every day, couldn't leave the house without it, wouldn't open my front door without it on...yea (major life changing), It was a problem with my life, yea"

<Internals\Interviews\Dermatology-Individual Interviews\II-02>

"Yes and also my skin is very sensitive so I can't wear any makeup...yes (major decision not to wear make up)...on a day to day basis it doesn't worry me particularly. I'm the sort of person who are made up all the time but I have not worn make up for so many years I've forgotten how it is like. It would be nice to able to use make up on occasions, socially or whatever"

<Internals\Interviews\Dermatology-Individual Interviews\II-06>

"I can't wear makeup at all, which is horrific. If I could find somebody that made a makeup that I could wear I would be there. I cannot wear makeup and I would love to wear makeup...yes (major life changing decision), (emotional-crying) especially being a woman you need to be able to do that...(Crying) a lot. Just, like, to be normal"

<Internals\Interviews\Dermatology-Individual Interviews\II-19>

"I do stop and think about things now. Even if I open a front door I think about how it might be, can I go because I haven't my wig on. I don't like to wear it in the house. Who will it be and what, you know, and what will the impact be. If it is particularly my son's friends...yes, I mean I will open the door, I just don't like the reaction of shock you know, but some time the postman, I haven't got the time to think about that too much but I will open it and here I am again dealing with that, oh shock and you just think "oh god". It is completely frustrating and when this first happened I didn't have wigs and walking around town and people I know over the years just didn't recognise me, walked pass and that was incredibly difficult..."

<Internals\Interviews\Dermatology-Individual Interviews\II-23>

"Yes (life changing), because people wear all these things and I've always been afraid to use it"

<Internals\Interviews\Dermatology-Individual Interviews\II-35>

"Sometimes I have gone to my job, I just shove the wig on and I haven't got, you know, because I have to put pencil in my eyebrows and everything and sometimes I haven't done it but I don't worry about it now. I used to...yea (always wear make up) because of my eyebrows, eyelashes have gone. Before I didn't have to, you can get up and "oh I can go out today without makeup, I am just going down the road, it won't matter"...oh yea (life changing decision), definitely, you can't be normal, my husband would say "hurry up", I said "I have got to put my eyebrows, my eyeliners on"...that gives me confidence, if I've not got it on it's just like a, my husband asked me to take him to Barry, he goes out with his mate on Friday nights and we were picking up friends of ours up the road and I didn't realise that I didn't have enough make up on so (name) was talking to me and I am sort of holding my head down and I can't look at him because I realised I didn't have any make up on, I felt embarrassed...It just looks horrible, you know, not like normal...well, that is yea (life changing decision), definitely. If we didn't have make up, I don't know what we would do, you know what I would do... but I often think, I was in a car accident and I was parked in the middle of the road and a car came in to the back of me and my wig fell off you know, and then a witness saw it and he picked it up and, I am not worried about getting hurt at all, I am worried about him seeing my head and he picked it up and I felt so embarrassed, he was bald anyway, but you get so worried about things like that"

<Internals\Interviews\Dermatology-Individual Interviews\II-46>

"Yes, it is an important one; I think because it's related to my job, if I have got eczema on my face and I often teach and I do presentations. I am not going to go and stand up in front of people looking like I have got eczema. So makeup is very useful to me but of course there's a pay trade off which is that it's actually not good for the

skin: as soon as I get out of the situation I need to take it off. Again, I have conflicts at times with the professionals who would say "do not use it". And I say I have to if I am going to feel confident enough to get up in front of people and to teach and to feel that sense of confidence. I do not want to think that people are just looking at my skin rather than hearing what I say"

<Internals\Interviews\Dermatology-Focus Group Discussion\FG-2FP1>

Non MLCD issues

Driving

Deciding not to drive has a knock on effect on other aspects of life, especially on the family. It makes patients more dependent, and also creates a situation that other people cannot be dependent. For example, in a family situation if a wife or a husband decides not to drive, then the burden on lifting children or going shopping falls on one person, impinging on other aspects of life.

A considerable number of patients reported an impact of their chronic illness on driving. Although they didn't mention this as an MLCD, during content analysis it appeared strongly that this could be a life changing decision. It was obvious from the views expressed by patients that their finance, leisure, visiting family and friends, daily activities and overall feeling of freedom was directly connected to driving. Patients had to choose between surrendering their driving licence on health grounds or keep driving and put their and the lives of others at risk. For those patients who decided not to drive again on health grounds, their lives were changed in a major way. Several patients' jobs were related to driving; hence giving up driving had an impact on their finance and family life.

Patients' comments

"Learning to drive, my eyesight was badly affected due to Marfan's syndrome and I thought I would never drive. Due to advances in eye surgery I had operations on both eyes and passed my driving test"

<Internals\Cardiology\CARD-114>

"I am unable to drive my car for any distance or to enjoy a day out with my family"

<Internals\Cardiology\CARD-128>

"Coping with short-notice deterioration of my health, affecting plans such as driving to a destination and unable to continue/complete it in the original planned method

(e.g. self driving, then relying on others to finish the journey, or having to use alternative method)"

<Internals\CF\Cystic Fibrosis\CF-500>

"Driving: I have a temporary driver's licence now because of my diabetes"

<Internals\Diabetes\DIAB-554>

"Diabetes has restricted my driving"

<Internals\Diabetes\DIAB-560>

"Driving, I am more conscious of my blood sugar level, what I have eaten etc because of diabetes"

<Internals\Diabetes\DIAB-598>

"Not being able to drive through lack of confidence after many operations"

<Internals\Nephrology\NEPH-203>

"Do not drive to any different places"

<Internals\Rhuematology\RHEU-611>

"Should I give up driving my car: I keep asking myself this question because car driving is more stressful than usual as my neck is fused? At times driving is out of the question, especially when I have a bout of iritis"

<Internals\Rhuematology\RHEU-612>

The following patient's comment sums up the entire approach of this content analysis:

"Like many branches on a tree, you know, that makes up that one disease. It's very hard to put on one thing that's what it is, everything is involved"

<Internals\Interviews\Dermatology-Individual Interviews\II-25>

Patients' comments in relation to study secondary objectives

During individual interviews, along with the main research question two subsidiary questions were asked in relation to the secondary objectives of this study: 1) How can we help patients in a similar situation to you to take appropriate MLCDs? 2) What do you think about the idea of this study? These questions were asked at the end of each interview in order to obtain the patients' suggestions about MLCD strategies and their views on the idea of this study. Patients' responses were scrutinised in detail and later used for the development of appropriate strategies for patients to consider before any MLCD. Patients' comments were as follows;

1) How can we help patients to take appropriate MLCDs in a similar situation to you?

"Give them the tablet I am now on... tried all the other treatments from the doctors and they were not good enough"

<Dermatology-Individual Interviews\II-02>

"I think it is very good actually because if I had some kind of support in my teenage years when it was so bad then I probably would have been a lot more confident and been out there and done lots of things you know. It is not just cosmetics, it really is psychological and it really does affect you and, you know, if they can see this that somebody has so bad acne they got to think that, you know, they need help"

<Dermatology-Individual Interviews\II-03>

"Don't suffer, if there is any way that you can't suffer, by going to the doctors or changing your attitudes, then do it. Always find a sense of humour; always find a way of laughing"

<Dermatology-Individual Interviews\II-04>

"I don't know. They (doctors) do their best. It is not going to go away, is it?"

<Dermatology-Individual Interviews\II-05>

"I think everyone's circumstances and situations are different. You just have to see an individual, whether they can cope with illness or not"

<Dermatology-Individual Interviews\II-06>

"Only just one small thing. You brought up the point about life changing decisions and this is important. I guess, I have based a lot of my decisions on the fact that I may never get over this. I mean never get rid of this condition, so therefore, I had to think if I stop dancing (sorry dancing, another thing), if I stop sports I can live without it for the rest of my life. With partners, could I live the rest of my life without a partner and job, you know, can I do this job for the rest of my life? I had to be able to think is this the situation that I can sustain, not just for tomorrow but after, to look as far forward as possible. It is not easy to get to do that at times but yes I have had to consider very long-term, assuming the worst case scenario which is that you know the condition would not correct itself. So that has been a major factor in my thinking. Just regarding decision making, I think it would be interesting to analyze not just the decisions that we have made but how the decisions have been made, what I mean is make decisions for physical reasons or for emotional reasons or for logical reasons. It just strikes me, and again it depends on the type of person you are, but some people may be very emotional and therefore if the appearance of their skin is more important to them that would affect their decisions. Some people are more logical and they think it does not matter that my skin looks like this, but I have to take this decision because this is the logical or the right decision but some may take a random decision. It just strikes me that we could look further at what is the main impulse which decides the decision, whether the emotional, the physical, the mental or the logical. This is what I wanted to add"

<Dermatology-Individual Interviews\II-07>

"It is in you already. If you have that personality, you will get through it no matter what. There is a lot of depression that goes with eczema. Suicide as well. However, I do not have that mind set. I have been built differently...Just have to be positive. At the end of the day, it is not going to kill you; you have to work around it. You have to get through your life around it...There are different help groups but if no one goes there then they will not be able to help...I think if you catch the kids early enough and you are good with your school there is a difference now, you have the internet and can get education at home, in the 70's we were not even given a book. These days they have better options to complete their studies"

<Dermatology-Individual Interviews\II-08>

"In a similar situation, is to plug your doctor, your doctor. Tell your doctor how you feel because that's the only way I read it. Explain how you are feeling, I wanted to know if is there anything further we can look at, like today you can do a lot but it was never about when we were young. But you look at general things that you could improve in yourself, because you can. It is a hereditary gene with us; I can see what my father's like...stay positive and everything, if you don't think that anybody is better then you. You are your own individual and if you want something you just got to go for it, you just really got to go for it because you shouldn't be discriminated against, and nobody should not be discriminated"

<Dermatology-Individual Interviews\II-09>

"Don't be afraid to ask for help because if you keep it to yourself it will cause more animosity to yourself and it will make you feel more depressed. This will aggravate your eczema because you are not talking about what you need to get off your chest...Make your own decisions within what you are comfortable to make and hope and try to influence people and society to be more open minded. Just because you have a skin condition, it's supposed to be an equal society today"

<Dermatology-Individual Interviews\II-10>

"Talk to people about it; don't feel embarrassed about it, I would say. You know, don't try to hide, that's what I did a lot you know and it's for people to come to terms with...I think if I had had someone to talk to, if you give people someone to talk to about it as well you know how they would feel, I think they get on better with life as well, you know what I mean. Surprising the way we hide, you hide it and nothing is said about it, you just keep it to yourself you know, you talk to like I talk to my sister. I wasn't embarrassed about this and that and when you are talking I can talk to you about it and its not too embarrassing, but if I had been able to talk about it in my younger years I think it would be a lot better and I would have had more confidence"

<Dermatology-Individual Interviews\II-11>

"I think everybody should know about psoriasis and that will encourage people not to hide, not to think this is some disease or burden on your life. You are part of everyday society like other people. If you got psoriasis, you just put your head up and just take one step forward. If they don't like you with psoriasis, time to go away. You can get all the help from the hospital. They are the one. You can't wear anything, like you can

put gel on your head, you can't use any shampoo, you can't use perfumes, you can't use things in the bath. That is why it is so much about your life. It is with everything you do, with hygiene, with anything really...I don't think, it's made me feel that I am there. I should be down there still. If I am on my own it is ok but when I am out, I feel people looking at me because they can see psoriasis. I change my opinion of everybody because I don't think they would like to talk to me. I think they just want to talk to me because they want to see what is the matter with you. When you just go, you look around, who said that joke about me? You think it is in their own mind, you know what I mean. They look at you and they have already judged you and you're scabby and you are no good, you are dirty"

<Dermatology-Individual Interviews\II-13>

"Well, for the last 20 years it has had a huge effect on every decision just about I think...I am aware of it, I am the one who had to make the decisions"

<Dermatology-Individual Interviews\II-14>

"I don't know, I think I talked about this with my mum but I haven't really had to face many major life changing decisions yet, so I wouldn't really know how older people with the same condition are affected and I only know one person with the same condition by chance so she kind of helped me. Talked me through things and advises me when doctors recommended medication. I think people just need to try network and find each other, so they can share stories"

<Dermatology-Individual Interviews\II-15>

"Better education for people. They can understand what eczema and skin complaints are about and haven't got the attitude that it is contagious or anything like that"

<Dermatology-Individual Interviews\II-16>

"I don't know, I just want to say that people shouldn't worry about these things. I sometimes, when I see like people with a really bad burn and scarring and they are ok so why should I worry about this. I mean like I have two hands and two legs, one brain and everything. I mean many people don't have this and shouldn't really worry about this. Life is just too short"

<Dermatology-Individual Interviews\II-17>

"No, it's always been at the back of my mind I couldn't do various things because of it. Because of its limitations"

<Dermatology-Individual Interviews\II-18>

"You have to turn around, this is my life not theirs. This is mine and I have what I have and that's it and that's the only way it goes"

<Dermatology-Individual Interviews\II-19>

"I think the doctors at the moment are doing a great job. What they have done for me over the years has helped me to make those decisions which are got to be made"

<Dermatology-Individual Interviews\II-20>

"I think people need to know that it is not contagious and what is the cause...I mean you have campaigns of other things on television, like cancer and how it affects your

life...I think skin diseases are sort of shut to the back. It doesn't seem to be a major factor to people"

<Dermatology-Individual Interviews\II-21>

"I have never gone to the alopecia society, I think for me that is a bit denial. I don't want to admit that I am within that group, that's probably totally the wrong attitude. I still can't do that, I don't know why...I do anything you know, if you ask me to do anything to help, I would do it. When I saw (name of specialist nurse) about my camouflage makeup, I went to see her about putting camouflage makeup on my eyebrows but it is a hassle everyday, you don't want to wake up and have to put, your eye brows on to give definition but between us we looked on the internet about fake eye brows because I said I have to have these done and these were three hundred pounds, so its expensive, but we looked and she said I might be able to get some funding for this so I said it's not going to be any help for me, but if its helps one other person get eyebrows on the NHS, its fantastic. They might not have three hundred pounds to have these done"

<Dermatology-Individual Interviews\II-23>

"Nothing I need to say but there should be more help, the help I have had is from my GP. This clinic thing is fine though. You get to visit them in 3 months. Somewhere you can go as a person and get some general advice. Then group sessions are essential I think"

<Dermatology-Individual Interviews\II-25>

"There probably does need to be yea support, I can imagine, specially for younger people, teenagers, maybe through school because obviously that's the large part of somebody's life, decision making part of life, and so best thing you need more support which is not just medical, perhaps the counselling support comes along with the medical support. As opposed to just "creams go, away", you know there should be counselling support along with it. The counselling should be the advice other than the medical advice, should be there along with medical advice...it could be educational authority, primarily it has to be health authority because that is going to be the first point of contact. The first point of contact could be a consultant or a doctor so it starts from there because I seen for example a doctor more than happy to help, ask for help in school, then going to see doctor regularly...when you are younger and you just had little experience in terms of disease it might affect you more and make it more difficult to take major life changing decisions"

<Dermatology-Individual Interviews\II-26>

"My parents, specially my mum, is brilliant...didn't know about the help available to me specially looking back on it as a teenager...a lot of people used to think it's a burn and asked me if you have been in a fire. My mobility was very limited a lot of times as a teenager. Things like disabled badges etc. I didn't know about it. It would have made a big difference. So more information would have changed...probably workshops or funding schemes, specially transition between living at home as a teenager and then living away was a big change and all the questions you can ask your GP is a big thing you know...I suppose it's a difficult question. If you have a

long term disease getting a treatment is paramount, that influences everything else. Long term means you will always have this"

<Dermatology-Individual Interviews\II-28>

"I think it is difficult because everyone is different and their needs would be different...how you deal with your illness psychologically has an impact on your physical disease and that why it's important for people to understand how somebody's mentality is linked to their illness. People should treat the patient not the person, treat the people to understand the impact of someone's psychological state on physical illness"

<Dermatology-Individual Interviews\II-29>

"Information, find out as much as you can about your problem, get all the information you can, be that from hospitals, doctors, libraries, know your illness and then you can fight it. "If you know your enemy you know your illness" you know how to deal with it but for that you have to have knowledge, gaining knowledge of your illness will help you take control of your life"

<Dermatology-Individual Interviews\II-30>

"On a number of occasions I did seek advice but not professional advice. Advice of people either I knew professionally through my work or contacts with the psoriasis support group and from their experiences I found out that if they did not have an answer for something immediately then they knew somebody who could or did have an answer and I found it helpful. Occasionally the advice was that decision is up to me. At least there was always a shoulder to cry on. This thankfully is a great help...yes, I would not want to jump out of the frying pan into the fire. Therefore, I thought seeking advice is better rather than just making a decision. This could be worse...I think that there could be better public awareness. Even though these days it is much better than it was before. I still feel there is some room for an improvement...One example that comes to mind is better media coverage. Which I can appreciate is extremely expensive, but better than newspaper, television, radio coverage. That would be a mighty advantage to people who are potentially going through what I have been through and hopefully it will stop a lot of things that have happened in the past from happening in the future because the public's attitude in this kind of area is essential"

<Dermatology-Individual Interviews\II-32>

"It isn't there, I would have thought honestly when you are young, especially as a teenager. The very first referral I should have had was probably to a psychologist, if they know them. I think they look at the impact it has had it on your life at that stage. In a sense this conversation is the first conversation I had in my life...yes, for example if you got cancer, you have a year to live, you will certainly get them...a nurse and get people to try to cope, what is the difference?...yes I know, you could argue it's worse. At least with dying, six months and you are gone, yes it's a very serious situation but buddy it's a hell of a situation if you've got 40 years ahead of you...absolutely. I think you have to deal with people's perception what this condition is and how it affects them at an early age...the one thing you can do is counselling. Problem with it is that it also focuses on something you might not have focused on...yes, everything has mental element. That should go alongside...if you think that a pimple can have a massive effect on someone's self esteem, because all of us look in the mirror and look

at the pimple and many people decide, particularly a girl, that they will not go out at night because of that pimple. And if you start taking that pimple, that I've got many. That tells you the magnitude of the effect"

<Dermatology-Individual Interviews\II-33>

"If I knew from my early age that it can influence my decisions I probably might have gone for specific help. Now, I think I realise how important it could be. I think it is very important. In my point of view, the big issue is inside not outside, therefore, the psychological aspect should be considered along with other treatment. It is not physical disability for me but I think it is psychological disability"

<Dermatology-Individual Interviews\II-34>

"I think talking to people, somehow let people know about these kind of studies, targeting people in school perhaps because they are the most affected by this, teenagers, so going to school, talking to people in schools about these kind of things and this kind of study really and letting people know"

<Dermatology-Individual Interviews\II-37>

"I don't know, education or media for more publicity for this...there was this TV series and there was a detective in it, he had psoriasis so people may relate to it. I mean there isn't any coverage for this on TV, there is for all other kinds of things but not for this. And there is a huge number of people suffering from psoriasis. I would be interested in a group session, I wonder what I might get out of that...I don't know if I am consciously or sub-consciously making decisions based on just about skin"

<Dermatology-Individual Interviews\II-39>

"I am registered with the association. If somebody wants to talk to somebody else about their skin they can phone another sufferer, so I put my name for that and I had a couple of people call...if you said to me 2 years ago about counselling, I would say you are barking mad....yes, I think if I had it at the very first, if my parents had had that sort of family counselling sessions when I was younger, they would not have felt so guilty about it, some of the decisions they made, I don't blame them. They did the best thing they could do with the information they had in front of them, but they blame themselves a lot and I think I only know...I think having counselling, I suppose, not a scary thing. Americans have made counselling something more dramatic. It wasn't a pleasant experience, it wasn't something that I enjoyed doing, but I think it would have been less traumatic for me if I done it earlier. Because some other things I was dealing with came up when I was 15 or 16, so we had to cover a lot of ground to understand some of my thought processes, because I am learning how to make friends at 32 years of age, that's quite pathetic...it's only now that the psychological element has been taken seriously. So it's long overdue but I think it will definitely benefit, well it will benefit me"

<Dermatology-Individual Interviews\II-40>

"Help from doctors, I had a lot of help from doctors and, like, moral support from your parents and school teachers, that helps a lot as well....you can't really change the public's attitude really, because people are entitled to their own opinion really...I mean music could do it...yea, just to show them the person with eczema could be just

as normal and want to do just the same things as themselves, not the most pleasant thing to look at but I can do as many things, as possibly for far more"

<Dermatology-Individual Interviews\II-42>

"I don't really know because I never really looked in to any of these associations in-depth. I really couldn't tell you what they offer now to be honest; I mean that's the problem. I have had this, probably a bit daft I am, not, you know seeking contact to see what they can do with regard to supporting you or advising you or whatever. So it's difficult for me to answer that, but, I mean, it's just for me if anybody, any association or any society is going to give you any advice, it has to come not only from you guys, the doctors who research it, it's got to come from people who suffer with it. Because, no disrespect to anybody you know, the dermatologists here have been fantastic...I think yea, but I think it got to come from both sides (doctor and associations). I will go home and have a look at the internet tonight, because we have been talking about it, but I never looked into it in-depth. I think any advice or any information has not only to come from the medical side but it's also got to be somebody involved in these associations somewhere that does or has suffered with it and is able to give you a personal reassurance. Look, you know, I know the doctors are helping medically, they are helping you, you know your drug, your treatment and everything and they support you as much as they can, but actually "I know what you are going through" that's the sort of approach you know"

<Dermatology-Individual Interviews\II-43>

"Yes, for acceptance, so they can, there should be something like a clinic where you can come and if you like to talk, to accept the disease, you have got to, and how to get on with it and carry forward in society...I think counselling at the start would be good because, you know, if you learn to accept the situation and, right, don't wear long sleeves, wear short sleeves, you know, you got it just the way you got it, tell them. And you know if you go to counselling like that, and come to terms with your condition, then life changing decisions that you are making in the future are not so hard because if you accept it and you sort of go into society, you are not going to be held back by yourself. This is what a lot of major decisions are altered by, your imagine what's going to happen when people find out...it would be good to be warned about this thing, because if you warned them about how this is going to affect you in life, life changing decisions you know, may be when one of these life changing decisions comes up before you, because you have been warned it's not going to hold you back so much. And you think, hang on, you know I know this, and this is how I want to do it and that's it...that's it, yea, you know for people initially to go where they are told but the disease, taught the disease, taught how to accept it and what sort of influences on major decisions it could have throughout your life. That would be a good thing, I think "therapy" I suppose you call it...I don't know whether the consultant should do it really, I mean it is psychiatric I suppose...well, you don't realise, you know, until you sort of sit down and talk about it and think about it, Oh, yea, it is like the holidays, I think you don't realise this is a major decision and of course affects other people like my wife and things, my wife might want to go staying in a nice hotel and things like that"

<Dermatology-Individual Interviews\II-44>

"It is, definitely, don't be embarrassed, its nothing to ashamed of, its not like people can catch it, they are scared and shy away from you, its nothing...just improve their (young patients) confidence, just tell them its nothing to be embarrassed of, especially if there is bullying at school, people looking at you... it would be good to advise them about the long term treatment plan"

<Dermatology-Individual Interviews\II-45>

"I say "don't isolate yourself go out there, speak to your doctor and find out what help is available", even, you know, like come here to dermatology get the help yourself and talk about your problems to people, family and friends, you know who you can trust, because its surprising who will support you out there and you won't be on your own, specially if you join Hair Line. You get these news letters coming through, for other people writing in their own experiences and they were cured, some of them are cured...well, I am amazed you know, because when you talk, all these things come out and you can't believe over the years how many decisions you have made which have influenced your life, and talking about it you feel better...oh yea, it's self healing, talking really (very important part of rehabilitation), heals from within, because you are getting rid of your negatives and your worries and it makes you positive. Well a problem shared is a problem halved that's what I say, so anybody you know, and don't hesitate to get in touch with anybody whose got the same problem and meet up with them and become friends and support each other, you know"

<Dermatology-Individual Interviews\II-46>

"I would definitely recommend it (specialist school) because when I was going to school, you walked in a pathway like a subway and I sat under there scratching my legs so badly, it was so bad. And the doctor literally had to come up from the surgery and pick me up. I was crying, my legs were hurting so much and I didn't want to go to the school. You know, I really didn't want to go because they were so spiteful to me, you know. I did not have much hair with it because my hair was quite thin on my head as well, so when I did go to the school I done really well...trying to be a bit more confident. I have lost mine you know, because there is a lot going on in my life but I'm trying to be more confident with it"

<Dermatology-Individual Interviews\II-49>

"I suppose to make sure that you have the best advice, medical advice you can and to try be referred from the GP to a dermatologist. Sometimes it takes a while because again they are more expert in that field and even my GP said to (name) she is not an expert, because of his age he had to be referred, which was fine, that was really good...I suppose, I would say to people trying to do what they feel to be happy and as long as they can get the care they need, in terms of moving to a different city or going to university, getting married, as long as they got care in terms of knowing which cream to use, and for instance, I had a short course of steroids when I was getting married. That helped me to think, well I am not going to be left on my wedding day whether it is a bad flare up of eczema, I've always got a back up plan I suppose in place"

<Dermatology-Individual Interviews\II-50>

Identification of key words and phrases

Various key words and phrases from the patients' comments were also identified during content analysis to understand their attitude for developing strategies for patients in a similar situation. These are as follows:

"I was classified as disabled", "I had no alternatives", "I should have been working for another five years", "your disease is a full time job", "it is like a curse on me", "would have to suffer", "it was an inevitable decision", "it is being locked away now", "I had to take this decision", "I could not look after myself", "this has been hard", "I had no option", "my health wouldn't let me do", "I realised I could not cope", "have no quality of life", "I didn't accept this", "you react to the way other people perceive you", "people bring to your face", "I grew up thinking I was dirty", "made me make a choice", "it seems impossible", "I could have had a nicer better education and decent job", "I am still not dealing with it very well", "I just couldn't visualise", "you have to do what you can do", "it scared me what may happen", "all of a sudden you get and its falling apart", "I can work around it", "it has ended up being a good decision for me but at the time it was a difficult decision to make", "having flexibility", "I have always done things differently", "I might be in different profession", "prevents me from fulfilling my full potential", "had to reconsider my commitment", "encouraged by parents", "suitable for my health", "was told", "I knew I would be discriminated against", "I wanted to do", "I had to take", "the opportunity wasn't available for me", "was not my first choice", "I didn't know what to do, I couldn't decide", "he advised me", "thought hard", "I gave serious consideration", "once you make a decision that's it, you have to live with that", "It was hard to explain", "it is just how I have to react", "survival reflex", "it was a breakdown", "how you perceive and how you think people are going to perceive you", "I couldn't accept it", "how I dealt with it", "I could have done better", "it was an easy way out", "I couldn't think too hard", "it was a waste of time", "I had enough of it", "choose to do", "so it is kind of back to where I should have been when I was younger", "the course leader advised me", "you never know how you are from day to day", "a sudden change in life", "this has changed my life", "it was a fairly hard decision to make", "This is a daily struggle and frustrating", "I live for today not for tomorrow".

2) What do you think about the idea of this study?

"I think it's probably a very good study, I am surprised, that there has not been more research. I can imagine that the way people look is quite a major factor in their decision making"

<Dermatology-Individual Interviews\II-04>

"I think it is a good idea. It is very difficult to quantify the effect on something like this. It's probably easier to quantify the effect on somebody who suddenly gets a disability because you can see a before and after sort of thing"

<Dermatology-Individual Interviews\II-06>

"I think it is really good; it could help people, mentally and physically because if you could see somebody else having (the same problem) too then you (could) really help him"

<Dermatology-Individual Interviews\II-09>

"If you can help people over a problem we have had by understanding how we have dealt with it, it would make it easier for them, and help doctors and nurses to help people get through a traumatic time with their eczema. There is a light at the end of the tunnel and it is all for good not for bad, these are the things we tried and dealt with"

<Dermatology-Individual Interviews\II-10>

"This is about getting across the message to other people, how somebody's life is and has been and possibly will be in the future, hopefully"

<Dermatology-Individual Interviews\II-16>

"I think it will help other people, hopefully that other people will realise what you have gone through and they think, well you have got to take these decisions and help other people take them. So I think it is a good research study. This could help other people who got this disease to help them realise what they can do and what they can't do"

<Dermatology-Individual Interviews\II-20>

"Think it's very good. I think this study needs to be done to see how it exactly affects the lives of people. As I said, I never realised how it's affected until we spoke now"

<Dermatology-Individual Interviews\II-21>

"I think it is excellent. Anything, anything will do to help raise awareness and help people get confidence back"

<Dermatology-Individual Interviews\II-23>

"It is quite interesting to see what the outcome of it is. What you discover and what other people's experiences are, you know, because I can imagine if I was in school

with it that probably would have influenced my choice of career more than it did because I was already going down that route"

<Dermatology-Individual Interviews\II-24>

"I think it is a good thing. You can develop a good reaction from it as not many people are involved in it, but different people comment about their lives. It can only be good though there is lot to learn"

<Dermatology-Individual Interviews\II-25>

"I think it is a good study. Like I said a normal healthy person has difficulty making decisions, so yea it is another aspect just another aspect of decision making, process of thinking, well can I afford to do that? Shall I move there? Or you know, it's, I have got to think of my eczema as well"

<Dermatology-Individual Interviews\II-26>

"I think it's a really good idea because personally I didn't realise how much my eczema has impacted on my major life changing decisions and it really has and if people can be more aware and can get more support when making life changing decisions then it would be brilliant"

<Dermatology-Individual Interviews\II-27>

"It's a great study, particularly for medical people/community. If there could be some empathy. It's understanding I suppose. It's important that people listen to the patient. This department is fine, the problem I had with management etc, was because of a misunderstanding. I was viewed as a young guy with a boil on your bum. That's it. Anything that helps decision makers. It would be good as far as I am concerned. Understand why I would have complained when I complained etc. It was important for me to push for the treatment or whatever and if somebody could have understand that better that's going to be good thing"

<Dermatology-Individual Interviews\II-28>

"I think it's very important that these studies continue because the more you learn about what people need the better it is"

<Dermatology-Individual Interviews\II-29>

"I think it's very good and will be very helpful to people"

<Dermatology-Individual Interviews\II-30>

"I think it is an incredible idea, it is shame really it has not happened years ago. I took part in it because if my experiences could be of any help to anyone I'm thankful for it. They may not suffer like I have in the past. I fully support it"

<Dermatology-Individual Interviews\II-32>

"Anything that raises the profile of the consequence of people having a skin condition and for it to be taken seriously. I think for a serious condition, like Parkinson's it's more obvious and more easier for people to understand the impact, I don't think people understand this, even though if you tell them what it feels like to be sore or itchy, all day ugly etc. They are not going to think like that. But people would imagine what is like with cancer because they are afraid of it themselves"

<Dermatology-Individual Interviews\II-33>

"I think it is very good idea, it can widen the area which will help understand treating people with very long illnesses. I think it is necessary to understand. As I said I never thought about how psoriasis can impact on my life decisions. Now, I think it is important because ultimately it affects other things and your life style. If you know how to deal with that sort of things then you can do better. Yea, I know it is different for different people but at least it can give some idea through other's experiences in life"

<Dermatology-Individual Interviews\II-34>

"It is quite good actually, it does make you really think back the things, maybe at the time you didn't think it was influenced by your skin, but deep down you know they were"

<Dermatology-Individual Interviews\II-41>

"I think it would be a good thing obviously for a study and I think it would be nice for people to understand what it's like to have eczema and live with it so long"

<Dermatology-Individual Interviews\II-42>

"It should be sort of warn people, anything like this"

<Dermatology-Individual Interviews\II-44>

"For younger people it's definitely a good idea"

<Dermatology-Individual Interviews\II-45>

"Well, I think its brilliant, because it will help you in your research and it is a teaching hospital and it will help the new ones coming in and the patients, so this is all part of research which can help this problem with hair loss in the long-term and hopefully for good"

<Dermatology-Individual Interviews\II-46>

"I think it's fantastic, I was really interested in it when I had the information in the post, that is why I agreed to it. I thought it is amazing and I think it's really good"

<Dermatology-Individual Interviews\II-50>

Part V. Development of a definition for MLCDs

One of the most fundamental aspects of the aims of this study was to understand and formulate a basic definition of health-related major life changing decision (HRMLCD). As far as it is evident from the literature there was no previous scientific definition available of HRMLCDs. It was necessary to develop a definition before the development of any measuring tool in order to ensure that items in the tool meet the definition of HRMLCD. Information was gathered from a total of 316 patients through individual interviews (n=50), postal surveys (n= 258) and focus group discussions (n=8), in order to be able to conceptualise and define HRMLCDs. After the initial data collection and its statistical and content analysis, the data was thoroughly reviewed again. The main conceptual points, emerging themes, influential factors and individual patients' circumstances were re-examined and meticulously discussed in several meetings of the participating researchers (ZU Bhatti, AY Finlay and S Salek). Finally, the following working definition of "Health-Related-Major Life Changing Decision" (HRMLCD) was formulated;

"We define a "Health-Related Major Life Changing Decision" (HRMLCD) as a person's decision, that is influenced by having a chronic disease, that has a profound long-term impact on the course of the person's life, in the context of the person's circumstances and expectations"

The term *person's decision* refers to the concept of various important decisions people take at different life stages and at different life events such as major decisions related to education, career, marriage and having a family. These are some examples of decisions taken at an early stage of life. The phrase *influenced by having a chronic disease* refers to the life situation where a person is suffering from a long-term health problem and a person has to take their illness into account when taking any decision. In other words their illness influenced their decisions in that the person has to consider their health and future consequences before taking any MLCDs. The term *profound long term impact* refers to the magnitude of the decision impact over time. The term *course of the person's life* encompasses the various stages of life where people normally face various life events and take MLCDs, such as the stages of youth, middle age and old age. For example, generally people take life changing decisions related to education and career at a young age. In middle age people normally take decisions related to job or marriage and in old age people take decisions related to retirement. Many MLCDs can occur at any stage, such as those related to relationships, moving abroad, travelling and housing. The phrase *in the context of* the *person's circumstances and expectations* refers to an individual's personal situation (level of health, income, available medical care, family support, physical and psychological wellbeing, living conditions and available opportunities). The word *expectations* refer to the persons perception, beliefs and attitude towards life and their approach (realistic or unrealistic) to important issues in life. The phrase *in the context of the person's circumstances and expectations* refers to the highly subjective nature of these decisions as circumstances and expectations may vary from one person to another, and what is a minor decision to one person, may be perceived by another person to be a major decision.

This is the first attempt of its kind to define MLCDs. This definition was actually firmly derived from patients' comments and emerged during detailed content analysis. The research team reviewed patients' comments, their expectations, perception and reported circumstances and formulated this robust definition. It was considered whether or not to mention disease "negative or positive impact" in the definition. The researchers were agreed that this was not the prime purpose of this definition. Presumably mostly the impact of disease would be negative because of the onset of chronic disease (negative life event). It was acknowledged though that there might be circumstances where disease influence on a MLCD might be positive. It was also considered that people could make MLCDs as a result of different life events in their lives, not necessarily because of the co-existing chronic condition, and this could result in the description of a different set of MLCDs. Therefore, the position was adopted in making the definition, to make it clear that this definition was formulated only in the context of MLCD potentially influenced as a result of suffering from chronic disease. No examples of MLCDs were given within the definition in order to make it simple and more flexible.

The QoL of patients was also discussed at this stage, as it became clear that the new domain and definition of MLCD could substantially add to our understanding of the intricate subject of QoL. The acknowledgment of the impact of disease on MLCDs within the wider definition of HRQoL could contribute towards a closer match between HRQoL description and the broader life-long reality experienced by patients.

Summary

- This chapter provides information about how initial data that was collected for conceptualisation and development of the new scale.
- NVivo 8 qualitative software was used for managing large quantities of data and for content analysis.
- Three main qualitative techniques (postal survey, individual interviews and postal survey) were used for data collection.
- It is clear from the initial data that chronic disease can influence MLCDs.
- The initial results were presented according to specialities to provide a snap shot of the results, which indicate that the magnitude of the influence of disease on MLCDs may vary between different medical specialities due to the nature of the disease and particular patients' circumstances.
- The MLCDs related to wearing make up and having children were reported more frequently by female patients than by male patients.
- MLCDs related to choice of clothing, stopped swimming, not to socialise and wearing make up were only reported by dermatology patients.
- There was a significant negative correlation between patient age and the number of influenced MLCDs reported by patients.
- A variety of health-related influential factors have also been indentified.
- Patients' responses were reviewed in detail and through content analysis, main themes were identified, grouped under main MLCD domains and later used for item generation and development of the new tool.

- 41 themes were grouped under 15 MLCDs core categories.
- Information obtained at this stage was used for the development of the MLCD definition and MLCD Profile.

CHAPTER 4

Item reduction and development of the Major Life Changing Decisions Profile (MLCDP)

INTRODUCTION

The verbatim transcripts, information and strategies on questionnaire development (Streiner 2003) and the Quality of Life Questionnaire Compendium (Salek 1998, 2007) were consulted at this stage.

All themes generated at Stage 1 were analysed using qualitative techniques to reduce the data identified by the participants to the core items and yet retain population and gender specific items. After qualitative analysis, three brain storming sessions were carried out to develop appropriate taxonomy, rephrase items and fit them into broad categories or domains. Standard techniques concerning language, reading age and item length were applied in the development of the new tool "Major Life Changing Decision Profile" MLCDP (version 1).

METHODS

The following 5 steps were used for the MLCDP developmental process:

1. General check list for profile development
2. Domain generation
3. Item/statement generation
4. Item reduction
5. Development of the draft profile

RESULTS

General check list for profile development

The use of the check list initially allowed the research team to formally think about what kind of questionnaire or profile should be developed. This check list (Table 4.1) raised very basic fundamental developmental issues which were considered in detail (Streiner 2003). Its use was therefore constructive in order to make sure that no vital technical points were overlooked during the developmental phases of the new instrument. For example, detailed consideration was given to type, pattern, communication type, length, design, structure, layout, and scale options (Table 4.1). This list also ensured that items/statements in the new instrument would meet standard developmental criteria.

Initially the qualitative data was reviewed and discussed by the research team in order to form a consensus on the fundamental structural points, as given in the check list. Because of the ordinal nature of the data and the retrospective nature of the initial research question asked, the researchers agreed to develop a self-administered general health profile with multi-dichotomous close-ended simple statements. Agreements on fundamental points are identified with an asterisk (*) sign in Table 4.1. The type of the new instrument was kept "general" due to the nature of the data obtained from the patients who were from seven medical specialities and suffering from one of 28 chronic conditions. The pattern was kept as a "profile" rather than a "questionnaire" because of the nature of the data. It was decided by the research team that the way patients responded to initial research question, each item should be constructed as a single statement rather than a question format in order to create spontaneity. It was considered important for patients to be able to demonstrate the extent to which different areas were affected. It was considered how the new tool would be administered. Consensus was reached on it to be self administered; this has the advantage that it could also be used for postal surveys. The length of the profile was not a major issue at this stage and there was no preconceived length requirement. General questionnaires or profiles are normally longer than disease specific ones but the researchers were aware that questionnaires or profiles may later go through a process of evolution to meet the need for a shorter format. More importance was given to ensuring appropriate length of the individual items/statements. Efforts were made to keep statements between 6 to 10 words in length so that respondents could easily understand and respond in the shortest possible time and thereby encourage spontaneity in responding. There was discussion concerning the time frame of statements. It was clear during these discussions that the time frame should be the life time of the respondent, due to the nature of the MLCD concept and the way the initial information had been obtained.

Domain generation

The main MLCD categories were reviewed according to the nature, type and percentages reported by patients. A flip chart was used for this phase to help understand the link between patients' comments, the main categories and the new domain of MLCDs. After long discussions and deliberations among the research team, 15 main MLCD categories (Tables, 3.11, 3.12, and 3.13), and some individual items identified at stage 1, were grouped under the following six MLCD domains:

A. Education
B. Career/work
C. Family/relationships
D. Social
E. Physical
F. Major treatment decisions

Examples of the groupings of different items under these domains are given in Table 4.2.

Table 4.1: General check list for profile development

Type

- General health measure*
- Disease specific health measure

Pattern

- Questionnaire
- Profile*
- Index
- Inventory

Communication type

- Self-administered*
- Staff-administered
- Postal*

Length

Design/structure and lay out

- Question wording (relevant to study purpose, no ambiguity)*
- Time frame (last week, last month, last year, over a life time*)
  Last week, last month, over a life time*, past* or present tense
- Question response format
  Open-ended (unstructured)
  Closed ended (structured)*
    -Single close ended (asking age and sex etc)
    -Dichotomous close-ended (Yes or No)
    -Multi-dichotomous close-ended (4 or 5 choices under one question, it means 4 or 5 choice related questions under one category)*
- Ordering of question (sensitive and difficult should be put at the end)*

Type of scoring system

- Likert Scale (Bipolar), two extreme values on each end, agree or disagree
- Adjectival Scale (Unipolar), none or little at one end, maximum at the other*
- Face Scales (for under age and patients with cognitive disorders)
- VAS (Visual Analogue Scale)

Data category

- Ordinal* (required ranking) level of influence should be assigned to each item
- Nominal (Nominal doesn't require ranking, such as eye colour etc)

*Agreements on fundamental points

Table 4.2: MLCD domains with relevant categories

- **A. Education**
    - Education
- **B. Career/Work**
    - Career choice
    - Early retirement
    - Job
    - Professional bodies
    - Professional sports
- **C. Family/Relationships**
    - Having children
    - Relationships
- **D. Social**
    - Lifestyle (smoking, drinking alcohol)
    - Holidays/travel abroad
    - Housing
    - Move abroad
    - Move city
    - Clothing
    - Swimming
    - Not socialise
    - Make up
- **E. Physical**
    - Sports
    - Driving
- **F. Major treatment decisions**
    - Dialysis
    - Organ transplant
    - Surgery

Item/Statement generation

The verbatim transcription of the patient interviews and survey responses were consulted during each item generation. Patients' comments were reviewed and discussed in the context of the main categories and MLCD domains to formulate appropriate and relevant statements. Core MLCD domains and statements were arranged in a logical way to reflect life stages or in the sequence of life activities. Items were kept as short as possible. The majority of the statements were constructed using between 6 to 10 words and there were only two statements with 11 words. Also, double barrelled questions were avoided; asking two things in one question is not only difficult for patients and for analysis but also may create confusion over to which aspect the response refers. For complex MLCDs, such as life style decisions, examples from patients' quotations were used for guidance in order to avoid double barrelled statements. Statements were specifically phrased in the past tense (covering the whole life) to guide and instinctively remind patients to look back over their lives and answer whether or not their chronic disease had influenced any important and major life changing decisions.

Each item should correspond to its core MLCD domain and statements should be designed to be clear to respondents rather than to researchers. Therefore, "key words" related to MLCD themes such as career choice, job selection, early retirement, having children, marriage, divorce, separation, moving abroad were included in each statement to direct patients to think about more specific aspects of MLCDs, in order to encourage more accurate responses.

Two non MLCD "life style" issues, item number E2 "I decided to take part in other sports activities" and E3 "I decided to give up driving" were grouped under the "physical" domain. Another issue related to "community activities" emerged as a MLCD during the detailed review of the "leisure and social activity" themes. From patients' comments, it appeared that patients' life long commitments to community activities were influenced by their long term illness, making the decision to give up these commitments was life changing for them. Therefore item D13 "I decided not to be involved in community activities" was included under the "social" domain. The MLCD related to "wearing make up" was gender specific and after a further review of patients' comments it was evident that it should have been addressed separately. Another separate item D16 "I decided to wear a wig/toupee" was also included under the "social" domain.

The profile was designed to be kept generic and items were formatted to allow its potential international use. For example, in item D8 "I decided to return to this country", the word "country" was used instead of "UK" and in item number D10 "I decided to move back to my home area", the phrase "home area" was used instead of the "city name". Similarly, particular examples attached to each statement were avoided in order to make the profile more general and internationally acceptable.

Item reduction

Initially, 48 items/statements were generated in the development of the first draft profile. Another qualitative review of the draft profile was carried out and statements considered inappropriate, vague and conceptually ambiguous were deleted. Several items were rephrased and combined together (Items D2, D3 and F1), and comprehensively modified to make them more appropriate and to fit the intended purpose. The following basic criteria were used for item reduction and modification:

- **Frequency:** Themes reported by <5% of the sample population were not included. 5% was taken as the cut off point for item reduction.
- **Appropriateness:** Statements should be relevant and linked to the intended purpose.
- **Universality:** Statements should capture patients' perceptions, feelings and attitude accurately across the observed population regardless of their age and gender.
- **Wording:** The wording of statements must be clear and understandable to lay people and make sense to any individual with a minimum intelligence of 12 years old.

One theme under the job category "not to mention illness on job application" was removed due to the inappropriateness of this action. Another theme in the same category "not to seek employment" was removed because of its similarity with the theme of "unemployed or remain unemployed". One independent main category "to quit from professional sports" was excluded; this theme was reported by <5% of the patients. However some gender and speciality specific categories were retained, such as "major treatment decisions" and "to wear make up". The statement, "To leave a professional association/committee" was retained because of its generic nature. One life style MLCD related to "swimming" was put under the "physical" domain rather than the "social" domain. It was only reported by patients who were suffering from skin conditions which reflected the obvious aesthetic reasons rather than physical ability. It was felt therefore that it should not fall under the physical domain. However, if this item were included under the "physical" domain, this would also be of relevance to other medical specialities (rheumatology, cardiology and respiratory medicine) along with dermatology and thereby made it more general. It was also noted that "swimming" is a specific type of sport. To make the "physical" domain more generic, another item E2 "I decided not to take part in other sports activities" was included.

Initially, statements were phrased using five different styles starting with; "I decided not to", "I decided to", "I wanted to", "I have to" and "I had to". All statements were again thoroughly reviewed in the context of patients' comments as part of "item extraction validation". One by one, quotes were read and discussed for item retention and item extraction. With the consensus of the research team, the majority of the statements (31 out of 45 statements) were modified into the format of "I decided to" in order to make them uniform and consistent for the respondent. Eleven statements were phrased as "I decided not to" and three statements (D6, D9 and D15) were phrased in the "I wanted to" style because of the patients' comments, to create originality in the statements and to help respondents to relate to these statements better and hence respond more accurately.

At this stage it was noted that there was a very fine line between some types of MLCDs, such as "give up a job" and "completely change my work". Giving up a job means patients may start the same job at a later date or a similar kind of work later but "completely change my work" means patients changed their type of employment because of their illness. There was a very subtle difference between various issues but it was not possible to address every subtlety because this would have made the items more complex. Due to the intricate nature of this subject, profile statements were carefully reviewed and modified. Separate new statements were created, if required to eliminate subtle differences, in the simplest way possible for patients to understand.

Development of the draft profile

The 45-item draft profile was finally designed by a consensuses of the research team, covering six MLCD domains related to education (4 items), career/work (13 items), family/relationships (8 items), social (16 items), physical (3 items) and major treatment decisions (1 item). It was discussed whether career and work might be included as two separate domains but the research team was of the view that both terms are interchangeable. However, as separate MLCD domains could create more confusion for lay people and for subsequent potential cross-cultural adaptation. Patients placed more emphasis on "social" and "career/work" domains and that is why these consists of a larger item pool.

Before the selection of a response scale, the possible options were considered and discussed (Streiner 2003). The generated data was ordinal in nature and that generally requires ranking of level of response (level of influence) which should be assigned to each statement for its evaluation. Several patients reported that their chronic disease had no influence on MLCDs. Some patients reported that their disease impacted on their MLCDs and some reported that their chronic disease partly influenced MLCDs. Conceptually it was obvious that this newly developed profile (the MLCDP) required a scale option which could record the influence of chronic disease in a logical way. It was agreed that the new tool should measure the level of the intensity of the disease influence on MLCDs in order to record whether each MLCD is partially influenced, moderately influenced or strongly influenced by the chronic disease. Various scale options were discussed in detail and a 5 point (0 to 4) uni-polar "Adjectival scale" (No influence=0, Slight influence=1, Moderate influence=2, Strong influence=3 and A very strong influence=4) was chosen for the evaluation of the level of the influence of chronic disease on MLCDs (Streiner 2003). This response option provides "descriptors along a continuum" as a continuous series of options and is often used to rate "self-reported health" (Streiner 2003). The use of a bi-polar Likert scale (similar in nature to an adjectival scale but generally providing two ends of extreme values separated by a neutral option) was also discussed but rejected as in their responses patients might drift towards the central point, which normally represents either a neutral point, no option, neither agree nor disagree or undecided (Streiner 2003). A 7-option scale was also discussed in detail, but it was the balance between friendliness, ease of response and reliability which resulted in the consensus for a 5-point scale.

At the end of the developmental process, it was decided to write an introduction to the MLCDP and to provide instructions for the respondent taking into account the statements and the selection of the response scale. An instruction sentence was placed at the top of every page of the profile to remind patients and to keep them focused. Very concise and clear introductory sentences were formulated for each section and placed under the heading of each MLCD domain for the guidance of patients. Despite the design of a large and open format lay out, the profile was kept to a maximum three pages to give a friendly and professional look. The final 45-item draft instrument MLCDP (version 1) (Figure 4.1) was presented to the panel of experts for its "content validation".

Figure 4.1: MLCDP version 1 (Date: 29.01.2010)

PLEASE TICK THE BOX WHICH BEST DESCRIBES HOW YOUR CONDITION HAS INFLUENCED YOUR MAJOR DECISIONS IN YOUR LIFE.

A EDUCATION

The following statements refer to the influence of your chronic condition on your decisions about your education.

	No influence	Slight influence	Moderate influence	Strong influence	A very strong influence
1. I decided to leave school education early......................	☐	☐	☐	☐	☐
2. I decided to change my study subject..........................	☐	☐	☐	☐	☐
3. I decided to study near home.....................................	☐	☐	☐	☐	☐
4. I decided to leave college/university education...............	☐	☐	☐	☐	☐

B CAREER/WORK

The following statements refer to the influence of your chronic condition on your decisions about your career/work.

1. I decided to change my choice of career.....................	☐	☐	☐	☐	☐
2. I decided to abandon my chosen career after starting..	☐	☐	☐	☐	☐
3. I decided to completely change my work/profession.....	☐	☐	☐	☐	☐
4. I decided to take early retirement.............................	☐	☐	☐	☐	☐
5. I decided to work flexible working hours......................	☐	☐	☐	☐	☐
6. I decided to give up a job..	☐	☐	☐	☐	☐
7. I decided to select a job suitable to my health..............	☐	☐	☐	☐	☐
8. I decided not to take promotion..................................	☐	☐	☐	☐	☐
9. I decided to work shorter hours..................................	☐	☐	☐	☐	☐
10. I decided to become self-employed..............................	☐	☐	☐	☐	☐
11. I decided to stay in the same employment....................	☐	☐	☐	☐	☐
12. I decided to remain unemployed..................................	☐	☐	☐	☐	☐
13. I decided to leave a professional association/committee.	☐	☐	☐	☐	☐

PLEASE TICK THE BOX WHICH BEST DESCRIBES HOW YOUR CONDITION HAS INFLUENCED YOUR MAJOR DECISIONS IN YOUR LIFE.

C FAMILY/RELATIONSHIPS

The following statements refer to the influence of your chronic condition on your decisions about your family/relationships.

	No influence	Slight influence	Moderate influence	Strong influence	A very strong influence
1. I decided to delay my plans for having children	☐	☐	☐	☐	☐
2. I decided not to have more children	☐	☐	☐	☐	☐
3. I decided not to have any children	☐	☐	☐	☐	☐
4. I decided to have IVF (In Vitro Fertilisation) treatment	☐	☐	☐	☐	☐
5. I decided not to have an intimate relationship	☐	☐	☐	☐	☐
6. I decided not to marry	☐	☐	☐	☐	☐
7. I decided to separate from my partner	☐	☐	☐	☐	☐
8. I decided to get divorced	☐	☐	☐	☐	☐

D SOCIAL

The following statements refer to the influence of your chronic condition on your decisions about your social life.

1. I decided to change my eating habits	☐	☐	☐	☐	☐
2. I decided to change my smoking/drinking alcohol habits.	☐	☐	☐	☐	☐
3. I decided not to travel abroad or go for holidays abroad.	☐	☐	☐	☐	☐
4. I decided not to purchase any property	☐	☐	☐	☐	☐
5. I decided to move my home	☐	☐	☐	☐	☐
6. I wanted to move abroad but decided not to	☐	☐	☐	☐	☐
7. I decided to move abroad	☐	☐	☐	☐	☐
8. I decided to return to this country	☐	☐	☐	☐	☐
9. I wanted to move to another city but decided not to	☐	☐	☐	☐	☐
10. I decided to move back to my home area	☐	☐	☐	☐	☐

PLEASE TICK THE BOX WHICH BEST DESCRIBES HOW YOUR CONDITION HAS INFLUENCED YOUR MAJOR DECISIONS IN YOUR LIFE.

	No influence	Slight influence	Moderate influence	Strong influence	A very strong influence
11. I decided to move to another part of the country...........	☐	☐	☐	☐	☐
12. I decided to wear different types or colour of clothes.....	☐	☐	☐	☐	☐
13. I decided not to be involved in community activities......	☐	☐	☐	☐	☐
14. I decided not to socialise..	☐	☐	☐	☐	☐
15. I wanted to wear make up but decided not to.....	☐	☐	☐	☐	☐
16. I decided to wear a wig/toupee..................................	☐	☐	☐	☐	☐

E PHYSICAL

The following statements refer to the influence of your chronic condition on your decisions about your physical aspects of life.

1. I decided not to go swimming..................................	☐	☐	☐	☐	☐
2. I decided not to take part in other sports activities..........	☐	☐	☐	☐	☐
3. I decided to give up driving.......................................	☐	☐	☐	☐	☐

F MAJOR TREATMENT DECISIONS

The following statement refers to the influence of your chronic condition on your decision about your major treatment.

1. I decided to make a major treatment decision................ (For example dialysis, organ transplant, surgery, biologics)	☐	☐	☐	☐	☐

THANK YOU FOR YOUR HELP

Date ....

This questionnaire is not to be reproduced or photocopied without the permission of the authors

Summary

- At the stage of item reduction and design of the new instrument, a process was followed involving five steps. After several brain storming sessions, the main MLCD categories were grouped under six MLCD domains.

- 48 items were generated for the development of the first draft of the new scale.

- In developing the wording and structure of the new scale, the basic criteria of frequency, appropriateness, universality and appropriate wording were used.

- The 45-item draft instrument MLCDP (version 1) was developed and then presented to the panel of judges for "content validation".

CHAPTER 5

The Validation of the MLCDP: Content Validity

INTRODUCTION

Content validation is a process of establishing validity of an instrument by using the judgment of experts to remove items from the instrument or modify unrelated or inappropriate items which may cause error in evaluation. The opinion of the experts is also sought as to whether the scale is appropriate for the intended purposes and has the right focus and emphasis for the content being measured in the targeted population (Streiner 2003). Haynes et al (1995) defined content validity as:

> "*Content validity* is the degree to which elements of an assessment instrument are relevant to and representative of the targeted construct for a particular assessment purpose"

Instrument content validation is a process which may encompasses several methods and both "quantitative" and "qualitative" approaches are appropriate as part of this process. It has been recommended that items should be judged by multiple experts using a 5 or 7-point assessment scale covering item relevance, representativeness, specificity and clarity. If there are more than five judges this may help to eliminate early items which if left in might be "outliers" at a later stage of analysis (Haynes et al. 1995). It is hoped to establish the content validity of the MLCDP in this chapter.

METHODS

The 45-item MLCDP (version 1) profile was subjected to content validation by a team of experts (panel of judges). Their task was to review the profile and rate each item on 4-point scale (strongly agree to strongly disagree) for its language clarity, completeness, scaling and relevance and suggest appropriate changes as necessary in order to develop a profile which could accurately measure what it was intended to measure. Consultant physicians, specialist nurses and academic experts from different disciplines were invited to join the panel of judges and to take part in this process.

Procedure

Content validation is an important process whereby a new measuring instrument is examined for its focus and emphasis relating to the target population. The content validation of MLCDP (version 1) was carried out in the following two phases:

Phase 1: Quantitative assessment
Phase 2: Qualitative assessment

During both phases, members of the panel of judges raised various issues related to MLCDP items' language clarity, completeness, relevance, scaling, structure and layout of the draft instrument. The suggestions were in the context of their clinical and academic experience which allowed the group to make necessary changes and ensure that items were sufficiently comprehensive for the intended use.

Phase 1: Quantitative assessment

The MLCDP (version 1) and the "questionnaire items rating sheets" (Appendix R) were sent out to the panel of judges to rate each item and for their expert opinion. A covering letter (Appendix S) explaining the task accompanied these documents. The members of the panel were asked to bring their items rating sheets for more detailed discussion at the subsequent meeting for qualitative assessment. Instruction was provided for rating of the MLCDP (version 1) on a four point Likert type ordinal scale (1=Strongly agree, 2=Agree, 3=Disagree and 4=Strongly disagree) for each of the following four criteria:

Language clarity: The sentence and wording should be clear, understandable, straightforward and simple. Make sure the phrases and wording are unambiguous and jargon free and should be understood by a person who has the mental aptitude of a 12 year old child.

Completeness: The sentence structure should be complete, not broken and should end properly.

Relevance: Each item should be relevant to the subject area and target population.

Scaling: 5-point adjectival scale is used for the scaling system (No influence, Slight influence, Moderate influence, Strong influence, Very strong influence). Panel members should rate the scaling system as to whether or not the response options fit the statements/item.

Under each item, a separate section was provided for the panel of judges to write their suggestions for change.

Phase 2: Qualitative assessment

This process of content validation was based on the discussion between the members of the panel of judges. Only six members (clinicians=4, academic experts=2) were able to attend the qualitative assessment (discussion phase). Those members who did not attend this validation phase (n=9), returned their item rating sheets in order to include their responses in the discussion phase. The discussion for qualitative assessment was organised in the Department of Dermatology, School of Medicine, Cardiff University on 25 February 2010. The meeting lasted two hours and was digitally recorded for later analysis.

A Power Point presentation and an introduction were given by Z U B at the start of the discussion to remind the panel members about the purpose of the discussion, the time frame and the planned further course of the resultant outcome. At the request of the panel members, patients' comments which had been obtained at an early stage (conceptualisation stage 1) of this study were consulted again on various complex MLCD issues, in order to understand them better and to assist modification of items. Relevant patients' comments were projected on a digital electronic board using NVivo 8 transcript files via a computer, so that the panel of judges could discuss their responses and view the patients' comments at the same time. With the consensus of the panel of judges, the outcome of this discussion resulted in making changes (item inclusion, retraction, modification, and sequence) to remove further ambiguity and to make the new measuring tool more simple, user friendly and easy to understand for respondents.

Data processing and analysis

Data was processed using SPSS16 statistical software for windows. Descriptive statistics were used to record the demographics of the panel of judges. Kappa coefficient and intraclass correlation coefficient (ICC) techniques were used to evaluate the agreement among the panel of judges for inter-rater reliability.

The responses of the panel of judges as recorded on item rating sheets were analysed. Agreement among the panel of judges concerning each item was analysed by calculating the mean values of their ratings for "language clarity", "completeness", "relevance", and "scaling".

The detailed discussion, which took place during the second phase of the content validation process, was digitally recorded and transcribed verbatim. The level of agreement among the panel members for each item of the MLCDP was assessed statistically by using kappa coefficient. The SPSS software generally provide kappa statistics for only two judges. The Cohen Kappa macro syntax file was computed using SPSS12 software to calculate the multiple inter-rater agreement (>2 raters).

Kappa versus ICC: There is much discussion in the literature about which technique is better for inter-rater reliability. For non-quantitative data (categorical/nominal), the kappa coefficient is the techniques of choice. The ICC is more appropriate and better than the kappa technique for analysing data obtained from ratings using any scale (e.g.1 to 10) (Futrell 1995; Gwet 2008). Therefore, it was decided to use ICC for the quantitative and kappa technique for the qualitative phase to measure the level of agreement (inter-rater reliability) among the panel of judges.

RESULTS

Demographic characteristics of the panel members

Fourteen people were invited to form a "panel of judges" and to take part in the content validation processes for the MLCDP (version 1). The panel members included clinicians from seven participating medical specialities and 13 took part in the first (quantitative) phase of whom seven were clinicians (Male=5; Female=2) and six specialist nurses (Female=6). The panel members' professional backgrounds are listed in Table 5.1. Only four members (clinicians=4: Male=2, Female=2) from the panel of judges and two academic experts (Male=2), who both had vast experience in developing QoL questionnaires took part in the next panel discussion phase (qualitative) of the content validation.

Panel of judges' ratings of the MLCDP items (Quantitative assessment)

Thirteen members of the expert panel completed and returned their content validation item rating sheets. The mean scores of each item (total=45) for each of four criteria are shown in Table 5.2. The median values of the judges' (n=13) ratings for the four criteria (Table 5.3) indicated good expert consistency (agreement) in overall four criteria of language clarity, relevance, completeness and scaling.

Table 5.1: The panel members' professional backgrounds

Department	Number	Position	Initials
Cardiology	2	Clinician Specialist nurse	JH LE
Dermatology	3	Clinician Specialist nurse Academic expert	MC AT AYF
Nephrology	2	Clinician Specialist nurse	SR JJ
Rheumatology	2	Clinician Specialist nurse	SJ GM
Respiratory medicine	1	Clinician	CB
Cystic Fibrosis services	2	Clinician Specialist nurse	IK CD
Diabetes	2	Clinician Specialist nurse	LG JB
Pharmacoepidemiology	1	Academic expert	SS

The overall percentages of their agreement (strongly agree, agree, disagree or strongly disagree) on the four criteria also indicate that the majority of judges either "strongly agreed" or "agreed" on the four criteria. Concerning language clarity of the items, 58% of judges strongly agreed, 28% agreed, 12% disagreed and only 2% strongly disagreed. In terms of the relevance of the items, 55% of the judges strongly agreed, 33% agreed, 9% disagreed and 3% strongly disagreed. Concerning completeness, 50% judges rated strongly agree and 33% rated agree. Only 13% of the judges viewed some items as incomplete and 2% of the judges strongly disagreed in this respect. The panel of judges also viewed the scaling criteria in a very similar way as to their rating of other criteria; 57% strongly agreed, 28% agreed, 13% disagreed and 2% strongly disagreed. The overall disagreement level between the judges was <15% overall criteria with <5% recording strong disagreement (Table 5.4).

Panel of judges' disagreement with the four criteria

More specific analysis of each item revealed that several judges raised concern over language clarity and some judges were not sure about the relevance, completeness and scaling of some items. Only three (23%) experts (speciality nurses) disagreed on > 20% of the items across the four criteria. The experts (≥ 3 panel members) disagreement or strong disagreements concerning the four criteria for specific MLCDP items were as follows:

Language clarity: In terms of language clarity, experts were asked to assess whether the wording of an item was clear, understandable, simple, unambiguous and jargon free. Several judges raised concern over 13 items. Panel members either disagreed or strongly disagreed on items A1 (n=3), A2 (n=4), A 4 (n=3), B1 (n=3), B6 (n=5), B8 (n=3), B11 (n=10), B12 (n=3), B13 (n=6), C4 (n=3), D5 (n=3), D13 (n=3) and F1 (n=10) (See Figure 4.1 for item detail).

Relevance: Relevance was the most important aspect of the rating criteria. Panel members were asked to assess whether or not items were relevant to the subject area and the target population. Some panel members either disagreed or strongly disagreed on the relevance of items B6 (n=6), B8 (n=3), B11 (n=7), B13 (n=7), C4 (n=3), D15 (n=3) and F1 (n=3) (See Figure 4.1 for item detail).

Completeness: 14 items were considered to be incomplete by some panel members: A2 (n=3), A4 (n=3), B1 (n=4), B6 (n=4), B8 (n=3), B11 (n=8), B13 (n=8), C4 (n=4), C8 (n=6), D7 (n=3), D12 (n=7), D15 (n=6), D16 (n=5), F1 (n=11) (See Figure 4.1 for item detail).

Scaling: For 10 items, the proposed scaling option was considered to be inappropriate as reported by panel members. These were item B1 (n=3), B7 (n=3), B8 (n=3), B11 (n=3), B13 (n=4), C6 (n=3), D12 (n=3), D15 (n=4), D16 (n=3) and F1 (n=3) (See Figure 4.1 for item detail).

The items which failed to gain agreement across all four criteria when judged by panel members were B8 (language clarity: n=3, relevance: n=3, completeness: n=3 and scaling: n=3), B11 (language clarity: n=10, relevance: n=7, completeness: n=8 and scaling: n=3), B13 (language clarity: n=6, relevance: n=7, completeness: n=8 and scaling: n=4), F1 (language clarity: n=10, relevance: n=3, completeness: n=11 and scaling: n=3), and on three criteria were B1, B6, C4, and D15 (See Figure 4.1 for item detail).

Panel of judges' suggestions for change

The panel members also proposed various suggestions for the improvement of some items. These suggestions, opinions and comments are listed in detail in Table 5.5. During the next discussion phase (qualitative) of the content validation, all items were examined again in great detail by the panel of judges, all suggestions were discussed and decision made for their implementations.

Table 5.2: Mean scores of each of the four criteria as rated by the panel of judges (n=13)

Domain Category	Variables (Items)	Mean (n=13)			
		Language clarity	Completeness	Relevance	Scaling
Education A	1	1.53	1.46	1.69	1.61
	2	2.00	1.92	2.00	1.79
	3	1.46	1.38	1.76	1.61
	4	1.76	1.69	1.76	1.61
Job / career B	1	1.76	1.69	1.84	1.76
	2	1.38	1.30	1.38	1.38
	3	1.23	1.23	1.30	1.38
	4	1.30	1.38	1.53	1.53
	5	1.15	1.30	1.23	1.38
	6	2.00	2.07	2.00	1.48
	7	1.61	1.69	1.69	1.48
	8	1.76	1.76	1.76	1.76
	9	1.23	1.23	1.23	1.38
	10	1.30	1.30	1.38	1.46
	11	2.61	2.38	2.46	2.46
	12	1.76	1.53	1.53	1.61
	13	2.23	2.38	2.46	2.07
Family / relationships C	1	1.30	1.53	1.61	1.38
	2	1.30	1.30	1.53	1.38
	3	1.30	1.30	1.46	1.38
	4	1.92	1.92	2.00	1.61
	5	1.53	1.53	1.61	1.53
	6	1.53	1.76	1.61	1.61
	7	1.30	1.46	1.38	1.38
	8	1.38	1.61	2.46	2.46
Social D	1	1.46	1.38	1.38	1.38
	2	1.38	1.30	1.23	1.38
	3	1.53	1.53	1.46	1.53
	4	1.30	1.61	1.69	1.76
	5	1.69	1.61	1.38	1.38
	6	1.46	1.46	1.46	1.53
	7	1.53	1.69	1.84	1.61
	8	1.38	1.38	1.46	1.30
	9	1.53	1.46	1.46	1.46
	10	1.38	1.38	1.38	1.30
	11	1.30	1.30	1.53	1.38
	12	1.76	1.76	2.46	1.69
	13	1.69	1.61	1.69	1.61
	14	1.38	1.38	1.38	1.46
	15	1.53	1.61	2.23	1.69
	16	1.69	1.76	2.23	1.69
Physical E	1	1.30	1.76	1.76	1.38
	2	1.38	1.53	1.69	1.38
	3	1.23	1.23	1.46	1.30
Major treatment decisions F	1	2.76	3.07	3.15	2.69

Table 5.3: Median scores of ratings (range=0-4) by the panel of judges on four criteria

Judges	Language clarity	Relevance	Completeness	Scaling
1	1.00	1.00	1.00	1.00
2	1.00	1.00	1.00	1.00
3	1.00	1.00	1.00	1.00
4	1.00	1.00	1.00	1.00
5	1.00	1.00	2.00	1.00
6	2.00	2.00	2.00	3.00
7	2.00	2.00	2.00	2.00
8	2.00	2.00	2.00	2.00
9	1.00	1.00	1.00	1.00
10	1.00	2.00	2.00	2.00
11	1.00	1.00	1.00	1.00
12	1.00	1.00	1.00	1.00
13	2.00	2.00	2.00	2.00

Table 5.4: Agreement level in the ratings of the panel of judges (n=13) on the four criteria

Response option	Judges ratings across four criteria of the 45 items (%)			
	Language clarity	Relevance	Completeness	Scaling
Strongly agree	58	55	50	57
Agree	28	33	33	28
Disagree	12	9	13	13
Strongly disagree	2	3	4	2

Table 5.5: Comments and suggestions proposed by the panel of judges

Panel members	Item	Expert opinion/suggestions
1. Consultant (Cardiology)	**A1**	"Early" is not defined. Do you mean<18? Or between GCSE or others
	A2	Study subject is suggesting why / subject being studied. Recommended "....study subject (s)"
	A4	Possibly split into two questions. I. I decided not to go into higher education (college/university) II. I decided to leave college/university education early
	B3	This overlaps somewhat with B1 and B6
	B6	Some overlaps between B1 and B3
	B9	Place adjacent to B5 (more logical order)
	B11	Not sure where this is heading. Are you trying to see whether they stayed in the same employment rather than looked to develop their career?
	C8	Some overlaps with C7
	D9	"city" region, area?
	D10	Some people may feel "home area" hard to define
	D15	Less relevant for some diseases, more than others
	D16	Less relevant for some diseases
	E2	Perhaps add further statement or two here, to show difference, sports from high intensity to low intensity
	F1	It will be hard to make objective judgment for this question, which will be so dependent on the nature of the condition, the specific treatment proposed by their physician (s) and patient's understanding of what major treatment decision is.
	Other	1. Not applicable should be included in response option
2. Specialist nurse (Cardiology)	**D12**	Interesting, not sure on relevance. Are you trying to see if mood/attitude will change colour of clothes?
3. Consultant (Dermatology)	**A2**	"subject studies"? what do you mean in school or university
	B2	"abandon" is this same as B1
	B6	"a job"? any job
4. Specialist nurse (Dermatology)	**A4**	Early (word addition). Not to complete
	B7	I decided to select a suitable job for my health
	C4	Word "seek" instead of "have". Word "fertility" instead of "IVF"
	C6	Or have long term partner
	D4	Buy own home
	D5	I decided to move back
5. Consultant (Cystic Fibrosis)	**B13**	May leave because of too busy rather than ill health etc.
	C1	Delay? (change my plans)
	C4	"Fertility" instead of "IVF"
	C5	"Sexual" instead of "intimate"
	C6	Or have a long term partner
	D4	Explain property? Own home

	D7	Not CF specific. OK if general
	D11	As already asked in D5
	D15	Make up? "cosmetics"
	E1	Why swimming highlighted
	F1	What's biologics? But ok for general question
6. Specialist nurse (Cystic Fibrosis)	**A1**	Before or after 16? ambiguous
	A2	Not clear what is meant by this
	B1	Not everyone would feel that they had a career-just a job
	B2	"Career" implies something professional
	B4	At what age should the decision to stop work due to ill health be termed early retirement
	B6	Bit ambiguous
	B9	Shorter than what?
	B11	What is the purpose of this statement?
	B13	What is the relevance of this statements
	C4	To have IVF is not a decision that can be made by the patient "I decided to explore the possibility of referral for IVF"
	D5	I decided to move house
	D8	Ambiguous –which country?
	D10	If you would move away in the first place
	D11	Which country?
	D12	Relevance?
	D15	Relevance?
	D16	Relevance?
	E1	Relevance?
	E2	What sports activities?
	F1	What is biologics? Patients may not understand this. Are dialysis and organ transplant really in the same league? With regard to question this question may cause anxiety
	Other	1. All questions should have a N/A option 2. This questionnaire is far too long
7. Consultant (Rheumatology)	**B8**	?
	B11	Out
	C1	Delay to word change
	C4	Change "IVF" to "fertility"
	C5	Change "intimate" to "sexual"
	D4	Change "purchase" to "buy" and "property" to "own home"
	F1	Ambiguous
8. Specialist nurse (Rheumatology)		No comments
9. Consultant (Diabetes)	**A2**	May be positive or negative influence
	A4	Early?
	B3	But why?
	B5	Why?
	B6	Same as changing career/abandoned career/retirement
	B7	Why? Physical / psychological
	B9	Similar to flexible hours

	B11	Why? Weak
	B13	? more likely to join one
	C1	Change "delay" to "change timing"
	C4	Only CF? change to seek fertility
	C6	Or long term partner
	D2	Add "or" before word "drinking"
	D4	Own house
	D6	-ve
	D7	+ve
	D11	Overlap with above
	F1	X sign on the statement as not agree
10. Specialist nurse (Diabetes)	**A2**	I felt restricted on my choice of study subject
	B1	I was forced to change
	C4	Cross sign (strongly disagree)
	D1	Decided?
	D5	Post code lottery
	D9	Post code lottery
11. Consultant (Nephrology)	**A1**	In renal I would say majority will not have had condition until late in life. Whether or not applicable?
	A2	See A1
	A4	See A1
	B2	Abandon?
	B3	Is this the same as part 1
	C1	May need a "not applicable" but I guess covered by no influence
	C4 to C7	I think these 4 questions are very difficult but you have more experience than I in that area
	C8	Is "decided" the right word? Maybe they were decided but not their idea?
	D7	Seems unlikely they will be answering this. They have moved abroad
	D11	I feel there is some repetition here but may be cannot get around this
	F1	I don't think this question is clear, as to what you want from patients
12. Specialist nurse (Nephrology)	**B6**	My job
	B13	Why is this relevant?
	C2	For some patients they do not have any choice due to illness leading to fertility problems
	C3	As above
	C4	Accessibility of IVF may present problems
	C5	These decisions may be out of the patients' control due to individual circumstances
	C6	See above
	D1	I decided to change my diet. Word or instead of (/)
	D2	Is this two questions not one?
	D5	I decided to move house
	D12	Is colour relevant?

	E1	Decisions may be made for partners due to circumstances not choices
	E2	As above
	E3	As above
	F1	Patients may not have choice in the decisions but may be forced by circumstances to make a decision. This question may need to be re-phrased
	Other	? Need “not applicable” option for onset of disease rather than “no influence”
13. Consultant (Respiratory Medicine)	**A1 to A4**	Not relevant to COPD
	B1	Clarify before start. Career not relevant to COPD
	B2	Job/Career
	B6	Career/Job
	B7	“for” my health
	B11	?
	B13	Relevance?
	C1 to C4	Not relevant to COPD
	C5	“sexual” big decision in COPD
	C6	Long term partner Could be relevant?
	D2	Word “or” instead of (/)
	D3	Modern trend
	D10	Seems overlaps in these questions D8 to D9
	D12	Colour relevance to COPD. Loose clothes
	D15	Not really relevant to COPD
	D16	Not relevant to COPD
	E1	Need not applicable. Change? Many take it up
	E2	Separate out? Group/exertion/give up dog/activities
	F1	I don’t like this question. Not really relevant at all to COPD patients and could be awkward to raise transplant

Test of agreement: Interclass Correlation Coefficient (ICC)

For the quantitative assessment part of content validity, the items of MLCDP (version 1) were rated by the panel of judges on a four point ordinal scale (strongly agree, agree, disagree and strongly disagree). Due to the type of rating method/scale used (ordinal scale) for the assessment, the quantitative nature of the data and in order to be statistically relevant (Futrell 1995), the ICC technique was used to measure the inter-rater reliability among the panel of judges.

The Interclass Correlation Coefficient (ICC) analysis of absolute agreement showed an ICC of 0.707 ($p=<0.0001$; CI=0.606 to 0.782) indicating a good level of agreement among the thirteen members of the panel and supporting the content validation of the instrument (Table 5.6).

Table 5.6: Level of absolute agreement among the panel members using ICC statistics

Intraclass Correlation	95% Confidence Interval		P value
	Lower Bound	Upper Bound	
0.707	0.606	0.782	<0.0001

Panel discussion and the resultant improved MLCDP (Qualitative assessment)

Each item of the new profile was reviewed and discussed by the panel members. The ratings of the panel of judges and their suggestions about each item (results of phase 1) were discussed until consensus was reached and members agreed on the retraction of items, addition and modifications of the final version of the MLCDP (version1a).

During the discussion it was noted that some items were more disease specific than others, but panel members were agreed over the broader concept and the general nature of the instrument.

In the light of the panel members' suggestions and comments item B2 (I decided to abandon my chosen career after starting) was merged with item B6 (I decided to give up a job) due to the similar nature of both items. Item C7 (I decided to separate from my partner) was merged with C8 (I decided to get divorced), and D7 (I decided to move abroad) merged with D8 (I decided to return to this country) to make more comprehensive statements. Items B11 (I decided to stay in the same employment), B13 (I decided to leave a professional association/committee) and F1 (I decided to make a major treatment decision) were removed because panel members considered these items as being unrelated to the topic area. The items E3 (I decided to change to different sporting activities) and E4 (I decided to be more physically active) were included as new items to broaden the physical domain (Table 5.7).

Table 5.7: List of items merged, removed and added
(See Figure 4.1 for item detail)

Items merged	Items removed	Items added
B2 with B6	B11	E3
C7 and C8	B13	E4
D7 and D8	F1	

By consensus the response option of "No influence" was changed to "No influence OR Not applicable". This change was necessary because some items may not be applicable to respondents. The domain B (Career/Work) name was changed to "Job/Career" in order to reflect the items included under this domain. The phrase "career and work" was also changed in the relevant introductory statements to "job/career". The domain F "major treatment decisions" consisted of only one item "F1" and removal of this item reduced the profile to only five domains. Various changes to several items were also suggested by panel members and implemented to make the profile more unified, simple and easy to understand for respondents. Further changes to the structure and layout were also made. The general instruction was removed from the top of every page and one simple introduction and instruction was placed at the beginning of the first page. The sentence "For each statement please tick one box" was placed at the top of page 2 and page 3 of the profile to remind the respondent about the scale response options. The words "Name/Code number" "Date" and "Confidential" were added at the top of the first page of the profile to enhance its professional use. The profile development date and the version number were also placed at the end of the profile to avoid any confusion with previous or subsequent versions.

All of the changes suggested by panel members at the qualitative discussion phase of the content validation highlighted in bold are shown in Table 5.8.

Table 5.8: Changes proposed by the panel members which received group consensus (identified in bold)

MLCDP version 1	MLCDP version 1a (consensus changes after meeting of panel members)
A1 to A3	Unchanged
A4. I decided to leave college/university education	A4. I decided to leave college/university education **early**
B. Career/Work The following statements refer to the influence of your chronic condition on your decisions about your career/work	**B. Job/Career** The following statements refer to the influence of your chronic condition on your decisions about your **job/career**
B1. I decided to change my choice of career	B1. I decided to change my choice of **job/career**
B2. I decide to abandon my chosen career after starting	B2. I decided to **give up my job/career** after starting
B3. I decided to completely change my work/profession	B3. I decided to completely change my **job/career**
B4 to B5	Unchanged
B6. I decided to give up job	Merged with **Item B2**
B7. I decided to select a job suitable to my health	Moved to B6. I decided to select a **job/career** suitable **for** my health
B8 to B10	Unchanged and moved to B7 to B9
B11. I decided to stay in the same employment	**Removed**
B12	Unchanged and moved to B10
B13. I decided to leave a professional association/committee	**Removed**
C1. I decided to delay my plans for having children	C1. I decided to **change** my plans for **when to have** children
C2 and C3	Unchanged
C4. I decided to have IVF (In Vitro Fertilisation) treatment	C4. I decided to **seek fertility** treatment

C5. I decided not to have an intimate relationship	C5. I decided not to have **a sexual** relationship
C6. I decided not to marry	C6. I decided not to marry **or have a long term partner**
C7. I decided to separate from my partner and C8. I decided to get divorced	C7. I decided to get divorced **or separate from my partner** (C7 and C8 merged together to make one comprehensive statement)
D1 and D2	Unchanged
D3. I decided not to travel abroad or go for holidays abroad	D3. I decided not to travel or go for holidays abroad **(word abroad removed after travel)**
D4. I decided not to purchase any property	D4. I decided not to **buy my own home**
D5 and D6	Unchanged
D7. I decided to move abroad D8. I decided to return to this country	D7. I decided to move **from one country to another.** (D7 was merged with D8 to make it one comprehensive statement to cover the meaning of both statements)
D9. I wanted to move to another city but decided not to	This statement **moved to D8**
D10. I decided to move back to my home area	This statement **moved to D9**
D11. I decided to move to another part of the country	This statement **moved to D10**
D12. I decided to wear different types or colour of clothes	I decided to wear different **types/colour of clothes/shoes (moved to D11)**
D13. I decided not to be involved in community activities	**moved to D12**
D14. I decided not to socialise	**moved to D13**
D15. I wanted to wear make up but decided not to	**moved to D14**
D16. I decided to wear a wig/toupee	**moved to D15**
E1	Unchanged

E2. I decided not to take part in other sports activities	E2. I decided not to take part in **any sports** activities
E3. I decided to give up driving	**moved to E5**
	Item E3 and E4 were included as new items
F1	**Removed**

Test of agreement: Kappa coefficient

The Cohen's kappa (κ) statistics have been used to determine the level of agreement between two raters (Cohen 1960) but Fleiss (1971) incorporated multiple (>2) raters statistics to obtain a generalised kappa value for any number of raters. Kappa is defined as "the proportion of agreement between raters after agreement by chance has been removed" (Futrell 1995). The following ranges of kappa values is normally used to measure the level of agreement between raters (Norusis 2005): values below 0.40 indicate **poor** agreement above chance; values in the range of 0.40 to 0.75 indicate **fair** level of agreement above chance; and values exceeding 0.75 indicate **strong** agreement above chance.

Landis & Koch (1977) assigned the following interpretation bands to kappa values:

Kappa	**Interpretation**
< 0	Poor agreement
0.0 – 0.20	Slight agreement
0.21 – 0.40	Fair agreement
0.41 – 0.60	Moderate agreement
0.61 – 0.80	Substantial agreement
0.81 – 1.00	Almost perfect agreement

The kappa coefficient is an appropriate technique for analysing non-quantitative (categorical/nominal) data (Futrell 1995). Therefore, in order to measure the level of agreement among the panel members who took part in the discussion (qualitative assessment phase), their responses were coded and analysed using SPSS12 statistical software. As there were multiple raters (>2), a SPSS macro syntax file was computed with the actual data file to obtain the Kappa value.

The value of Cohen's Kappa for multiple raters (n=6) was 0.81, (p=<.0001, CI=0.6946 to 0.9292). This value of kappa is “almost perfect agreement” (Landis and Koch 1977) and is highly significant, indicating substantial agreement among the panel of judges on the 45 items and supporting the content validity of the new instrument, MLCDP (version 1).

The final changes proposed by the panel of judges were implemented to produce the new 41-item version (version 1a) of the new MLCDP instrument (Figure 5.1). The six initial domains were reduced to five MLCD domains: education (4 items), job/career (10 items), family/relationships (7 items), social (15 items) and physical (5 items). This revised version of the new instrument was then taken forward for the next stage of the validation factor analysis.

DISCUSSION

The content validation of the MLCDP was the essential process in order to render it fit for purpose. Therefore, as recommended both quantitative and qualitative assessment techniques were applied (Haynes et al. 1995). Other general prerequisite criterion were met, such as the use of more than five experts (panel of judges), and assessment of each MLCDP item using a 4-point scale for its language clarity, completeness, relevance and scaling. The appropriate composition of the panel of judges (clinicians, specialist nurses and academic experts) was very effective at both the quantitative and qualitative (discussion phase) stages and their suggestions resulted in appropriate changes being made to several items. In subsequent qualitative panel discussion each item was discussed in the light of panel members' proposed suggestions and the transcribed patients' responses to ensure their relevance, coverage and potential responsiveness.

The guidelines for panel members were simple and no issues were raised concerning these. There was a varying degree of agreement among the panel members when they rated each item on the 4-point scale. However, when the results (rating of each item by panel members and suggestions) of this quantitative stage were considered at the panel discussion phase then the two academic experts played a vital role, particularly answering technical questions from other panel members in relation to questionnaire development. It was noted that some panel members were not sure about the inclusion of some disease specific items, but after review of the patients' comments and hearing the expert opinion of the members from the relevant medical speciality, some disease and gender specific items were retained. This detailed discussion also resulted in a consensus among panel members on various other issues. For example, the natural grouping of items under specific MLCD domains, the removal of three items, the merger of six items to form three comprehensive items, the inclusion of two more items under the physical domain and the structure of the MLCD profile.

The most important concern among the panel members was the language clarity of several items. This was resolved with consensus by application of appropriate phraseology. The majority of the experts agreed that the content of the MLCDP was straight forward, the content seems appropriate in relation to the specific MLCD concepts and the profile was relevant to the target population. This agreement among the panel members was measured and found to be highly significant, giving confidence that the outcome of this stage is satisfactory in terms of establishing proof of concept for the MLCDP.

Summary

- Both qualitative and qualitative methods were used for content analysis.
- A panel of judges was brought together for the content validation process. Thirteen members (clinicians=7, specialist nurses=6) took part at the quantitative stage and 6 members (clinicians=4; academic experts=2) took part at the qualitative stage.
- At the quantitative stage, panel members judged and rated each item using a 4-point Likert scale on four criteria: language clarity, completeness, relevance and scaling.
- More than 50% judges strongly agreed on these criteria for the majority of items.
- The response and comments of each panel members was recorded in a structured way to inform the detailed discussion and final decisions.

- Decisions at the qualitative stage were based on the panel's discussion concerning each item and the way the judges rated each item at the quantitative stage of content validity.

- Various changes were implemented, based on the consensus of the panel of judges and on the basis of the quantitative stage results.

- Six items were merged together, three items were removed and two new items were included.
- Agreement among the panel of the judges was measured by using ICC and kappa techniques. The value of ICC, 0.707 (p=<0.0001; CI=0.606 to 0.782) and kappa 0.8119, (p=<.0001, CI=.6946 to .9292) were highly significant.

- After the final changes, as suggested by the panel of judges, the six initial domains were reduced to five domains and a new 41-item MLCDP (version 1a) was formulated ready for the next stage of psychometric evaluation, factor analysis.

Figure 5.1: MLCDP version 1a (Date: 10.05.2010)

Name/Code Number: **Confidential**
Date:

Major Life Changing Decisions Profile

MLCDP

Instructions: The aim of this profile is to measure how your health condition has influenced major life decisions in your life. For each statement please tick one box.

A EDUCATION

The following statements refer to the influence of your chronic condition on your decisions about your education.

	No influence OR Not applicable	Slight influence	Moderate influence	Strong influence	Very strong influence
1. I decided to leave school education early	☐	☐	☐	☐	☐
2. I decided to change my study subject	☐	☐	☐	☐	☐
3. I decided to study near home	☐	☐	☐	☐	☐
4. I decided to leave college/university education early	☐	☐	☐	☐	☐

B JOB / CAREER

The following statements refer to the influence of your chronic condition on your decisions about your job / career.

1. I decided to change my choice of job/career	☐	☐	☐	☐	☐
2. I decided to give up my job/career after starting	☐	☐	☐	☐	☐
3. I decided to completely change my job/career	☐	☐	☐	☐	☐
4. I decided to take early retirement	☐	☐	☐	☐	☐
5. I decided to work flexible working hours	☐	☐	☐	☐	☐
6. I decided to select a job/career suitable for my health	☐	☐	☐	☐	☐
7. I decided not to take promotion	☐	☐	☐	☐	☐
8. I decided to work shorter hours	☐	☐	☐	☐	☐
9. I decided to become self-employed	☐	☐	☐	☐	☐
10. I decided to remain unemployed	☐	☐	☐	☐	☐

For each statement please tick one box

C FAMILY / RELATIONSHIPS

The following statements refer to the influence of your chronic condition on your decisions about your family / relationships.

	No influence OR Not applicable	Slight influence	Moderate influence	Strong influence	Very strong influence
1. I decided to change my plans for when to have children	☐	☐	☐	☐	☐
2. I decided not to have more children	☐	☐	☐	☐	☐
3. I decided not to have any children	☐	☐	☐	☐	☐
4. I decided to seek fertility treatment	☐	☐	☐	☐	☐
5. I decided not to have a sexual relationship	☐	☐	☐	☐	☐
6. I decided not to marry or have a long term partner	☐	☐	☐	☐	☐
7. I decided to get divorced or separate from my partner	☐	☐	☐	☐	☐

D SOCIAL

The following statements refer to the influence of your chronic condition on your decisions about your social life.

1. I decided to change my eating habits	☐	☐	☐	☐	☐
2. I decided to change my smoking/drinking alcohol habits	☐	☐	☐	☐	☐
3. I decided not to travel or go for holidays abroad	☐	☐	☐	☐	☐
4. I decided not to buy my own home	☐	☐	☐	☐	☐
5. I decided to move my home	☐	☐	☐	☐	☐
6. I wanted to move abroad but decided not to	☐	☐	☐	☐	☐
7. I decided to move from one country to another	☐	☐	☐	☐	☐
8. I wanted to move to another city but decided not to	☐	☐	☐	☐	☐
9. I decided to move back to my home area	☐	☐	☐	☐	☐
10. I decided to move to another part of the country	☐	☐	☐	☐	☐

For each statement please tick one box

	No influence OR Not applicable	Slight influence	Moderate influence	Strong influence	Very strong influence
11. I decided to wear different types/colour of clothes/shoes	☐	☐	☐	☐	☐
12. I decided not to be involved in community activities	☐	☐	☐	☐	☐
13. I decided not to socialise	☐	☐	☐	☐	☐
14. I wanted to wear make up but decided not to	☐	☐	☐	☐	☐
15. I decided to wear a wig/toupee	☐	☐	☐	☐	☐

E PHYSICAL

The following statements refer to the influence of your chronic condition on your decisions about your physical aspects of life.

1. I decided not to go swimming	☐	☐	☐	☐	☐
2. I decided not to take part in any sports activities	☐	☐	☐	☐	☐
3. I decided to change to different sporting activities	☐	☐	☐	☐	☐
4. I decided to be more physically active	☐	☐	☐	☐	☐
5. I decided to give up driving	☐	☐	☐	☐	☐

Please check you have answered all the statements

Thank you for your help

Date: 10.05.2010
Version 1a

CHAPTER 6

The Validation of the MLCDP: Factor Analysis

INTRODUCTION

The next stage, after content validation of the revised version of the new tool (MLCDP, version 1a) was the confirmation of the breadth and depth of the allocated domains through the application of the statistical technique of factor analysis.

Factor analysis is a statistical technique to analyse, explore and identify the relationships between a set of variables (items) measured or observed, particularly between those with similar concepts. Factor analysis is widely used to reduce a large number of correlated variables to a more manageable number, and therefore can be used to reduce the number of items in a questionnaire (Pallant 2005).

In a nutshell, Norusis (2005) explained that "the goal of factor analysis is to reproduce observed correlations among variables by identifying a smaller number of shared factors that account for the observed correlations". Thus, factor analysis was employed in this chapter to refine the MLCDP prior to its full scale psychometric evaluation which should include predictive validity, responsiveness and interpretability.

METHODS

Norusis (2005) and Pallant (2005) have recommended three key steps that should be considered for conducting factor analysis namely, assessment of the suitability of the data for factor analysis, factor extraction and factor rotation and interpretation. Furthermore, there are two types of factor analysis; exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) which will be briefly described here.

Exploratory factor analysis (EFA)

EFA is the technique, often used early on as the first step to explore whether there is any correlation among a set of items (Tabachnick and Fidell 2001; Pallant 2005). This type of factor analysis has two exploratory uses, to identify the underlying dimensions, and to reduce data (Floyd and Widaman 1995). EFA groups together creates clusters of correlated variables (items) which allow researchers to explore and confirm the appropriateness of the structure of an instrument and help to identify items which may not contribute to underlying factors and which therefore may be deleted. Also, EFA is widely used to determine the "construct validity" of newly developed QoL instruments (Fayers and Hand 1997).

Confirmatory factor analysis (CFA)

CFA allows researchers to examine the "goodness-of-fit" of a prespecified factor model. CFA is considered by some researchers to be an appropriate method on theoretical grounds of testing an instrument's underlying structure (construct validation), but its potential value in QoL research appears to be very limited (Fayers and Hand 1997). CFA's complex techniques are normally used later in the analysis than EFA in order to test a hypothesis or theory and to confirm the structure underlying a set of variables (Pallant 2005).

Procedure

210 patients (30 patients from each of the seven participating medical specialities: dermatology, cardiology, respiratory medicine, cystic fibrosis services, rheumatology, diabetes clinic and nephrology) were recruited from the out-patients departments at the University Hospital of Wales, Cardiff and the University Hospital Llandough, Llandough and were asked to complete the revised MLCDP (version 1a). The MLCDP was printed on thick blue paper in order to give a professional look and to increase the response rate (Sharpe 1974; LaGarce and Khun 1995; Beebe et al. 2007). A patient information sheet was given to every patient (Appendix T) before they were asked to read and sign a consent form (Appendix U). A personal information sheet was used for the purpose of obtaining demographic data of patients (Appendix V). For the purpose of gaining information about "face validity and practicality" of the MLCDP, patients were asked to complete a separate questionnaire sheet (Appendix W). The result of this analysis is described later in this chapter.

Data processing and analysis

In this study, EFA was used and "principle component analysis" technique was applied using SPSS16 statistical software. This was to explore the underlying structure of the MLCDP (version 1a), to confirm its appropriateness (construct validity) and to help further develop the instrument by reducing inappropriate items that may not contribute to underlying factors. A correlation and component matrix was created for the assessment of data suitability followed by application of the

Kaiser-Meyer-Olkin (KMO) measure and Bartlett's test of sphericity for adequate sampling. For factor extraction, Kaiser's criterion and Cattell's scree test were carried out and subsequently the Varimax technique was used for factor rotation and final interpretation. In addition, the statistics of Cronbach's alpha were used to measure the internal consistency reliability of the instrument. This test was carried out along with factor analysis in order to generate more evidence for the retention and deletion of the items during subsequent analysis.

The following steps and rules were applied during the process of factor analysis:

1. Reliability test (Cronbach's alpha) of 41 items was carried out before factor analysis. Items with "corrected items-total correlation" values <0.2 (not discriminating well) were removed.

2. Factor analysis of the remaining items was carried out.

3. Items which failed to load on any component were removed (well below the standard minimum recommended value of 0.3).

4. Items with a low loading (<0.4) were removed. As a rule of thumb 0.32 is considered to be a minimum loading for an item (Costello and Osborne 2005) but in this study due to the large number of variables >0.4 was considered to be the minimum loading to represent strong correlation.

5. Items loaded on multiple components with not much difference between values (weak complex variables) were removed. However, items with significantly higher loading were retained.

6. Further factor analysis was carried out to see whether or not the remaining items with a similar concept fitted together under the appropriate corresponding components.

7. Another separate factor analysis was carried out, without conducting the reliability test at the beginning in order to examine the difference (similarities, number of items removed and the types of items removed) between the results of two sets of factor analysis carried out in two different ways (with the reliability test at the beginning and without the reliability test at the beginning).

8. An examination of the prevalence of items, displayed as a table showing the ranking of items according to patients' response, was used to explore the prevalence ranking of deleted items. It was also used to assess the feasibility of reinstating any removed items, if considered necessary for conceptual reasons, and to assist decisions concerning whether or not removed items could be merged together. The lowest ranking items were compared with the items removed as a result of factor analysis to see the nature of both sets of items for further scale refinement. This was simply done by "eyeballing" the items' prevalence (%)/ranking table to review the degree of corroboration between the two sets of data.

9. Remaining and deleted items were re-examined again by the research team as part of the scale refinement. Final decisions were made on the basis of the results of the initial factor analysis, the factor analysis carried out for comparative reasons and of the examination of item prevalence. Each item was discussed in detail. Items were deleted, retained, merged or rephrased on statistical, conceptual and philosophical grounds. Although the research team reviewed again all 41 items, more emphasis was given to those items with low prevalence and to those suggested for deletion by factor analysis.

10. Items that conceptually misfitted in the extracted components were moved to conceptually more appropriate and meaningful components in order to create a sense of logical order for respondents.

RESULTS

Demographic characteristics of the study participants

A total of 210 patients completed the MLCDP (version 1a) (female=108 (51.4%), male=102 (48.6%); mean age=50.8 years, median=52 years; range=16-89 years) (Table 6.1). 122 (58%) of the participants only had school education, 52 (25%) patients had college level and 36 (17%) had university education. Half of the patients 105 (50%) were married, 55 (26.2%) were single and 24 (11.4%) were divorced. In terms of employment status, 71 (33.8%) patients were employed, 42 (20%) were unemployed, 42 (20%) were retired and 46 (21.9%) patients had retired early due to the impact of chronic disease. Patients' demographics are shown in detail in Table 6.1.

Patients had been suffering from one of 32 different chronic conditions. The overall mean disease duration was 19 years (range 2 to 74 years) (Table 6.2).

Table 6.1: Socio-demographic characteristics of the study participants (n=210)

Variables	Number (%)
Age (years)	
Range	16-89
Median	52
Mean	50.8
Gender	
Female	108 (51.4)
Male	102 (48.6)
Education	
School	122 (58.1)
College	52 (24.8)
University	36 (17.1)
Marital status	
Single	55 (26.2)
Married	105 (50)
Divorced	24 (11.4)
Living with partner	6 (2.9)
Widowed	19 (9)
Civil partnership	1 (0.5%)
Employment status	
Employed	71 (33.8)
Unemployed	42 (20)
Retired	42 (20)
Early retirement	46 (21.9)
Self employed	6 (2.9)
Housewife	2 (1)
Student	1 (0.5)

There were two cycles of factor analysis performed and will be reported in this chapter. However, for the purpose of clarity they will be labelled as "factor analysis I" and "factor analysis II". Factor analysis II was carried out at scale refinement stage for comparison.

Table 6.2: Prevalence of different disease status in the study participants (n=210)

Specialities/diseases	**N**	**Percent**
1. Cardiology		
Coronary artery disease (CAD)	7	3.3
Congenital heart disease	12	5.7
Atrial fibrillation (AF)	6	2.9
Myocardial infarction (MI)	3	1.4
Congestive pericarditis	1	0.5
Congestive heart failure	1	0.5
2. Nephrology		
CKD IV	23	11.0
CKD V	7	3.3
3. Respiratory Medicine		
COPD	30	14.3
4. Cystic Fibrosis (CF)	30	14.3
5. Diabetes		
Diabetes Type 2	23	11.0
Diabetes Type 1	7	3.3
6. Rheumatology		
Rheumatoid arthritis	12	5.7
Ankylosing spondylitis	1	0.5
Psoriatic arthritis	6	2.9
Osteoarthritis	1	0.5
Polymyalgia rheumatica	1	0.5
Systemic lupus erythematosus	2	1.0
Sjorgen's syndrome	1	0.5
Reflex sympathetic dystrophy	1	0.5
Connective tissue disorder	1	0.5
Sarcoidosis	1	0.5
Antiphospholipid syndrome	1	0.5
Fibromyalgia	1	0.5
Reflex sympathetic dystrophy	1	0.5
7. Dermatology		
Psoriasis	16	7.6
Atopic eczema	8	3.8
Acne	2	1.0
Hidradenitis suppurativa	1	0.5
Alopecia areata	1	0.5
Pityriasis lichenoides chronica	1	0.5
Behcet's syndrome	1	0.5
Total	210	100.0

Factor Analysis I

Reliability of the MLCDP

The reliability of the MLCDP (version 1a) was measured before factor analysis to determine whether or not items could be removed in order to increase the overall scale reliability. In the "items total statistics" table (generated by SPSS software), items are normally considered weak and less discriminative if their "items-total correlation" value is <0.2. Therefore, if the item is not discriminating well within the scale, removal of this item will increase the overall evaluative power of the scale. The cut-off value of item-total correlation varies in the literature from 0.2 to 0.4 (Nunnally and Bernstein 1994; Traub 1994; Lounsbury et al. 2006). The higher the value the more discriminating the item will be. Due to the unique conceptual basis of each item, the cut-off value of items-total correlation was kept to <0.2. The "items total statistic" also forecasts the level of Cronbach's alpha if a particular item/items are deleted. An item should be considered for removal if it improves the reliability of a scale. Otherwise, in the case of small changes, it is better to retain the item (Pallant 2005).

The internal consistency reliability was measured by using Cronbach's alpha coefficient (Cronbach 1951). The Cronbach's alpha reliability of the 41 items was 0.84 indicating that the scale has good reliability (Pallant 2005).

The "individual items statistics" indicated that for 7 items, the "corrected total-item correlation" values were <0.2 and therefore were removed. These items most likely would have not discriminated well within the scale. The removed items are highlighted in Table 6.3 in bold type. The full description of the removed items is given in Table 6.4. The removal of 7 items slightly increased the reliability of the scale (34 items) from Cronbach's alpha of 0.84 to 0.85. No item was identified which, if it had been deleted, would have resulted in significantly better reliability.

Exploratory factor analysis

Exploratory factor analysis of the remaining 34 items of the MLCDP was carried out for the purpose of construct validity (Fayers and Hand 1997) and to determine the number of factors necessary to represent data using "principal component analysis" in SPSS16 statistical software (Table 6.5).

Table 6.3: Item-total statistics for the MLCDP (version 1a)

	Scale mean if item deleted	Scale variance if item deleted	Corrected item-total correlation	Cronbach's alpha if item deleted
Leave school education early	23.9	293	.285	.843
Change study subject	23.9	292	.301	.842
Study near home	23.8	293	.231	.843
Leave college/university education early	23.9	291	.358	.841
Change choice of job/career	23.2	276	.453	.838
Give up job/career after starting	23.4	275	.529	.836
Completely change job/career	23.3	276	.467	.837
Take early retirement	23.2	281	.278	.844
Flexible working hours	23.5	283	.399	.840
Select a job/career suitable for health	23.2	282	.349	.841
Not to take promotion	23.8	289	.326	.841
Shorter working hours	23.3	282	.361	.840
Become self-employed	**23.8**	**296**	**.092**	**.846**
Remain unemployed	23.3	278	.404	.839
Change plans for having children	23.7	286	.353	.841
Not to have more children	23.8	291	.225	.843
Not to have any children	**23.8**	**294**	**.161**	**.845**
Seek fertility treatment	23.9	291	.392	.841
Not to have a sexual relationship	23.6	291	.230	.843
Not to marry or have a long term partner	23.9	292	.275	.843
Divorce or separation from partner	23.9	292	.281	.842
Change my eating habits	22.1	279	.364	.840
Change my smoking/drinking/alcohol habits	22.3	283	.241	.845
Travel or holidays abroad	22.8	279	.368	.840
Not to buy my own home	23.9	290	.349	.841
Move my home	23.5	286	.296	.842
Move abroad	**23.5**	**295**	**.072**	**.847**
Move from one country to another	**24.0**	**298**	**.110**	**.845**
Move to another city	23.8	289	.354	.841
Move back to home area	23.9	290	.440	.841
Move to another part of the country	23.9	295	.221	.844

Wear different types/colour clothes/shoes	23.0	279	.332	.842
Involved in community activities	22.9	273	.507	.836
Not to socialise	23.0	274	.524	.836
Wear make up	23.9	292	.305	.842
Wear wig/toupee	24.0	298	**.181**	**.844**
Not to go swimming	22.9	274	.457	.837
Not to take part in sports activities	22.8	269	.544	.834
Change to different sports activities	23.3	286	.284	.842
More physically active	22.9	290	**.156**	**.846**
Give up driving	23.7	292	**.182**	**.844**

Table 6.4: Full description of 7 removed items

Item number	Full description of the removed item
B9	I decided to become self-employed
C3	I decided not to have any children
D6	I wanted to move abroad but decided not to
D7	I decided to move from one country to another
D15	I decided to wear a wig/toupee
E4	I decided to be more physically active
E5	I decided to give up driving

All of the 34 items of the MLCDP (version 1a) were subjected to a "factor extraction" process. It has been recommended that analysis should ideally be based on 300 cases, however 150 cases should be sufficient to consider the data suitable for factor analysis (Pallant 2005). The sample size of 210 patients in this study was therefore considered sufficient for conducting factor analysis.

Correlation matrix

The data was statistically assessed for its appropriateness for factor analysis. A correlation matrix was generated as part of steps to be followed for factor analysis. A correlation matrix should show correlation coefficients of a magnitude at least r=0.3 and above between variables (Pallant 2005). The correlation matrix for the 34 items of MLCDP demonstrated the presence of correlation coefficients r=0.3 and above between several variables, thereby providing evidence of the suitability of the data for carrying out factor analysis. (Appendix X)

Table 6.5: Remaining items (34) used for factor analysis

Item numbers	Item numbers in MLCDP (version 1a)	Item short description
Item 1	A1	Leave school education early
Item 2	A2	Change study subject
Item 3	A3	Study near home
Item 4	A4	Leave college/university education early
Item 5	B1	Change choice of job/career
Item 6	B2	Give up job career after starting
Item 7	B3	Completely change job/career
Item 8	B4	Take early retirement
Item 9	B5	Flexible working hours
Item 10	B6	Select a job/career suitable for health
Item 11	B7	Not to take promotion
Item 12	B8	Shorter working hours
Item 13	B10	Remain unemployed
Item 14	C1	Change plans for having children
Item 15	C2	Not to have more children
Item 16	C4	Seek fertility treatment
Item 17	C5	Not to have a sexual relationship
Item 18	C6	Not to marry or have a long term partner
Item 19	C7	Divorce or separation from partner
Item 20	D1	Change my eating habits
Item 21	D2	Change my smoking/drinking/alcohol habits
Item 22	D3	Travel or holidays abroad
Item 23	D4	Not to buy my own home
Item 24	D5	Move my home
Item 25	D8	Move to another city
Item 26	D9	Move back to home area
Item 27	D10	Move to another part of the country
Item 28	D11	Wear different types/colour clothes/shoes
Item 29	D12	Involved in community activities
Item 30	D13	Not to socialise
Item 31	D14	Wear make up
Item 32	E1	Not to go swimming
Item 33	E2	Not to take part in sports activities
Item 34	E3	Change to different sports activities

Test for sample adequacy

Along with the correlation and component matrix, two more statistical techniques "Bartlett's test of sphericity" (Bartlett 1954) and "Kaiser-Meyer-Olkin (KMO) measure" (Kaiser 1970, 1974) were applied to check the adequacy of sampling. Bartlett's test of sphericity should be statistically significant at $p<0.05$ and the KMO value should be 0.6 or above (Pallant 2005). The following KMO descriptors have been defined by Kaiser (1974) to allow their interpretation:

Measure in the 0.90's = Marvellous
Measure in the 0.80's = Meritorious
Measure in the 0.70's = Middling
Measure in the 0.60's = Mediocre
Measures below 0.50 = Unacceptable

In this study, the Kaiser-Meyer-Olkin (KMO) value was 0.73. This is greater than the recommended minimum of 0.6. Bartlett's test of sphericity was significant at $p=0.0001$ confirming the sampling adequacy of the data and fulfilling the statistical criteria for carrying out factor analysis (Table 6.6).

Table 6.6: KMO and Bartlett's test: assessment of the suitability of the 34 items of MLCDP for factor analysis

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		.736
Bartlett's Test of Sphericity	Approx. Chi-Square	2359.626
	df	561
	Sig.	.0001

Factor extraction

To determine how many factors were able to be extracted, Kaiser's criterion and Cattell's scree test statistical techniques were applied:

Kaiser's criterion

In Kaiser's criterion rule, factors of Eigenvalue of one or more are retained for further analysis. Factor extraction using principle component analysis determines the numbers of factors (components) which represent the data. The components that are suitable should have an Eigenvalue of one or above (Pallant 2005). This principle component analysis for the initial factor extraction revealed 12 components with Eigenvalues >1, with percentages of variance 18.3, 8.0, 6.8, 5.2, 4.8, 4.3, 4.1, 3.7, 3.5, 3.3, 3.2 and 2.9 respectively. These 12 components explained 68.6% of the variance. The Eigenvalues with the percentage of variance of all the factors is presented in Table 6.7 in detail. Kaiser's criterion rule has been criticised because its use may retain too many factors in some cases (Pallant 2005). The default Eigenvalue is 1.0 in most statistical software packages, which therefore retain all factors with an Eigenvalue >1.0. This technique is therefore considered to be the least accurate method for factor extraction (Costello and Osborne 2005).

Component matrix

The component matrix for the 34 items of MLCDP was generated; this showed the loadings of 34 items on 12 components. It is obvious from the matrix that most of the items loaded strongly (0.3 and above) on the first six components. It is recommended by SPSS software that any loading above this value should be considered for future analysis. Of the 34, 20 items had values of >0.40 (Table 6.8).

Cattell's scree test

The use of a scree plot is another commonly used technique which allows retention of the exact numbers of factors for further analysis. The Cattell's scree test (Catell 1966) depends on a visual analysis, and involves creating a graph by plotting the Eigenvalue of each factor, also known as "scree plot" resembling an "elbow" shape. The key part of this test is the identification of the position of any sharp variation or break point on the "elbow" of the graph. It is recommended that factors above this break point should be retained or be considered for further analysis (Catell 1966). In the scree plot shown in Figure 6.1, four components were retained for further analysis. The first factor has the highest Eigenvalue. There is a sharp drop after the first factor indicating that the first factor accounts for most of the variance (18%). Each successive factor indicates a smaller amount of total variance.

Table 6.7: Principle component analysis describing the total variance

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	**6.23**	18.33	18.33	**6.23**	18.33	18.33
2	**2.73**	8.04	26.38	**2.73**	8.04	26.38
3	**2.32**	6.82	33.20	**2.32**	6.82	33.20
4	**1.79**	5.28	38.48	**1.79**	5.28	38.48
5	**1.63**	4.80	43.29	**1.63**	4.80	43.29
6	**1.49**	4.39	47.68	**1.49**	4.39	47.68
7	**1.39**	4.10	51.78	**1.39**	4.10	51.78
8	**1.25**	3.70	55.48	**1.25**	3.70	55.48
9	**1.19**	3.52	59.01	**1.19**	3.52	59.01
10	**1.13**	3.34	62.35	**1.13**	3.34	62.35
11	**1.10**	3.25	65.61	**1.10**	3.25	65.61
12	**1.02**	2.99	**68.61**	**1.02**	2.99	68.61
13	.93	2.74	71.35			
14	.81	2.40	73.76			
15	.80	2.37	76.12			
16	.76	2.25	78.38			
17	.70	2.06	80.44			
18	.64	1.90	82.35			
19	.59	1.73	84.08			
20	.55	1.62	85.71			
21	.53	1.57	87.28			
22	.47	1.39	88.68			
23	.46	1.36	90.04			
24	.43	1.28	91.33			
25	.41	1.22	92.55			
26	.38	1.13	93.69			
27	.35	1.04	94.74			
28	.31	.92	95.67			
29	.29	.85	96.52			
30	.28	.83	97.35			
31	.25	.73	98.09			
32	.23	.70	98.79			
33	.22	.65	99.44			
34	.18	.55	100.00			

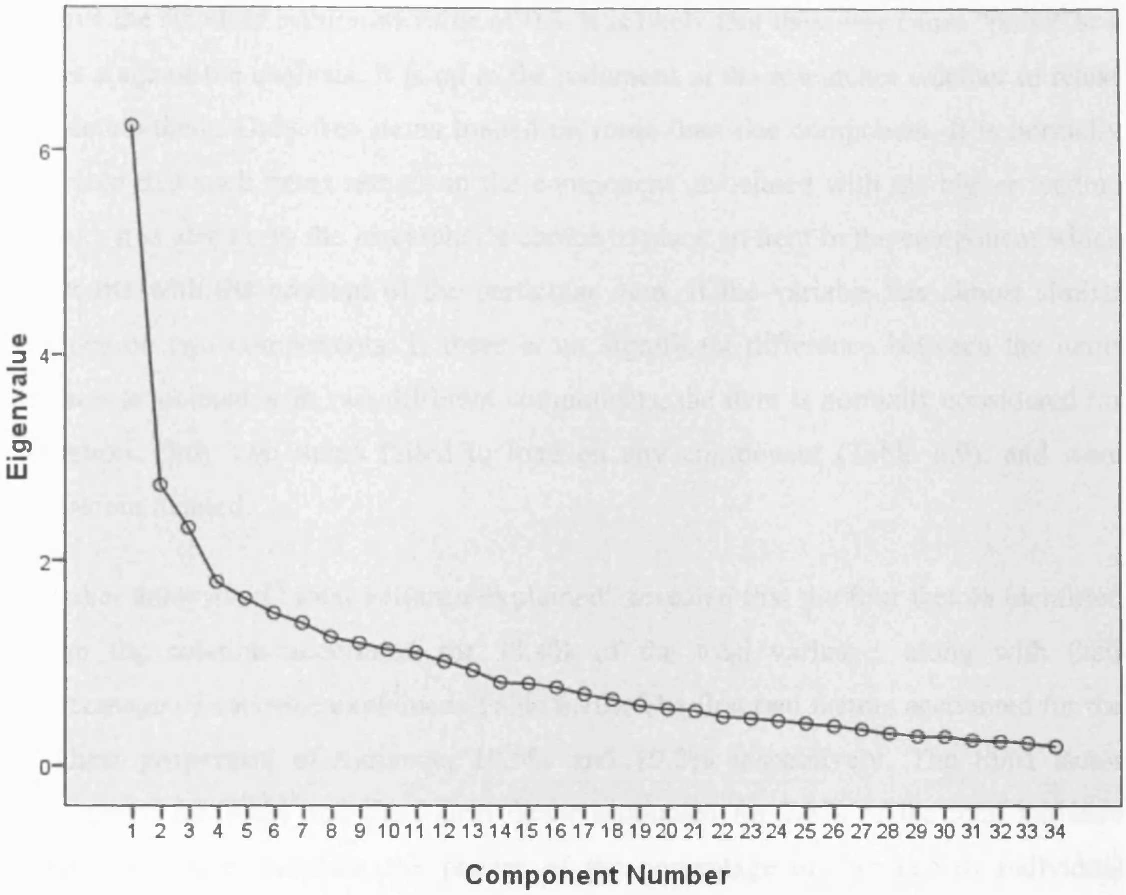
Extraction Method: Principal Component Analysis.

Table 6.8: Component matrix (twelve components extracted) of MLCDP

MLCDP Items	Components											
	1	2	3	4	5	6	7	8	9	10	11	12
B2	.580	-.118	-.110	.503	-.126		-.112	.229			-.110	-.206
E2	.576	-.454				-.132	-.215	-.108		-.222	.139	-.183
D13	.564	-.449	.102	-.295				-.114				.140
D12	.562	-.447	.113	-.393								.129
B3	.545		-.363	.266	.101		-.244	.101	.369		-.169	.123
D9	.543	.289	.168	-.162	-.336			-.123		.267		-.190
B1	.540		-.300	.324	.251	-.173	-.253		.246	.114		.147
E1	.523	-.390	-.201	-.223	.114	-.172	-.234		-.205	-.170		
C4	.497	.418	.178	-.112	-.173					.185	-.443	
A4	.472	.388			-.164	-.397				.183	-.289	.175
B5	.457	.115	-.379	.125	-.223	.156	.224	-.111	-.206	-.273	-.113	-.125
B10	.448	-.168	.205	.367		.352	-.148	.125		-.138		-.137
D8	.438	.357		-.198	-.314			.170	.138	.186	.223	
B8	.424		-.348				.392		-.405	-.185	-.158	
D11	.422	-.365	-.175	-.218		-.112	-.179	.413	-.123	.162	.128	
D3	.411	-.308	.171	-.304	-.203		.140		.251		-.188	.301
D1	.379	-.251			-.123	.372	.248	-.242	.294			
D5	.354		.279	.351	-.261	-.197		-.216	-.329			.270
A3	.347	.534		-.245	.101	.191			.226	-.311	.199	
A2	.402	.444	-.203	-.189				.271	.106	-.283		-.270
B6	.432	.137	-.525	.153	.237			-.186		-.106		.247
C7	.363	.177	.514		.261	-.369	.134	.100		-.119		
C6	.370	.272	.508				-.309	-.101			.230	
B4	.301	-.257	.428	.398		-.118	.211	.345		-.125		-.165
C5	.259	-.213	.334	.196	-.168	.120		.291			.178	.199
C2	.269				.511	.497	.110		-.195	.334		
A1	.346	.237	.294	-.132	.502	-.208	.286		.121	-.244		
D10	.245	.124	-.127		-.476		.262	.134	-.141	-.102	.366	.303
C1	.431	.306		-.101	.124	.509	-.208				.128	.156
B7	.333		-.239	.237		-.171	.424		.199	.264	.383	.110
D4	.426	.208	.305	.168	.181	-.143		-.474	-.210		.104	
D2	.229	-.318	.175	.191	-.156	.107	.300	-.308	.334			-.254
D14	.358	-.140		-.252	.283		.373	.175	-.279	.395		
E3	.321	-.151	-.261	-.159	-.105	-.249	-.120	-.288		.188	.350	-.411

Extraction Method: Principle Component Analysis.
12 components extracted.

Figure 6.1: Scree plot showing the amount of variance (34 items)



Factor rotation and interpretation

Once the exact numbers of factors have been determined, the next step is to rotate factors either by "orthogonal" rotation (Varimax, Quartimax and Equamax) or by "oblique" rotation (Direct oblimin, Promax). The factor rotation technique reveals clearly the pattern of loadings which assists their interpretation. The varimax technique is by far the most commonly used method for exploratory factor analysis and the direct oblimin method is the most commonly used for oblique rotation (Pallant 2005).

In this study, the orthogonal varimax rotation technique was applied. The varimax rotated component matrix revealed, that after rotation, thirty items loaded strongly (>0.40) (Table 6.9-highlighted in bold) on one of the four components, indicating a strong correlation between the item and the corresponding components or factors. Most items strongly loaded on component 1 (11), component 2 (7) and component 3 (7). Two items loaded weakly (<0.4) on component 2. Although these two items were above the standard minimum value of 0.3, it is likely that they may cause "noise" at a later stage of the analysis. It is up to the judgment of the researcher whether to retain or delete them. Only five items loaded on more than one component. It is normally advised that such items remain in the component associated with the higher loading value. It is also up to the researcher's choice to place an item in the component which best fits with the concept of the particular item, if the variable has almost similar values on two components. If there is no significant difference between the items values associated with two different components, the item is normally considered for deletion. Only two items failed to load on any component (Table 6.9), and were therefore deleted.

Further analysis of "total variance explained" revealed that the four factors identified from the rotation accounted for 38.4% of the total variance, along with their percentage of variance explained (Table 6.10). The first two factors accounted for the highest proportion of variance, 10.5% and 10.2% respectively. The third factor accounted for 9.8% and the fourth factor accounted for 7.8% of the total variance explained. After rotation, the pattern of the percentage of variance of individual components and their cumulative percentage changed from the total variance explained earlier in Table 6.7. However, cumulative total variance explained (38.4%) does not change after rotation.

Further examination

In the rotated component matrix, two items which failed to load into any component (well below the standard minimum recommended value of 0.3) were removed from further analysis. There were two items with weak loading (<0.4) and one item loaded on multiple components with no significant difference in their values. Therefore, in total five items were removed from further analysis (Table 6.11).

Table 6.9: Factor analysis of the MLCDP: Varimax rotated matrix with item loading

MLCDP Items	Components			
	1	2	3	4
Seek fertility treatment	**.658**		.146	
Study near home	**.639**		.149	-.185
Move back to home area	**.603**	.196	.139	.109
Not to marry or have a long term partner	**.594**		-.168	.303
Leave college/university education early	**.534**		.292	
Move to another city	**.519**	.125	.255	-.122
Change study subject	**.514**		.341	-.228
Change plans for having children	**.504**		.175	
Leave school education early	**.496**			.147
Divorce or separation from partner	**.486**		-.134	.417
Not to buy my own home	**.430**		.107	.386
Not to have more children	.177	-	.137	.167
Involved in community activities	.147	**.800**		.147
Not to socialise	.113	**.749**		.205
Not to go swimming		**.663**	.273	
Not to take part in sports activities		**.645**	.275	.243
Wear different types/colour clothes/shoes		**.588**	.206	
Travel or holidays abroad	.156	**.578**		.143
Wear make up	.168	**.423**		
Change my eating habits		.381		.247
Change to different sports activities		.370	.270	
Select a job/career suitable for health			**.691**	
Completely change job/career	.121	.134	**.671**	.139
Change choice of job/career	.137		**.650**	.206
Give up job career after starting		.120	**.585**	.507
Flexible working hours	.155	.126	**.584**	
Shorter working hours	.177	.195	**.483**	
Not to take promotion			**.444**	.146
Move to another part of the country	.148		.275	
Take early retirement				**.700**
Remain unemployed		.141	.223	**.575**
Move my home	.198		.140	**.517**
Not to have a sexual relationship		.154		**.484**
Change my smoking/drinking/alcohol habits		.214		**.406**

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.

Table 6.10: Four factors with total variance explained

Component	Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
1	3.60	10.59	10.59
2	3.49	10.28	20.87
3	3.33	9.80	30.68
4	2.65	7.80	38.48

Extraction Method: Principle Component Analysis

Table 6.11: Full description of the five removed items with reasons for their removal

Reason	Item	Full description of removed item
Failed to load	C2	I decided not to have more children
	D10	I decided to move to another part of the country
Loaded weakly (<0.4)	D1	I decided to change my eating habits
	E3	I decided to change to different sporting activities
Loaded weakly on two components with not much difference b/w the two values	D4	I decided not to buy my own home

Further analysis can be performed if there is a large set of data to remove additional weak items and to maintain strong factors (Costello and Osborne 2005). A further factor analysis of the remaining 29 items of MLCDP was carried out to see whether or not the remaining items were fitting well together in their respective components. A similar step by step procedure as described earlier in "factor analysis I" was followed. KMO and Bartlett's test of sphericity (Table 6.12), correlation matrix (Appendix Y) and component matrix (Table 6.13) were undertaken, fulfilling the basic criteria of carrying out factor analysis. The table of total variance explained (Table 6.14) extracted nine factors which explained 63.8% of the variance. From the scree plot examination (Figure 6.2), three factors were extracted for further analysis. This scree plot was relatively improved (smooth) compared to the previous scree plot where four factors were extracted. Again varimax rotation was applied to aid final interpretation.

Table 6.12: KMO and Bartlett's test: assessment of the suitability of 29-items of MLCDP for factor analysis

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.756
Bartlett's Test of Sphericity	Approx. Chi-Square	1938.227
	df	406
	Sig.	.0001

Table 6.13: Component matrix (nine components extracted) of the MLCDP

MLCDP Item	Component								
	1	2	3	4	5	6	7	8	9
B2	.589	-.129	-.143	.515	-.178			-.110	.168
E2	.574	-.449	-.113			-.149		-.123	
D13	.566	-.448		-.317				.164	-.129
B3	.562		-.384	.258		-.253	-.260	.220	
D12	.559	-.435		-.417	-.104			.108	
B1	.549		-.333	.308	.165	-.299	-.285	.119	-.130
E1	.535	-.383	-.194	-.272		-.204		-.276	-.150
D9	.534	.291	.250		-.332	.262	-.121		
C4	.505	.411	.240		-.120	.252	-.235	-.163	-.220
A4	.487	.376			.117	.191	-.479	-.115	-.102
B5	.450	.150	-.383		-.159	.302	.326	-.184	
B10	.441	-.198	.138	.370	-.167	-.251	.254	-.196	
D8	.440	.378		-.139	-.195	.200		.275	.331
B8	.430	.113	-.356		.113	.386	.357	-.293	
D3	.422	-.298	.196	-.286		.140		.324	-.210
C1	.419	.308	.107		-.274	-.325	.168		
A3	.353	.550		-.215		-.308	.294	.182	
A2	.427	.476	-.108	-.148			.295		.220
B6	.437	.170	-.559		.136	-.138			-.162
C6	.359	.219	.539		-.182	-.220			
C7	.366	.119	.526	.112	.508			-.108	
B4	.309	-.325	.380	.433	.219	.101	.193		.219
D5	.341		.242	.353	-.125	.126	-.100	-.210	-.225
A1	.337	.203	.294	-.126	.642	-.163	.208		
D14	.360	-.134		-.292	.372	.255	-.141	-.225	.260
B7	.314		-.259	.194	.363	.251		.431	.172
D2	.212	-.311	.141	.226		.326	.223	.414	-.302
D11	.447	-.350	-.151	-.238			-.200	-.118	.504
C5	.261	-.255	.312	.230	-.153				.371

Extraction Method: Principal Component Analysis.
9 components extracted.

Table 6.14: Principle component analysis describing the total variance explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	**5.74**	19.82	19.82	5.74	19.82	19.82
2	**2.63**	9.09	28.91	2.63	9.09	28.91
3	**2.20**	7.61	36.53	2.20	7.61	36.53
4	**1.75**	6.04	42.57	1.75	6.04	42.57
5	**1.47**	5.10	47.67	1.47	5.10	47.67
6	**1.32**	4.56	52.23	1.32	4.56	52.23
7	**1.17**	4.06	56.29	1.17	4.06	56.29
8	**1.11**	3.83	60.13	1.11	3.83	60.13
9	**1.09**	3.76	63.89	1.09	3.76	63.89
10	.97	3.35	67.24			
11	.87	3.00	70.25			
12	.82	2.85	73.10			
13	.79	2.73	75.84			
14	.74	2.58	78.43			
15	.70	2.41	80.84			
16	.60	2.07	82.92			
17	.56	1.95	84.88			
18	.54	1.88	86.76			
19	.49	1.70	88.47			
20	.47	1.62	90.09			
21	.45	1.55	91.64			
22	.40	1.41	93.05			
23	.35	1.23	94.29			
24	.32	1.13	95.42			
25	.31	1.07	96.50			
26	.28	.98	97.48			
27	.26	.90	98.38			
28	.24	.84	99.23			
29	.22	.76	100.00			

Extraction Method: Principal Component Analysis.

Figure 6.2: Scree plot showing the amount of variance (29 items)

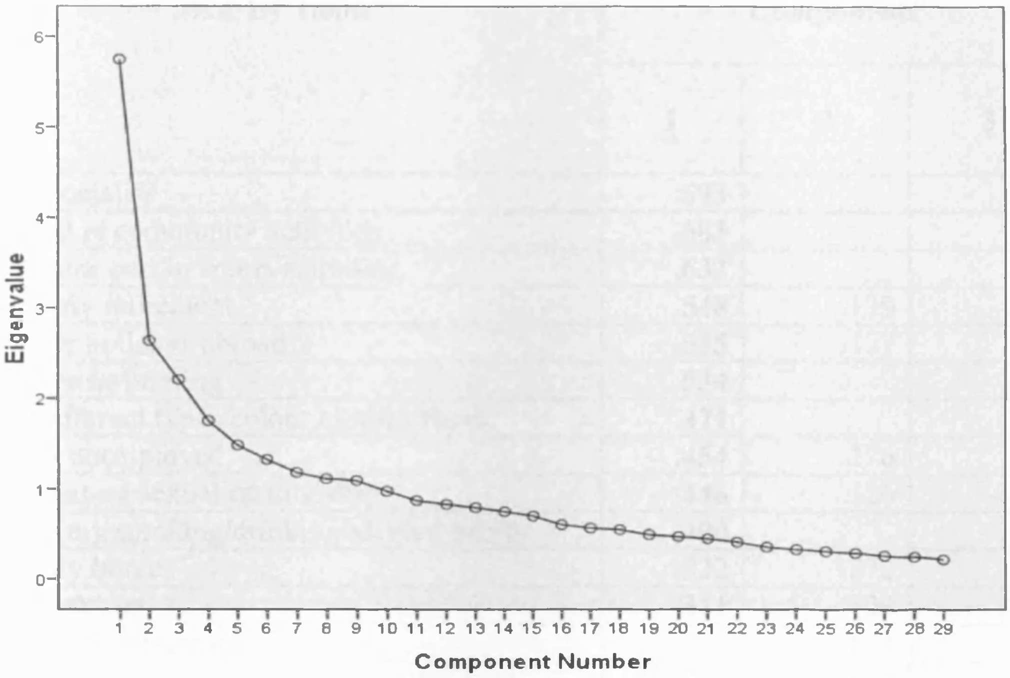


Table 6.15 confirms the initial structure of the scale after varimax rotation which reduces the number of MLCDP items and augments interpretation. All 29 items loaded to 3 extracted components. 26 items loaded highly (0.4 and above). 3 items loaded weakly (<0.4). Six items loaded on two components, and for 3 of these items, the values on two components were very close (weak complex variables). It is recommended that 5 or more strongly loading items (0.5 or above) are desirable to create a solid factor (Costello and Osborne 2005). Component 1 (factor) comprises of 12 items in which only 2 items loaded weakly (range=0.31 to 0.69). Component 2 comprises of 10 items with factor loading ranging from 0.46 to 0.67, with no weak loading. Component 3 comprises of 7 items with loadings ranging from 0.38 to 0.72, with only one weak loading. Table 6.16 shows the total variance explained of the extracted component, demonstrating that the 3 factors accounted for 36.5 % of the total variance. Although there were 5 more items in the first rotation and four components were extracted, there was not much difference compared to the percentage of total variance explained after the first rotation (38.4%). The first factor accounted for the highest proportion of variance, 12.7%. The second and third factors accounted for an almost similar proportion of the variance; 11.9% and 11.8% respectively.

Table 6.15: Varimax rotated matrix with items loading

MLCDP Items	Components		
	1	2	3
Not to socialise	**.693**		.215
Involved in community activities	**.683**		.201
Not to take part in sports activities	**.632**		.377
Take early retirement	**.548**	.139	-.160
Travel or holidays abroad	**.535**	.127	
Not to go swimming	**.534**		.426
Wear different types/colour clothes/shoes	**.471**		.344
Remain unemployed	**.454**	.176	.126
Not to have a sexual relationship	**.446**	.126	-.125
Change my smoking/drinking/alcohol habits	**.400**		
Move my home	.322	.272	
Wear make up	.311	.103	.201
Seek fertility treatment		**.672**	.153
Not to marry or have a long term partner	.235	**.612**	-.194
Move back to home area	.190	**.611**	.148
Study near home	-.167	**.599**	.214
Leave college/university education early		**.558**	.268
Divorce or separation from partner	.308	**.542**	-.191
Move to another city		**.510**	.280
Change study subject	-.129	**.499**	.393
Change plans for having children		**.489**	.197
Leave school education early	.151	**.467**	
Select a job/career suitable for health			**.725**
Completely change job/career	.143	.174	**.648**
Change choice of job/career	.155	.181	**.599**
Flexible working hours		.156	**.589**
Shorter working hours		.133	**.551**
Give up job career after starting	.398	.163	**.446**
Not to take promotion	.129		.387

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.

Rotation converged in 7 iterations.

Table 6.16: Three factors with total variance explained

Component	Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %
1	3.69	12.74	12.74
2	3.45	11.91	24.66
3	3.44	11.86	36.53

Extraction Method: Principal Component Analysis.

From the above data it is apparent that the majority of items are close to each other in their corresponding components. For example, component 1 comprises of 12 items of which 9 items deal with MLCDs related to social and physical aspects of patients' lives. Component 2 comprises of 10 items and 8 of these items deal with MLCDs related to family/relationships and education. The third component comprises of 7 items and all the items are related to job/career MLCDs. The full description of each item in their corresponding components is shown in Table 6.17.

Table 6.17: Full description of 29 items loaded on three components with reasons for removal of further six items

Extracted component number	MLCDP (v1a) number	Item full description	Items deleted
1	B4	I decided to take early retirement	
	B10	I decided to remain unemployed	
	C5	I decided not to have a sexual relationship	
	D2	I decided to change my smoking/drinking alcohol habits	
	D3	I decided not to travel or go for holidays abroad	
	D5	I decided to move my home	Weakly loaded (<0.4)
	D11	I decided to wear different types/colour of clothes/shoes	Weakly loaded complex variable on component 1 and 3
	D12	I decided not to be involved in community activities	
	D13	I decided not to socialise	
	D14	I wanted to wear make up but decided not to	Weakly loaded (<0.4)
	E1	I decided not to go swimming	Weakly loaded complex variable on component 1 and 3

	E2	I decided not to take part in any sports activities	
2	A1	I decided to leave school education early	
	A2	I decided to change my study subject	Weakly loaded complex variable on component 2 and 3
	A3	I decided to study near home	
	A4	I decided to leave college/university education early	
	C1	I decided to change my plans for when to have children	
	C4	I decided to seek fertility treatment	
	C6	I decided not to marry or have a long term partner	
	C7	I decided to get divorced or separate from my partner	
	D9	I decided to move back to my home area	
	D10	I wanted to move to another city but decided not to	
3	B1	I decided to change my choice of job/career	
	B2	I decided to give up my job/career after starting	
	B3	I decided to completely change my job/career	
	B5	I decided to work flexible working hours	
	B6	I decided to select a job/career suitable for my health	
	B7	I decided not to take promotion	Weakly loaded (<0.4)
	B8	I decided to work shorter hours	

Weakly loaded and complex variables were considered for deletion (six more items) (Table 6.17). In total eighteen MLCDP items were deleted as a result of factor analysis I, and were considered at the next refinement stage of the scale. Items which did not conceptually fit in their extracted corresponding factors were also discussed at this stage and the total number of items were finalised. For example, item "B4: I decided to take early retirement" was grouped in component 1, along with most items related to the social aspects of peoples' lives. This item could arguably fit in this component, as early retirement could be viewed as being a socially related MLCD. From an individuals' perception and from a broader conceptual approach, this item could fit with social aspects. However, if we take a tighter specific approach, this item should be in the component where items are related to job and career. It is the responsibility of the researcher to judge whether an item conceptually fits with a component or not, and if it doesn't belong there, either move it alongside other similar items or remove it all together.

Scale refinement

For the purpose of scale refinement and for selection of the final item, all the items that had been deleted as a result of factor analysis were compared with (a) the items deleted as a result of factor analysis of 41 items (Factor analysis II) carried out in different way (without any items being removed at the beginning through the reliability test) and (b) the prevalence of the items (items ranking).

(a) Factor Analysis II

An additional factor analysis of the 41 items of MLCDP (version 1a) was carried out in a different way. The purpose of this analysis was to compare the deleted items of this analysis with the deleted items of the initial analysis (factor analysis I) as described earlier in this chapter. In this analysis of 41 items, it was decided not to remove any item on the basis of any internal consistency reliability test at the beginning and so all 41 items of MLCDP (version 1a) were considered for factor analysis. In this analysis, items were deleted after the final varimax rotation based on the same criteria used for the previous analysis as described earlier in the methodology. The nature of the deleted items of this analysis were discussed by the research team and compared to the items deleted by the previous analysis, to inform the final decisions.

The same basic steps of factor analysis were applied. All the data values for suitability were in an acceptable range. Four factors were extracted after scree plot examination and varimax rotation was applied to assist final interpretation. As this analysis was carried out for comparative reasons to see whether any similar items were suggested for deletion by the two different factor analyses, only a brief description of this analysis is described here.

The final rotated component matrix (Table 6.18) revealed that four items failed to load (well below the standard minimum recommended value of 0.3) on any component, six items loaded weakly (<0.4) and one item loaded on two components with little difference between their values. Therefore, from this analysis 11 items were considered for removal (Table 6.19).

Table 6.18: Varimax rotated matrix with 41 items loading

MLCDP Items	**Component**			
	1	**2**	**3**	**4**
Involved in community activities	**.761**	.129		
Not to socialise	**.745**			
Not to take part in sports activities	**.669**		.284	
Not to go swimming	**.576**		.320	
Travel or holidays abroad	**.545**			.158
Wear different types/colour clothes/shoes	**.510**		.259	
Change my eating habits	**.418**		.122	
Change my smoking/drinking/alcohol habits	.392			
Give up driving	.383			
Wear make up	.381	.201		
Change to different sports activities	.310	.158	.243	-.296
Seek fertility treatment	.133	**.661**		
Move back to home area	.269	**.617**		
Study near home		**.614**	.101	
Change study subject		**.570**	.241	-.126
Move to another city		**.546**	.260	
Not to marry or have a long term partner	.146	**.488**	-.166	.396
Change plans for having children		**.471**	.207	.245
Leave college/university education early		**.452**	.330	.207
Leave school education early		**.450**		.357
Not to buy my own home	.120	.437		.329
Move abroad		.331		
Move from one country to another	-.148	.291	.108	
Not to have more children	.119	.250		.102
Become self-employed		.143		-.107
Select a job/career suitable for health		.177	**.611**	-.160
Wear a wig/toupee	-.137	-.150	**.583**	.306
Completely change job/career	.221	.192	**.579**	
Flexible working hours	.137	.206	**.558**	
Change choice of job/career	.200	.194	**.550**	
Give up job career after starting	.323		**.517**	.240
Move to another part of the country	-.118		**.503**	.269
Not to take promotion			**.468**	
Shorter working hours	.178	.250	**.434**	-.156

More physically active		.207	.251	-.245
Not to have any children	-.204	.217	.148	**.588**
Take early retirement	.341			**.526**
Move my home	.121		.210	**.493**
Divorce or separation from partner	.179	.368	-.149	**.488**
Not to have a sexual relationship	.257			**.456**
Remain unemployed	.364		.165	.384

Extraction Method: Principal Component Analysis.

Table 6.19: Reasons for the removal of 11 items

Reason for item removal	Item number	Full description of removed item
Failed to load	B9	I decided to become self-employed
	C2	I decided not to have more children
	D7	I decided to move from one country to another
	E4	I decided to be more physically active
Loaded weakly (<0.4)	B10	I decided to remain unemployed
	D6	I wanted to move abroad but decided not to
	D14	I wanted to wear make up but decided not to
	D2	I decided to change my smoking/drinking alcohol habits
	E3	I decided to change to different sporting activities
	E5	I decided to give up driving
Loaded weakly on two components with not much difference between the two values	D4	I decided not to buy my own home

These 11 deleted items were compared with the 18 items deleted as a result of the factor analysis I (Table 6.20). The comparison of the deleted items demonstrated that nine of the items were the same, which supported the initial approach of our factor analysis. In the next stage, the items deleted as a result of factor analyses were also compared with the prevalence (and their ranking) of these items.

Table 6.20: Comparison of the items deleted as a result of two different processes of factor analysis

Comparison of two different EFA*	**Item number**	**Full description of the removed item**
Common items deleted	B9	I decided to become self-employed
	C2	I decided not to have more children
	D7	I decided to move from one country to another
	E4	I decided to be more physically active
	D6	I wanted to move abroad but decided not to
	E3	I decided to change to different sporting activities
	E5	I decided to give up driving
	D4	I decided not to buy my own home
	D14	I wanted to wear make up but decided not to
Items only deleted after factor analysis I along with the above 9 common items	C3	I decided not to have any children
	D15	I decided to wear a wig/toupee
	D10	I decided to move to another part of the country
	D1	I decided to change my eating habits
	D5	I decided to move my home
	D11	I decided to wear different types/colour of clothes/shoes
	E1	I decided not to go swimming
	A2	I decided to change my study subject
	B7	I decided not to take promotion
Items only deleted after factor analysis II along with the above 9 common items	B10	I decided to remain unemployed
	D2	I decided to change my smoking/drinking alcohol habits

* Exploratory Factor Analysis

(b) The examination of prevalence of items

The item prevalence method is a simpler and possibly more appropriate way for considering which item to delete. This simple technique of comparison of items by eyeballing the table of item prevalence provides another insight into the appropriateness of the deletion of items as suggested by factor analysis. As the large sample is highly representative (n=210), examination of items prevalence is a powerful additional tool for selecting items.

An "examination of items' prevalence" or items ranking table was used to compare the lowest ranked items (bottom of the ranking table) with the items deleted as a result of factor analyses. If an item conceptually did not belong to a specific component, then this examination also helped to inform the decision whether or not to retain that item, remove it or move it to a more conceptually relevant component.

A total of 210 (93.3%) of 225 patients completed the MLCDP (version 1a). Fifteen (6.6%) patients declined to take part. Patients answered all the items (41) in the profile. Each item in the profile represents one MLCD. The influence of chronic disease on the MLCDs of patients was measured on a 5-point scale (No influence or not applicable, slight influence, moderate influence, strong influence and very strong influence). The level of disease influence on MLCDs was evaluated according to the percentage of patients who reported this influence. Patients (n=210) answered all the items in the profile and no item was left unanswered. Items were ranked according to their prevalence (%) (Table 6.21). Only 16 items had a prevalence of <10%, as identified in bold text at the bottom of Table 6.21. The top three affected MLCD items reported by patients were related to life style and were placed in the social category (item D1. I decided to change my eating habits: 71.4%, item D2. I decided to change my smoking/drinking alcohol habits: 58.5%, item D3. I decided not to travel or go for holidays abroad: 50.9%.

Table 6.21: Prevalence of 41 MLCDP items, ranked according to the percentage of participating patients who reported them

MLCDP items	Item full description	% of subjects reported	Item ranking
D1	I decided to change my eating habits	71.4	1
D2	I decided to change my smoking/drinking alcohol habits	58.5	2
D3	I decided not to travel or go for holidays abroad	50.9	3
E4	I decided to be more physically active	48.5	4
E2	I decided not to take part in any sports activities	46.1	5
D12	I decided not to be involved in community activities	45.7	6
D13	I decided not to socialise	42.3	7
E1	I decided not to go swimming	40	8
B8	I decided to work shorter hours	36.1	9
D11	I decided to wear different types/colour of clothes/shoes	34.7	10
B6	I decided to select a job/career suitable for my health	30.9	11
B1	I decided to change my choice of job/career	28.5	12
E3	I decided to change to different sporting activities	27.1	13
B3	I decided to completely change my job/career	26.6	14
B4	I decided to take early retirement	24.2	15
B10	I decided to remain unemployed	23.3	16
B2	I decided to give up my job/career after starting	23.3	17
C5	I decided not to have a sexual relationship	22.3	18
D6	I wanted to move abroad but decided not to	22.3	19
B5	I decided to work flexible working hours	21.9	20
D5	I decided to move my home	19	21
C1	I decided to change my plans for when to have children	14.2	22
E5	I decided to give up driving	12.8	23
B7	I decided not to take promotion	10.4	24
C3	I decided not to have any children	10	25
A3	**I decided to study near home**	**9.5**	**26**
D8	**I wanted to move to another city but decided not to**	**9**	**27**
C2	**I decided not to have more children**	**8**	**28**
C6	**I decided not to marry or have a long term partner**	**8**	**29**
B9	**I decided to become self-employed**	**7.6**	**30**
C7	**I decided to get divorced or separate from my partner**	**7.1**	**31**
D14	**I wanted to wear make up but decided not to**	**7.1**	**32**
A2	**I decided to change my study subject**	**6.6**	**33**
D9	**I decided to move back to my home area**	**6.1**	**34**
D10	**I decided to move to another part of the country**	**6.1**	**35**
D4	**I decided not to buy my own home**	**6.1**	**36**
A1	**I decided to leave school education early**	**5.7**	**37**
A4	**I decided to leave college/university education early**	**5.7**	**38**
C4	**I decided to seek fertility treatment**	**4.2**	**39**
D7	**I decided to move from one country to another**	**2.8**	**40**
D15	**I decided to wear a wig/toupee**	**0.4**	**41**

The comparison of ranked items with items deleted as a result of initial factor analysis demonstrated that of the 18, 8 deleted items (A2, B9, C2, D4, D7, D10, D14 and D15) appeared in the lowest (<10%) section of the items prevalence ranking and 10 deleted items appeared in the highest section of the prevalence ranking (>10%). Similarly, six deleted items as a result of factor analysis II, appeared highest in prevalence ranking. For example, item D1 (71.4%), D2 (58.5%) and item E4 (48.5%) appeared first, second and fourth in the prevalence ranking but these items were suggested by factor analyses to be removed. The complete details of this comparison are described in Table 6.22. This comparison was considered by the research team in their final selection of the items.

Table 6.22: Comparison of items deleted as a result of both factor analyses with item prevalence/ranking

	Item deleted as a result of EFA*		**%**	**Items ranking**	**Full description of item**
	1st EFA	**2nd EFA**			
lowest in items prevalence ranking	D15	-	0.4	41	I decided to wear a wig/toupee
	D7	D7	2.8	40	I decided to move from one country to another
	D4	D4	6.1	36	I decided not to buy my own home
	D10	-	6.1	35	I decided to move to another part of the country
	A2	-	6.6	33	I decided to change my study subject
	D14	D14	7.1	32	I wanted to wear make up but decided not to
	B9	B9	7.6	34	I decided to become self-employed
	C2	C2	8	28	I decided not to have more children
highest in items prevalence ranking	D1	-	71.4	1	I decided to change my eating habits
	-	D2	58.5	2	I decided to change my smoking/drinking alcohol habits
	E4	E4	48.5	4	I decided to be more physically active
	E1	-	40	8	I decided not to go swimming
	D11	-	34.7	10	I decided to wear different types/colour of clothes/shoes
	E3	E3	27.1	13	I decided to change to different sporting activities
	-	B10	23.3	16	I decided to remain unemployed
	D6	D6	22.3	19	I wanted to move abroad but decided not to
	D5	-	19	21	I decided to move my home
	E5	E5	12.8	23	I decided to give up driving
	B7	-	10.4	24	I decided not to take promotion
	C3	-	10	25	I decided not to have any children

* Exploratory Factor Analysis

The conflict between the patients' perception and scientific scrutiny

After factor analysis, some conceptually important items such as item C3 "I decided not to have any children", item D6 "I wanted to move abroad but decided not to" and item E5 "I decided to give up driving" were deleted. However, these items were high in the items prevalence ranking (>10%); at 25th, 19th and 23rd respectively. The question was raised in discussion whether the factor analysis was "wrong" in identifying for rejection conceptually important and frequently reported items, or whether the patients were "wrong" in reporting or verbalising their perception. This conflict between the patient reality and scientific scrutiny was very evident. To resolve this in a way which accommodates both the concepts of the patients' reality and the scientific approach appeared to be a difficult task. It would be ideal if the two coincided, but when these concepts don't coincide, then researchers have to take some logical and informed but arbitrary decisions. It was felt that these decisions should be based on the side of the patient and the experience that patients shared during the detailed interviews and through the postal survey responses. Although it is difficult to justify this philosophical approach logically, in our view statistical analysis can be legitimately combined with clinical intuition and patients' experiences. For example, there are National Institute for Health and Clinical Excellence (NICE) guidelines available to guide clinical decisions, but to maximise the quality of care of patients, clinician judgment can be based on a wide range of information about an individual patient combined with guideline information to make it more appropriate for patients.

Decisions related to the selection of items were not straight forward. For example, if we look at item D1 "I decided to change my eating habits", 71.4 % of subjects reported this MLCD and it was top of the item prevalence ranking. However, one of the factor analyses suggested that this item should be deleted. Item E4 "I decided to be more physically active" was reported by 48.5% of the patients and appeared fourth in the item prevalence ranking, but both factor analyses suggested that this item should be removed. Similarly, item E1 "I decided not to go swimming" was reported by 40% of patients but again was suggested to be removed by one factor analysis. Another item D6 "I wanted to move abroad but decided not to" was reported by 22.3% but suggested by both factor analyses to be removed. Statistical analyses suggested that these items should be removed, even though they were frequently reported by patients. On the other hand, items B9 "I decided to become self-employed", C2 "I decided not to have more children" and D14 "I wanted to wear make up but decided not" appeared lowest in the items prevalence ranking and were also suggested by both factor analyses to be removed, but a close look at these items gives insight into the true nature of MLCDs. Therefore, this delicate situation was discussed in great detail; does removing items which genuinely represent MLCDs really make sense?

It was reassuring that nine identical items were removed by two different methods of factor analyses but in reality these items (41) are valid items by definition. All the items of the scale were generated by patients' responses, after a long process of content analysis and lengthy discussions and it is possible to argue that in reality they should not be removed. The point of view was shared by the research team that if we end up creating a questionnaire which has excellent statistical validity but is less representative of the patient experience due to deletion of some very obvious MLCD items, then the whole processes might have to be repeated again in order to include a specific item if reported frequently again by patients. Therefore, it was decided to take a conservative approach to deleting items at the scale refinement stage.

Another question raised during discussion was whether three components, as extracted by EFA, are enough for a profile to be patient friendly. Initially, five domains were generated to reflect specific sets of items but as a result of factor analysis these five were squeezed to three tight components with lots of items in each component. So the concern was obvious: is this structure better for eliciting real information while possibly sacrificing vital information for the sake of "statistical correctness". A useful profile should be user friendly and easy to understand by respondents, in order to get optimal responses. Taking this argument further, the factor analysis was of course very important in providing insight into the nature of the data but what 210 patients told about their real life experiences should be and were the key for the conceptualisation and generation of items. For example, factor analysis is helpful in identifying items to be considered for removal but the grouping of items created at the beginning of the process was based on patients' responses concerning the nature of MLCDs. It was a logical grouping of items which reflected the way people live in the society and MLCDs were ordered relating to different life stages.

After the process of statistical analysis the question was raised during the refinement stage that, "would it not be odd if we grouped two MLCDs of a different nature together in one component, such as "I decided not to have any children" and "I decided not to buy my own home".

This obvious tension between patients' reality and science could be reduced by accepting items for removal which may significantly "create noise" at a later stage in the validation process, some items can for example be merged and rephrased. The researchers' judgment is vital. The combination of a statistical approach, a philosophical approach and a conceptual approach provides researchers with an overall broader picture of the construct. This combined approach assists the critical decisions concerning item selection, and allows the possibility of really representing the views of patients and their experiences without loosing any critical data in the process.

Synthesis of the factor analysis findings

Instead of removing conceptually important items, it was decided to apply appropriate "phraseology" and to collapse similar items into one compact item to remove any ambiguity which may have been created by having similar items. In particular there was a discussion concerning items related to "moving". D9 "I decided to move back to my home area" and D10 "I decided to move to another part of the country" were merged and rephrased to encompass the broader concept of that particular MLCD theme. Similarly, the wordings of some other items were also reviewed by the research team as the particular wording used may have been the problem picked up by factor analysis and resulting in the implication for item removal. For example, the double phraseology of items such as item D6 "I wanted to move abroad but decided not to" and D14 "I wanted to wear make up but decided not to" may have resulted in confusion. The second part of the items "I decided not to" may have caused a problem and hence these items may be identified by both factor analyses as weak items.

The research team considered all the items deleted by both factor analyses and the items prevalence ranking in great detail and adopted a three-pronged strategy of item deletion, merger and application of appropriate phraseology for scale refinement. All 41 items were reviewed and discussed again but more attention was given to those items which had an item prevalence of <10% (Table 6.21) and which were also suggested by one of the factor analyses to be removed (Table 6.20). The final results of scale refinement are as follows, which is presented according to the item number as it appeared in the profile and their prevalence/ranking (Table 6.21).

Low prevalence items suggested by factor analyses for deletion

Item D15: I decided to wear a wig/toupee

Item D15 was removed on the basis of its very low prevalence (0.4%). It was reported by only one subject and appeared last in the ranking (41st). One of the factor analyses also suggested that this item should be removed.

Item D7: I decided to move from one country to another

Item D7 was removed because it was reported by only 2.8% of the subjects and came second from the bottom of the item prevalence ranking list. It was also suggested by both factor analyses to be deleted. The other reason for the removal of this item was there were several other items covering the MLCD theme related to "moving". Item D7 was therefore removed because of the similar nature of three other items D5, D9 and D10.

Item D4: I decided not to buy my own home

Item D4 was suggested to be removed by both factor analyses. It was also reported by only a few patients (6.1%) and came 36th in the items ranking list. Also, this item was only reported by cystic fibrosis patients. Therefore, it had narrow specificity, very low prevalence and its removal was suggested by both factor analyses. The item was therefore removed from the scale.

Item D5: I decided to move my home,
Item D9: I decided to move back to my home area and
Item D10: I decided to move to another part of the country

Item D5 was reported by 19% of the patients and was reasonably high in the item prevalence table (21st) but it was identified by the initial factor analysis for deletion. Item D9 was low in the ranking (34th) but it was not suggested by either factor analysis for removal. Item D10 also came low in the ranking (35th) but was suggested by one of the factor analyses to be removed. The research team discussed whether "I decided to move my home" also includes a move back to "my home area" and "another part of the country", because when people move to another part of the country, they normally of course move their home. Similarly, if someone was going to move back to their original home area, this would also result in them moving home. It was suspected that because there were several items of a similar nature concerning this area, this may have caused problems for respondent and hence in factor loading. There was concern that retention of these items might cause strong "noise" at a later stage. On the basis of the above arguments, all three items D5, D9 and D10 were merged together into a single item "I decided to move". This newly phrased item covers the general concept of "moving" regardless of the type of move.

Item A2: I decided to change my study subject

Item A2 was not a straightforward item and was discussed in detail. Both factor analyses and its ranking in item prevalence (item ranking=33rd) highlighted it as a weak item and suggested that this item should be removed. However, the information obtained at the conceptualisation and item generation stages was reviewed and this item appeared to be a very important MLCD for young people. The concept of this item was not covered by any other item, and it was also reported by patients from several different specialities. On the basis of this information and particularly on the nature of the responses received at the conceptualisation stage, it was decided to retain this item.

Item D14: I wanted to wear make up but decided not to

Item D14 was suggested by both factor analyses to be removed and also came lowest in ranking, reported by only 7.1% of the population. We argued earlier in this chapter that the wording of some of the items may have caused problems during factor analyses, such as the second part of this item "but decided not to". Although this is a dermatology specific item, it was decided to retain the concept of this item on strong conceptual grounds. This item was rephrased to "I decided not to wear make up"

Item B9: I decided to become self-employed

On reviewing the original patients' comments, item B9 was a very big decision for patients who were taking positive control over their lives. However, both factor analyses suggested that this item should be removed. This item also appeared very low in the prevalence ranking (7.6%). It was discussed that this item is a positive item, a very important MLCD for patients, is related to a very major change in life and is not covered by any other item. Therefore, it was decided by the research team that on common sense and conceptual grounds this item should be retained.

Item C2: I decided not to have more children and
Item C3: I decided not to have any children

Item C2 was suggested by both factor analyses for deletion and also emerged low in the item prevalence ranking 28th (8%). Item C3 was suggested by the initial factor analysis to be removed, but this item was reported by 10% of the patients. It was suspected by the research team that as these items are very similar in nature, with only a subtle difference, this might have made it difficult for patients to think clearly. They may therefore have responded to only one of the two statements, and answering only one statement would have resulted in serious problems when other psychometric tests were later carried out. The option of one compact single statement was discussed in order to try to capture the true response to the item, to enhance spontaneity in answering and to reduce ambiguity to respondents. It was decided to merge both items in a way that the concept of having children remained intact. Item C2 and C3 were merged together to form "I decided not to have children".

Items suggested by factor analyses for deletion, but with high prevalence

Item D1: I decided to change my eating habits

Item D1 was suggested by the initial factor analysis for removal but appeared highest in the item prevalence ranking (71.4%). On the basis of its extremely high prevalence, item D1 was retained.

Item E4: I decided to be more physically active

This item was identified by both factor analyses for consideration for deletion but it emerged fourth in the prevalence ranking, which made it one of the most highly prevalent items. Almost half of the population (48.5%) reported the influence of their chronic disease on this MLCD. It is a positive item and it appears from the interviews that physical activity is a very important issue to the patients. Item E4 was retained because of its high prevalence ranking.

Item E1: I decided not to go swimming

Item E1 was suggested by initial factor analysis for removal, but reported by 40% of patients. Due to its high prevalence, this item was retained.

Item D11: I decided to wear different types/colour of clothes/shoes

Item D11 was also suggested by initial factor analysis to be deleted but it was reported by 34.7% of patients. Due to its high prevalence, the research team decided to retain this item.

Item E3: I decided to change to different sporting activities

Item E3 was suggested by both factor analyses to be removed, but came 13th (27.1%) in the item prevalence ranking. Due to its high prevalence, this item was retained.

Item D6: I wanted to move abroad but decided not to

This item was reported by 22.3% of patients and ranked 19th in the items prevalence ranking. However, both factor analyses suggested that this item should be removed. It was suspected that this was because of the wording of this item. In particular the later part of the statement "but decided not to" may have caused problems during factor analysis. Due to its high prevalence it was decided to retain this item but it was rephrased to "I decided not to move abroad".

Item D5: I decided to move my home

This item was merged with item D9 and D10 and discussed earlier in detail.

Item E5: I decided to give up driving

Item E5 was suggested by both factor analyses to be removed but 12.8% of patients responded to this item, and it therefore ranked 23rd in the item prevalence ranking. Due to the high prevalence, the important nature of the MLCD, its major life-style implications and on simple common sense grounds, it was decided to retain this item.

Item B7: I decided not to take promotion

Item B7 was reasonably high in prevalence (10.4%) but was suggested by initial factor analysis to be removed. Due to its prevalence, the important nature of this MLCD and on conceptual and common sense grounds this item was retained.

Item C3: I decided not to have any children

This item was merged with item C2 and discussed earlier in detail.

Item D2: I decided to change my smoking/drinking alcohol habits

Item D2 was suggested by the second factor analysis to be removed but appeared high in prevalence (58.5%) and second in the items ranking. Due to its high prevalence this item was retained.

Item B10: I decided to remain unemployed

Item B10 was also suggested by the second factor analysis for deletion but it appeared high in prevalence, being reported by 23.3% of the subjects, ranking 16th. Due to its high prevalence this item was retained.

Other items discussed

Item C4: I decided to seek fertility treatment

Item C4 was not identified by the factor analyses for deletion as might have been expected, as it was only reported by 4.2% of patients and came third from the bottom of the items prevalence ranking. This item was very specific to male cystic fibrosis patients. The research team decided to review the patients' comments obtained at the conceptualisation and item generation stages of the study. It appeared that the majority of the patients who reported this were from the same group of patients who decided not to have children. Item C4 therefore specifically belongs to that CF population, and even out of that CF population only 9 patients (30% of n=30) reported any influence. The "I decided to seek fertility treatment" concept was also discussed in relation to items such as "I decided not to have any children" and "I decided not to have more children". It was suspected that the conflict of very similar concepts between these items may have confused respondents. Item C4 had a very low prevalence. It was entirely confined to one disease and it had limited applicability within a sub-group. Its possible conflict with other related items may have caused significant "noise" and error at later stages of the study. It was decided that on the basis of the above arguments item C4 should be removed from the profile.

Item A1: I decided to leave school education early and
Item A4: I decided to leave college/university education early

Items A1 and A4 were 37th and 38th in the ranking of items prevalence; both items were reported by only 5.7% of the patients. Both items were not identified by any of the factor analyses for deletion. It was suspected by the research team that the lower response might have been due to the similarity between the items and it might be better if there was only single item covering this issue. It was decided that it would be better to merge the items and they were merged to "I decided to leave education early".

Item C7: I decided to get divorced or separate from my partner

This item was discussed by the research team because it emerged low in the item prevalence ranking (7.1%). Item C7 was not identified by any of the factor analyses for deletion and conceptually it was a very important MLCD for patients. Even though it was low in prevalence, the research team decided to keep this item on the grounds of common sense.

Item C6: I decided not to marry or have a long term partner

This item was discussed because of its low prevalence in the prevalence ranking table (8%). It was not identified by any factor analysis for deletion. Like B9, this item was also considered as a very big change and important decision which was not covered by any other items. Due to the important nature of this MLCD, the research team was convinced that from every point of view, this item qualified as an MLCD item. Therefore, with consensus it was decided to retain this item.

Item D8: I wanted to move to another city but decided not to

Item D8 was low in prevalence (9%) but it was not suggested by factor analyses for removal. As part of the refinement of the scale, it was important to review this item in the context of items D5, D9 and D10. All of the three items were merged together and rephrased to a new statement "I decided to move" (see above). Item D8 however is completely the opposite or inverse of this concept, that the patient didn't move because of their chronic condition. That is why the research team was of the view that this item is a very important MLCD and should not be removed. This item was rephrased to form "I decided not to move".

Item A3: I decided to study near home

This item is of course relevant to students who would otherwise have gone to another part of the country for their education, but they decided to study near home because of their chronic disease, availability of family support and to maintain nearness to the hospital and medical team that they had known for a very long time. This item was not identified by the factor analyses and it was reported by 9.5% of the respondents. This MLCD is crucial for any young student and may have long term consequences for their professional development in the future; this is why it is a life changing decision. For conceptual reasons, because of the patients' comments and on the basis of common sense, it was decided to retain this item.

Item C1: I decided to change my plans for when to have children

Although this item was reasonably high in prevalence at 14.2% and was not suggested by any of the factor analyses for removal, the research team discussed its phrasing, particularly the latter part of the statement, "when to have children". It was discussed whether the word "when" is relevant or not in this statement. The research team came to the conclusion that the word "when" reflects the specific nature of the item and its removal may result in the item being too similar to the newly phrased item "I decided not to have children", which was developed as a result of merging item C2 and C3, thereby risking creating ambiguity among respondents. This item reflects that the concept of patients going to have children later or earlier than they otherwise would have chosen is different from the concept "not to have children". It was decided to retain this item on the basis of it being a separate concept.

Item B1: I decided to change my choice of job/career and
Item B3: I decided to completely change my job/career

Both items were high in prevalence (B1=28.5%, B3=26.6%) and not suggested by the factor analyses for removal. As a part of the overall refinement stage of the scale these items were discussed again in detail. It is clear that patients may respond to both items because of their similarity. Although there is a subtle difference between the items it would be a difficult task for many patients to differentiate between the two. This would also create "noise" at a later stage when other psychometric properties are tested. It was decided that merger of B1 and B3 with appropriate phraseology would result in a stronger statement. Both items were merged to form "I decided to change my job/career".

On the basis of both factor analyses and examination of items of low and of high prevalence (items ranking), 30 items were discussed in detail. Seventeen items were retained, of which three items were rephrased. Nine items were merged to create four new items and four items were completely removed. All the changes made after factor analysis and at the scale refinement stage are shown in Table 6.23. The list of the final 32 items is shown in Table 6.24.

Table 6.23: The full detail of all the changes made after factor analysis and at the scale refinement stage

Item Number	Item full description MLCDP-version1a	After factor analysis and scale refinement
A1	I decided to leave school education early	Merged with A4 to form " I decided to leave education early"
A2	I decided to change my study subject	Retained
A3	I decided to study near home	Retained
A4	I decided to leave college/university education early	See A1
B1	I decided to change my choice of job/career	Merged with B3 to from "I decided to change my job/career"
B2	I decided to give up my job/career after starting	No change
B3	I decided to completely change my job/career	See B1
B4	I decided to take early retirement	No change
B5	I decided to work flexible working hours	No change
B6	I decided to select a job/career suitable for my health	No change
B7	I decided not to take promotion	Retained
B8	I decided to work shorter hours	No change
B9	I decided to become self-employed	Retained
B10	I decided to remain unemployed	Retained
C1	I decided to change my plans for when to have children	No change
C2	I decided not to have more children	C2 and C3 merged together to form "I decided not to have children"
C3	I decided not to have any children	

C4	I decided to seek fertility treatment	Removed
C5	I decided not to have a sexual relationship	No change
C6	I decided not to marry or have a long term partner	Retained
C7	I decided to get divorced or separate from my partner	Retained
D1	I decided to change my eating habits	Retained
D2	I decided to change my smoking/drinking alcohol habits	Retained
D3	I decided not to travel or go for holidays abroad	No change
D4	I decided not to buy my own home	Removed
D5	I decided to move my home	Merged with D9 and D10 to form "I decided to move"
D6	I wanted to move abroad but decided not to	Retained and rephrased to "I decided not to move abroad"
D7	I decided to move from one country to another	Removed
D8	I wanted to move to another city but decided not to	Retained and rephrased to " I decided not to move"
D9	I decided to move back to my home area	See D5
D10	I decided to move to another part of the country	
D11	I decided to wear different types/colour of clothes/shoes	Retained
D12	I decided not to be involved in community activities	No change
D13	I decided not to socialise	No change
D14	I wanted to wear make up but decided not to	Retained and rephrased to form " I decided not to wear make up"
D15	I decided to wear a wig/toupee	Removed
E1	I decided not to go swimming	Retained
E2	I decided not to take part in any sports activities	No change
E3	I decided to change to different sporting activities	Retained
E4	I decided to be more physically active	Retained
E5	I decided to give up driving	Retained

Table 6.24: The MLCDP items retained for the final version

Serial number	New item number	Item full description
1	A1	I decided to leave education early
2	A2	I decided to change my study subject
3	A3	I decided to study near home
4	B1	I decided to change my job/career
5	B2	I decided to give up my job/career after starting
6	B3	I decided to take early retirement
7	B4	I decided to work flexible working hours
8	B5	I decided to select a job/career suitable for my health
9	B6	I decided not to take promotion
10	B7	I decided to work shorter hours
11	B8	I decided to become self-employed
12	B9	I decided to remain unemployed
13	C1	I decided to change my plans for when to have children
14	C2	I decided not to have children
15	C3	I decided not to have a sexual relationship
16	C4	I decided not to marry or have a long term partner
17	C5	I decided to get divorced or separate from my partner
18	D1	I decided to change my eating habits
19	D2	I decided to change my smoking/drinking alcohol habits
20	D3	I decided not to travel or go for holidays abroad
21	D4	I decided to move
22	D5	I decided not to move
23	D6	I decided not to move abroad
24	D7	I decided to wear different types/colour of clothes/shoes
25	D8	I decided not to be involved in community activities
26	D9	I decided not to socialise
27	D10	I decided not to wear make up
28	E1	I decided not to go swimming
19	E2	I decided not to take part in any sports activities
30	E3	I decided to change to different sporting activities
31	E4	I decided to be more physically active
32	E5	I decided to give up driving

Final structure of the MLCDP

The factor analysis extracted three components for variables loading. Component 1 comprised of 12 items and 9 items dealing with MLCDs related to social and physical aspects of patients' lives. Component 2 comprised of 10 items and 8 items dealing with MLCDs related to family/relationships and education. Component 3 comprised of 7 items and all items are related to job/career MLCDs. However, after factor analysis and at the scale refinement stage the number of final items increased from 29 items to 32 items.

In general, factor analysis suggested that the most of the items related to education, family and relationships should be in one component, items related to MLCDs covering social and physical aspects of patients' lives should go together in another component and items related to job/career should be in another component. The final 32 items were therefore placed in each conceptually relevant component as suggested by this factor analysis. Eight items were placed in the education/family/relationship section, nine items were placed in the job/career section and 15 items were grouped in the social/physical section (Table 6.25).

The majority of items correlated to each other and fitted well in their corresponding components. However, after factor analysis at the scale refinement stage, the research team decided to remove some items as suggested by factor analysis, retained some deleted items, merged various items and applied appropriate phraseology to make some items conceptually appropriate and user friendly. This scale refinement changed the final numbers and structure of some items, which made it inappropriate to keep the final 32 items in 3 extracted components as suggested by factor analysis. With the consensus of the research team, it was decided to keep the original format of the scale and present items according to life stages and life events under the original five MLCD domains in order to maximise patient understanding and acceptability (Table 6.26). The final 32 items MLCDP (version 2) was thereby designed for further psychometric evaluation. (Figure 6.3).

Table 6.25: MLCDP 32 items loading in three components

Component 1: Education/Family/Relationships

A1 I decided to leave education early
A2 I decided to change my study subject
A3 I decided to study near home
C1 I decided to change my plans for when to have children
C2 I decided not to have children
C3 I decided not to have a sexual relationship
C4 I decided not to marry or have a long term partner
C5 I decided to get divorced or separate from my partner

Component 2: Job/Career
B1 I decided to change my job/career
B2 I decided to give up my job/career after starting
B3 I decided to take early retirement
B4 I decided to work flexible working hours
B5 I decided to select a job/career suitable for my health
B6 I decided not to take promotion
B7 I decided to work shorter hours
B8 I decided to become self-employed
B9 I decided to remain unemployed

Component 3: Social/Physical
D1 I decided to change my eating habits
D2 I decided to change my smoking/drinking alcohol habits
D3 I decided not to travel or go for holidays abroad
D4 I decided to move
D5 I decided not to move
D6 I decided not to move abroad
D7 I decided to wear different types/colour of clothes/shoes
D8 I decided not to be involved in community activities
D9 I decided not to socialise
D10 I decided not to wear make up
E1 I decided not to go swimming
E2 I decided not to take part in any sports activities
E3 I decided to change to different sporting activities
E4 I decided to be more physically active
E5 I decided to give up driving

Table 6.26: Final 32 MLCDP items distributed under the original conceptually relevant five MLCD domains

A. Education
A1 I decided to leave education early
A2 I decided to change my study subject
A3 I decided to study near home

B. Job/Career
B1 I decided to change my job/career
B2 I decided to give up my job/career after starting
B3 I decided to take early retirement
B4 I decided to work flexible working hours
B5 I decided to select a job/career suitable for my health
B6 I decided not to take promotion
B7 I decided to work shorter hours
B8 I decided to become self-employed
B9 I decided to remain unemployed

C. Family /Relationships
C1 I decided to change my plans for when to have children
C2 I decided not to have children
C3 I decided not to have a sexual relationship
C4 I decided not to marry or have a long term partner
C5 I decided to get divorced or separate from my partner

D. Social
D1 I decided to change my eating habits
D2 I decided to change my smoking/drinking alcohol habits
D3 I decided not to travel or go for holidays abroad
D4 I decided to move
D5 I decided not to move
D6 I decided not to move abroad
D7 I decided to wear different types/colour of clothes/shoes
D8 I decided not to be involved in community activities
D9 I decided not to socialise
D10 I decided not to wear make up

E. Physical
E1 I decided not to go swimming
E2 I decided not to take part in any sports activities
E3 I decided to change to different sporting activities
E4 I decided to be more physically active
E5 I decided to give up driving

Figure 6.3: 32 Items MLCDP version 2 (Date: 04.04.2011), final structure and format

Name/Code Number: **Confidential**
Date:

Major Life Changing Decisions Profile

MLCDP

Instructions: The aim of this profile is to measure how your health condition has influenced major life decisions in your life. For each statement please tick one box.

A EDUCATION

The following statements refer to the influence of your chronic condition on your decisions about your education.

	No influence OR Not applicable	Slight influence	Moderate influence	Strong influence	Very strong influence
1. I decided to leave education early	☐	☐	☐	☐	☐
2. I decided to change my study subject	☐	☐	☐	☐	☐
3. I decided to study near home	☐	☐	☐	☐	☐

B JOB / CAREER

The following statements refer to the influence of your chronic condition on your decisions about your job / career.

1. I decided to change my job/career	☐	☐	☐	☐	☐
2. I decided to give up my job/career after starting	☐	☐	☐	☐	☐
3. I decided to take early retirement	☐	☐	☐	☐	☐
4. I decided to work flexible working hours	☐	☐	☐	☐	☐
5. I decided to select a job/career suitable for my health	☐	☐	☐	☐	☐
6. I decided not to take promotion	☐	☐	☐	☐	☐
7. I decided to work shorter hours	☐	☐	☐	☐	☐
8. I decided to become self-employed	☐	☐	☐	☐	☐
9. I decided to remain unemployed	☐	☐	☐	☐	☐

For each statement please tick one box

C FAMILY / RELATIONSHIPS

The following statements refer to the influence of your chronic condition on your decisions about your family / relationships.

	No influence OR Not applicable	Slight influence	Moderate influence	Strong influence	Very strong influence
1. I decided to change my plans for when to have children	☐	☐	☐	☐	☐
2. I decided not to have children	☐	☐	☐	☐	☐
3. I decided not to have a sexual relationship	☐	☐	☐	☐	☐
4. I decided not to marry or have a long term partner	☐	☐	☐	☐	☐
5. I decided to get divorced or separate from my partner	☐	☐	☐	☐	☐

D SOCIAL

The following statements refer to the influence of your chronic condition on your decisions about your social life.

1. I decided to change my eating habits	☐	☐	☐	☐	☐
2. I decided to change my smoking/drinking alcohol habits	☐	☐	☐	☐	☐
3. I decided not to travel or go for holidays abroad	☐	☐	☐	☐	☐
4. I decided to move	☐	☐	☐	☐	☐
5. I decided not to move	☐	☐	☐	☐	☐
6. I decided not to move abroad	☐	☐	☐	☐	☐
7. I decided to wear different types/colour of clothes/shoes	☐	☐	☐	☐	☐
8. I decided not to be involved in community activities	☐	☐	☐	☐	☐
9. I decided not to socialise	☐	☐	☐	☐	☐
10. I decided not to wear make up	☐	☐	☐	☐	☐

For each statement please tick one box

E

PHYSICAL

The following statements refer to the influence of your chronic condition on your decisions about your physical aspects of life.

		No influence OR Not applicable	Slight influence	Moderate influence	Strong influence	Very strong influence
1.	I decided not to go swimming	☐	☐	☐	☐	☐
2.	I decided not to take part in any sports activities	☐	☐	☐	☐	☐
3.	I decided to change to different sporting activities	☐	☐	☐	☐	☐
4.	I decided to be more physically active	☐	☐	☐	☐	☐
5.	I decided to give up driving	☐	☐	☐	☐	☐

Please check you have answered all the statements

Thank you for your help

Date: 04.04.2011
Version 2

The end result of this phase was the final version of the new tool MLCDP (version 2) which will be examined for its other psychometric properties such as clinical validity, reliability, responsiveness and interpretability in future work.

Face validity and practicality

When the data was collected for factor analysis, an additional separate sheet was handed to the 210 patients along with the 41-item MLCDP (version 1a) in order to assess its face validity and practicality. The "face validity and practicality questionnaire sheet" (Appendix W) consisted of six questions asking patients to record their views and comments about the newly developed profile.

210 patients returned their responses along with the completed MLCDP (version 1a). The results of their replies are presented here according to the sequence in which the questions were asked.

1. The mean time taken by the patients to complete the MLCDP was 5.7 minutes (range = 2-15 minutes) and median time was 5 minutes (Table 6.27).

Table 6.27: MLCDP completion time (n=210)

Time taken to complete by patients (in minutes)	Number of patients	Percentage
2	5	2.4
3	10	4.8
4	29	13.8
5	65	31
6	43	20.5
7	27	12.9
8	15	7.1
9	7	3.3
10	8	3.8
15	1	0.5

2. When patients were asked whether the questionnaire was easy to complete, 204 (97.1%) patients answered "yes" and only six (2.9%) patients answered "no".
3. 198 (94.3%) patients answered that "the response options for the statements in the questionnaire" was straight forward. Only 12 (5.7%) patients disagreed.

4. The next question was “How clear and understandable were the instructions and statements?” 131 (62.4%) patients answered “very clear”, 76 (36.2%) patients answered “clear” and only three (1.4%) patients answered “not clear”.

5. Question 5 aimed to understand from the patients’ point of view whether the statements in the MLCDP were comprehensive enough to measure the influence of disease on important life decisions. 181 (86.2%) patients answered “yes” and 29 (13.8%) patients answered “no” to this question.

6. In this section patients who had answered “no” to question 5 were asked to write down the aspects of life they thought should be added to the questionnaire. No patients suggested any new life aspect which was not covered by the tool. However, some patients mentioned other points which are listed in Table 6.28 in detail.

Table 6.28: Comments reported by the patients on the face validity and practicality questionnaire sheet

Patient ID	Patients’ comments
05	Maybe a box for explanation is required
09	Lots of question is not relevant to myself
10	• Change of job/job role taken was positive decision rather than negative • My loss of hair trigger to start something new
14	The general activities and home life are severely affected by the condition (psoriasis) plus psoriatic arthritis which limits what one is able to or not able to do
16	An opportunity to explain reason
19	Impact on work i.e. psychological worry, emotional, stress, financial
23	Reasons for decisions to questions e.g. if a person decides not to take part in social activities, why is this?
24	Question about other people’s reactions
25	• Except no influence and not applicable should be two columns • Emotional impact on decisions
27	Was the decision out of your hand e.g. not allowed to take work because of condition
29	Effects on other family members also relationships with friends
32	A question on whether or not you would consider taking any “life insurance” or financial protection products as a result of being diagnosed
67	Some not relevant to my life
71	• could include a box for extra interrogation • Time scale; in the past 5 year or 10 year?
73	The statement “I decided to’ is misleading. I had no choice on many occasion due to my bad health
84	Allow comments to some answer as an option for example empty box to fill in
93	All the options were too broad
173	Can be use or more effective in follow up 5, 10, 15, 20 can see the adjustment
192	No provision for anticipated effects on life style

DISCUSSION

Costello and Osborne (2005, p. 7) stated that "exploratory factor analysis is a complex procedure, exacerbated by the lack of inferential statistics and the imperfections of "real world" data". Therefore, the researchers' judgment concerning the deletion and retention of specific items is important and should be based on the patients' responses and the research concept. For example, the researchers' judgment is important when deciding whether cross loading items should be dropped or retained (Costello and Osborne 2005). It is also up to the judgment of the researcher to consider why an item was included at the first place. Indeed, the purpose of factor analysis was to see to what degree the mathematical approach confirms clinical intuition. This was demonstrated by the way that factor analysis was performed by various methods and at the same time we set the bar higher for the confirmation of appropriate results. For example, items with >0.4 loading were retained, factor analysis was carried out in two different ways and the examination of the prevalence of items generated enough evidence to take appropriate decisions for item deletion, retention, merger and application of new phraseology at the refinement stage.

These analyses were reviewed in detail in order to make decisions about removal or retention of items, or the possibilities of merging deleted items together to form one comprehensive item if required for conceptual reasons. Items deleted by both analyses were compared with the items prevalence table in order to allow an informed judgment for appropriate item selection. Statistical factor analyses suggested that some items should be removed, even though they were frequently reported by patients. This situation was discussed in detail in order to exercise some degree of judgment in making better sense of the data.

Having examined the exploratory factor analysis results and also after looking at the prevalence of the items responses it was decided to take a very conservative approach during the item selection process. Therefore, it was decided to keep in conceptually sound items at this stage, even though they may have been suggested by the factor analyses to be removed. It was decided to reserve those items for future work when other more sophisticated techniques, such as, Rasch analysis and items response theory, could be applied to the data for further scale refinement. The reasons for this conservative approach were very clear: all the items came directly from the patients and the patient origin had the paramount influence in our decisions concerning the development of the revised version (version 2) of the new scale. Another reason was to create a degree of spontaneity on the part of the respondent by ensuring that items were perceived as relevant.

Specific recommendations for further factor analysis

- Because of the deletion, merger and rephrasing of some items, it will be necessary to obtain a new set of data for another factor analysis in the future. This is necessary in order to see how the new set of modified items will behave. Following this an internal consistency reliability and test-retest relaiblity of the final remaining items needs to be carried out.

- The use of more sophisticated techniques, such as Rasch analysis and the application of item response theory is appropriate for further scale refinement. This could be carried out along with other classical test theory psychometric properties which are described later under “future recommendations”.

Uses of MLCD Profile (version 2) and response interpretation

The MLCDP (version 2) may be helpful in the following situations:

1. Broad epidemiological studies to identify which diseases have the biggest impact on patients’ lives in terms of their MLCDs and which disease is most important in terms of impacts on specific decisions. The MLCD Profile could be used as one measure of the disease burden.

2. In the clinic, to provide clinicians with a one-off insight into how a chronic disease has already impacted on a patient’s life decisions, in order to identify those at risk.

3. The profile could be useful for a general practitioner at a patient’s annual medical review to enable the clinician to discuss the highlighted issues.

4. To use it alongside a QoL questionnaire designed to measure current impact to obtain an overall picture of disease impact, encompassing both the long term and the current impact.

After deciding on the final layout of the 32-item MLCDP (version 2), the research team discussed the possible scoring methods and interpretation of the profile in order to give meaning to a completed MLCD Profile. The discussion concerned the following fundamental points:

1. What would be the perceived "value" of a patient reporting only one MLCD influenced, if this one MLCD were to be compared with the 32 items of the profile or the total score of the profile, if such a scoring system were devised?

2. Does the MLCD Profile conceptually require any scoring system?

3. Would the total score be useful for meaningful interpretation of the data?

It was clear from the patients' comments and the data obtained at the factor analysis stage that if a patient reported even only one MLCD influenced by their disease, that by definition is very important, particularly at one stage of their life. If a patient reported that two MLCDs had been influenced then that is even more critical and important for that patient. This study demonstrates that some patients reported that their disease had influenced >10 MLCDs, indicating an extraordinary level of long term impact on those patients' lives. When we compare only one MLCD influenced to the 32 items listed in the MLCDP, it might at first glance appear that the patient has experienced minimal impact on their life, but in reality one MLCD influenced can change a patient's life forever. After all, by definition each decision recorded by the profile as being influenced is a major decision which is life changing. There is a virtually no possibility that all 32 MLCDs would ever be affected in any one patient. This therefore, begs the question whether the profile should be scored in terms of a percentage or as an absolute value.

It would be totally inappropriate to express the number of MLCDs affected as a percentage of the total number of MLCDs in the profile because it is quite clear from this study that no patient would ever have experienced influence on all 32 MLCDs identified. The MLCDP is based on a unique concept, covering a patient's whole life and is different from the traditional health questionnaires which normally have questions based on experience on the previous week or month's duration of disease impact (current impact). The MLCDs in the profile were uncovered from across the population and therefore it would be inappropriate, unscientific and misleading to express the number of MLCDs affected in an individual as a percentage or proportion of a total score of the MLCDP. For an individual patient, even if the patient reported that only one MLCD had been influenced by the disease then this is, by definition affecting his life. It was decided on the basis of the nature of the concept, the accumulative nature of the impact of MLCDs and the mean number of reported MLCDs recorded in this study that the best way of presenting this type of data for an individual is the total number of MLCDs affected. Therefore, the fundamental unit for expressing data of MLCDP is the "total number of MLCDs that have been affected".

Of course because this profile has 32 items, by definition, the maximum score that could be reached would be 32 items. In reality however, no patient would ever reach this score as our study (at conceptualisation stage) has shown that out of 308 patients only two reported more than 10 MLCDs affected. To allocate a "maximum value" to express this number of MLCDs in percentage terms would be meaningless. Thus, further research and hard data is required at the psychometric analysis stage in order to review whether for the final scoring model a single overall score, or a series of sub-domain scores is most appropriate. Also it remains to be determined whether individual item weighting is meaningful as compared to the unit of total number of MLCDs affected.

Summary

- The factor analysis of MLCDP (version 1a) was carried out on 210 subjects (30 patients from each of the seven participating specialties)

- Cronbach's alpha of 0.84 showed a high internal consistency reliability of the 41-items version, but 7 items with item total correlation value of <0.2 were removed before factor analysis.

- "Exploratory factor analysis" of 34 items was performed using the "principle component analysis" technique to measure the new scale construct validity.

- Statistical techniques such as Eigenvalue >1 and scree plot examination were applied for factor rotation.

- Three factors were extracted for final interpretation.
- The standard was set at a high level for items loading and items scoring <0.4 were removed.
- Complex items with low double loading were removed.
- After "varimax rotation", 11 items were removed and in total, 18 items were removed as a result of the initial factor analysis.
- Another factor analysis was carried out without the reliability test at the beginning. 11 items were removed and compared with 18 items removed as a result of initial factor analysis to see any similarity between the deleted items.
- Deleted items were reviewed through "examination of items' prevalence" (lowest and highest ranking items).
- Conflict between scientific scrutiny and patients' reality was observed during factor analysis as high prevalence items were suggested to be deleted by factor analysis.
- Final decisions were made on the basis of items deleted by both factor analyses, examination of item prevalence, conceptual and common sense grounds, detailed review of the patients' comments and the judgment of the research team.
- Thirty items were discussed in great detail and 17 were retained, in which three items were rephrased. Nine items were merged to create four new items (conceptually the same but new in construct) and four items were removed.
- The researchers' judgment was used to design the final structure and lay out of the profile.
- Scale refinement changed the final number and structure of some items, which made it inappropriate to keep items in the three extracted components as suggested by factor analysis. The original format was considered by the

research team to be more appropriate for better patient understanding and response. Items were presented in five MLCD domains.

- Finally, the 32-items MLCDP (version 2) was developed for further psychometric evaluation.
- Various potential uses of the MLCDP have been suggested in this section.
- The logical unit for expressing the data of the MLCD Profile is the "total number of MLCDs that have been affected".
- The face validity and practicality of the initial version (1a) (mean time taken by patients to complete the MLCDP=5.7 minutes; range = 2-15 minutes) was excellent but should be tested again, along with other psychometric properties, after development of the final version.
- It was decided by the research team that a new set of data is required for further factor analysis and more sophisticated techniques such as Rasch analysis and items response theory will help in further scale refinement.

CHAPTER 7

General Discussion

Very little information is available in the literature about the influence of chronic disease on Major Life Changing Decisions (MLCDs), but there are some studies which give an indication about how chronic disease may influence MLCDs. These studies were not designed for the evaluation of the long-term impact of disease or the influence of disease on MLCDs, but are still crucial for the understanding of the novel concept of MLCD in a broader health perspective. Due to the lack of information in the literature, extra emphasis is given in this discussion to the conceptualisation of the MLCD concept from the experiences of respondents, the role of qualitative techniques, the issues raised by patients regarding health and MLCDs, the role of influential factors, the developmental and validation process of the MLCD Profile and the formation of strategies to support patients when taken MLCDs.

One of the aims of this study was to understand the magnitude of the influence of chronic diseases on MLCDs and the subsequent impact on patients' lives. Conceptualisation of the notion of MLCDs was therefore one of the crucial parts of this study. A robust and comprehensive review of the literature was carried out to obtain all of the available information. All major health, social and psychological related databases were searched and thousands of articles were reviewed over a period of more than two years. It was surprising that only two articles were found that matched the search term "major life changing decisions" and more surprising that no relevant information was found about chronic diseases and their influence on MLCDs. Even if there was no obvious domain, indicator or descriptor concerning MLCDs, every questionnaire, profile and index was searched for this important aspect of patients' lives. The lack of published information made the task of conducting this study more challenging but also more interesting because of the likelihood of obtaining some original and novel information directly from patients.

The significance of HRQoL is well established and has been widely studied from the perspective of patients. The evaluation of the current impact of disease on patients' lives still remains the main focus of HRQoL research. Very few attempts have been made to evaluate the long term impact of chronic disease on patients' lives. Life changing decisions have been studied in psychology as the "crystallization of desire and crystallization of discontent" (Bauer et al. 2005) and in neuroeconomics as "intertemporal choices" (Berns et al. 2007). These papers gave no information about the influence of disease on MLCDs. Although both studies used the term "life changing decision" their focus was not related to disease or its impact on patients' lives. Similarly, there is very little information available about the long term impact of chronic diseases on patients' lives. The literature review revealed information about life course (Ben-Shlomo and Kuh 2002; Kuh et al. 2003; Lynch and Smith 2005), life transition (Bridges 1980; Heatherton and Nichols 1994; Bauer and McAdams 2004b), life goals (Elliot and Sheldon 1998; Bauer and McAdams 2004a) and life events (Lief 1948; Graham and Stevenson 1963; Rahe et al. 1964; Holmes and Rahe 1967; Kiecolt 1994), and these concepts also helped in the conceptualisation of the notion of MLCD.

Some negative life events (e.g. chronic illness, accident, injury) may influence MLCDs such as marriage, divorce, job, education, having children, moving abroad, moving house, and retirement. For example, a diagnosis of chronic illness may influence an important life decision related to employment, such as whether to carry on in full time work or take a part time job or retire early, which might be a good option from the perspective of health. Such a decision might seem quite easy and simple but in fact may be very difficult to make because of the implications and consequences of the decisions which may result in financial instability, or may lead to other problems related to the patient's mortgage, life style, family and relationships. This "knock on effect" may lead to further health deterioration.

Although studies identified in the literature review were not designed to capture the influence of chronic diseases on MLCDs, some of their findings aid our understanding of the concept of MLCDs. For example, Kimball et al (2010) reviewed the long term impact of psoriasis and proposed the concept of "Cumulative Life Course Impairment" (CLCI). This concept results from an interaction between "(a) the burden of stigmatization and physical and psychological co-morbidities and (b) coping strategies and external factors" (Kimball et al. 2010). The concept of CLCI as described (Kimball et al. 2010) does not specifically address the impact of psoriasis on MLCDs. However, if a MLCD is influenced by psoriasis, this is likely to contribute to CLCI and indeed it may be that influences on MLCD are of equal or greater importance than stigmatisation and coping strategies in contributing to CLCI. Although Kimball et al (2010) claimed this concept as their own, it has been suggested by others that cumulative life damage is an older concept, mainly studied in sociology and psychology (Ibler and Jemec 2011).

The decision to have children is a normal decision as part of a person's life course. The desire to have children may be interrupted as a result of disease (Dow 1994). This issue was studied in relation to the experience of haemophilia patients in pregnancy and their reproductive choices (Kadir et al. 2000). However, our study, reported in this thesis, investigated this matter in more detail and demonstrated that the problem is far greater and more complex than previously reported. This aspect of patients' lives has various dimensions. For example, chronic disease can influence patients' decisions as to when to have children, whether or not to have any children or whether to have more children. This range of possible important decisions of patients may possibly not have emerged without the exploration of the MLCD concept.

Patients' constant and long term struggle with their disease and other disease associated factors remains the key element contributing to the influence on MLCDs. It has been studied how poor health may impact on marriage (Wilson and Waddoups 2002; Seidler and Kimball 2009) and these studies identified that chronic disease impacted patients' relationships as a whole. As a result related MLCDs such as separation, divorce and not to marry or have a long term partner were influenced significantly by their chronic illness. Even a patient's decision not to have a sexual relationship was reported as a MLCD by patients as part of their coping strategy to avoid embarrassment. The employment implications of disease and the resulting financial hardship is a very important issue for patients (Meding et al. 2005; Cvetkovski et al. 2006; Malcomson et al. 2008). The results of our study confirm our initial rationale that this problem is much deeper and wider than previously realised. During our study, a series of influenced MLCDs were reported by patients, such as their decision to take early retirement, change career, change job, select job only suitable for their health, work shorter and flexible working hours, self employment or remain unemployed. This whole range of impacts has never been studied before and this study not only explored the areas mentioned above but also identified disease associations in the form of "influential factors".

One negative life event, such as onset of a chronic disease, limb amputation, death of a family member, imprisonment, addiction or divorce may negatively influence other subsequent life events, such as choice over education, career, employment, marriage, housing, having children or moving abroad. It is obvious that the life decisions that people make are normally intended to gain the desirable outcome of a better life. However, not every life decision turns out to be a positive or a correct decision. Clinicians are aware that after the diagnosis of a chronic or life threatening condition, acceptance is always a great challenge for patients. Patients search all available avenues for a cure and may take a considerable time to realise that they might have to live with the condition for the rest of their lives. Subsequently patients go through a process of denial, depression/anger, acceptance and adjustment (Lee 2005). A change in attitude to acceptance may give a patient motivation for the future but life changing decisions and related choices may remain very limited due to long term illness and other associated factors (severity, depression, treatment etc). Therefore, the ability to reach the desired future outcome may not be as successful as for disease free individuals.

Decisions at the right time about higher education and early career development or having children are important as part of the natural course of life and occur at different life stages. The continuous long term impact of chronic disease on patients' lives may influence these decisions. Patients might either decide differently or might delay their decision. This is where health providers and clinicians may play a very important role in warning patients at an early stage about the long term consequences of chronic disease, which in turn might not only minimise the disease impact on patients' lives, particularly on MLCDs, but also possibly reduce the burden on the healthcare system. It is possible that the specific individual circumstances and personality of an individual may influence the nature of and their approach to life changing decisions. This theory is supported by the factual observation of Baumeister et al (2001) that "bad is stronger than good". They suggested that bad (negative) life events have a greater and more intense impact on individuals than good (positive) life events. People always react strongly to negative events. The intensity of response may differ due to the type of negative life events that people face. For example, response to imminent death will be immediate, whereas the reaction to the diagnosis of a chronic disease will be long term and the response may be reflected in much later subsequent life changing decisions. People may change their predefined life goals because of ill health and set new priorities for the future, such as not to have a child, to change career or to retire.

Understanding the possible long term impact of childhood disorders was an additional crucial part of MLCD conceptualisation. Through individual interviews and focus groups, it became clear that patients suffering from chronic skin conditions faced various health-related issues during their childhood that directly influenced them to take MLCDs differently. Bullying at school, lack of understanding from teachers and other pupils, constant treatment related distress, depression, and inability to take part in physical and social activities all had an influence. Similarly, the impact of disease on children could also influence important decisions of family members (Fine et al. 2005), and possibly cause deterioration in normal family structure, parent-child relationships and impact on children's personal growth and development and on their ability to perform to their full potential in later life.

Three qualitative methods, postal survey, individual interviews and focus group discussions were used to obtain the initial data for the conceptualisation of MLCDs. All three techniques were combined to produce rich data which allowed scrutiny of the information at a very detailed level. The postal survey was conducted in as systematic way as possible. A single open ended research question was asked that allowed participants to express themselves in a subjective and holistic way to obtain a broader picture of the concept. The simple instructions in the patient information sheet, the clinicians' personal letter and reminders appeared to make a considerable impact on the response rate of participants. Despite an initial concern from the Cardiff and Vale NHS Trust and Research and Development Department (at the study ethical approval stage) about the very ambitious scope of this study in terms of large sample size (n=600) and the limited time frame, six medical specialities were invited to take part in the postal survey and the study was successfully completed. Limited resources, time and facilities did not allow recruitment of patients from all the medical specialities for individual interviews and focus group discussions. Much thought was given at the study protocol stage to obtain single ethical approval for all the stages of the study in order to avoid delays and allow smooth running of the project. This strategy was proved to be successful.

The poor initial response rate to the postal survey was one big concern during this project, which caused considerable delay. However; assurance of strict confidentiality, the clinicians' personal letter and reminders helped to obtain a desirable (51.6%) response rate for appropriate data analysis (Oppenheim 1992). Only dermatology patients were recruited for individual interviews and focus group discussions. The use of interviews and focus groups not only strengthened the study (Morgan 1997) but also confirmed and supported the information obtained from the postal survey. The only difference or new information obtained between the interviews/focus groups and the postal survey was related to "life style decisions" reported as MLCDs by the dermatology patients in the interviews.

The semi-structured individual interviews yielded more detailed information than the postal survey, as was expected. However, it was an emotional experience for the patients and the researcher (Z U Bhatti) alike to discuss their painful past experiences, particularly the undesirable outcome of their MLCDs. Similarly, during the focus group discussions it was noted that patients were nervous to discus this intimate aspect of their life in front of other participants. The MLCD concept appeared to be more sensitive than was initially anticipated; this may be one of the reasons why this area has not been studied before. Following guidelines (Krueger 1997; Morgan 1997) resulted in the smooth running of interviews and discussions and helped to create confidence between the patients and the moderator (Z U Bhatti). This great opportunity of having a direct conversation with patients was also of benefit to this study as it allowed the obtaining of patients' personal views and their suggestions which contributed to the formulation of some strategies for other patients faced with similar situations, particularly for younger patients. This aspect will be discussed later in this chapter.

It was evident from the literature that the majority of studies concerning the impact of disease on quality of life have been based on evaluating the physical, social and psychological aspects of patients' lives. This current study has produced completely new information which has never been explored before and which has introduced a completely new dimension in health outcome research. The obtained data highlight the intricate nature of health and the concept of MLCDs but have also revealed the type and the magnitude of MLCDs influenced by chronic illness and the subsequent impact on patients' lives and on their family members.

The data presented in this study demonstrate that chronic diseases have a profound influence on MLCDs. The majority of patients reported that their chronic disease had influenced their decisions concerning early retirement, job, career choice or having children. These four MLCDs were the most frequently reported. Minor life style decisions, such as choice of clothing, stopped swimming, not to socialise and wearing make up were only reported as MLCDs by dermatology patients in the interviews and focus group discussions. This information was completely new and not reported in the postal survey. These MLCDs were discussed in detail with the patients during interviews and focus group discussions and clarification was sought for time and again. The reason for this approach was that these decisions are normally considered to be "routine" decisions, not major life changing ones. This information further enhanced the knowledge beyond the initial understanding, so it is now undersood that any decision perceived as routine by disease free individuals could be a MLCD for patients who had been suffering from a chronic condition for a long period of time. The persistent nature of their chronic condition and the resulting influential factors, such as embarrassment or the physical impact made patients think and act differently. Ultimately this change in behaviour becomes a permanent part of their lives and personality. When facing and coping with such constant difficulties, pain and anxiety on a daily basis, "small" decisions such as what colour and types of clothes to wear, appeared to change their life in a major way, and also had long term consequences on patients' lives such as change in attitude and personality.

In certain situations, it was evident that patients did use "trade off" scenarios. For example, whether to wear out of fashion clothes and hide their skin and have peace of mind or whether to wear fashionable clothes/colour and thereby expose their skin and health problem, risking facing an ignorant public attitude. To hide their skin with make up may have also made their skin condition worse but doing so the patients successfully avoided embarrassment. Due to the effects of make up on their skin condition some patients were unable to hide their skin and they experienced painful questioning and embarrassment. These situations are very difficult for patients and so the make up choice may be life changing for them. Several patients reported in their interviews that since childhood they had never worn short sleeves, skirts or dark colours or a swimsuit. Patients even kept themselves isolated for years from taking part in normal routine social activities such as clubbing, visiting the pub or beach activities. These activities would otherwise have been a normal part of their lives, particularly for adult patients and it was a very hard and difficult decision for them to stay at home and avoid public places. Similarly, it was very surprising to see that patients regarded decisions to change their life style habits as MLCDs. For example, a large number of patients changed their eating, drinking alcohol and smoking habits. For patients, it was difficult changing these life long habits which therefore made these decisions major and life changing for them. The decisions related to holidays and travelling and life style change were also regarded as MLCDs by patients, indicating the highly "subjective" and "perceived" nature of this concept. For example, a MLCD related to education might have been taken once or twice in a life time but life style decisions such as choice of clothing, swimming, holidays has a constant impact and remain with patients on a daily basis throughout their lives. The emotional concern attached to these decisions and the specific family and public nature of involvement can make these decisions MLCDs for patients. For example, people with psoriasis hardly ever wear short sleeves; this is clearly a QoL issue but it may become a MLCD because clothing is a part of one's character and personality.

Holidays and travelling abroad was another area of life decisions regarded as MLCD by patients. People consider it a normal activity, a yearly family occasion, to relax and boost their energy for the coming year. In the modern world, particularly in the western world, it has become a very important part of their lives: whereas years ago nobody would have dreamt of such types of activities. Therefore, this activity would not have been a problem for patients in the past and it is to do with today's society, culture and the attached expectations which people have. Now regular holidays have become so common that people take them for granted and any deviation due to change in circumstances makes it a major issue and life changing for them. Such an attitude in society is also related to the culture of a society. This emerging point of "expectation" is also incorporated with "patients' circumstances" in our new definition of health influenced MLCD in order to make it more robust. It was evident throughout the study that some MLCDs are highly subjective in nature, as described earlier, and solely depend upon the nature of an individuals' circumstances. In simple words, some decisions might be minor to disease-free people but may be major and life changing for patients suffering from long term health problems. This change in circumstances, from a "disease free life" to a "disease affected life" and associated long-term complications also affected patients' "life functionality", "life development", "functional behaviour" and "expectations". This most detailed information related to the MLCD concept emerged during this study. This information was specifically discussed and highlighted during the formulation of our proposed "HRMLCD definition" and was included as a major conceptual part of the MLCD definition.

The formation of the definition of MLCD was a unique experience and making it a workable but robust definition was a difficult task. This is the first attempt of its kind and this study provides this fundamental basis of the MLCD concept, which in future will allow researchers to use it for further research. This definition was developed at the end of the conceptualisation of the notion of MLCD and also reviewed as planned in the light of data obtained at factor analysis. No new information had emerged from this data, and after long consideration, no change was made to the proposed MLCD definition.

This study allows researchers to understand the importance of taking the right decision in life at the right time. One wrong decision at an early age of a patients' life or at an early stage of a chronic disease may change the subsequent course of life and may result in an undesirable outcome. For example, the decision to leave college or university education early, left patients with very limited career opportunities to develop professionally and earn a good income. Most of the patients had to take part in un-healthy menial employment to support their families. This not only resulted in further deterioration of their health, frequent hospital admissions, reduced working hours and less income, but also resulted in early retirement, which in turn influenced various MLCDs, such as break up of their relationships and their decision not to have more children due to financial difficulties. This outcome is in contrast to those patients' experiences who planned their education and career path at an early stage with the advice and help of their parents and thereby gained a better health outcome and a more appropriate career.

Usually, patients do not routinely seeks any advice from any health professional before taking any MLCD, apart from the genetic counselling situation where in some cases a decision is to be taken about having children. Some patients did report that they had consulted their family members before taking major decisions. Some patients thought that the constant nature of their illness had left no choice but to take certain MLCDs. Early retirement was one of the most frequently influenced MLCDs reported by the patients. This decision appeared to be one of the most difficult decision patients faced, due to its daunting repercussions at a later stage of their lives, including financial issues and change in status. This impact is viewed as a "MLCD-knock on effect". The issue of early retirement was a major concern for patients but again they weighed their decision and it appeared that some patients traded off less money against better health in order to take control over their lives. Less income not only changed their life style but also impacted heavily on their social status and standing. This dramatic change also caused depression among many patients which ultimately led to further deterioration of their health. Therefore, it is not inevitable that the decision taken by a patient in the interests of better health always turns out to be a good decision. This situation raised the importance of developing strategies and tailoring help for patients at the right time. The patients' first hand experiences highlighted in this study and the way they took their MLCDs, will help to inform the formulation of appropriate MLCD strategies for other patients.

By considering this aspect in more detail, then the difference between taking early retirement and not working will become obvious. Several patients reported that they wanted to work but there were not enough jobs suitable for their health. It was obvious from their comments that these patients did not want to retire early and if there had been enough jobs suitable for their health, these patients would have worked until their normal retirement age. This specific discussion, from the patients' perspective, indicates that policies for better employment opportunities for patients suffering from chronic illnesses should be formulated with identification of this important area. This study and information arising from the use of the MLCD Profile could be used to highlight this issue at the highest government level. This could be of financial benefit to health providers, government and patients. Although the content analysis of this study provides enough information to strongly support the case for a review of health and employment policies, however, a detailed and more specific exploration in this area is needed for in-depth analysis and understanding. The new MLCD Profile could be used to assist in obtaining this information.

It was noted that some patients raised their concern over state benefits. They thought that there was not enough support from government and health providers and they were worried that they might not get proper benefits again if they had to take time off from work due to their constant battle with their long term illness. That was a risk that some patients did not want to take and so they decided to remain unemployed. It was difficult to understand how widespread this problem was and in view of personal financial reasons some patients may have not discussed this issue in detail. Further exploration of this area is needed to understand patients' behaviour from a combined health and financial perspective and in terms of the resulting impact on MLCDs. This is another good example of how complex MLCD issues can be.

This study also indentified the issues relating to patients' change in personality and changing attitude and approach to life. It was evident from patients' comments that adversity can still allow personality to grow and develop and indeed be a spur to such a development. This aspect of some patients' lives was very interesting. Patients were very enterprising and demonstrated resilience and improvisation, for example, becoming self employed or working shorter and flexible hours. The adversity of their disease appeared to be a blessing in disguise for some patients. It brought new opportunities for them and patients re-invented themselves to overcome their health problem in the best possible way. It was very interesting that one patient reported that "my disease saved my life". This patient forcefully decided to change some life style habits; otherwise he may not have contemplated changing. Similarly, some patients decided to become self employed or decided to work flexible working hours, and this decision not only helped them to take control over their health, but also helped them to grow their personality and develop themselves.

The MLCD example of "career choice" in this study also provides evidence that wrong selection of a career at an early stage caused more problems at a later stage for some patients. For them, it was more difficult to live with the consequences of an inappropriate career choice than to face the difficulties earlier while still having their education. It was very hard and difficult for patients when they eventually found that their chosen career was not suitable for their health and they had not only wasted an important time of their lives but also their efforts and the money they had spent. They had no choice but to change their career to one suitable for their health. In some cases it was difficult to find a suitable job and patients even had to consider low paid, difficult and less attractive jobs with no growth opportunities in the future.

Divorce, marriage and separation were the obvious affected MLCDs concerning relationships. The decision "not to become involved in relationships" was also reported as a MLCD by some patients. This is another example of the highly subjective nature of the MLCD concept. The patients found relationships very difficult and embarrassing because of their illness and they did not want to be judged by their illness. The fear of deep involvement in relationships and possible rejection, had their partners found out about their illness, was one of the main reasons behind this particular decision. In fact some patients had experienced this problem several times while they were in relationships, and then they felt forced to take this important life changing decision. Patients felt that they became more isolated and appeared to be more emotional and psychologically unstable. Although one patient regarded this behaviour as a "survival reflex", it was decided to describe this patient behaviour as a "MLCD psycho-reactionary reflex". One could easily understand how difficult this could be for patients emotionally and psychologically; and this survival reflex or "patient survival instinct" to avoid this situation sums up the reason why this decision is categorised as a MLCD.

The majority of MLCDs affected as a consequence of their long term illness were reported in a negative sense by patients. However, some decisions were reported in a positive sense such as the decision related to "moving abroad", which some patients thought had helped them to have a better health outcome because of more suitable weather conditions. One decision which was reported entirely in a positive sense was the decision to be "more physically active". This created a sense of purpose in their lives and became a major life changing decision for them. For example to do more exercise and loose weight were major challenges for some patients. To change their eating habits and do exercise appeared to be life saving for many patients.

In terms of the relationship of gender to the type of MLCD affected, it was evident that the MLCDs related to early retirement, career choice and moving abroad was more prevalent in male patients. The MLCDs related to having children was more prevalent in female patients. The MLCDs related to wearing make up was only reported by female dermatology patients, indicating the gender and speciality specific nature of some MLCDs. It is important that more attention should be paid to specific MLCDs while dealing with particular gender group or speciality groups.

It was not possible to quantify the link between participants' age and specific MLCDs reported, due to the retrospective nature of the research question asked. Patients were not asked at what age a specific MLCD was influenced by their chronic condition. The patients instead reported their entire past experiences covering their whole life while having the disease up to the time of the interview or survey and no attempt was made to link reported MLCDs encompassing the patients' whole life with their age. Although examples can be obtained from the literature of creating arbitrary age groups for the purpose of descriptive analysis, the idea was rejected. This area could be explored at the next stage if this research is continued in order to ascertain whether at a certain age chronic disease may have influenced certain types of MLCDs. Although, the patients were not asked at what age they took a particular MLCD this study highlights the importance of this aspect. For example, the CF population consisted mostly of relatively young patients (mean age=27 years, range=18 to 53 years) and the MLCDs reported by this group of patients were related to having children, job, career choice and education. In contrast, COPD patients were an older age group of participants (mean age= 66 years, range=53-84) who reported MLCDs were more related to early retirement, holidays and travelling abroad and job. It was clear that the types of MLCDs mostly taken by CF and COPD patients also reflect their respective age groups, which seems logical in terms of MLCDs, life course and from a life stage perspective. At this stage, the specific nature of the MLCDs reported by CF and COPD patients cannot be linked with their respective age groups as we do not know at what age they took these decisions. Perhaps some COPD patients might have taken the MLCD of early retirement at a relatively young age because of the severity of their chronic disease or physical disability. This study also highlights therefore the importance of this interesting aspect for future research work.

The identification of influential factors in this study provides a crucial in-depth insight into patients' lives. In total, twenty five types of influential factors have been identified. These influential factors were basically the main disease associated reasons why patients took MLCDs differently. It was noted that these influential factors were very important to the patients. The patients' accounts of emotional turmoil (anger, depression and anxiety) raised the issue that health providers should consider the psychological stability or mental ability of patients to take MLCDs. It was no surprise to see that "ill health and severity of disease", "frequent hospital visits and treatment", "physical disability", "stress, fear and anxiety" were the most prevalent influential factors reported by patients. However, the influential factors such as weather, insurance cost, discrimination and job insecurity were indicative of the importance of patients' individual circumstances, and that is why it was very crucial to incorporate this aspect within the working MLCD definition.

Strategies for appropriate decision taking

This research clearly confirms that chronic diseases can significantly influence MLCDs. It also signifies the importance of the formation of life changing decision making strategies in order to guide patients to reach the most appropriate life changing decisions; with the best long term outcome.

We had an example in this study where the patients chose the wrong career because of confusion, lack of knowledge and because they did not consider seeking advice. After completion of their education when they started working, they realised that they were in the wrong career because of their health. Some patients then changed their career and some did not bother to try to do so, as they thought they were too late for further education or to follow another career path, perhaps due to their long term struggle with their illness. During the interviews some patients seemed confused on various occasions in their lives and there was a possibility that this confusion might have played a part in their taking the wrong MLCD which ultimately affected their health, family, and social life over a very long period of time. This study demonstrates that the impact of their chronic disease on their MLCDs could be minimised by seeking appropriate help and advice at an early stage.

The formation of appropriate MLCD strategies was the final stage of this study. Data collected from patients were meticulously scrutinized in detail and used for the development of possible strategies. These strategies may help patients to learn how to make appropriate long-term decisions which may in turn improve their Quality of Life.

Throughout this study it was noted that as a "preventative measure", appropriate strategies would enable patients to make the correct decisions but that this approach could only be based on patients' own experiences. During the individual interviews we had the opportunity to ask patients "how can we help patients to take appropriate MLCDs in a similar situation to you". The responses from patients are reported in the content analysis section of this thesis. All responses were examined in detail and used for the development of appropriate strategies to help patients to take the most appropriate MLCDs in the future.

Patients' personal efforts, professional help and sharing experiences could all be helpful in making important decisions in life (Dow 1994). Another important aspect that has resulted from this research is that now we have some understanding about what patients think when they have to make MLCDs. This information should enable us to formulate better strategies to support them. During the decision-making process a patient may ask themselves a series of simple questions such as, is it the right time? am I taking the right decision? what will happen in the future? what will happen to my family and children? can I do it? and what are my options? The influential factors identified provided additional insight for developing MLCD strategies. In addition various words and phrases from the patients' comments, identified during content analysis also hold the key for developing strategies. For example, "I was classified as disabled", "I had no alternatives", "it is like a curse on me", "I had no option", "I didn't accept this", "you react to the way other people perceive you", "I am still not dealing with it very well", "I just could not visualise", "you have to do what you can do", "I can work around it", "had to reconsider my commitment", "encouraged by parents", "I did not know what to do, I couldn't decide", "once you make a decision that's it, you have to live with that", "survival reflex", "I could have done better".

All the above selected words and phrases are from patients' comments, indicating patients' attitudes, personality, uncertainty, fear, psychological and mental pressures which have developed over the years in patients, and therefore, might benefit from structured systematic assistance, to help deal with MLCDs. Patients realised in later life that calculated and informed decisions can be made. It is true that patients have to take their decisions but strategies can provide various options to be looked at before any final decision is made. There is a possibility that strategies may not be successful in all cases, due to the subjective nature of MLCDs, individual circumstances and high level of expectations, but at least patients can look at all available options in order to find the best possible solution.

There is no doubt that to predict the exact (positive) outcome of every decision is very difficult. This study has demonstrated that decision-making is important for patients and their health depend a great deal upon the best possible outcome of their decisions. The diagnosis of chronic disease is part of the undesirable life transition from a disease free life stage to a disease life phase. This phase remains throughout their lives which makes it more difficult for patients to forget about their previous good life and to move forward. It is possible that mental rehabilitation may help patients to accept the reality of their current life status in order to plan their role for future life stages. Whether someone is suffering from chronic disease or not, a right frame of mind is always required to make appropriate decisions. This study has also demonstrated that this may be achieved successfully if the impact of disease-associated influential factors is minimised. The right frame of mind takes our thoughts through the decision-making process, where people create rationales and see the pros and cons of decisions and eventually make a judgement and expect best possible outcome.

The concept of living with a chronic condition for a long period of time, possibly for the rest of their lives, has a huge psychological impact on patients and their families and may harm their ability to think in a right frame of mind. This study has also indicated that the realization and acceptance of circumstances, personal limitations, ability to adjust and adopt an appropriate approach at the right time, along with frequent contact with a physician and other healthcare providers to ensure appropriate treatment and advice, may help patients to take control over their lives and guide them towards making the right decisions, resulting in better long-term outcomes.

The process of taking MLCDs is a battle between choices. This battle starts with the individuals' thinking process; strategies which are currently available could assist making the decision process easier and better. Flipping a coin to make a decision, although such an attitude might not harm disease-free individuals, is not an option for patients suffering from chronic conditions. In everyday life, we face the dilemma of difficult choices. Taking chances in every difficult choice situation is not a common practice. People normally think carefully and judge their decisions carefully about what is best for them. Intuition also plays a role in this situation when an individuals' understanding of the issues is very limited. However, if we were to leave all our decisions to our unconscious minds, then what is our conscious mind for? We should rationalise our choices using the best of our mental ability. A calculated approach may help patients make more appropriate decisions. MLCDs are subjective in nature and depend upon individuals' circumstances and their expectations. Therefore, it is very difficult to formulate one unified strategy or guideline which can fit all patients and decisions. However, through the findings of this study it is possible that patients can adopt a strategy or strategies according to their circumstances and need. Before making any MLCDs, patients may consider the following strategies which have arisen from this study (Figure 7.1): these strategies are based upon the views of patients and their suggestions for strategies, obtained at the individual interview stage. These are summarised as follows:

1. Establish regular contact with a physician to maximise treatment options and long term management planning. This will help patients to plan better for the future and to make MLCDs. Patients should discuss current and possible future MLCDs with their consultant or healthcare providers in the light of their management plan and the possible future outcomes of their health, thereby enabling them to take better decisions.

2. Contact the relevant local authorities such as the health, education, work and pension departments to gain knowledge about their rights, available facilities, funds and support before taking a major decision. If possible patients should seek an individual appointment to discuss the nature of their health condition, their particular disease associated needs, and their ability and inability to do things in the light of possible future outcomes.

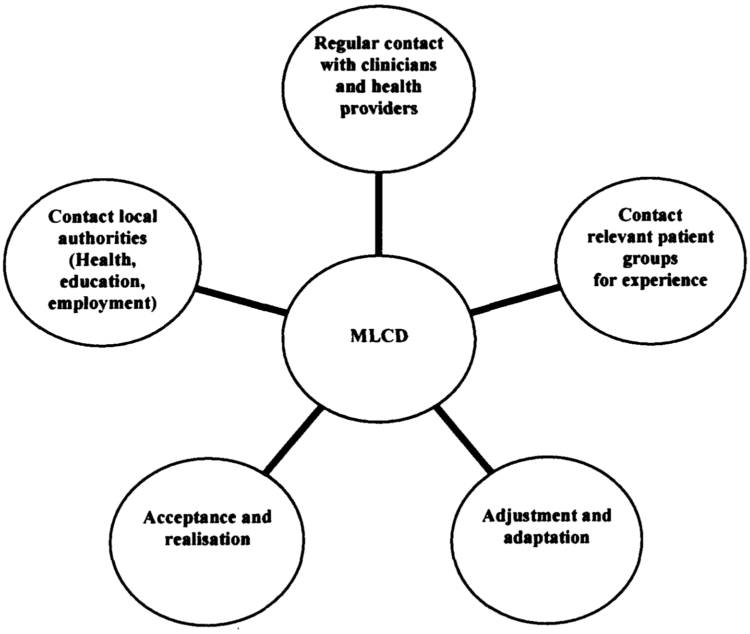
3. Keep in touch with relevant patient associations and support groups in order to gain knowledge from the real life experiences of others. This may be helpful not only to assist better decision taking, but also to keep updated on new research and treatment.

Creation of possible real life scenarios, choices and options and comparison with positive and negative MLCDs outcomes should be considered by patient. Advice from other patients and their family members and organisations to assist patients is essential and can be obtained through patients' welfare associations and from support groups suffering from a similar condition. Being aware of the experiences of others and how others have faced similar situations will help patients to take informed decisions.

4. Early realisation and acceptance of the chronic nature of an illness is crucial in order for a patient to move forward and look for better options for their health and for their current and future QoL. Understanding of personal circumstances (the situation that a patient is in when a decision has to be made), realisation of their likely limitations because of their illness (physical and financial) and understanding the difference between what they want to do and what they can do will help patients to make better MLCDs.

5. Adjustment approach: patients should consider their options to take control over their limitations caused by their chronic illness and try to adjust as soon as possible to minimise the disease long term impact, for example, adjustment to their physical and financial status.

Figure 7.1: MLCD strategies for patients



Study implications

- The detailed robust literature review presented in this thesis has revealed that there is very little information available in terms of the long term impact of disease on patients, particularly the influence of disease on MLCDs. This study should help future researchers to understand the basic elements of the long term impact of chronic disease and its influence on MLCDs. This study has developed the initial understanding of this concept.

- To our knowledge this study is the first one of its kind. It will help researchers in the future to incorporate the concept of health and MLCD into the concept of life course and life events in the fields of psychology, sociology and epidemiological studies.

- As there is now a new understanding of Health-related MLCDs, the current definitions of the scope of QoL are incomplete. The incorporation of the MLCD concept into such definitions is now needed to make them reflect this wider understanding.

- This study demonstrates that MLCD is a missing dimension in HRQoL research and should be considered in future development of HRQoL questionnaires.

- This study identifies the need for evaluation of long term impact of chronic disease on patients' lives, particularly the influence on MLCDs. This study will allow future researchers to use the domain of "MLCD" as a parameter in the assessment of disease long term impact and the overall assessment of HRQoL.

- The potential uses of the MLCD Profile, as defined earlier in the thesis, will be helpful for future researchers.

- The data from this study can be used to inform health, education and employment policies and will enable the creation of more patient friendly and patient centred policies. The new tool, the MLCDP, can play a potential role in achieving this goal, along with current QoL questionnaires, by quantifying this area.

- The information obtained from this study and the use of the MLCDP in the future will help educate health providers, particularly in the area of study related to possible long term consequences of chronic conditions. Healthcare providers will be better prepared to warn and help patients at an early stage of their disease, or immediately after the diagnosis, and offer a long term management plan.

- The MLCDP could be used for epidemiological surveys to find out which chronic conditions have the most influence on which type of MLCDs.

- Along with the development of the MLCD Profile, one of the major outcomes of this study is to devise strategies for chronic patients' life cycle management. These strategies are based on the preliminary findings of this study and provide an initial structure. A more robust plan could be refined with further research.

Study limitations

- Due to the long process of recruiting a large number of patients (in total 900 patients were contacted) for the two separate stages of the study (stage 1 and stage 4), time restrictions did not allow to carry out further validation or detailed psychometric testing of the MLCDP.

- For the individual interviews and the focus group discussions, patients were only recruited from the Department of Dermatology. This was because one of the supervisors was the head of the Department of Dermatology, hence making access to Dermatology patients much easier. Time restrictions and practical resources made it difficult to widen the interview base. There were some aspects of MLCDs that were only revealed in the Dermatology interviews, it is therefore possible that there might have been other MLCDs specific to patients from other specialities that might have been revealed if direct interviews had been carried out in other speciality groups.

- Patient recruitment for focus group discussions was very difficult. This was perhaps because of the sensitivity of the MLCD topic. Patients did not want to discuses these life issues in front of other patients. More new information might have been obtained if more focus group sessions had been held. However, the information from the focus group sessions that were completed simply repeated information obtained through interviews.

- Initially, it was envisaged to include many different medical specialties in this project but due to time restrictions it was decided to include only a selection of major specialties. Our sample size from seven medical specialties was more than sufficient, but more specialities would have resulted in more diversity.

Future work

- Development of a "Patient experience and MLCDs database": The results of this study and the MLCD Profile could be used for the formation of a "Patient experience and MLCD database". This anonymised database could be developed to record all the MLCDs that patients have taken in their lives along with their reflection whether these MLCDs were right or wrong and what in retrospect they would have done differently. Patients could be referred to this database at any time in their life when they have to take a MLCD. The use of a database, with real life examples and scenarios narrated from patients' actual experience, is an idea which could be realised without major resources. For example, this study has already gathered enough examples and scenarios from patients' responses to form the basis of a database for the guidance of patients and to enhance public awareness about the lives and MLCDs of patients with chronic illness. The content analysis part of this thesis could be consulted for various examples.

  The ethical, practical, administrative and financial issues are substantial for developing this kind of database. Therefore, a pilot study is needed to establish evidence for its viability and cost effectiveness. This proposed project therefore could be tested at a small level such as in one or two medical specialities (e.g. Dermatology or Rheumatology) of a local NHS Trust and could be extended further to other specialities for more observations, if it proved to be practical, cost effective and useful for patients.

- Introduction of psycho-social rehabilitation care: As a result of this study, it is clear that leaving patients alone without organised help may lead to depression, isolation and may cause further deterioration in their health, with increased hospital visits, less hours working, less income and ultimately an increased financial burden on the healthcare system. It is noted from the patients' comments that psycho-social rehabilitation care would be helpful for some patients and this approach could be explored in future work. In this proposal for possible additional care for patients suffering form chronic disease over a very long time, consultants would work with specialist nurses, psychologists and psychiatrists to ensure optimised psycho-social rehabilitation care. Trained patient volunteers suffering from chronic disease would be available to provide first hand advice to patients. Professionals with expertise in career advice, education and social services would also contribute to the wider team.

After the diagnosis of chronic illness, this team could make a patient's life journey more productive and healthy by means of offering a better long term management plan, regular counselling, genetic counselling and connecting with people suffering from same chronic condition. Patients could meet with education and employment professionals and discuss their specific issues. This would be particularly helpful for younger patients to guide them through their life and make their disease less burdensome and themselves more productive.

Initially, such a multidisciplinary care approach would need to be tested in a pilot study based on one medical speciality in a local NHS Trust to asses its applicability, practicality and usefulness before any further recommendations could be made. Currently, no hospital offers such a programme or similar facilities for patients suffering from chronic conditions. One programme, the "Expert Patients Programme" (EPP) has been developed and licensed by Stanford University, California, USA and is run by volunteers and some employees of local health boards in the UK (http://www.expertpatients.co.uk). EPP is a community based programme but none of our participants (>300) mentioned any knowledge of this programme. However, it is proposed that due to the magnitude of the disease influence on MLCDs, the nature of the disease associated influential factors, patients' individual circumstances and the specific needs attached to various gender and age groups, the patients' multidisciplinary psycho-social rehabilitation care concept should be explored in future studies.

- New data is required for further factor analysis and internal consistency reliability of the remaining items. In addition, full further psychometric evaluation of the MLCDP should be carried out using both classical test theory approach and novel techniques, such as items response theory.

- Further studies are required to create a tool similar to the MLCD Profile which would be sensitive to clinical change. The current profile is not designed to detect change over time (amenable to change) or to be used in follow up studies, such as before and after drug intervention.

- A degree of understanding about the relationship between patient age and the specific nature of MLCDs affected is important for the development of appropriate strategies, to help and advise patients. This area should be more precisely explored in future research, where patients could be asked about their age at the time when a disease influenced a specific MLCD. This might be helpful in targeting a particular age group for giving advice concerning specific MLCD.

- This study has demonstrated that the prevalence of specific MLCDs affected by the disease may be different among patients from different medical specialities. This area could be explored separately with a larger sample size to confirm the preliminary findings of this study.

- It has been learnt from the individual interviews and focus group discussions that some of the MLCDs might have been taken with the involvement of parents or family members, teachers and employers or even may have been imposed upon patients. In future work, patients could be asked specifically about each MLCD taken, whether or not it was their own MLCD or whether the MLCD, particularly at an early age, is in effect taken by parents, teachers or clinicians for them.

- The detailed accounts of patients in this study provide enough material to produce a book. Such a publication could act as a "reality novel" which could provide a learning curve for both patients and the general public. Such a book could enable unaffected people to have a better understanding about people who are suffering from a long term chronic disease.

- The development of strategies to influence government regulations and policies could be achieved in related future works. For example, it would be helpful to generate information to be incorporated by health, education and work and pension departments to give to patients and health providers. This would allow ready access to available help for patients suffering from long term health problems and for those who have developed physical and psychological disability as a result of their chronic illness.

- The next level of exploring this concept is the understanding of the influence of chronic disease on the MLCDs of family members. This secondary influence of disease could be incorporated into QoL questionnaires aimed at family members.

- The MLCD Profile could be used in long term follow up studies to identify the cumulative types of MLCDs affected over time.

- The issues surrounding MLCDs are very complex and highly subjective. Even for normal people this is a very important subject due to its long term consequences. There is a need to study a control group to see the difference in the approach between people with or without chronic disease and to confirm that MLCDs are, by nature, part of the normal course of life and of life stages in everyone.

Patients' views about the study

At the end of each individual interview, when patients were asked about what they thought about the idea of this study, their replies were not surprising. The majority of patients were aware of the influence of their disease on MLCDs and this was the first time for them that anyone has asked question about this subject. Patients were very surprised to know about the lack of information in this area.

One patient stated:

"I think it is an incredible idea, it is shame really it has not happened years ago. I took part in it because if my experiences could be of any help to anyone I'm thankful for it. They may not suffer like I have in the past. I fully support it"

<Dermatology-Individual Interviews\II-32>

Another patient stated:

"I think it's probably a very good study, I am surprised, that there has not been more research. I can imagine that the way people look is quite a major factor in their decision making"

<Dermatology-Individual Interviews\II-04>

The following comments from patients indicate that some patients did not realise that how much their disease has already impacted on their MLCDs.

"I think it's a really good idea because personally I didn't realise how much my eczema has impacted on my major life changing decisions and it really has and if people can be more aware and can get more support when making life changing decisions then it would be brilliant"

<Dermatology-Individual Interviews\II-27>

"Think it's very good. I think this study needs to be done to see how it exactly affects the lives of people. As I said, I never realised how it's affected until we spoke now"

<Dermatology-Individual Interviews\II-21>

These findings were similar to the study conducted by Eghlileb et al (2007), in which they measured the attitudes of subjects to QoL enquiry. Patients' comments are reported in detail in the content analysis section of this thesis.

Conclusion

This study provides a new insight into the magnitude of the long term impact of chronic disease on patients' lives, most importantly the influence on MLCDs. Examining long term impact, life transition, life course and life events helps the understanding of the exceptional nature of life changing decisions in the context of health. Although the MLCDP requires further validation, it provides a means to measure this impact on patients' lives. It is easy to complete as a generic tool and covers most MLCDs. This novel concept requires further research to ensure all relevant aspects of patients' lives are covered. The magnitude and the nature of this impact may be different in patients from different medical specialities due to the nature of the illness, its duration, the patients' age and gender and individual circumstances. This study confirms that a holistic approach in treating patients is important. From the perspective of health and illness, any factor outside traditional dimensions (physical, social, psychological), which could improve a patients' life, should also be considered for evaluation in the hope that better understanding may lead to improvement in the QoL of patients with long term disease. This also supports the concept of identifying "what things are important in people's lives?" (Bowling 1995).

The new HRQoL domain of "MLCD" appears to be a "missing link" in the QoL literature. This study highlights the importance of assessing long term impact and the MLCD Profile could be used as a parameter for the assessment of long term impact of chronic diseases on patients' lives.

The most important outcomes of any study are those that are patient centred. The development of strategies for patients also highlights the need of awareness of this concept among health providers and among health, education and employment policy makers in order to consider patients' long term illness, its impact and the MLCDs that patients take in life. Clinician understanding is vital in this area, so they can warn patients about the consequences of their chronic condition at an early stage and can offer better long term management plans. At the same time, patients can develop contact with patient associations, psychiatrists and psychologists. This approach will not only help patients to take better informed MLCDs but also help them develop their personality and maintain a positive attitude. This in turn gives patients more control over their lives and should result in fewer hospital visits and a reduced burden on the healthcare system. The knowledge of health providers and clinicians about MLCDs, particularly about the "knock on effects of MLCDs" is crucial. This approach would give patients the opportunity to make "well advised" MLCDs and increase their mental, physical and social strength for their personal development and personality growth.

The results presented in this thesis will potentially add considerable knowledge to this relatively unknown area of health outcome research. Patients' comments and quotes presented in this thesis provide a unique body of information and insight to patients' lives which was previously unknown. In particular, knowledge has been gained about patients' perceptions, attitudes, personalities, behaviour and the way they think in different life situations where they have to make important life changing decisions. Understanding patients' health and its relationships with their life changing decisions opens the door for researchers to re-think the way long term impact of disease has been evaluated.

Finally, it would be fitting to bring this thesis to close with words from Dubos (1976, p. 9) which encapsulated the essence of this work: "Medicine cannot by itself determine the quality of life. It can only help people to achieve the state of health that enables them to cultivate the art of life but in their own way... It implies also the ability for each person to do what he wants to do and become what he wants to become, according to human values that transcend medical judgment". This indicates that a patient's own willingness to have control over life is absolutely essential. Therefore, along with medical interventions, the personality factor can impact on health (Kressin et al. 2000) and the way in which people approach life circumstances (Wrosch and Scheier 2003).

References

Abbott, J. and Hart, A. 2005. Measuring and reporting quality of life outcomes in clinical trials in cystic fibrosis: a critical review. *Health and Quality of Life Outcomes* 3, p. 19.

Abbott, J. et al. 1997. Quality of life in cystic fibrosis. *Journal of the Royal Society of Medicine* 90(Suppl 30), pp. 37-42.

Albrecht, S. L. et al. 1983. *Divorce and Remarriage: Problems, Adaptations, and Adjustment*. Westport CT: Greenwood Press.

Alonso, J. et al. 2004. Health-related Quality of Life associated with chronic conditions in eight countries: results from the International Quality of Life Assessment (IQOLA) Project. *Quality of Life Research* 13, pp. 283-298.

Ampon, R. D. et al. 2005. Impact of asthma on self-reported health status and Quality of Life: a population based study of Australians aged 18-64. *Thorax* 60, pp. 735-739.

Anderson, J. O. and Martin, P. G. 2003. Narratives and healing: Exploring one family's stories of cancer survivorship. *Health Communication* 15(2), pp. 133-143.

Arnold, L. M. et al. 2008. Patient perspective on the impact of fibromyalgia. *Patient Education and Counselling* 73, pp. 114-120.

Austin, M. 2004. Fighting and living with vitiligo. *Journal of the American Academy of Dermatology* 51, pp. S7-S8.

Badley, E. M. and Tenant, A. 1993. Disablement associated with rheumatic disorders in a British population: problems with activities of daily living and level of support. *British Journal of Rheumatology* 32, pp. 601-608.

Ballas, D. and Dorling, D. 2007. Measuring the impact of major life events upon happiness. *International Journal of Epidemiology* 36, pp. 1244-1252.

Barnack, J. L. and Chrisler, J. C. 2007. The experience of chronic illness in women: a comparison between women with endometriosis and women with chronic migraine headaches. *Women and Health* 46(1), pp. 115-133.

Barnett, D. B. 1991. Assessment of Quality of Life. *The American Journal of Cardiology* 67, pp. 41C-44C.

Barnett, M. 2005. Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences *Journal of Clinical Nursing* 14, pp. 805-812.

Bartlett, M. S. 1954. A note on multiplying factors for various chi-squared approximations. *Journal of the Royal Statistical Society* 16, pp. 296-298.

Bauer, J. J. and Bonanno, G. A. 2001a. Doing and well (for the most part): Adaptive patterns of narrative self-evaluation during bereavement. *Journal of Personality* 69(3), pp. 452-482.

Bauer, J. J. and Bonanno, G. A. 2001b. I can, I do, I am: The narrative differentiation of self-efficacy and other self-evaluation while adapting to bereavement. *Journal of Research in Personality* 35, pp. 424-448.

Bauer, J. J. and McAdams, D. P. 2004a. Growth goals, maturity and well being. *Developmental Psychology* 40(1), pp. 114-127.

Bauer, J. J. and McAdams, D. P. 2004b. Personal growth in adults' stories of life transitions. *Journal of Personality* 72(3), pp. 573-602.

Bauer, J. J. et al. 2005. Crystallization of desire and crystallization of discontent in narratives of life-changing decisions. *Journal of Personality* 73(5), pp. 1181-1213.

Baumeister, R. F. 1994. The crystallization of discontent in the process of major life change. In: Heatherton, T.F. and Weinberger, J.L. eds. *Can personality change?* Washington, DC: American Psychological Association.

Baumeister, R. F. et al. 2001. Bad is stronger than good. *Review of General Psychology* 5(4), pp. 323-370.

Beattie, P. E. et al. 2003. Characteristics and prognosis of idiopathic solar urticaria. *Archives of Dermatology* 139, pp. 1149-1154.

Beebe, T. J. et al. 2007. Selected questionnaire size and colour combinations were significantly related to mailed survey response rates. *Journal of Clinical Epidemiology* 60(11), pp. 1184-1189.

Ben-Shlomo, Y. and Kuh, D. 2002. A life course approach to chronic disease epidemiology: conceptual models, empirical challenges and interdisciplinary perspectives. *International Journal of Epidemiology* 31, pp. 285-293.

Bergner, M. et al. 1976. The Sickness Impact Profile: conceptual formulation and methodology for the development of a health status measure. *International Journal of Health Services* 6(3), pp. 393-415.

Berns, G. S. et al. 2007. Intertemporal choice - toward an integrative framework. *Trends in Cognitive Sciences* 11(11), pp. 482-488.

Blackford, S. et al. 1997. Quality of life in Behcet's syndrome: 335 patients surveyed. *British Journal of Dermatology* 136, p. 293.

Blake, D. J. et al. 1987. Sexual quality of life of patients with arthritis compared to arthritis free controls. *The Journal of Rheumatology* 14(3), pp. 570-576

Blane, D. et al. 2004. Life course influences on quality of life in early old age. *Social Science and Medicine* 58(11), pp. 2171-2179.

Bosch, A. M. et al. 2007. The course of life and quality of life of early and continuously treated Dutch patients with phenylketonuria. *Journal of Inherited Metabolic Disease* 30, pp. 29-34.

Bott, U. et al. 1998. Validation of diabetes specific quality of life scale for patients with Type 1 diabetes. *Diabetes Care* 21, pp. 757-769.

Bowling, A. 1995. What things are important in people's lives? A survey of the public's judgements to inform scales of health related quality of life. *Social Science and Medicine* 41, pp. 1447-1462.

Bradley, C. et al. 1999. The development of an individualised questionnaire measure of perceived impact of diabetes on quality of life: the ADDQoL. *Quality of Life Research* 8, pp. 79-91.

Braido, F. et al. 2007. Allergic rhinitis and asthma ad hoc survey: clinical and psychological perspectives. *Clinical and Experimental Allergy* 37, pp. 788-793.

Brenninkmeijer, E. E. A. et al. 2009. The Course of Life of Patients with Childhood Atopic Dermatitis. *Pediatric Dermatology* 26(1), pp. 14-22.

Bridges, W. 1980. *Transitions: making sense of life's changes.* Reading, Massachusetts: Addison-Wesley.

Brown, C. et al. 1994. Symptoms, Health and Illness behaviour in Cystic Fibrosis. *Social Science and Medicine* 39(3), pp. 375-379.

Brown, G. W. and Harris, T. O. 1987. *The social origins of depression.* London: Tavistock.

Burge, S. M. and Wilkinson, J. D. 1992. Darier-White disease: A review of the clinical features in 163 patients. *Journal of the American Academy of Dermatology* 27, pp. 40-50.

Burman, B. and Margolin, G. 1992. Analysis of the association between marital relationships and health problems: an interactional perspective. *Psychological Bulletin* 112(1), pp. 39-63.

Busschbach, J. et al. 1994. Measuring the quality of life before and after bilateral lung transplantation in patients with cystic fibrosis. *Chest* 105, pp. 911-917.

Cameron, L. D. and Muller, C. 2009. Psychosocial aspects of genetic testing. *Current Opinion in Psychiatry* 22, pp. 218-223.

Cannon, C. A. et al. 1998. Chronic illness in the context of marriage: a systems perspective of stress and coping in chronic obstructive pulmonary disease. *Families, Systems and Health* 16(4), pp. 401-418.

Carels, R. A. 2004. The association between disease severity, functional status, depression and daily quality of life in congestive heart failure patients. *Quality of Life Research* 13, pp. 63-72.

Carey, M. P. et al. 1991. Reliability and validity of the appraisal of diabetes scale. *Journal of Behavioral Medicine* 14, pp. 43-51.

Carr, A. J. and Higginson, I. J. 2001. Measuring quality of life: Are quality of life measures patient centred? *British Medical Journal* 322, pp. 1357-1360.

Cassidy, B. et al. 2004. Quality of life: information and learning resources in supporting people with severe life-changing injuries to return to independence. *TheScientificWorldJOURNAL* 4, pp. 536-543.

Catell, R. B. 1966. The scree test for number of factors. *Multivariate Behavioural Research* 1, pp. 245-276.

Cella, D. F. et al. 1993. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *Journal of Clinical Oncology* 11(3), pp. 570-579.

Chambers, L. W. et al. 1976. Development and application of an index of social function. *Health Services Research* 11(4), pp. 430-441.

Chen, H. et al. 2006. Impact of adolescent mental disorders and physical illnesses on Quality of Life 17 years later. *Archives of Pediatrics & Adolescent Medicine* 160, pp. 93-99.

Chren, M. M. and Weinstock, M. A. 2004. Conceptual issues in Measuring the Burden of Skin Disease. *Journal of Investigative Dermatology, Symposium Proceedings* 9, pp. 97-100.

Clark, J. et al. 2004. Developing a comprehensive cancer centre rehabilitation program. *Journal of Oncology Management* 13(5), pp. 13-21.

Cohen, J. 1960. A coefficient of agreement for nominal scale. *Educational and Psychological Measurement* 20, pp. 37-46.

Cohen, J. D. and Jones, G. A. 2005. Decisions amid uncertainty. *Nature* 436, pp. 471-472.

Congleton, J. et al. 1996. Quality of life in adults with cystic fibrosis. *Thorax* 51, pp. 936-940.

Constantinides, V. A. et al. 2006. Long term health related quality of life comparison in patients undergoing single vs staged resection for complicated diverticular disease. *Colorectal Disease* 8, pp. 663-671.

Cooper, N. J. 2000. Economic burden of rheumatoid arthritis: a systematic review. *Rheumatology* 39, pp. 28-33.

Costello, A. B. and Osborne, J. W. 2005. Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Practical Assessment, Research & Evaluation* 10(7), pp. 1-9.

Cotterill, J. A. and Cunliffe, W. J. 1997. Suicide in dermatological patients. *British Journal of Dermatology* 137, pp. 246-250.

Craft, S. M. et al. 2007. Pregnancy decisions among women with HIV. *AIDS and Behavior* 11(6), pp. 927-935.

Cronbach, L. J. 1951. Coefficient alpha and the internal structure of tests *Psychometrika* 16(3), pp. 297-334.

Cvetkovski, R. S. et al. 2006. Prognosis of occupational hand eczema: a follow-up study. *Archives of Dermatology* 142, pp. 305-311.

Cystic Fibrosis Foundation 2008. [Online]. Available at: http://www.cff.org [Accessed: 30 October 2008].

Cystic Fibrosis Trust 2008. [Online]. Available at: http://www.cftrust.org.uk [Accessed: 30 October 2008].

Daud, L. R. et al. 1993. Psychosocial adjustment in preschool children with atopic eczema. *Archives of Disease in Childhood* 69, pp. 670-676.

de-Bock, G. H. et al. 1995. Health Related Quality of Life in patients with osteoarthritis in a family practice. *Arthritis Care and Research* 8 pp. 88-93.

de-Jong, W. et al. 1997. Quality of Life in Patients With Cystic Fibrosis. *Pediatric Pulmonology* 23, pp. 95-100.

Dornhoffer, J. L. et al. 2008. Impact on quality of life after mastoid obliteration. *The Laryngoscope* 118(8), pp. 1427-1432.

Dow, K. H. 1994. Having children after breast cancer. *Cancer Practice* 2(6), pp. 407-413.

Downie, R. S. et al. 1996. *Health Promotion: Models and Values*. 2nd ed. Oxford: Oxford University Press, pp. 9-26.

Dubos, R. 1976. The State of Health and the Quality of Life. *The Western Journal of Medicine* 125(1), pp. 8-9.

Eghlileb, A. M. et al. 2007. Psoriasis has a major secondary impact on the lives of family members and partners. *British Journal of Dermatology* 156, pp. 1245-1250.

Elkins, M. and Cavendish, R. 2004. Developing a plan for pediatric spiritual care. *Holistic Nursing Practice* 18(4), pp. 179-184.

Elliot, A. J. and Sheldon, K. M. 1998. Avoidance personal goals and the personality-illness relationship. *Journal of Personality and Social Psychology* 75(5), pp. 1282-1299.

Emmons, R. A. 1986. Personal strivings: An approach to personality and subjective well-being. *Journal of Personality and Social Psychology* 51(5), pp. 1058-1068.

Engel, J. et al. 2004. Quality of Life Following Breast-Conserving Therapy or Mastectomy: Results of a 5-Year Prospective Study. *The Breast Journal* 10(3), pp. 223-231.

EuroQoL Group 1990. EuroQoL - a new facility for the measurement of health-related quality of life. The EuroQoL - Group. *Health Policy* 16(3), pp. 199-208.

Fayers, P. M. and Hand, D. J. 1997. Factor analysis, causal indicators and quality of life. *Quality of Life Research* 6, pp. 139-150.

Felce, D. 1997. Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research* 41(2), pp. 126-135.

Feldman, S. R. et al. 1997. The economic impact of psoriasis increases with psoriasis severity. *Journal of the American Academy of Dermatology* 37, pp. 564-569.

Ferrer, M. et al. 1997. Chronic obstructive pulmonary disease stage and health-related quality of life. *Annals of Internal Medicine* 127(12), pp. 1072-1079.

Fine, J. D. et al. 2005. Impact of inherited epidermolysis bullosa on parental interpersonal relationships, marital status and family size. *British Journal of Dermatology* 152(5), pp. 1009-1014.

Finlay, A. Y. 1992. Facing up to acne. *Occupational Health* 44, pp. 339-341.

Finlay, A. Y. 1996. Measures of the effect of adult severe atopic eczema on quality of life. *Journal of the European Academy of Dermatology and Venereology* 7, pp. 149-154.

Finlay, A. Y. and Coles, E. C. 1995. The effect of severe psoriasis on the quality of life of 369 patients. *British Journal of Dermatology* (132), pp. 236-244.

Finlay, A. Y. and Ortonne, J. P. 2004. Patient satisfaction with psoriasis therapy. *Journal of Cutaneous Medicine and Surgery* 8(5), pp. 310-320.

Fisher, G. S. et al. 2007a. Chronic pain and occupation: an exploration of the lived experience. *American Journal of Occupational Therapy* 61(3), pp. 290-302.

Fisher, M. A. et al. 2007b. Sociodemographic characteristics and diabetes predict invalid self-reported non-smoking in a population-based study of U.S. adults. *BMC Public Health* 7, p. 33.

Flanagan, J. C. 1982. Measurement of quality of life: current state of the art. *Archives of Physical Medicine and Rehabilitation* 63(2), pp. 56-59.

Fleiss, J. L. 1971. Measuring nominal scale agreement among many raters. *Psychological Bulletin* 76, pp. 378-382.

Fletcher, A. and Bulpitt, C. 1993. Measuring quality of life in hypertension. In: Walker, S.R. and Rosser, R.M. eds. *Quality of Life assessment: Key issues in the 1990s*. London: Kluwer Academic Publication, pp. 321-332.

Fletcher, A. E. et al. 1989. The effects of verapamil and propranolol on quality of life in hypertension. *Journal of Human Hypertension* 3, pp. 125-130.

Fletcher, C. and Peto, R. 1977. The natural history of chronic airflow obstruction. *British Medical Journal* 1, pp. 1645-1648.

Floyd, F. J. and Widaman, K. F. 1995. Factor analysis in the development and refinement of clinical assessment instruments. *Psychological Assessment* 7(3), pp. 286-299.

Foo, C. and Schofield, O. M. V. 2000. Influences on the quality of family life in atopic eczema. *British Journal of Dermatology* 143 (Suppl. 57), p. 45.

Foreign and Commonwealth Office. 2010. *New life in the sun? Don't get burned!* [Online]. Available at: www.fco.gov.uk [Accessed: 05 March 2010].

Fowler, C. and Bass, L. S. 2006. Illness Representations in Patients with Chronic Kidney Disease on Maintenance Hemodialysis. *Nephrology Nursing Journal* 33(2), pp. 173-186.

Futrell, D. 1995. When quality is a matter of taste, use reliability indexes. *Quality Progress* 28(5), pp. 81-86.

Gandjour, A. and Lauterbach, K. W. 1999. Review of quality-of-life evaluations in patients with angina pectoris. *Pharmacoeconomics* 16, pp. 141-152.

Ganong, L. H. and Coleman, M. 1991. Remarriage and health. *Research in Nursing and Health* 14(3), pp. 205-211.

Garrido, P. C. et al. 2006. Negative impact of chronic obstructive pulmonary disease on the health-related Quality of Life of patients. Results of the EPIDEPOC study. *Health and Quality of Life Outcomes* 4, p. 31.

Gee, L. et al. 2003. Quality of life in cystic fibrosis: the impact of gender, general health perceptions and disease severity. *Journal of Cystic Fibrosis* 2(4), pp. 206-213.

Glaser, B. G. and Strauss, A. L. 1967. *The discovery of grounded theory: strategies for qualitative research*. Chicago: Aldine.

Goldberg, D. P. 1972. *The Detection of Psychiatric Illness by Questionnaire: a technique for the identification and assessment of non - psychotic psychiatric illness*. London: Oxford University Press.

Goodwin, S. S. 1997. The marital relationship and health in women with chronic fatigue and immune dysfunction syndrome: views of wives and husbands. *Nursing Research* 46(3), pp. 138-146.

Gosselink, R. and Decramer, M. 1998. Peripheral skeletal muscles and exercise performance in patients with chronic obstructive pulmonary disease. *Monaldi Archives for Chest Disease* 53(4), pp. 419-423.

Goulden, V. et al. 1997. Prevalence of facial acne in adults. *British Journal of Dermatology* 137 (Suppl. s50), p. 40.

Gove, W. R. et al. 1983. Does marriage have a positive effect on the psychological well-being of the individual? *Journal of Health and Social Behaviors* 24, pp. 122-131.

Goz, F. et al. 2007. Effects of diabetes patients' perceived social support on their quality of life. *Journal of Clinical Nursing* 16, pp. 1353-1360.

Graham, D. T. and Stevenson, I. 1963. Disease and response to life stress. In: Lief, H.I. et al. eds. *The psychosocial basis of medical practice*. New York: Harper and Row.

Guillemin, F. et al. 1995. Stressful life events and disability in early rheumatoid arthritis. *The European Journal of Public Health* 5(3), pp. 163-168.

Gupta, M. A. and Gupta, A. K. 1997. Psoriasis and Sex: a study of moderately to severely affected patients. *International Journal of Dermatology* 36, pp. 259-262.

Gupta, M. A. and Gupta, A. K. 2003. Psychiatric and Psychological Co-Morbidity in Patients with Dermatologic Disorders: Epidemiology and Management. *American Journal of Clinical Dermatology* 4(2), pp. 833-842.

Guyatt, G. H. et al. 1987. A measure of quality of life for clinical trails in chronic lung disease. *Thorax* 42(1), pp. 45-54.

Gwet, K. L. 2008. Intrarater Reliability.*Wiley Encyclopedia of Clinical Trials*. John Wiley & Sons, Inc, pp. 1-13.

Hagren, B. et al. 2005. Maintenance haemodialysis: patients' experiences of their life situation. *Journal of Clinical Nursing* 14, pp. 294-300.

Halioua, B. et al. 2000. Quality of life in dermatology. *International Journal of Dermatology* 39, pp. 801-806.

Halonen, K. I. et al. 2003. Long-term health-related quality of life in survivors of severe acute pancreatitis. *Intensive Care Medicine* 29(5), pp. 782-786.

Halpin, D. M. G. and Miravitlles, M. 2006. Chronic Obstructive Pulmonary Disease: The Disease and its Burden to Society. *Proceedings of the American Thoracic Society* 3, pp. 619-623.

Harris, A. J. et al. 1996. Handicap in Darier's disease and Hailey-Hailey disease. *British Journal of Dermatology* 135, pp. 959-963.

Harris, A. J. et al. 1995. Quantifying Disability in Darier's Disease. *British Journal of Dermatology* 133 (Suppl. 45), p. 43.

Hay, I. C. et al. 2000. Quality of life assessment of alopecia areata - a comparison of two geographical areas in Scotland. *British Journal of Dermatology* 143 (Suppl. 57), pp. 46-47.

Haynes, S. N. et al. 1995. Content validity in psychological assessment: A functional approach to concepts and methods. *Psychological Assessment* 7(3), pp. 238-247.

Heald, A. H. et al. 2004. Long-term negative impact on quality of life in patients with successfully treated Cushing's disease. *Clinical Endocrinology* 61, pp. 458-465.

Heatherton, T. F. and Nichols, P. A. 1994. Personal accounts of successful versus failed attempts at life change. *Personality and Social Psychology Bulletin* 20(6), pp. 664-675.

Herschbach, P. et al. 1997. Psychometric Properties of the Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R). *Health Psychology* 16, pp. 171-174.

Heydendael, V. M. R. et al. 2004. The burden of psoriasis is not determined by disease severity only. *Journal of Investigative Dermatology Symposium Proceedings* 9, pp. 131-135.

Hill, J. F. et al. 1985. Angiotensin converting enzyme inhibitors and quality of life: the European trial. *Journal of Hypertension* 3, pp. (Suppl) S91-94.

Holmes, T. H. and Rahe, R. H. 1967. The Social Readjustment Rating Scale. *Journal of Psychosomatic Research* 11, pp. 213-218.

Homan, M. W. L. et al. 2008. Impact of childhood vitiligo on adult life. *British Journal of Dermatology* 159, pp. 915-920.

Hon, K. L. E. et al. 2008. Does age or gender influence quality of life in children with atopic dermatitis? *Clinical and Experimental Dermatology* 33, pp. 705-709.

Huggins, R. H. et al. 2009. Quality of life assessment and disease experience of patient members of a web-based hydroa vacciniforme support group. *Photodermatology, Photoimmunology and Photomedicine* 25, pp. 209-215.

Hunt, S. M. 1988. Subjective health indicators and health promotion. *Health Promotion* 3(1), pp. 23-34.

Hunt, S. M. et al. 1981. The Nottingham Health Profile: subjective health status and medical consultations. *Social Science and Medicine* 15, pp. 221-229.

Husser, E. K. and Roberto, K. A. 2009. Older women with cardiovascular disease: perception of initial experience and long-term influences on daily life. *Journal of Women and Aging* 21(1), pp. 3-18.

Huurre, T. M. and Aro, H. M. 2002. Long-term psychosocial effects of persistent chronic illness. A follow-up study of Finnish adolescents aged 16 to 32 years. *European Child and Adolescent Psychiatry* 11(2), pp. 85-91.

Ibler, K. and Jemec, G. B. E. 2011. Cumulative life damage in dermatology. *Dermatology Reports* 3(1), pp. 8-10.

Jacobson, A. M. 1994. The DCCT Research Group: The diabetes quality of life measure. In: Bradley, C. ed. *Handbook of Psychology and Diabetes*. Switzerland: Harwood Academic Publishers, pp. 65-87.

Janson, C. et al. 1994. Anxiety and depression in relation to respiratory symptoms and asthma. *American Journal of Respiratory and Critical Care Medicine* 149, pp. 930-934.

Javadi, H. R. et al. 2004. Quality of Life in Cardiovascular Disease: The case for routine use of the MacNew (Farsi version) Questionnaire in Iranian patients. *Noncommunicable Disease in Malaysia* 3(4), pp. 19-25.

Jayaprakasam, A. et al. 2002. Comparison of assessments of severity and quality of life in cutaneous disease. *Clinical and Experimental Dermatology* 27, pp. 306-308.

Jette, A. M. et al. 1986. The Functional Status Questionnaire: reliability and validity when used in primary care. *Journal of General Internal Medicine* 1(3), pp. 143-149.

Jones, P. W. 1995. Quality of life measurement in asthma. *European Respiratory Journal* 8, pp. 885–887.

Juenger, J. et al. 2002. Health related quality of life in patients with congestive heart failure: comparison with other chronic diseases and relation to functional variables. *Heart* 87(3), pp. 235-241.

Kadir, R. A. et al. 2000. Reproductive choices of women in families with haemophilia. *Haemophilia* 6, pp. 33-40.

Kaiser, H. F. 1970. A second generation little jiffy. *Psychometrika* 35, pp. 401-415.

Kaiser, H. F. 1974. An index of factorial simplicity. *Psychometrika* 39, pp. 31-36.

Kalender, B. et al. 2007. Quality of life in chronic kidney disease: effects of treatment modality, depression, malnutrition and inflammation. *International Journal of Clinical Practice* 61(4), pp. 569-576.

Katz, P. 1995. The impact of rheumatoid arthritis on life activities. *Arthritis Care and Research* 8, pp. 272-278.

Katz, S. et al. 1963. Studies of illness in the aged. The Index of ADL: a standardized measure of biological and psychosocial function. *Journal of the American Medical Association* 185, pp. 914-919.

Kelley, K. et al. 2003. Good practice in the conduct and reporting of survey research. *International Journal for Quality in Health Care* 15(3), pp. 261-266.

Kenning, P. and Plassmann, H. 2005. NeuroEconomics: An overview from an economic perspective. *Brain Research Bulletin* 67, pp. 343-354.

Khan, M. E. and Manderson, L. 1992. Focus groups in tropical diseases research. *Health Policy and Planning* 7, pp. 56-66.

Kiecolt, K. J. 1994. Stress and the decision to change oneself: A theoretical model. *Social Psychology Quarterly* 57(1), pp. 49-63.

Kimball, A. B. et al. 2010. Psoriasis: is the impairment to a patient's life cumulative. *Journal of European Academy of Dermatology and Venereology* 24(9), pp. 989-1004.

King, L. A. et al. 2000. Stories of life transition: Subjective well-being and ego development in parents of children with Down Syndrome. *Journal of Research in Personality* 34, pp. 509-536.

Koivumaa-Honkanen, H. et al. 2001. Life satisfaction and suicide: A 20-year follow-up study. *American Journal of Psychiatry* 158, pp. 433-439.

Koivunen, K. and Lukkarinen, H. 2008. One-year prospective health-related quality-of-life outcomes in patients treated with conservative methods, endovascular treatment or open surgery for symptomatic lower limb atherosclerotic disease. *European Journal of Cardiovascular Nursing* 7(3), pp. 247-256.

Kormeili, T. et al. 2004. Psoriasis: immunopathogenesis and evolving immunomodulators and systemic therapies; U.S.A. experiences. *British Journal of Dermatology* 151, pp. 3-15.

Korte, J. D. et al. 2004. Quality of Life in patients with psoriasis: A Systemic Literature Review. *Journal of Investigative Dermatology Symposium Proceedings* 9, pp. 140-147.

Kovacs, S. O. 1998. Vitiligo. *Journal of the American Academy of Dermatology* 38(5), pp. 647-666.

Kressin, N. R. et al. 2000. Negative Affectivity and Health-Related Quality of Life. *Medical Care* 38(8), pp. 858-867.

Kroner, R. 1936. Philosophy of Life and Philosophy of History. *The Journal of Philosophy* 33(8), pp. 204-212.

Krueger, G. et al. 2001. The Impact of Psoriasis on Quality of Life: Result of a 1998 National Psoriasis Foundation Patient-Membership Survey. *Archives of Dermatology* 137(3), pp. 280-284.

Krueger, R. A. 1997. *Moderating focus groups: Focus group kit 4*. California: Sage Publication.

Kuh, D. et al. 2003. Life course epidemiology. *Journal of Epidemiology and Community Health* 57, pp. 778-783.

Kuriya, B. et al. 2008. Quality of Life over time in patients with systemic lupus erythematosus. *Arthritis & Rheumatism* 59(2), pp. 181-185.

LaGarce, R. and Khun, L. D. 1995. The effect of visual stimuli on mail survey response rates. *Industrial Marketing Management* 24, pp. 11-18.

Landis, R. and Koch, G. G. 1977. The Measurement of Observer Agreement for Categorical Data. *Biometrics* 33(1), pp. 159-174.

Langer, E. J. and Roth, J. 1975. Heads I win, tails it's chance: The illusion of control as function of the sequence of outcomes in a purely chance task. *Journal of Personality and Social Psychology* 32(6), pp. 951-955.

Lanigan, S. W. and Cotterill, J. A. 1989. Psychological disabilities amongst patients with port wine stains. *British Journal of Dermatology* 121, pp. 209-215.

Lawson, V. et al. 1998. The family impact of childhood atopic dermatitis: the Dermatitis Family Impact Questionnaire. *British Journal of Dermatology* 138(1), pp. 107-113.

Lee, A. V. 2005. *Coping with disease*. New York: Nova Science Publishers, Inc.

Lewin, R. J. P. 1999. Improving quality of life in patients with angina. *Heart* 82, pp. 654-655.

Lief, A. 1948. *The common sense psychiatry of Dr Adolf Meyer*. New York: McGraw-Hill.

Lim, J. et al. 2004. Short and long-term impact of receiving genetic mutation results in women at increased risk for hereditary breast cancer. *Journal of Genetic Counseling* 13(2), pp. 115-133.

Lin, N. et al. 1979. Social support, stressful life event, and illness: A model and an empirical test. *Journal of Health and Social Behavior* 20(2), pp. 108-119.

Linn, M. W. and Linn, B. S. 1982. The Rapid Disability Rating Scale-2. *Journal of the American Geriatrics Society* 30, pp. 378-382.

Lounsbury, J. W. et al. 2006. Scale development. In: Leong, F.T.L. and Austin, J.T. eds. *The Psychology Research Handbook: A Guide for Graduate Students and Research Assistants*. 2nd ed. Thousand Oaks, CA: Sage, pp. 125-146.

Lundberg, C. et al. 2008. Long-term health-related quality of life after maze surgery for atrial fibrillation. *Annals of Thoracic Surgery* 86(6), pp. 1878-1882.

Luttik, M. L. et al. 2007. Caregiver burden in partners of heart failure patients; limited influence of disease severity. *European Journal of Heart Failure* 9, pp. 695-701.

Lynch, J. and Smith, G. D. 2005. A life course approach to chronic disease epidemiology. *Annual Review of Public Health* 26, pp. 1-35.

Lyons, R. A. et al. 1994. Comparative health status of patients with 11 common illnesses in Wales. *Journal of Epidemiology and Community Health* 48(3), pp. 388-390.

Mahoney, F. I. and Barthel, D. W. 1965. Functional evaluation: The Barthel index. *Maryland State Medical Journal* 14, pp. 61-65.

Malcomson, K. S. et al. 2008. What can we learn from the personal insights of individuals living and coping with multiple sclerosis? *Disability and Rehabilitation* 30(9), pp. 662-674.

Malhotra, S. K. and Mehta, V. 2008. Role of stressful life events in induction or exacerbation of psoriasis and chronic urticaria. *Indian Journal of Dermatology Venereology and Leprology* 74(6), pp. 594-599.

Mannino, D. M. et al. 2002. Surveillance for Asthma---United States, 1980--1999. *Morbidity and Mortality Weekly Report (MMWR)* 51, pp. 1-13.

Martensson, J. et al. 2003. Living With Heart Failure: Depression and Quality of Life in Patients and Spouses. *The Journal of Heart and Lung Transplantation* 22(4), pp. 460-467.

Mastaglia, B. and Kristjanson, L. J. 2001. Factors influencing women's decisions for choice of surgery for stage-I and stage-II breast cancer in Western Australia. *Journal of Advanced Nursing* 35(6), pp. 836-847.

McAdams, D. P. 1995. What do we know when we know a person? *Journal of Personality* 63(3), pp. 365-396.

McFarland, K. et al. 2006. Teaching communication and listening skills to medical students: Using life review with older adults. *Gerontology and Geriatric Education* 27(1), pp. 81-94.

McHugh, G. A. and Luker, K. A. 2009. Influence on individuals with osteoarthritis in deciding to undergo a hip or knee joint replacement: A qualitative study. *Disability and Rehabilitation* 31(15), pp. 1257-1266.

Meding, B. et al. 2005. Fifteen-year follow-up of hand eczema: persistence and consequences. *British Journal of Dermatology* 152(5), pp. 975-980.

Meenan, R. F. et al. 1978. The costs of rheumatoid arthritis: a patient-orientated study of chronic disease costs. *Arthritis and Rheumatism* 21, pp. 827-833.

Melsop, K. A. et al. 2003. Quality of Life and time trade-off utility measures in patients with coronary artery disease. *American Heart Journal* 145, pp. 36-41.

Meszaros, A. et al. 2003. Evaluation of asthma knowledge and Quality of Life in Hungarian asthmatics. *Allergy* 58, pp. 624-628.

Miller, N. C. and Askew, A. E. 2007. Tibia fracture. An overview of evaluation and treatment. *Orthopaedic Nursing* 26(4), pp. 216-223.

Mishra, G. et al. 2009. A structured approach to modelling the effects of binary exposure variables over the life course. *International Journal of Epidemiology* 38, pp. 528-537.

Moffitt, K. H. and Singer, J. A. 1994. Continuity in the life story: Self-defining memories, affect, and approach/avoidance personal strivings. *Journal of Personality* 62(1), pp. 21-43.

Morgan, D. L. 1997. *Focus Groups: Qualitative Research Method Series 16.* California: Sage.

Moskowitz, E. and McCann, C. B. 1957. Classification of disability in the chronically ill and aging. *Journal of Chronic Disease* 5, pp. 342-346.

Myers, J. K. et al. 1972. Life events and mental status: A longitudinal study. *Journal of Health and Social Behavior* 13, pp. 398-406.

Nijsten, T. et al. 2006. Refinement and reduction of the Impact of Psoriasis Questionnaire: Classical Test Theory vs. Rasch analysis. *British Journal of Dermatology* 154, pp. 692–700.

Norman, R. M. G. and Malla, A. K. 1993. Stressful Life Events and Schizophrenia I: A Review of the Research. *British Journal of Psychiatry* 162, pp. 161-166.

Norusis, M. J. 2005. *SPSS 13.0 advanced statistical procedures companion.* NJ: Upper Saddle River.

Nunnally, J. C. and Bernstein, I. H. 1994. *Psychometric theory.* 3rd ed. New York: McGraw-Hill.

Nussbaum, J. F. et al. 2003. Health, communication, and aging: cancer and older adults. *Health Communication* 15(2), pp. 185-192.

Oppenheim, A. N. 1992. *Questionnaire design, interviewing and attitude measurement.* London: Pinter.

Pallant, J. 2005. *SPSS survival manual: a step-by-step guide to data analysis using SPSS for Windows (Version 12)*. 2nd ed. Maidenhead: Open University Press.

Parkerson, G. R. et al. 1990. The Duke Health Profile: A 17-item measure of health and dysfunction. *Medical Care* 28(11), pp. 1056-1072.

Parsad, D. et al. 2003. Quality of life in patients with vitiligo. *Health and Quality of Life Outcomes* 1(58), pp. 1-3.

Paykel, E. S. 1979. Casual relationships between clinical depression and life events. In: Barrett, J.E. ed. *Stress and mental disorder*. New York: Raven, pp. 71-86.

Paykel, E. S. et al. 1969. Life event and depression: A controlled study. *Archives of General Psychiatry* 21(6), pp. 753-760.

Perini, G. I. et al. 1984. Life events and alopecia areata. *Psychotherapy and Psychosomatics* 41(1), pp. 48-52.

Perlman, R. L. et al. 2005. Quality of life in Chronic Kidney Disease (CKD): A cross-sectional analysis in the Renal Research Institute - CKD study. *American Journal of Kidney Diseases* 45(4), pp. 658-666.

Phillips, T. J. and Dover, J. S. 1991. Leg ulcers. *Journal of the American Academy of Dermatology* 25, pp. 965-987.

Poikolainen, K. et al. 1994. Smoking, alcohol and life events related to psoriasis among women. *British Journal of Dermatology* 130, pp. 473-477.

Polonsky, W. H. 2000. Understanding and Assessing Diabetes Specific Quality of Life. *Diabetes Spectrum* 13, p. 36.

Poon, E. et al. 1999. The extent and nature of disability in different urticarial conditions. *British Journal of Dermatology* 140, pp. 667-671.

Rahe, R. 1975. Epidemiological studies of life change and illness. *International Journal of Psychiatry in Medicine* 6, pp. 133-146.

Rahe, R. H. et al. 1964. Social stress and illness onset. *Journal of Psychosomatic Research* 8, pp. 35-44.

Rapp, S. R. et al. 1999. Psoriasis causes as much disability as other major medical diseases. *Journal of the American Academy of Dermatology* 41, pp. 401-407.

Redd, W. H. and Jacobsen, P. B. 1988. Emotion and Cancer: New perspectives on an old question. *Cancer* 62, pp. 1871-1879.

Rempel, G. R. et al. 2004. Parents' perspectives on decision making after antenatal diagnosis of congenital heart disease. *Journal of Obstetric, Gynaecologic, and Neonatal Nursing* 33(1), pp. 64-70.

Renne, K. S. 1977. Health and marital experience in an urban population. In: DeBurger, J.E. ed. *Marriage today: Problems, issues, and alternatives.* New York: Shenkman, pp. 304-331.

Revicki, D. A. et al. 2000. Recommendations on health-related quality of life research to support labelling and promotional claims in the United States. *Quality of Life Research* 9(8), pp. 887-900.

Riekert, K. A. et al. 2007. The association between depression, lung function, and health-related quality of life among adults with cystic fibrosis. *Chest* 132(1), pp. 231-237.

Robinson-Smith, G. 2002. Prayer after Stroke. Its Relationships to Quality of Life. *Journal of Holistic Nursing* 20(4), pp. 352-366.

Roebuck, A. et al. 2001. Health-related quality of life after myocardial infarction: an interview study. *Journal of Advanced Nursing* 34(6), pp. 787-794.

Ross, C. E. et al. 1990. The impact of the family on health: The decade in review. *Journal of Marriage and the Family* 52(4), pp. 1059-1078.

Roth-Roemer, S. and Kurpius, S. E. R. 1996. Beyond marital status: an examination of marital quality and well-being among women with rheumatoid arthritis. *Womens Health* 2, pp. 195-205.

Rubin, R. R. 2000. Diabetes and Quality of Life. *Diabetes Spectrum* 13, p. 21.

Rubin, R. R. and Peyrot, M. 1999. Quality of Life in Diabetes *Diabetes/Metabolism Research and Reviews* 15, pp. 205-218.

Rudolph, T. et al. 2008. The Long-term functional status in patients with Guillain–Barré syndrome. *European Journal of Neurology* 15(12), pp. 1332-1337.

Ryan, A. 2006. The social implications of rheumatic disease. In: Hill, J. ed. *Rheumatology Nursing: A creative approach.* 2nd ed. Chichester: John Wiley and Sons, Ltd, p. 193.

Saarni, S. L. et al. 2006. The impact of 29 chronic conditions on health-related Quality of Life: A general population survey in Finland using 15D and EQ-5D. *Quality of Life Research* 15(8), pp. 1403-1414.

Saha, S. K. et al. 2009. Neurodevelopmental sequelae in pneumococcal meningitis in Bangladesh: A comprehensive follow-up study. *Clinical Infectious Diseases* 48 (Suppl 2), pp. S90-S96.

Salek, M. S. 1998. *Compendium of Quality of Life Instruments. Volume 1-5.* Chichester: John Wiley & Sons.

Salek, M. S. 2007. *Compendium of Quality of Life Instruments. Volume 6-7.* Haslemere: Euromed Communications.

Sawka, A. M. et al. 2009. The impact of thyroid cancer and post-surgical radioactive iodine treatment on the lives of thyroid cancer survivors: qualitative study. *PLoS ONE[electronic]* 4(1), p. e4191.

Schafer, T. 2006. Epidemiology of Atopic Eczema. In: Ring, J. et al. eds. *Handbook of Atopic Eczema.* 2nd ed. New York: Springer, pp. 21-30.

Schier, J. K. et al. 1998. The impact of asthma on health related quality of life. *Journal of Asthma* 35, pp. 585-597.

Seidler, E. M. and Kimball, A. B. 2009. Socioeconomic disability in psoriasis. *British Journal of Dermatology* 161(6), pp. 1410-1412.

Seligman, M. E. P. 2000. Positive Psychology: An introduction. *American Psychologist* 55(1), pp. 5-14.

Sharpe, D. T. 1974. *The psychology of color and design.* Chicago: Nelson-Hall.

Shen, W. et al. 1999. Development and validation of the Diabetes Quality of Life Clinical Trail Questionnaire. *Medical Care* 37, pp. AS45-66.

Sigerist, H. E. 1941. Medicine and Human welfare. New Haven: Yale University Press, p. 100.

Sillanpaa, M. et al. 2004. Perceived impact of childhood-onset epilepsy on Quality of Life as an adult. *Epilepsia* 45(8), pp. 971-977.

Sin, D. D. et al. 2002. Can continuous positive airway pressure therapy improve the general health status of patients with obstructive sleep apnea? A clinical effectiveness study. *Chest* 122(5), pp. 1679-1685.

Smedstad, L. M. et al. 1995. Life events, psychosocial factors, and demographic variables in early rheumatoid arthritis: relations to one-year changes in functional disability. *The Journal of Rheumatology* 12, pp. 2218-2225.

Smith, C. O. et al. 2004. Impact of presymptomatic genetic testing for hereditary ataxia and neuromuscular disorders. *Archives of Neurology* 61, pp. 875-880.

Smith, M. 2002. Efficacy of specialist versus non-specialist management of spinal cord injury within the UK. *Spinal Cord* 40(1), pp. 6-10.

Soriano, J. B. et al. 2000. Recent trends in physician diagnosed COPD in women and men in the UK. *Thorax* 55, pp. 789-794.

Spitzer, W. O. et al. 1981. Measuring the quality of life of cancer patients: A concise QL-Index for use by physicians. *Journal of Chronic Diseases* 34, pp. 585-597.

Staab, D. et al. 1998. Quality of life in patients with cystic fibrosis and their parents: what is important besides disease severity? *Thorax* 53, pp. 727-731.

Stam, H. et al. 2006. Young Adult Patients with a History of Pediatric Disease: Impact on Course of Life and Transition into Adulthood. *Journal of Adolescent Health* 39, pp. 4-13.

Stern, R. S. et al. 2004. Psoriasis is common, carries substantial burden even when not extensive and is associated with widespread treatment dissatisfaction. *Journal of Investigative Dermatology Symposium Proceedings* 9, pp. 136-139.

Stevens, P. E. and Hildebrandt, E. 2006. Life changing words: Women's responses to being diagnosed with HIV Infection. *Advances in Nursing Science* 29(3), pp. 207-221.

Stewart, A. J. and Vandewater, E. A. 1999. "If I had it to do over again...": Midlife review, midcourse corrections, and women's well-being in midlife. *Journal of Personality and Social Psychology* 76(2), pp. 270-283.

Stewart, S. et al. 2003. The current cost of angina pectoris to the National Health Service in the UK. *Heart* 89(8), pp. 848-853.

Stone, C. E. 1984. The lifetime economic costs of RA. *The Journal of Rheumatology* 11, pp. 819-827.

Strauss, A. and Corbin, J. 1990. Basics of qualitative research. *Grounded theory, procedures and techniques*. London: Sage, p. 124.

Streiner, D. L. 2003. *Health measurement scales: A practical guide to their development and use*. 3rd ed. Oxford: Oxford University Press.

Sullivan, M. 1992. Quality of life assessment in medicine: concepts, definitions, purposes, and basic tools. *Nordic Journal of Psychiatry* 46, pp. 79-83.

Sulzberger, M. B. and Zaidens, S. H. 1948. Psychogenic Factors in Dermatologic Disorders. *Medical Clinics of North America* 32, p. 669.

Svedlund, J. et al. 1999. Long term consequences of gastrectomy for patient's quality of life: the impact of reconstructive techniques. *The American Journal of Gastroenterology* 94(2), pp. 438-445.

Tabachnick, B. G. and Fidell, L. S. 2001. *Using multivariate statistics*. 4th ed. New York: Harper Collins.

Tausig, M. 1982. Measuring life events. *Journal of Health and Social Behavior* 23(1), pp. 52-64.

Terrell, J. E. et al. 1998. Long-term quality of life after treatment of laryngeal cancer. *Archives of Otolaryngology Head Neck Surgery* 124(9), pp. 964-971.

The Japanese Respiratory Society 2006. Concept and use of the guidelines: The committee for The Japanese Respiratory Society guidelines for management of cough. *Respirology* 11 (Suppl. 4) pp. S135–S136.

Traub, R. E. 1994. *Reliability for the social sciences: theory and applications.* Thousand Oaks, CA: Sage.

U.S. Department of Health and Human Services 2004. The Burden of Chronic Diseases and Their Risk Factors: National and State Perspectives. Atlanta: Centers for Disease Control and Prevention,. p. X.

Unaeze, J. et al. 2006. Impact of Psoriasis on Health-Related Quality of Life Decreases Over Time: An 11-year Prospective Study. *Journal of Investigative Dermatology* 126, pp. 1480-1489.

van-Ede, L. et al. 1999. Prevalence of depression in patients with chronic obstructive pulmonary disease: a systemic review. *Thorax* 54, pp. 688-692.

VandenBurg, M. J. 1993. Measuring the quality of life of patients with angina. In: Walker, S.R. and Rosser, R.M. eds. *Quality of Life Assessment: Key issues in the 1990s.* London: Kluwer Academic Publishers.

Vartanian, J. G. et al. 2004. Long-term quality of life evaluation after head and neck cancer treatment in a developing country. *Archives of Otolaryngology Head Neck Surgery* 130, pp. 1209-1213.

Veer, L. V. et al. 2008. Quality of life, developmental milestones, and self-esteem of young adults with congenital hypothyroidism diagnosed by neonatal screening. *Journal of Clinical Endocrinology & Metabolism* 93(7), pp. 2654-2661.

Vermeulen, K. M. et al. 2004. Improved Quality of Life after Lung Transplantation in individuals with cystic fibrosis. *Pediatric Pulmonology* 37, pp. 419-426.

Wainwright, N. W. J. et al. 2007. Psychosocial factors and incident asthma hospital admissions in the EPIC-Norfolk cohort study. *Allergy* 62(5), pp. 554-560.

Ware, J. E. et al. 2000. *SF-36 Health Survey: Manual and interpretation guide.* Lincoln: Quality Metric Inc.

Warren, R. B. and Griffiths, C. E. M. 2008. Systemic therapies for psoriasis: methotrexate, retinoids, and cyclosporine. *Clinics in Dermatology* 26, pp. 438-447.

Wei, A. L. et al. 2005. Hypertension and health related Quality of Life: an epidemiological study in patients attending hospital clinics in China. *Journal of Hypertension* 23 pp. 1667-1679.

WHO 1946. Constitution of the World Health Organization. Geneva: World Health organization, p. 2.

WHO 1958. The first ten year of the World Health Organization. Geneva: World Health organization, p. 459.

WHO 1980. World Health Organization: International Classification of Impairment, Disability and Handicap. *Geneva*, pp. 27-29.

WHO 1999. ICIDH-2: International Classification of Functioning and Disability. Beta-2 draft, short version. Geneva: World Health Organization.

WHO 2001. International Classification of Functioning, Disability and Health. Geneva: World Health Organization.

WHO 2007. International Classification of Functioning, Disability and Health: Children and Youth Version. Geneva: World Health Organisation.

WHO Technical Report Series 919 2003. The Burden of Musculoskeletal Conditions at the Start of the New Millennium. Geneva: World Health Organization.

WHOQOL Group 1994. The development of the World Health Organization quality of life assessment instrument (the WHOQOL). In: Orley, J. and Kuyken, W. eds. *Quality of Life assessment: International perspective.* Berlin: Spinger-Verlag, pp. 41-57.

WHOQOL Group 1998. Programme on mental health, WHOQOL. User Manual Draft. Division of Mental Health and Prevention of substance abuse. World Health Organization. pp. 1-88.

Williamson, D. et al. 1997. Quality of Life in patients with hair loss. *British Journal of Dermatology* 137 (Suppl. 50), p. 47.

Wilson, S. E. and Waddoups, S. L. 2002. Good marriages gone bad: Health mismatches as a cause of later-life marital dissolution. *Population Research and Policy Review* 21, pp. 505-533.

Wolff, K. et al. 2005. *Fitzpatrick's Color Atlas and Synopsis of Clinical Dermatology.* Fifth ed. New York: McGraw-Hill.

Wright, P. et al. 2004. Helping people assess the health risks from lifestyle choices: Comparing a computer decision aid with customized printed alternative. *Communication & Medicine* 1(2), pp. 183-192.

Wrosch, C. and Scheier, M. F. 2003. Personality and quality of life: The importance of optimism and goal adjustment. *Quality of Life Research* 12 (Suppl.1), pp. 59-72.

Yelin, E. et al. 1987a. The work dynamics of the person with rheumatoid arthritis. *Arthritis and Rheumatism* 30(5), pp. 507-512.

Yelin, E. et al. 1987b. The impact of rheumatoid arthritis and osteoarthritis: the activities of patients with rheumatoid arthritis and osteoarthritis compared to controls. *The Journal of Rheumatology* 14(4), pp. 710-717.

Zachariae, R. et al. 2004. Self reported stress reactivity and psoriasis-related stress of Nordic psoriasis sufferers. *Journal of the European Academy of Dermatology and Venereology* 18(1), pp. 27-36.

Zelnio, R. N. 1980. Data collection techniques: mail questionnaires. *American Journal of Hospital Pharmacy* 37(8), pp. 1113-1119.

PUBLICATIONS, PRESENTATIONS AND ONLINE COVERAGE

Published papers

1. Bhatti ZU, Salek MS, Finlay AY. Chronic diseases influence major life changing decisions: a new domain in quality of life research. J R Soc Med 2011; 104 (6): 241-250

2. Bhatti ZU, Salek MS, Finlay AY. Major Life Changing Decisions and Cumulative Life Course Impairment. Journal of the European Academy of Dermatology and Venereology 2011; 25 (2): 245-246

Abstracts and poster presentations

1. Z U Bhatti, A Y Finlay, S Salek. Can early detection of the impact of chronic diseases on major life changing decisions improve patient-clinician communication? Communication Medicine & Ethics 2009. Abstract Book, p121
(7th Interdisciplinary Conference on Communication Medicine & Ethics, COMET, June 2009, Cardiff)

2. Bhatti ZU, Finlay AY, Salek S. Chronic skin diseases influence major life changing decisions: a new frontier in health outcome research. *Br J Dermatol* 2009; 161 (Suppl. 1): 58-59.
(British Association of Dermatologists Annual Meeting July 2009, Glasgow)

3. Bhatti ZU, Finlay AY, Salek S, Ketchell IR, Bolton CE. Chronic respiratory diseases strongly influence major life changing decisions. *Thorax* 2009; 64 (Suppl. IV): A75-A174
(British Thoracic Society Winter Meeting, December 2009, London)

4. Bhatti ZU, Finlay AY, Salek MS, George LD. Diabetes influence on major life changing decisions: should this be an area of concern in management of patients? *Diabet Med* 2010; 27 (suppl. 1): 1-36
(Diabetes UK Annual Professional Conference, 3-5 March 2010, Liverpool)

5. Z U Bhatti, M S Salek, A Y Finlay, J J Halcox, L D George, R I Ketchell, S M Jones, C E Bolton, R H Moore. Can chronic diseases influence major life changing decisions? Exploring new territory in health outcome research. Welsh School of Pharmacy Postgraduate Research Day, 24 March 2010, Abstract Book.
(Venue: Welsh School of Pharmacy, Cardiff University, Cardiff)

6. Bhatti Z, Salek M, Finlay A, Moore R. Chronic Kidney Disease influences important life changing decisions over time. *Abstract Book BRS/RA Conference 2010; Manchester:* 174
(British Renal Society/Renal Association Conference, May 2010, Manchester)

7. Bhatti ZU, Salek SS, Finlay AY, Jones SM. Better understanding of the influence of rheumatic disorders on major life changing decisions. *Ann Rheum Dis* 2010; 69 (Suppl 3):715
(European League Against Rheumatism Conference. June 2010, Rome, Italy)

8. Bhatti ZU, Salek S, Finlay AY. The influence of chronic skin diseases on major life-changing decisions as a parameter for the assessment of long-term impact. *Br J Dermatol* 2010; 163 (Suppl 1): 39-40
(British Association of Dermatologists Annual Meeting, July 2010, Manchester)

9. Bhatti ZU, Finlay AY, Salek MS, Halcox JJ. The full impact of chronic cardiovascular diseases cannot be measured without an assessment of life decisions. *J Heart Dis* 2010; 7 (1): 71
(The International Academy of Cardiology, 15th World Congress on Heart Diseases, Annual Scientific Session, July 2010, Vancouver, Canada)

10. Zaheer U. Bhatti, M.S. Salek, A.Y. Finlay. The influence of skin disease on major life changing decisions. Acta Derm Venereol 2011; 91: 215-256
(14th congress of the European Society for Dermatology and Psychiatry. Zaragoza, Spain: March 17th-19th 2011)

11: Bhatti ZU, Salek S, Finlay AY. Development of the Major Life Changing Decisions Profile (MLCDP): A novel approach to measure the long term impact of disease. (*Abstract accepted for the British Association of Dermatologists Annual Meeting, July 2011, London)*

12. Bhatti ZU, Salek S, Finlay AY. Development of the Major Life Changing Decisions Profile: a novel approach to measure the long-term impact of disease. *Br J Dermatol* 2011; 165 (Suppl. 1): 52.
(B*ritish Association of Dermatologists Annual Meeting July 2011, London)*

Oral Presentations

1. British Thoracic Society Winter Meeting, 2-4 December 2009, London

2. Diabetes UK Annual Professional Conference, 5 March 2010, Liverpool

3. Welsh School of Pharmacy Postgraduate Research Day, 24 March 2010, Cardiff

4. A Y Finlay, Z U Bhatti, M S Salek. The influence of skin diseases on major life-changing decisions. Presented at the meeting of the European Society of Dermatology and Psychiatry, at the 7th European Academy of Dermatology and Venereology Spring Symposium, Cavtat, Crotia, 13th May 2010 (presented by Professor Finlay)

5. Zaheer U. Bhatti, M.S. Salek, A.Y. Finlay. The influence of skin disease on major life changing decisions. 14th Congress of the European Society for Dermatology and Psychiatry. Zaragoza, Spain: March 17th-19th 2011 (presented by Professor Salek)

6. A Y Finlay, Z U Bhatti, M S Salek. The impact of skin diseases on Major Life Changing Decisions. *European Society for Dermatology and Psychiatry Ancillary Meeting, May 23rd 2011, 22nd World Congress of Dermatology, Seoul, South Korea)* (presented by Professor Finlay)

Publication in preparation stage

1. Qualitative publication
2. Quantitative publication

REVIEW

Chronic diseases influence major life changing decisions: a new domain in quality of life research

ZU Bhatti • MS Salek • AY Finlay

Centre for Socioeconomic Research, School of Pharmacy and Department of Dermatology and Wound Healing, School of Medicine, Cardiff University, Cardiff, UK
Correspondence to: ZU Bhatti. Email: drzaheer121@hotmail.com

DECLARATIONS

Competing interests
AYF is joint copyright owner of the DLQI and CDLQI

Funding
This study was financially supported by the Centre for Socioeconomic Research, School of Pharmacy and the Department of Dermatology and Wound Healing, Cardiff University

Ethical approval
Not applicable

Guarantor
ZB

Contributorship
ZB wrote the initial draft; SS and AYF contributed extensively to its critical revisions and re-drafting

Acknowledgements
None

Summary

The purpose of this review is to identify knowledge about the influence of chronic disease on major life changing decisions (MLCDs). This review was carried out in three stages: identification of key search terms; selection of databases and searching parameters; and evaluation of references. Only two articles matched the main search term 'major life changing decisions'. No article reviewed or measured the influence of chronic disease on major life changing decisions. However, 76 articles and various sections of seven books were identified that provided insight into this area and these are reviewed in detail. This literature review has brought together previously scattered information on chronic disease impact on important patient life decisions. These include decisions related to having children, marriage and divorce, job and career choice, social life, holidays, travelling and education. Lifestyle decisions viewed by patients as major decisions are also documented. The influence of cancer on life decisions is discussed, as are affected life decisions of other family members. Very little information is available about the long-term impact of chronic disease on patients' lives and methodology to assess long-term impact is incomplete. This review points to a novel dimension to health-related outcome research, the impact of chronic disease on major life changing decisions, and its possible implication for patients' future health.

Introduction

The health sciences literature is replete with information related to the current impact of different diseases on patients' quality of life (QoL) and is mainly focused on the traditional health-related quality of life (HRQoL) domains (physical, social and psychological). In contrast, very little is known about the long-term impact of chronic diseases on patients' lives, for example the influence of chronic diseases on major life changing decisions (MLCDs) such as in relation to career choice, having children, marriage, divorce, early retirement and moving abroad. Through this literature review we introduce and explore this new concept and highlight its importance in a patient-centred healthcare system.

Methods

The search strategy was carefully formulated to retrieve appropriate publications and to reduce the chances of missing important relevant information. It involved three stages:

- *Stage 1: Identification of key search terms* – The key search terms were selected to gain a broad perspective and to ensure a wide coverage of the literature. The terms included life changing decision, long-term impact and QoL. The main key term 'life changing decisions' was combined with: influence, chronic disease, family, decisions and over time (Table 1).

- *Stage 2: Selection of databases and searching parameters* – OvidSP MEDLINE(R) database was selected for the initial comprehensive literature search. Searching limits were kept general in order to get more information from a broader perspective. The search was limited to original articles, and abstracts published in English. A separate questionnaire and item search was also carried out of the 'Compendium of Quality of Life instruments'.[1,2] Data resources searched are listed in Table 2.

Table 1
Search results of different individual and combined terms

Single or combined terms used in searches	*Retrieved references (n)*
Life changing decisions	2
Patient decisions	93
Personal decisions	45
Family decisions	52
Change in lifestyle	115
Patient fear	95
Patient opinions	73
Patient suggestions	12
Patient views	133
Patient recommendations	39
Patient experiences	480
Patient account	249
Patient perceptions	711
Patient feelings	19
Patient adaptations	1
Patient diary	93
Influence on Quality of Life	368
Long illness	44
Living with disease	95
Coping with disease	74
Quality of Life over time	70
Long-term impact	1255
Quality of Life, long-term impact and disease: combined search	60
Disease, influence, impact, family and decisions: combined search	73

Table 2
List of data resources searched

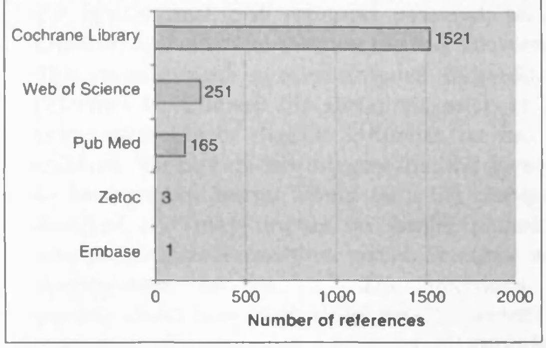
1. Ovid Medline
2. Google Scholar
3. Cardiff University electronic journals portal
4. Cardiff University Electronic Metalib resources: Cochrane Library (Wiley), Embase, Excerpta Medica (Ovid), PubMed, Web of Science, Zetoc

- *Stage 3: Searching results and evaluation of references* – A review of published studies and articles was conducted. The aim and methodology of each study given in the abstract of the article identified was read to determine its relevance. Articles were then retrieved from the main database. A total of 4251 articles were retrieved from the OvidSP MEDLINE (R) database for close inspection to identify any study with potential relevance to our research concept. Articles were obtained with a number of combinations of different selected key terms such as 'life changing decisions' and 'patient decisions' (Table 1). A total of 3397 articles were identified from a separate search using a combination of quality of life and different descriptors of studies such as prospective study, long-term study, qualitative study, longitudinal study, cohort study and follow-up study. When the term 'life changing decisions' was entered in the Cardiff University Metalib resources (Figure 1) 1941 articles were retrieved. Only two articles matched the exact term 'major life changing decisions'.

Quality of Life instruments search

An extensive search was carried out in the 'Compendium of Quality of Life instruments'.[1,2] This compendium describes over 150 questionnaires, profiles and inventories and covers general, disease specific, group specific and economic specific instruments. The purpose of the compendium search was to investigate in detail whether any questionnaire, profile or inventory has included the term 'life changing decision' for the assessment of disease impact on patients' lives. The search did not reveal any questionnaire, profile or inventory that has included any item,

Figure 1
Metalib resources result for the term 'life changing decisions'



domain, indicator or descriptor to cover the impact of illness on important life changing decisions.

Results

In the literature search, only two articles matched the term 'major life changing decisions'. These were related to psychology[3] and to neuroeconomics.[4] In the first article Bauer *et al.*[3] examined the personal stories of life changing decisions in relation to personality and wellbeing and discussed the concepts of 'crystallization of desire (approaching to a desired future) and crystallization of discontent (escaping an undesired past)'. In the second article Berns *et al.*[4] explained life changing decisions as an example of intertemporal choice. Intertemporal choice is a study of preferences, value allocation and decisions with consequences that play out over time. Life changing decisions related to education, marriage, fertility and how much food to eat, spending, investment, relationships and crime are some examples of intertemporal choices which contain trade-offs. Both studies were unrelated to the concept of health and life decisions.

Health and major life changing decisions

Life is about choices and decisions play an important role. Life choices may become limited and undesirable due to negative stressful life events, and in this situation any decision could be life changing. The diagnosis of a chronic disease is a negative life changing event in physical, psychological and social terms[5, 6] and the initial news of a life-threatening condition is often devastating for patients[7]. King *et al.*[8] suggested that 'Major life changes, by definition, require individuals to come to terms with a new set of life circumstances. Some life changes involve irrevocable alterations in our lives, requiring us to redefine the very meaning of our existence, to seek out new sources of purpose, and to reassess our priorities.' The diagnosis or onset of disease, however, is not a decision that a patient takes. Very little information is available about what constitutes a major life changing decision or how chronic disease can influence life changing decisions.

What can we learn from the available literature?

Our extensive review has not revealed any specific research evaluating health-related life changing decisions. Several studies[9–14] referred to disease as 'life changing' or as a 'major life changing event or experience' but remained focused on disease evaluation, treatment, patient education and quality of life. A few studies described how chronic disease might impact on important life decisions.

Having children

Reproductive choices are very important life decisions and disease may influence an individuals' choice to have children. Kadir *et al.*[15] suggested that the decision to have children is a complex one, even in the absence of disease. They conducted a survey of women with haemophilia to assess their experiences in pregnancy and their attitudes towards their reproductive choices. They found that age and emotional, social and financial factors were the main influences in planning pregnancy. Twenty-two of 160 women reported that the decision about their first pregnancy, and 13 of 132 women reported that the decision about subsequent pregnancies was influenced by counselling and the results of prenatal diagnostic tests. The following question was also asked to all women, whether they had 'ever made a conscious decision not to have children/any more children'. Fifty-four percent of women reported that having haemophilia was a major factor in this decision; 44% of women did not want to transfer haemophilia to their child, 6% had previous experience of haemophilia in the family, and 27% reported personal, social, financial and medical reasons for this decision.[15] This questionnaire survey revealed individuals' priorities in different life situations, such as the prime example of disease influence on having children. Various studies suggest that the decision to have genetic testing could be a life changing decision and may impact on family planning, interpersonal relationships, social, financial and employment aspects.[16–18] The decisions of parents about how to proceed after the antenatal diagnosis of congenital problems is important and difficult to make, as the decision may change their lives forever.[19]

Breast cancer is a life-threatening condition and deciding to have children after breast cancer is an important life changing decision for mothers. In 1994, Dow[20] carried out a study to identify the reasons why young women decided to become pregnant after breast cancer, to describe helpful behaviours in decision-making and to explore the meaning of having children after breast cancer. In this qualitative research, 16 women took part in semi-structured interviews. The participants were interviewed after breast cancer treatment and were asked to share their experiences following an open-ended question about breast cancer and subsequent pregnancy. Three main themes were identified that influenced having children after breast cancer treatment: having children as a cherished goal; a desire for sense of normalcy; and reconnection with others. Participants expressed a range of concerns about pregnancy (having a normal pregnancy, having a healthy infant, disease recurrence and concerns related to breastfeeding) and having children (recurrence and death, being hypervigilant, restructured living one day at a time, maternal concern). This research also highlighted in some patients that a longstanding desire for having children was interrupted by the diagnosis of breast cancer. Before the diagnosis, breast cancer participants were in control; however, after breast cancer, they lost control of their lives. The behaviour of their spouse and family, healthcare providers and other breast cancer survivors were identified as critical factors in decision-making.[20] These findings suggest that a patient's personal efforts, professional help and the process of sharing experiences could be helpful to the person making life changing decisions influenced by a recent health event. This area was also discussed in another study, where newly diagnosed patients with HIV chose not to become pregnant.[21]

Anderson and Martin[22] presented the narratives of one couple (a cancer survivor and her husband), who lived through the life changing events following a cancer diagnosis. The narratives are very moving and give insight into how a chronic life-threatening condition can change a patient's life. It is also evident that after the diagnosis, the patient's priorities changed and was preparing herself for the future. It is not clear whether the patient took any life changing decision, but words used by the patient in her story, such as 'I thought I was dying', 'I had no control over what was happening to me', 'I was still worried about my future' and 'It was dehumanizing and very lonely' indicate that the disease and its treatment have a physical impact and result in emotional fluctuation, fear and uncertainty which may influence a patient's priorities in life and may also change their family and social role and identity.

Marriage and divorce

Physical health and marital dissatisfaction have a direct effect on each other.[23] Health, mental well-being and its associations with marriage, relationships and family have been widely discussed in the literature, and any change in circumstances due to health may impact on the quality of life of family members and relationships. For example, if poor health causes a break-up in a relationship then divorce (as a stressful life event) may lead to poor health.[24–27] Wilson and Waddoups[28] carried out a study to investigate how health impacts on the breakup of a marriage. Data were used from the four 2-year periods of the Health and Retirement Study (1992, 1994, 1996 and 1998). In 1992, 4241 couples aged 51–61 years entered into this study. The health mismatch hypothesis was tested by using different spousal health combinations and separation was used as an indicator of marital dissolution. Marital dissolution was not observed from a life course perspective or from the perspective of health influence on separation. However, the study still suggests that the poor health of a spouse at a young age may cause marriage break-up over time. There is information concerning the impact of disease on marriage, marital adjustment and marital quality;[29–32] however, it is not clear whether chronic disease influenced patients' decisions to get married or prevented them becoming involved in any relationship.

Seidler and Kimball[33] suggest that patients with chronic skin disease may learn to cope over time but their important decisions early in life may have long-lasting impact on their quality of life. Seidler and Kimball used the Research Patient Data Repository (RPDR) database and cross-sectional analysis to determine any link between key ages or age ranges and social disconnection. Religious non-affiliation (for loss of social network), divorce (for loss of interpersonal connection) and use of Medicaid (for disconnection in the work place) were used as surrogate evaluative measures for the assessment of social connectivity among psoriasis patients. They found that divorce rates in psoriasis patients were higher in the age groups 29–31 years (1.3% vs. 1.7%; $P < 0.05$) and 32–34 years (2.3% vs. 1.1%; $P < 0.001$) than corresponding rates in the general population. Seidler and Kimball[33] highlighted the importance of the association of disease and age groups with the important life decision to divorce, but it is not clear whether psoriasis specifically had an influence on the patients' decision to get divorced or whether psoriasis contributed to the partners' decision to get divorced.

Chronic disease can also influence the major life changing decisions of other family members. In a cross-sectional study Fine *et al.*[34] asked a series of questions to parents of children suffering from inherited epidermolysis bullosa (EB) about the long-term impact of their child's illness on their marital life; 54–64% parents of children with dominant dystrophic EB (DDEB) and recessive dystrophic EB (RDEB) reported that they had decided not to have additional children; 88% of divorced couples with children affected by junctional EB (JEB), 50% of divorced couples with children affected by DDEB and 67% of divorced couples with children affected by RDEB reported that their child's disease was a major factor leading to their decision to divorce.

Job and career choice

In a 1-year follow-up study, Cvetkovski *et al.*[35] concluded that occupational hand eczema in later life is associated with poor quality of life and lower socioeconomic status and results in patients taking prolonged sick leave, becoming unemployed or changing their job. One year is a relatively short period for follow-up to assess these changes, but in this study 50% of patients had changed their jobs during the 12 months, which suggests how chronic illness can change life significantly. The frequency of reported change of job due to hand eczema was higher than when previously assessed by Meding *et al.*[36] in their 15 year follow-up study (1983–1998). They had found that 20 (3%) out of 706 patients from different employment backgrounds (medical and nursing work, cleaners, hairdressers, kitchen workers, painters and mechanics) reported change in their occupations because of their hand eczema, and 15 patients reported improvement after change in occupation. Eight percent of patients had reported change in their occupation before the initial 1983 examination. In terms of job change, both studies focused on occupational risk and did not discuss the nature or the consequences of the decision involved in relation to change in employment. It is obvious from both studies that chronic disease can influence a patient's decision related to selection of jobs or to change in occupation. Long-term illness can make it difficult for patients to remain in the same employment if their occupation is one of the major reasons for health deterioration. Choices become limited for patients and in some cases a change of job might result in financial loss. Patients might remain in the same employment and suffer because of socioeconomic reasons (family, better housing and children's education).

The effects of eczema 'over the last few years' on patients' quality of life were assessed in 92 eczema patients.[37] Eighty percent of the patients reported effects on their family life. Working patients lost around £5000 (median estimated) over the previous year. Other impacts identified were effects on sexual relationships (57%), effects on choice of career (51%) and 52% reported effects on long-term personal friendships and relationships.[37]

In another study, Malcomson *et al.*[38] conducted two qualitative focus group discussions to explore the impact of multiple sclerosis (MS) ($n = 13$, age 40–67 years, mean disease duration = 17 years) on patients' lives. Several patients reported changes to their employment circumstances along with other disease-related impacts (interpersonal and social life, stress, unpredictability, fear and impact on daily living). Despite the resulting loss in socioeconomic status, one patient made a decision to change from full-time to part-time employment and two patients gave up their paid jobs because of the impact (fatigue, lack of energy, decreased mobility and stress) of MS on their lives. The patients indicated that MS influenced their important decisions regarding employment and made them compromise (an undesirable objective) in the best way possible to accommodate their health needs and also take control of their resulting lifestyle changes.

Social life, holidays, travelling and education

Arnold *et al.*[39] conducted six focus group ($n = 48$) discussions with women suffering from fibromyalgia to assess its impact on their lives. Participants raised a variety of disease-related (cognitive impairment, emotional, functional and quality of life impact) and symptom-related (pain, fatigue and sleep) issues. Socially, fibromyalgia patients feel that due to the unpredictable nature of the disease, they are unable to plan any event and are judged by co-workers and friends as unreliable, resulting in loss of friendship and their withdrawal from social engagements. The participants also reported that they failed to properly look after their own children and families. Not being able to go for family trips was reported as life changing by patients and lack of participation in household activities and decreased sexual intimacy had caused great strain on their personal relationships. This study indicated that not to take part in simple things, such as social activities, is viewed by some people as a life changing decision. Those affected might still take part in different activities but embarrassment and humiliation and the long-term nature of the disease might drag them towards complete isolation. Similarly, the constant strain of disease on personal relationships may lead to taking more serious life decisions, such as separation or divorce. The participants also reported that their disease not only made them change their job frequently but made them reduce their working hours. Half of the patients left their jobs because of their illness, which ultimately resulted in financial difficulties. Some patients reported that their conditions stopped them from pursuing higher education; this is a very difficult life decision to take with resulting consequences in some circumstances of low paid menial hard work and further health deterioration.[39] Such patients may need more support and appropriate advice at those life stages when they have to take important life decisions regarding employment and education. Increased patient understanding seems necessary to reduce the inappropriate impact of the disease on decisions which determine the future course of life.

Lifestyle decisions as major life changing decisions

Life decisions and their perceived value are subjective in nature. Some decisions perceived as major by some patients may seem very minor to an observer and more related to day-to-day activities/choices. However, individuals' specific circumstances, such as experiencing the onset of chronic disease, could make these daily decisions and choices more important for that individual and life changing. Huggins *et al.*[40] surveyed young patients suffering from hydroa vacciniforme and suggested that both the type of chronic condition and the duration of disease (median age at onset 7 years) influenced the impact on quality of life. Concerning the Children's Dermatology Life Quality Index (CDLQI) responses, 63.6% patients ($n = 11$, age 9–17 years) reported impact on going out, playing and hobbies, 54.5% reported impact on choice of clothing, and 36.4% reported impact on swimming and sports activities. On their Dermatology Life Quality Index (DLQI) responses 75% adult patients ($n = 4$, age ≥ 18 years and over) reported that their skin condition influenced their choice of clothing. It is understandable that disease-related aesthetic reasons and embarrassment (50%) could play an important part in influencing patients to view simple decisions such as choice of clothing or swimming as 'major decisions' as they involve change in their lifestyle and image, which patients may feel to be wrongly perceived by others. In another study Hon *et al.*[41] found that young girls with atopic dermatitis had more problems concerning clothes or shoes than boys, indicating the importance of gender on disease influence on specific aspects of patients' lives. Decisions about lifestyle, for example smoking, drinking and over-eating, may have serious consequences on health.[42] Any decision to modify these habits may determine an individual's future health, reflecting the significance of lifestyle-related decisions. Similarly, other health-related decisions such as the decision over choice of treatment (whether surgery or medication) could be life changing for a patient.[43–45]

Are the long-term impacts of diseases being measured?

It is important to understand the long-term impacts of a chronic disease as these impacts may change over time. Understanding long-term impacts may assist clinicians in developing better management plans for patients.

Several studies have assessed the quality of life impact experienced by patients who had suffered from chronic diseases for a long period of time.[46–54] However, these studies predominantly assessed current experiences and were not specifically designed to assess the long-term impact. Similarly, in follow-up studies the assessment of disease impact mainly compares current impacts, and the changes which have occurred in the level of current impact over a period of time.[55–62] This may not reflect the different type of impacts that the patient has experienced over the intervening years. To record the true long-term impact, it would be necessary to ask patients how their illness has affected them over the full period of their illness. Such a holistic exploratory retrospective approach could provide a new insight into the nature of the long-term impacts faced by patients during different stages of their life including newly affected domains, such as health-related major life changing decisions.

Discussion

Some negative life events (e.g. chronic illness, accident, injury) may influence major life decisions such as marriage, divorce, job, education, having children, moving abroad, moving house and retirement. For example, a diagnosis of chronic illness may influence an important life decision related to employment, such as whether to carry on in full-time work or take a part-time job or retire early, which might be a good option from the perspective of health. Such a decision might seem simple but in fact may be very difficult to make because the consequences of the decision may result in financial difficulties, which may lead to other problems related to the patient's mortgage, lifestyle, family and relationships. This knock-on effect may lead to further health deterioration. Although studies included in this review were not designed to capture the influence of chronic diseases on major life changing decisions, some of their findings aid our understanding of this novel aspect of health-outcome research.

Kimball *et al.*[63] reviewed the long-term impact of psoriasis and proposed the concept of 'Cumulative Life Course Impairment' (CLCI). This concept results from an interaction between '(a) the burden of stigmatization and physical and psychological co-morbidities and (b) coping strategies and external factors'.[63] The concept of CLCI as described[63] does not specifically address the impact of psoriasis on major life changing decisions. However, if a major life changing decision is influenced by psoriasis, this is likely to contribute to CLCI,[64] and indeed it may be that influences on major life changing decision are of equal or greater importance than stigmatization and coping strategies in contributing to CLCI.

In other words, one negative life event, such as onset of a chronic disease, may influence decisions relating to several subsequent life events, such as choice over education, career, employment, marriage, housing, having children and moving abroad.

It is obvious that the life decisions that a patient makes are normally intended to gain the desirable outcome of a better life. However, not every life decision turns out to be a positive or a correct decision. After the diagnosis of a chronic or life-threatening condition, acceptance is usually a great challenge for patients. Patients search all available avenues for a cure and may take a considerable time to realize that they might have to live with the condition for the rest of their lives. A change in attitude to acceptance may give a patient motivation for the future but life changing decisions and related choices may remain very limited due to the ongoing illness and other health-related factors, such as severity, depression or treatment. Therefore, the desired future outcome may not be as successful as it would be in disease-free individuals. Decisions at the right time about higher education and early career development or having children are important as part of the natural course of life and occur at different life stages, but the continuous long-term impact of chronic disease on patients' lives may influence these decisions. Patients might either decide differently or might delay their decision. This is where health providers and clinicians may play a very important role to warn patients at an early stage about the long-term consequences of chronic disease, which in turn not only might minimize the disease impact on patients lives, particularly on major life changing decisions, but also reduce the burden on the health system.

Conclusion

There is little specific information in the literature about the impact of chronic diseases on major life changing decisions. There is no defined measure to capture this vital information. Up to now the assessment of the long-term impacts of a disease has been based on the repeated evaluation of its current impacts on patients' lives, thereby, potentially missing major aspects of the impact. Important specific questions remain unanswered: what is the definition of a 'major life changing decision'? How do patients take their life changing decisions while suffering from long-term health problems? To what extent do chronic diseases influence major life changing decisions? What influential factors are involved in life changing decision-making? How capable are patients to take appropriate life changing decisions? There is a need for strategies for healthcare providers to assist patients to take appropriate decisions and allow them to maximize their control over their lives.

The lack of knowledge in this area revealed by this review suggests new areas for research. In addition to both follow-up and prospective research techniques, exploratory retrospective research methodology is essential to understand the magnitude of the influence of chronic diseases on life changing decisions. This review has highlighted a novel dimension to health-related outcome research, the new domain of 'major life changing decisions'. Encompassing this concept may make health-related quality of life estimation closer to reality. There is a need for multidisciplinary research to capture fundamental information for further conceptualization, to determine the definition of health-associated major life changing decisions, to create a suitable instrument for its measurement, to assess the feasibility of this new concept as a new measurable dimension and to assess its possible implications on patients' lives and on healthcare resources.

References

1 Salek MS. *Compendium of Quality of Life Instruments. Volumes 1–5.* Chichester: John Wiley & Sons, 1998
2 Salek MS. *Compendium of Quality of Life Instruments. Volumes 6–7.* Haslemere: Euromed Communications, 2007
3 Bauer JJ, McAdams DP, Sakaeda AR. Crystallization of desire and crystallization of discontent in narratives of life changing decisions. *J Pers* 2005;**73**:1181–213
4 Berns GS, Laibson D, Loewenstein G. Intertemporal choice-toward an integrative framework. *Trends Cogn Sci* 2007;**11**:482–8
5 Barnack JL, Chrisler JC. The experience of chronic illness in women: a comparison between women with endometriosis and women with chronic migraine headaches. *Women Health* 2007;**46**:115–33
6 Nussbaum JF, Baringer D, Kundrat A. Health, communication,, aging: cancer, older adults. *Health Commun* 2003;**15**:185–92
7 Stevens PE, Hildebrandt E. Life changing words: Women's responses to being diagnosed with HIV Infection. *Adv Nurs Sci* 2006;**29**:207–21
8 King LA, Scollon CK, Ramsey C. Stories of life transition: Subjective well-being and ego development in parents of children with Down syndrome. *J Res Pers* 2000;**34**:509–36
9 Miller NC, Askew AE.Tibia fracture. An overview of evaluation and treatment. *Orthop Nurs* 2007;**26**:216–23
10 Fisher GS, Emerson L, Firpo C, Ptak J, Wonn J, Bartolacci G. Chronic pain and occupation: an exploration of the lived experience. *Am J Occup Ther* 2007;**61**:290–302
11 Fisher MA, Taylor GW, Shelton BJ, Debanne SM. Sociodemographic characteristics and diabetes predict invalid self-reported non-smoking in a population-based study of U.S. adults. *BMC Public Health* 2007;**7**:33
12 Smith M. Efficacy of specialist versus non-specialist management of spinal cord injury within the UK. *Spinal Cord* 2002;**40**:6–10
13 Robinson-Smith G. Prayer after stroke. Its relationships to quality of life. *J Holist Nurs* 2002;**20**:352–66
14 Cassidy B, Clarke A, Shahtahmasebi S. Quality of life: information and learning resources in supporting people with severe life changing injuries to return to independence. *Scientific World Journal* 2004;**4**:536–43

15 Kadir RA, Sabin CA, Goldman E, Pollard D, Economides DL, Lee CA. Reproductive choices of women in families with haemophilia. *Haemophilia* 2000;**6**:33–40

16 Smith CO, Lipe HP, Bird TD. Impact of presymptomatic genetic testing for hereditary ataxia and neuromuscular disorders. *Arch Neurol* 2004;**61**:875–80

17 Cameron LD, Muller C. Psychosocial aspects of genetic testing. *Curr Opin Psychiatry* 2009;**22**:218–23

18 Lim J, Macluran M, Price M, Bennett B, Butow P. Short and long-term impact of receiving genetic mutation results in women at increased risk for hereditary breast cancer. *J Genet Couns* 2004;**13**:115–33

19 Rempel GR, Cender LM, Lynam MJ, Sandor GG, Farquharson D. Parents' perspectives on decision making after antenatal diagnosis of congenital heart disease. *J Obstet Gynecol Neonatal* 2004;**33**:64–70

20 Dow KH. Having children after breast cancer. *Cancer Pract* 1994;**2**:407–13

21 Craft SM, Delaney RO, Bautista DT, Serovich JM. Pregnancy decisions among women with HIV. *AIDS Behav* 2007;**11**:927–35

22 Anderson JO, Martin PG. Narratives and healing: Exploring one family's stories of cancer survivorship. *Health Commun* 2003;**15**:133–43

23 Ganong LH, Coleman M. Remarriage and health. *Res Nurs Health* 1991;**14**:205–11

24 Gove WR, Hughes M, Style CB. Does marriage have a positive effect on the psychological well-being of the individual? *J Health Soc Behav* 1983;**24**:122–31

25 Rose CE, Mirowsky J, Goldsteen K. The impact of the family on health: The decade in review. *J Marriage Fam* 1990;**52**:1059–78

26 Renne KS. Health and marital experience in an urban population. In: DeBurger JE, ed. *Marriage today: Problems, issues, and alternatives*. New York, NY: Shenkman, 1977:304–31

27 Albrecht SL, Babr HM, Goodman KL. *Divorce and Remarriage: Problems, Adaptations, and Adjustment*. Westport, CT: Greenwood Press, 1983

28 Wilson SE, Waddoups SL. Good marriages gone bad: Health mismatches as a cause of later-life marital dissolution. *Popul Res Policy Rev* 2002;**21**:505–33

29 Burman B, Margolin G. Analysis of the association between marital relationships and health problems: an interactional perspective. *Psychol Bull* 1992;**112**:39–63

30 Roth-Roemer S, Kurpius SER. Beyond marital status: an examination of marital quality and well-being among women with rheumatoid arthritis. *Womens Health* 1996;**2**:195–205

31 Goodwins SS. The marital relationship and health in women with chronic fatigue and immune dysfunction syndrome: views of wives and husbands. *Nurs Res* 1997;**46**:138–46

32 Cannon CA, Cavanaugh JC, Delaware U. Chronic illness in the context of marriage: a systems perspective of stress and coping in chronic obstructive pulmonary disease. *Fam Syst Health* 1998;**16**:401–18

33 Seidler EM, Kimball AB. Socioeconomic disability in psoriasis. *Br J Dermatol* 2009;**161**:1410–12

34 Fine JD, Johnson LB, Weiner M, Suchindran C. Impact of inherited epidermolysis bullosa on parental interpersonal relationships, marital status and family size. *Br J Dermatol* 2005;**152**:1009–14

35 Cvetkovski RS, Zachariae R, Jensen H, Olsen J, Johansen JD, Agner T. Prognosis of occupational hand eczema: a follow-up study. *Arch Dermatol* 2006;**142**:305–11

36 Meding B, Wrangsjo K, Järvholm B. Fifteen-year follow-up of hand eczema: persistence and consequences. *Br J Dermatol* 2005;**152**:975–80

37 Finlay AY. Measures of the effect of adult severe atopic eczema on quality of life. *J Eur Acad Dermatol Venereol* 1996;**7**:149–54

38 Malcomson KS, Lowe-Strong AS, Dunwoody L. What can we learn from the personal insights of individuals living and coping with multiple sclerosis? *Disabil Rehabil* 2008;**30**:662–74

39 Arnold LM, Crofford LJ, Mease PJ, *et al*. Patient perspective on the impact of fibromyalgia. *Patient Educ Couns* 2008;**73**:114–20

40 Huggins RH, Leithauser LA, Eide MJ, Hexsel CL, Jacobsen G, Lim HW. Quality of life assessment and disease experience of patient members of a web-based hydroa vacciniforme support group. *Photodermatol Photoimmunol Photomed* 2009;**25**:209–15

41 Hon KLE, Leung TF, Wong KY, Chow CM, Chuh A, Ng PC. Does age or gender influence quality of life in children with atopic dermatitis? *Clin Exp Dermatol* 2008;**33**:705–9

42 Wright P, Belt S, John C. Helping people assess the health risks from lifestyle choices: Comparing a computer decision aid with customized printed alternative. *Commun Med* 2004;**1**:183–92

43 Mastaglia B, Kristjanson LJ. Factors influencing women's decisions for choice of surgery for stage-I and stage-II breast cancer in Western Australia. *J Adv Nurs* 2001;**35**:836–47

44 McHugh GA, Luker KA. Influence on individuals with osteoarthritis in deciding to undergo a hip or knee joint replacement: A qualitative study. *Disabil Rehabil* 2009;**31**:1257–66

45 Warren RB, Griffiths CEM. Systemic therapies for psoriasis: methotrexate, retinoids, and cyclosporine. *Clin Dermatol* 2008;**26**:438–47

46 Finlay AY, Coles EC. The effect of severe psoriasis on the quality of life of 369 patients. *Br J Dermatol* 1995;**132**:236–44

47 Rapp SR, Feldman SR, Exum ML, Fleischer AB, Reboussin DM. Psoriasis causes as much disability as other major medical diseases. *J Am Acad Dermatol* 1999;**41**:401–7

48 Krueger G, Koo J, Lebwohl M, Menter A, Stern RS, Rolstad T. The Impact of Psoriasis on Quality of Life: Result of a 1998 National Psoriasis Foundation Patient-Membership Survey. *Arch Dermatol* 2001;**137**:280–4

49 Zachariae R, Zachariae H, Blomqvist K, *et al*. Self reported stress reactivity and psoriasis-related stress of Nordic psoriasis sufferers. *J Eur Acad Dermatol Venereol* 2004;**18**:27–36

50 Alonso J, Ferrer M, Gandek B, *et al*. Health-related Quality of Life associated with chronic conditions in eight countries: results from the International Quality of Life Assessment (IQOLA) Project. *Qual Life Res* 2004;**13**:283–98

51 Ampon RD, Williamson M, Correll PK, Marks GB. Impact of asthma on self-reported health status and Quality of Life: a population based study of Australians aged 18–64. *Thorax* 2005;**60**:735–9

52 Saarni SL, Harkanen T, Sintonen H, *et al.* The impact of 29 chronic conditions on health-related Quality of Life: A general population survey in Finland using 15D and EQ-5D. *Qual Life Res* 2006;**15**:1403–14

53 Barnett M. Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences *J Clin Nurs* 2005;**14**:805–12

54 Hagren B, Pettersen IM, Severinsson E, Lutzen K, Clyne N. Maintenance haemodialysis: patients' experiences of their life situation. *J Clin Nurs* 2005;**14**:294–300

55 Husser EK, Roberto KA. Older women with cardiovascular disease: perception of initial experience and long-term influences on daily life. *J Women Aging* 2009;**21**:3–18

56 Saha SK, Khan NZ, Ahmed AS, *et al.* Neurodevelopmental sequelae in pneumococcal meningitis in Bangladesh: a comprehensive follow-up study. *Clin Infect Dis* 2009;**48**: S90–S96

57 Kuriya B, Gladman DD, Ibanez D, Urowitz MB. Quality of Life over time in patients with systemic lupus erythematosus. *Arthritis Rheum* 2008;**59**:181–5

58 Chen H, Cohen P, Kasen S, Johnson JG, Berenson K, Gordon K. Impact of adolescent mental disorders and physical illnesses on Quality of Life 17 years later. *Arch Pediatr Adolesc Med* 2006;**160**:93–9

59 Sillanpaa M, Haataja L, Shinnar S. Perceived impact of childhood-onset epilepsy on Quality of Life as an adult. *Epilepsia* 2004;**45**:971–7

60 Huurre TM, Aro HM. Long-term psychosocial effects of persistent chronic illness. A follow-up study of Finnish adolescents aged 16 to 32 years. *Eur Child Adolesc Psychiatry* 2002;**11**:85–91

61 Heald AH, Ghosh S, Bray S, *et al.* Long-term negative impact on quality of life in patients with successfully treated Cushing's disease. *Clin Endocrinol* 2004;**61**:458–65

62 Beattie PE, Dawe RS, Ibbotson SH, Ferguson J. Characteristics and prognosis of idiopathic solar urticaria. *Arch Dermatol* 2003;**139**:1149–54

63 Kimball AB, Gieler U, Linder D, Sampogna F, Warren RB, Augustin M. Psoriasis: is the impairment to a patient's life cumulative? *J Eur Acad Dermatol Venereol* 2010;**24**:989–1004

64 Bhatti ZU, Salek MS, Finlay AY. Major Life Changing Decisions and Cumulative Life Course Impairment. *J Eur Acad Dermatol Venereol* 2011;**25**:245–6

F Tjeerdsma,[†] MF Jonkman,[‡] JR Spoo[‡,*]
[†]Department of Intensive Care, De Tjongerschans Hospital, Heerenveen, The Netherlands
[‡]Department of Dermatology, University Medical Centre Groningen, Groningen, The Netherlands
*Correspondence: JR Spoo. E-mail: j.r.spoo@derm.umcg.nl

References

1 Ahmad N, Mukhtar H. Cutaneous photochemoprotection by green tea: a brief review. *Skin Pharmacol Appl Skin Physiol* 2001; **14**: 69–76.
2 Morley N, Clifford T, Salter L *et al.* The green tea polyphenol (-)-epigallocatechin gallate and green tea can protect human cellular DNA from ultraviolet and visible radiation-induced damage. *Photodermatol Photoimmunol Photomed* 2005; **21**: 15–22.
3 Elmets CA, Singh D, Tubesing K *et al.* Cutaneous photoprotection from ultraviolet injury by green tea polyphenols. *J Am Acad Dermatol* 2001; **44**: 425–432.
4 Katiyar SK, Perez A, Mukhtar H. Green tea polyphenol treatment to human skin prevents formation of ultraviolet light B-induced pyrimidine dimers in DNA. *Clin Cancer Res* 2000; **6**: 3864–3869.
5 Lou YR, Lu YP, Xie JG *et al.* Effects of oral administration of tea, decaffeinated tea, and caffeine on the formation and growth of tumors in high-risk SKH-1 mice previously treated with ultraviolet B light. *Nutr Cancer* 1999; **33**: 146–153.
6 Mantena SK, Meeran SM, Elmets CA, Katiyar SK. Orally administered green tea polyphenols prevent ultraviolet radiation-induced skin cancer in mice through activation of cytotoxic T cells and inhibition of angiogenesis in tumors. *J Nutr* 2005; **135**: 2871–2877.
7 Paul B, Hayes CS, Kim A *et al.* Elevated polyamines lead to selective induction of apoptosis and inhibition of tumorigenesis by (-)-epigallocatechin-3-gallate (EGCG) in ODC/Ras transgenic mice. *Carcinogenesis* 2005; **26**: 119–124.
8 Wang ZY, Huang MT, Ferrare T *et al.* Inhibitory effect of green tea in the drinking water on tumorigenesis by ultraviolet light and 12-O-tetradecanoylphorbol-13-acetate in the skin of SKH-1 mice. *Cancer Res* 1992; **1**: 1162–1170.
9 Zhao JF, Zhang YJ, Jin XH *et al.* Green tea protects against psoralen plus ultraviolet A-induced photochemical damage to skin. *J Invest Dermatol* 1999; **113**: 1070–1075.
10 Hebert JL, Khugyani F, Athar M *et al.* Chemoprevention of basal cell carcinomas in the ptc1+/− mouse – green and black tea. *Skin Pharmacol Appl Skin Physiol* 2001; **14**: 358–362.

DOI: 10.1111/j.1468-3083.2010.03722.x

Major life changing decisions and cumulative life course impairment

Editor

The proposal by Kimball *et al.*[1] of the concept of Cumulative Life Course Impairment (CLCI) is an important step forward in enhancing our appreciation of the wider burden of psoriasis. The authors state that 'CLCI results from an interaction between the burden of stigmatization and physical and psychological co-morbidities and coping strategies and external factors.' However, an additional critical potential influence on CLCI is the impact of psoriasis on Major Life Changing Decisions (MLCDs). We have been exploring this related, but separate concept both in dermatology[2,3] and across several medical specialties including cardiology,[4] respiratory medicine,[5] cystic fibrosis,[5] diabetes,[6] nephrology[7] and rheumatology.[8]

In 50 patients with chronic skin diseases, including 16 patients with psoriasis, the percentage of patients in whom MLCDs were affected by the skin diseases relating to career choice was 66%, job 58%, relationships 52%, education 44%, moving abroad 32%, having children 22%, early retirement 20%, housing 14% and moving to another city 12%,[3] It is clear therefore that chronic skin disease has a profound impact on these critical decisions in people's lives.

Several key influential factors on MLCDs have been identified including ill health and severity of disease, embarrassment, appearance, stress, fear and anxiety, frequent hospital visits and treatment, public attitude, risk to health, physical disability, working conditions and depression.[2,5–8] Some of these have also been noted by Kimball *et al.*[1] as being integral influences on CLCI, thereby emphasizing that CLCI and the impact on MLCDs are different aspects of the wider reality experienced by the patient.

While not all MLCDs that are influenced by chronic skin disease are necessarily negative in their outcome, several MLCDs such as the decision not to have children or not to continue in a particular career may add to the cumulative impairment caused by the disease.

It is of note that the types of MLCDs influenced by skin disease are similar to those affected by other non-dermatological disease, emphasizing that these issues are of importance across the whole of medicine and not confined to psoriasis or skin disease.

ZU Bhatti,[†,*] MS Salek,[‡] AY Finlay[†]
[†]Department of Dermatology and Wound Healing, School of Medicine, Cardiff CF14 4XN, UK
[‡]Centre for Socioeconomic Research, School of Pharmacy, Cardiff University, Cardiff CF10 3NB, UK
*Correspondence: ZU Bhatti. E-mail: drzaheer121@hotmail.com

References

1 Kimball AB, Gieler U, Linder D *et al.* Psoriasis: is the impairment to a patient's life cumulative? *J Eur Acad Dermatol Venereol* 2010; **24**: 989–1004.
2 Bhatti ZU, Finlay AY, Salek S. Chronic skin diseases influence major life changing decisions: a new frontier in health outcome research. *Br J Dermatol* 2009; **161**(Suppl. 1): 58–59.
3 Bhatti ZU, Salek S, Finlay AY. The influence of chronic skin diseases on major life-changing decisions as a parameter for the assessment of long-term impact. *Br J Dermatol* 2010; **163**(Suppl 1): 39–40.
4 Bhatti ZU, Finlay AY, Salek MS, Halcox JJ. The full impact of chronic cardiovascular diseases cannot be measured without an assessment of life decisions. *J Heart Dis* 2010; **7**(1): 71.
5 Bhatti ZU, Finlay AY, Salek S, Ketchell IR, Bolton CE. Chronic respiratory diseases strongly influence major life changing decisions. *Thorax* 2009; **64**(Suppl. IV): A75–A174.

6 Bhatti ZU, Finlay AY, Salek MS, George LD. Diabetes influence on major life changing decisions: should this be an area of concern in management of patients? *Diabet Med* 2010; **27**(suppl. 1): 1–36.
7 Bhatti Z, Salek M, Finlay A, Moore R. Chronic Kidney Disease influences important life changing decisions over time. Abstract Book BRS/RA Conference 2010; Manchester: 174.
8 Bhatti ZU, Salek SS, Finlay AY, Jones SM. Better understanding of the influence of rheumatic disorders on major life changing decisions. *Ann Rheum Dis* 2010; **69**(Suppl 3): 715.

DOI: 10.1111/j.1468-3083.2010.03930.x

Re. major life-changing decisions and cumulative life course impairment

Editor

We wish to thank Drs. Bhatti, Salek and Finlay for their comments, and also to recognize their substantial contributions to the field. We absolutely agree with their supposition that major life-changing decisions (MLCDs) can be substantially affected by skin disease and may add to the cumulative impairment of disease. We have three additional observations to make regarding the importance of MLCDs:

1 First, many of these decisions, such as marriage, career choice, education and child bearing, occur relatively early in most people's lives. We draw attention to the life-course models, and specifically the 'critical period model' proposed by Kuh and Ben-Shlomo.[1,2] The concept of critical and sensitive periods is applicable, and we postulate that the onset of psoriasis during critical or sensitive periods (e.g. adolescence and early adulthood), when a majority of these MLCDs are made, will have a greater impact on life course than later onset of psoriasis. Given that one of the peaks of psoriasis onset occurs in the late teens, this population may be particularly vulnerable to the effects of disease on MLCDs. In contrast, patients who are affected by psoriasis later in life in their 40s and 50s are likely to be more established in their career and relationships, having made many MLCDs earlier; thus, the effects of psoriasis may be less apparent. Data showing improved quality of life in older patients with similar disease severity support this concept.[3,4] Treatment plans and the risk–benefit ratio may therefore be somewhat different in this younger population, but further research is required to understand the impact of psoriasis in this group.
2 Secondly, the effects of MLCDs may magnify each other and not simply be additive. For example, poor economic status may also affect education and social status.
3 Lastly, we agree that these concepts are likely applicable to other chronic diseases in non-dermatological areas.

We continue to develop the concept of Cumulative Life Course Impairment (CLCI) in psoriasis. Specifically, we are investigating further the concept of critical time periods to understand the relative impact of various exposures on outcomes in CLCI. We look forward to seeing how this patient-centric concept and its attendant research will evolve.

AB Kimball,[†,*] U Gieler,[‡] D Linder,[§] F Sampogna,[¶]
RB Warren,[**] M Augustin[††]
[†]Department of Dermatology, Harvard Medical School, Boston, MA, USA
[‡]Department of Psychosomatic Medicine and Psychotherapy, Justus-Liebig-University Giessen, Giessen, Germany
[§]Dermatology University Clinic, Padua, Italy
[¶]Istituto Dermopatico dell'Immacolata IDI-IRCCS, Rome, Italy
[**]Dermatological Sciences, The University of Manchester, Manchester Academic Health Sciences Centre, Salford Royal Foundation Trust, Manchester, UK
[††]CVderm – German Center for Health Services Research in Dermatology, University Clinics of Hamburg, Hamburg, Germany
[*]Correspondence: Dr AB Kimball.
E-mail: harvardskinstudies@partners.org

References

1 Ben-Shlomo Y, Kuh D. A life course approach to chronic disease epidemiology: conceptual models, empirical challenges, and interdisciplinary perspectives. *Int J Epidemiol* 2002; **31**: 285–293.
2 Kuh D, Ben-Shlomo Y. Introduction. In Kuh D, Ben-Shlomo Y, eds. *A Life Course Approach to Chronic Disease Epidemiology*, 2nd edn. Oxford University Press, Oxford, 2004; 3–14.
3 Jobling R, Naldi L. Assessing the impact of psoriasis and the relevance of qualitative research. *J Invest Dermatol* 2006; **126**: 1438–1440.
4 Gelfand JM, Feldman SR, Stern RS, Thomas J, Rolstad T, Margolis DJ. Determinants of quality of life in patients with psoriasis: a study from the US population. *J Am Acad Dermatol* 2004; **51**: 704–708.

DOI: 10.1111/j.1468-3083.2010.03931.x

Online Coverage

Interview published in Medical Independent (accessed 10th December 2010)

British Association of Dermatology calls for patient-centred disease treatment

Judith Leavy | 09 Dec 2010 | 0 Comment(s)

Treatment of chronic skin diseases need to target physical, psychological, and social issues, Judith Leavy reports

Researchers from the British Association of Dermatologists say that recent findings on major life-changing decisions (MLCDs) among dermatology patients strongly suggest that the future of chronic skin disease treatment should be patient centred and should cover the patient's physical, psychological, social and MLCDs domain.

Data presented at the British Association of Dermatologists' conference in Manchester showed that 90 per cent of patients with a chronic skin condition said it had influenced a major life-changing decision, with 22 per cent saying that their disease had even influenced their decision on whether or not to have children.

Speaking to the *Medical Independent*, Dr Zaheer Bhatti, a consultant dermatologist in Bristol and research group leader said: "Being a dermatologist having a special interest in the impact of chronic skin diseases on patients' QoL and in health outcome research, we were aware of long-term impacts and noticed that some patients had taken different life decisions only because of their chronic skin condition.

'For example, MLCDs related to education, career choice, relationships, job and early retirement.

"At the start of our survey we were not sure about the magnitude of the impact on patients' MLCDs and in what ways chronic skin diseases had influenced their MLCDs. "Our literature review yielded no information from health and MLCDs perspective studies which increased our curiosity and determination to gain insight knowledge in this new area."

The research group focused on people with long-term skin diseases in both individual interviews and focus group discussions.

Related on the site

- The benefits of hydrotherapy
- Dementia services information and development centre seminar
- Helping the recently bereaved
- Men more willing to talk about the effects of ED

Share this

LATEST ON THE SITE »

- Irish charity opens Kenyan eye clinic
- HEMS still up in the air
- Metabolic bone disease as a differential in childhood illness
- The budget ruined my portfolio
- Capture the moment
- The Dorsal View - January 13th 2011

CONNECT WITH US

"We were surprised to see not only the magnitude of the disease influence on MLCDs but also about how minor and routine life decisions can become MLCDs for patients; particularly decisions related to choice of clothing, wearing makeup, not to go swimming, and withdrawal from social activities," Dr Batti said.

Similarly, decisions related to travelling and holidaying abroad were also reported as MLCDs by a considerable number of patients. Decisions to have children, moving abroad, moving to another city and decisions related to housing appeared to be more major and important than we initially anticipated.

Dr Bhatti and his team were also surprised at the way patients reported how the severity of their disease impacted hugely on their life decisions, with 82 per cent of patients reporting that these were affected by ill health and severity, embarrassment (78 per cent), appearance (74 per cent), lack of confidence/self consciousness (74 per cent), and stress and anxiety (64 per cent).

"We designed our survey in order to evaluate the longterm impact of chronic diseases on patients' lives, particularly on MLCDs. We asked our research questions retrospectively so that patients could look back on their lives and see whether their chronic skin disease had influenced any MLCDs over time.

"The majority of patients were suffering for very long periods of time (mean disease duration at individual interviews was 29 years, while among focus groups the average disease duration was 15.2 years) and was necessary to obtain the information from their life-time experience," said Dr Bhatti.

With psoriasis affecting about 2 per cent of the population and eczema affecting at least one in six school children and about one in 20 adults, the survey was designed to evaluate the long-term impact of chronic diseases on patients' lives.

Due to the fact that the impact of skin disease is so immense, the group stressed that patients should be advised about the consequences of chronic skin disease and should be supported by health professionals and new pharmacological advancements.

The authors added that public awareness and understanding should be included as part of a broader approach.

Dr Bhatti stressed the need for early patient education about the long-term effects of chronic skin diseases, saying: "Clinician understanding is vital so that patients can be warned early about the longterm consequences of the disease.

MOST COMMENTED ON THE SITE »

Consultant group launches protest website on new national paediatric hospital

University Hospital Galway teams with Sudan on diabetes training project

Boots pharmacists first in Ireland to offer vaccines

Irish ambulance services in a state of emergency

Under the radar

Will the last doctor to leave Ireland please turn the lights off

UPCOMING EVENTS »

20 Jan 2011
Irish Meteorological Society's lecture on 'Solar disinfection of drinking water', RCSI, Dublin

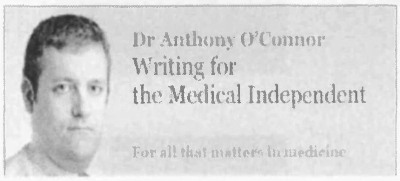
25 Jan 2011
7th National Health Summit, Croke Park Conference Centre, Dublin

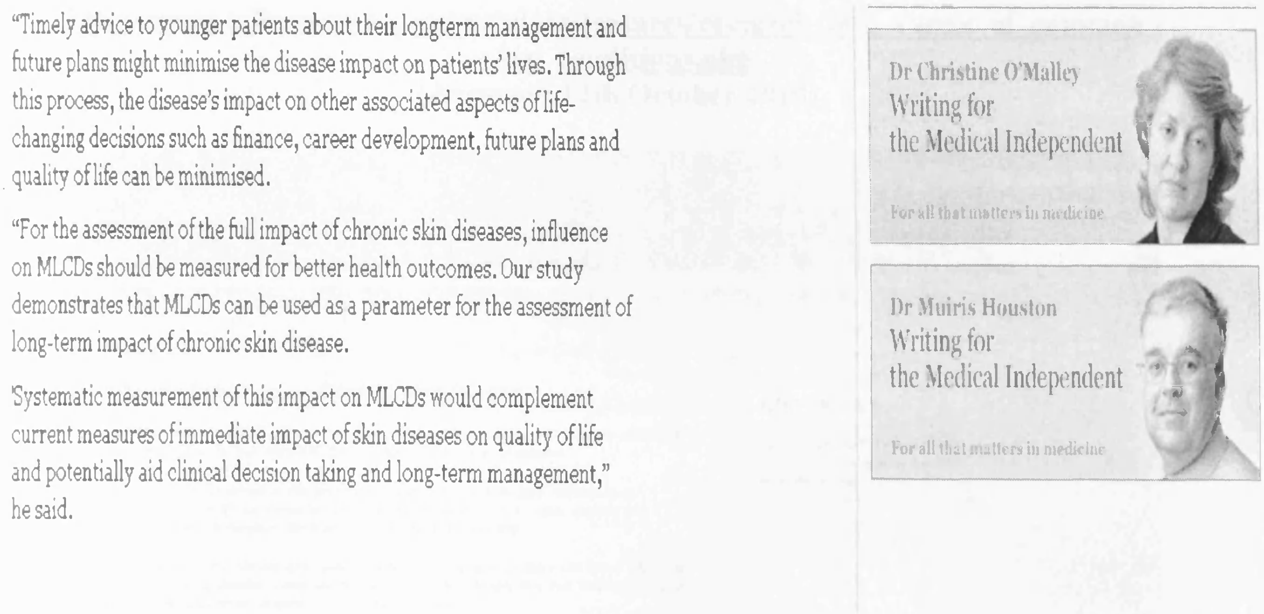
26 Jan 2011
Dean Clinic's GP Education Evening, The Maryborough Hotel, Maryborough Hill, Douglas, Cork

26 Jan 2011
RCSI Mini-Med Open Lecture series: 'Advanced Diagnostics in Cardiovascular Disease', Dublin

29 Jan 2011
Annual GP study day, UPMC Beacon Hospital, Sandyford, Dublin 18

02 Feb 2011
RCPI hosts a Masterclass on Clinical Pharmacology, Kildare Street, Dublin 2



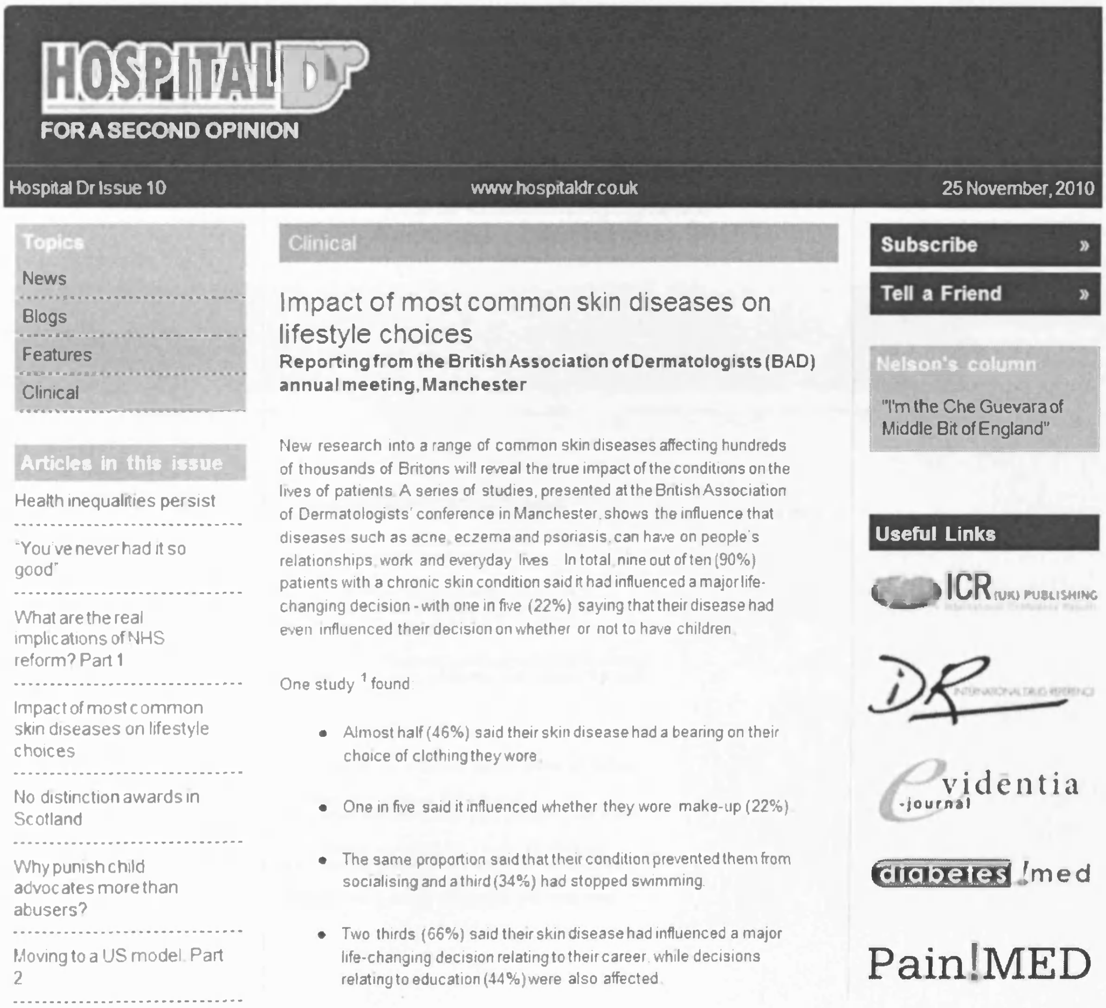


"Timely advice to younger patients about their longterm management and future plans might minimise the disease impact on patients' lives. Through this process, the disease's impact on other associated aspects of life-changing decisions such as finance, career development, future plans and quality of life can be minimised.

"For the assessment of the full impact of chronic skin diseases, influence on MLCDs should be measured for better health outcomes. Our study demonstrates that MLCDs can be used as a parameter for the assessment of long-term impact of chronic skin disease.

'Systematic measurement of this impact on MLCDs would complement current measures of immediate impact of skin diseases on quality of life and potentially aid clinical decision taking and long-term management," he said.

http://imi.newsweaver.ie/55x1zmuutcc?email=true
(Accessed 25th November 2010)



Impact of most common skin diseases on lifestyle choices

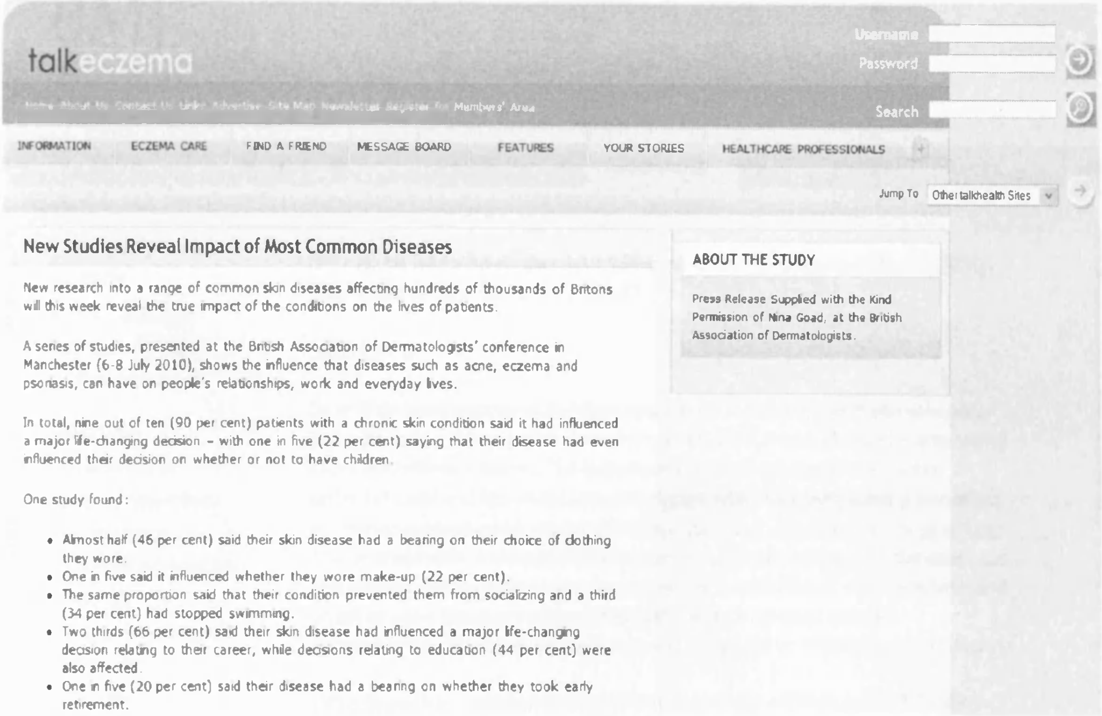
Reporting from the British Association of Dermatologists (BAD) annual meeting, Manchester

New research into a range of common skin diseases affecting hundreds of thousands of Britons will reveal the true impact of the conditions on the lives of patients. A series of studies, presented at the British Association of Dermatologists' conference in Manchester, shows the influence that diseases such as acne, eczema and psoriasis, can have on people's relationships, work and everyday lives. In total, nine out of ten (90%) patients with a chronic skin condition said it had influenced a major life-changing decision - with one in five (22%) saying that their disease had even influenced their decision on whether or not to have children.

One study [1] found:

- Almost half (46%) said their skin disease had a bearing on their choice of clothing they wore.
- One in five said it influenced whether they wore make-up (22%).
- The same proportion said that their condition prevented them from socialising and a third (34%) had stopped swimming.
- Two thirds (66%) said their skin disease had influenced a major life-changing decision relating to their career, while decisions relating to education (44%) were also affected.

http://www.talkeczema.com/webdocs/features/research_into_range_of_common_skin_conditions.php
(Accessed 12th October 2010)



New Studies Reveal Impact of Most Common Diseases

New research into a range of common skin diseases affecting hundreds of thousands of Britons will this week reveal the true impact of the conditions on the lives of patients.

A series of studies, presented at the British Association of Dermatologists' conference in Manchester (6-8 July 2010), shows the influence that diseases such as acne, eczema and psoriasis, can have on people's relationships, work and everyday lives.

In total, nine out of ten (90 per cent) patients with a chronic skin condition said it had influenced a major life-changing decision – with one in five (22 per cent) saying that their disease had even influenced their decision on whether or not to have children.

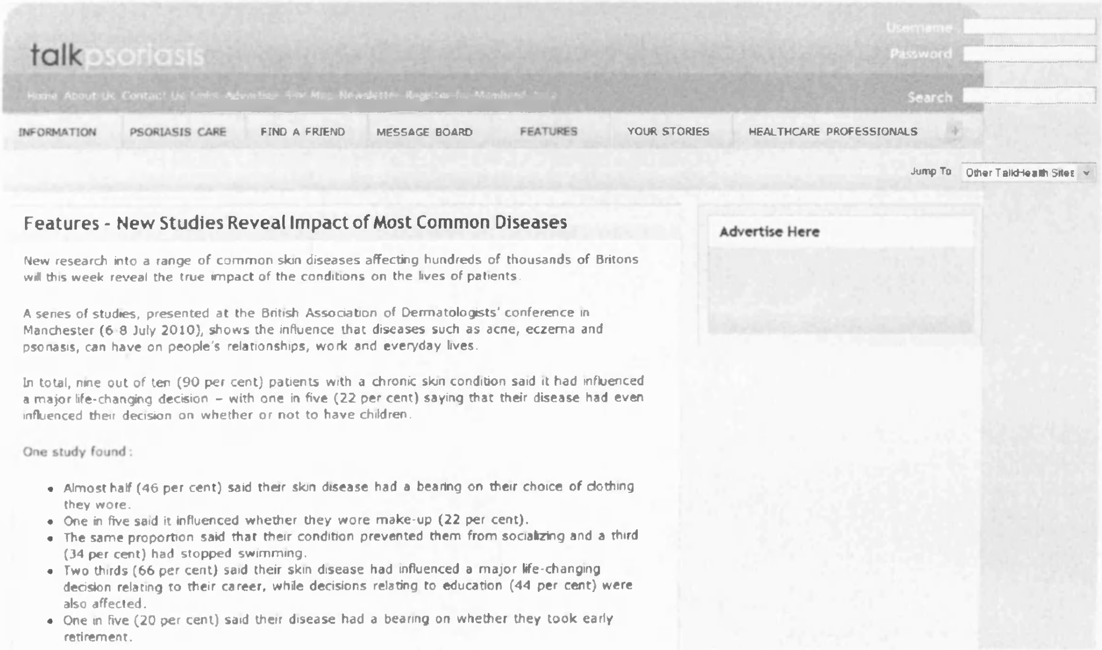
One study found:

- Almost half (46 per cent) said their skin disease had a bearing on their choice of clothing they wore.
- One in five said it influenced whether they wore make-up (22 per cent).
- The same proportion said that their condition prevented them from socializing and a third (34 per cent) had stopped swimming.
- Two thirds (66 per cent) said their skin disease had influenced a major life-changing decision relating to their career, while decisions relating to education (44 per cent) were also affected.
- One in five (20 per cent) said their disease had a bearing on whether they took early retirement.

ABOUT THE STUDY

Press Release Supplied with the Kind Permission of Nina Goad, at the British Association of Dermatologists.

http://www.talkpsoriasis.com/webdocs/features/research_into_range_of_common_skin_conditions.php
(Accessed 12th October 2010)



Features - New Studies Reveal Impact of Most Common Diseases

New research into a range of common skin diseases affecting hundreds of thousands of Britons will this week reveal the true impact of the conditions on the lives of patients.

A series of studies, presented at the British Association of Dermatologists' conference in Manchester (6-8 July 2010), shows the influence that diseases such as acne, eczema and psoriasis, can have on people's relationships, work and everyday lives.

In total, nine out of ten (90 per cent) patients with a chronic skin condition said it had influenced a major life-changing decision – with one in five (22 per cent) saying that their disease had even influenced their decision on whether or not to have children.

One study found:

- Almost half (46 per cent) said their skin disease had a bearing on their choice of clothing they wore.
- One in five said it influenced whether they wore make-up (22 per cent).
- The same proportion said that their condition prevented them from socializing and a third (34 per cent) had stopped swimming.
- Two thirds (66 per cent) said their skin disease had influenced a major life-changing decision relating to their career, while decisions relating to education (44 per cent) were also affected.
- One in five (20 per cent) said their disease had a bearing on whether they took early retirement.

Advertise Here

http://www.bmj.com/content/341/bmj.c3842.full
(Accessed 14th August 2010)

BMJ 2010;341:c3842 doi:10.1136/bmj.c3842 (Published 20 July 2010)
Cite this as: BMJ 2010;341:c3842

Minerva

Scientists have successfully taken apart a rat lung and rebuilt it with new cells. The new lung exchanged oxygen and carbon dioxide for a short time after being transplanted into a live rat. The technique involved removal of the spongy epithelial cells and blood vessels of the lungs with detergent, leaving a scaffold of connective tissue that retained the mechanical properties of the original lung. The scaffold was "marinated" in a mixture of lung epithelial and endothelial cells and within a few days the engineered lung contained alveoli, microvessels, and small airways that were repopulated with the appropriate cell types (*Sciencexpress* 2010; published online 24 June, doi:10.1126/science.1189345).

What impact do common skin conditions have on the British public? Studies presented to the *British Association of Dermatologists'* conference in Manchester about acne, eczema, and psoriasis report that 90% of those afflicted say their skin has influenced a major life changing decision, and 20% say it affected their decision whether to have children. Just under half said their skin condition affected their choice of clothing, one in five said it affected whether they wore make up; the same proportion said their condition prevented them from socialising, and a third said they had stopped swimming (www.bad.org.uk).

British Association of Dermatologists
PRESS RELEASE

New studies reveal impact of most common diseases on work, relationships and even decision to have children. For immediate release, Monday July 5th, 2010

New research into a range of common skin diseases affecting hundreds of thousands of Britons will this week reveal the true impact of the conditions on the lives of patients.

A series of studies, to be presented at the British Association of Dermatologists' conference in Manchester, will show the influence that diseases such as acne, eczema and psoriasis, can have on people's relationships, work and everyday lives.

In total, nine out of ten (90 per cent) patients with a chronic skin condition said it had influenced a major life-changing decision – with one in five (22 per cent) saying that their disease had even influenced their decision on whether or not to have children.

One study* found:

- Almost half (46 per cent) said their skin disease had a bearing on their choice of clothing they wore.

- One in five said it influenced whether they wore make-up (22 per cent).

- The same proportion said that their condition prevented them from socializing and a third (34 per cent) had stopped swimming.

- Two thirds (66 per cent) said their skin disease had influenced a major life-changing decision relating to their career, while decisions relating to education (44 per cent) were also affected.

- One in five (20 per cent) said their disease had a bearing on whether they took early retirement.

Another study[1] found that skin conditions are the most frequent reason for people to consult their GP with a new problem, more so than respiratory problems, musculoskeletal disorders and mental illness.

A third study[2], relating just to psoriasis, found that:

- Two thirds of patients with severe symptoms said the disease has had a negative impact on their working life.

[m/f]

- Four out of ten (42 per cent) said the disease had limited their income, or restricted their future employment or career choice.

- A third of such patients (32 per cent) reported discrimination in the workplace on the basis of their condition, while one in five (19 per cent) said that their disease had contributed to them resigning or being dismissed from a job.

- More than a third (37 per cent) felt that, owing to their disease, they have not performed as well in education as they could have done.

- Nine out of ten (87 per cent) felt that their mood, mental health and general enjoyment of life suffers, with three-quarters (73 per cent) saying they have reduced drive and 69 per cent saying they have reduced aspirations because they have psoriasis.

- Psoriasis was also found to influence patients' personal relationships, with 67 per cent saying that their disease has prevented them pursuing intimate relationships. Three out of ten (29 per cent) have ended an intimate relationship because of their condition.

- Most patients (87 per cent) believed there to be a lack of understanding about psoriasis among the public.

Chief Executive of The Psoriasis Association, Helen McAteer said: "This is the largest UK web-based survey to assess quality of life issues in psoriasis. Our findings illustrate that severe psoriasis has a significant and long-lasting impact on people's lives in the UK – far greater than was previously appreciated."

Nina Goad of the British Association of Dermatologists said: "I work with skin disease patients on a daily basis so I am aware of the profound effect that symptoms can have on people's lives, but despite this I was still stopped in my tracks by some of the findings of this research.

"The fact that such a high number of people cite having a skin disease as a major consideration in the decision of whether to have children, or say that it has brought about the end of a relationship or caused them to stop socializing, is just so sad.

"Add to this the statistics about job losses and discrimination in the workplace, and a clear picture begins to emerge of what so many people in the UK are having to endure. Of course not all patients will be influenced to this degree, but it is worrying that so many are. And we are not talking about one rare disease here, which would be bad enough. Skin conditions are incredibly common." [m/f]

-Ends-

Notes to editors:

1. Background statistics – prevalence of skin disease

- 24% of a GP's case load is for skin conditions[1]
- 26% of people report having suffered from a skin rash/allergies/irritated skin, 13% from eczema and 12% from acne/spots, over the preceding 12 months. ('A Picture of Health'; PAGB / Reader's Digest 2005, http://www.pagb.co.uk/information/PDFs/Pictureofhealth.pdf)
- Acne affects 80 to 90% of adolescents in the UK, and for 30% of these, their acne will be severe enough to warrant medical attention. 14% of women in the UK aged between 26 and 44 suffer from facial acne.
- Psoriasis is a common skin problem affecting about 2% of the population. It occurs equally in men and women, at any age, and tends to come and go unpredictably. It is not infectious, and does not scar the skin.
- Eczema (atopic eczema) affects at least 1 in 6 school children and about 1 in 20 adults. (Patient UK - http://www.patient.co.uk/health/Atopic-Eczema.htm)
- For information on other skin diseases visit www.bad.org.uk

2. Study details

*Patients with the following diseases were interviewed: psoriasis, eczema, acne, hidradenitis suppurativa, ichthyosis, palmoplantar genodermatosis, alopecia areata, Dariers disease. The influence of chronic skin diseases on major life-changing decisions as a parameter for the assessment of long-term impact.

Z.U. Bhatti, S. Salek* and A.Y. Finlay

Department of Dermatology, School of Medicine, Cardiff University, Cardiff, Wales, U.K. and *Centre for Socioeconomic Research, Welsh School of Pharmacy, Cardiff University, Cardiff, Wales, U.K.

[1] Updated Dermatology Health Care Needs Assessment: Skin conditions are the commonest new reason people present to general practitioners in England and Wales: implications for education and training.

J. Schofield, D. Fleming,* D. Grindlay† and H. Williams†

United Lincolnshire Hospitals Trust, Lincoln, U.K.; *Royal College of General Practitioners Research and Surveillance Unit, Birmingham, U.K. and †Centre of Evidence Based Dermatology, University of Nottingham, Nottingham, U.K.

[2]Survey of 1760 UK adults. 52% defined their disease severity as 'very active' or 'extremely active' and for the purpose of this study are therefore defined as having severe psoriasis. Severe psoriasis has a greater negative effect on quality of life than previously appreciated: a U.K. web-based patient survey.

A.V. Anstey, G. Edwards* and A. Lass†
[m/f]

Aneurin Bevan Health Board, Gwent, U.K.; *Psoriasis Association, London, U.K. and †Abbott UK, Maidenhead, U.K.

Further information and contacts

If using this research, please mention that the study was released at the British Association of Dermatologists' Annual Conference.

The conference will be held at Manchester Central conference centre, from July 6th to 8th 2010, and is attended by UK and worldwide dermatologists and dermatology nurses.

Case studies and interviews with the researchers available on request.

For more information please contact: Nina Goad, British Association of Dermatologists, Communications Manager, Phone: 07825 567717, Email: nina@bad.org.uk, Website: www.bad.org.uk

The British Association of Dermatologists is the central association of practising UK dermatologists. Our aim is to continually improve the treatment and understanding of skin disease.

http://www.healthcarerepublic.com/news/988644/Diabetes-influences-life-changing-decisions/

(Accessed 5th April 2010)

Diabetes influences life-changing decisions

By Tom Moberly, 08 March 2010

Diabetes influences decisions about life-changing events for three quarters of people who have the condition, a UK study has shown.

A survey found that the diabetes affected life choices of people living with the condition (Photograph: SPL)

Cardiff University researchers believe that improved clinician awareness of this effect, and provision of appropriate support, may improve the future health and lives of people with diabetes.

The researchers surveyed 60 patients about the effect of diabetes on major life changing events. Almost 74% of patients reported that diabetes influenced their decisions regarding major life changing events.

Among the respondents, 40% said that diabetes had influenced their decision to take early retirement and 22% said it had influenced a decision to change profession.

Respondents also said that diabetes had influenced decisions to change lifestyle (22%) or have children (14%).

The findings were presented at the Diabetes UK Annual Professional Conference in Liverpool last week.

Editor's blog: Diabetes clinicians as diabetes patients

Further Reading

- Diabetes education benefits 'sustained for years'
- Threat to QOF scores for diabetes
- Journals Watch - HbA1c, proteinuria and obesity
- GPs 'should not be complacent' over diabetes improvements

mims

Related Drug Categories

- Insulins

Related MIMS Tables

- Blood Glucose Testing Strips and Meters
- Insulin Preparations
- Finger Prickers and Compatible Lancets

Related articles from trip database

- Diabetes influences life-changing decisions
- Biomarker predicts heart failure risk
- Energy drinks and alcohol addiction link discovered

See all related articles ...

GP JOBS

Search by type:

- Salaried GP
- Part-time GP
- Private GP
- Associate GP
- Registrar
- Locum

Search all GP jobs

Most read Most commented

- Healthcare Republic becomes GPonline.com
- DoH issues final plans for community services reform
- Health Bill delayed by huge response to consultation
- Public health White Paper to set out inequalities plan
- Health Headlines: Public health White Paper, hospital deaths and lung cancer in women
- Demeaning phrases stop men checking health

SIGN UP TO OUR EMAIL BULLETINS

Select your bulletins from our eight alerts on news and key topics relevant to all GPs

MEDECONOMICS FEES DATABASE

Access our unique database of NHS fees and allowances, private and professional fees

APPENDICES

Appendix 1: Ethical approval from the South East Wales Research Ethics Committee
Appendix 2: Permission from UHW Research and Development (R&D) department

Postal survey
Appendix 3: Proforma for postal survey record
Appendix A: Pre-paid self addressed envelope
Appendix B: Follow up letter to patients from chief investigator
Appendix C: Covering letter from consultant physicians
Appendix D: Participant information sheet
Appendix E: Participant consent form
Appendix F: Participant personal details sheet
Appendix G: Exploratory Qualitative Assessment Sheet

Individual interviews
Appendix H: Clinicians' invitation letter
Appendix I: Participant information sheet
Appendix J: Participant consent form
Appendix K: Participant personal details sheet

Focus groups
Appendix L: Clinicians' invitation letter
Appendix M: Participant information sheet
Appendix N: Additional information sheet for focus groups
Appendix P: Participant consent form
Appendix Q: Participant personal details sheet

Content validity
Appendix R: Questionnaire items rating sheets
Appendix S: Covering letter to panel members

Factor analysis
Appendix T: Participant information sheet
Appendix U: Participant consent form
Appendix V: Participant personal details sheet
Appendix W: Face validity and practicality questionnaire sheet
Appendix X: Correlation matrix for the 34 items of the MLCDP (version 1a)
Appendix Y: Correlation matrix for 29 items of the MLCDP

Appendix 1

COPY FOR YOUR INFORMATION

Canolfan Gwasanaethau Busnes
Business Services Centre

South East Wales Research Ethics Committee Panel C
Direct Line: 02920 376823/376822

Telephone: 02920 376822/6823
Facsimile: 02920 376835

02 June 2008

Professor A Y Finlay
Professor of Dermatology,
Cardiff University and Head of the Dermatology Department,
University Hospital of Wales,
Heath Park,
Cardiff

Dear Professor Finlay

Full title of study:	**A cross-sectional prospective study to investigate the influence of chronic diseases on major life changing decisions.**
REC reference number:	**08/WSE03/16**

Thank you for your letter of 15 May 2008, responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information has been considered on behalf of the Committee by the Chair, Mrs J Jenkins.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Canolfan Gwasanaethau Busnes
Ty Churchill
17 Ffordd Churchill
Caerdydd, CF10 2TW
Ffôn: 029 20 376820 WHTN: 1809
Ffacs: 029 20 376826

Business Services Centre
Churchill House
17 Churchill Way
Cardiff, CF10 2TW
Telephone: 029 20 376820 WHTN: 1809
Fax: 029 20 376826

NHS WALES GIG CYMRU

rhan o Addysgu Bwrdd Iechyd Lleol Powys / part of Powys Teaching Local Health Board

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application	5.5	01 April 2008
Investigator CV	S Salek	04 February 2008
Investigator CV	A Y Finlay	04 February 2008
Protocol	1.1	18 March 2008
Covering Letter	S Salek	01 April 2008
Summary/Synopsis	1	25 January 2008
Letter from Sponsor	Cardiff University	05 February 2008
Peer Review	Joint Trust & University Peer & Risk Review Committee	20 March 2008
Compensation Arrangements	UMAL	01 August 2007
Participant Information Sheet: Postal Questionnaire	1.2	15 May 2008
Participant Information Sheet: Focus Group	1.2	15 May 2008
Participant Information Sheet: Individual Interview	1.2	15 May 2008
Participant Information Sheet: Additional Information Sheet for Focus Groups	1.1	15 May 2008
Participant Consent Form: Individual Interviews	1.1	15 May 2008
Participant Consent Form: Focus Groups	1.1	15 May 2008
Participant Consent Form: Postal Questionnaire Survey	1.1	15 May 2008
Response to Request for Further Information	A Y Finlay	15 May 2008
Response to Request for Further Information	A Y Finlay	29 April 2008
Invitation for Individual Interviews	1.2	15 May 2008
Invitation for Postal Questionnaire Survey	1.1	15 May 2008
Exploratory Qualitative Assessment Sheet	1.1	15 May 2008
Participant Personal Details	1.1	15 May 2008
Flow Chart	1	25 January 2008
Invitation for Focus Group	1.2	15 May 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/WSE03/16	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

p.p.

Mrs J Jenkins
Chair

Email: jagit.sidhu@bsc.wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" - *SL- AR2*

Copy to:

R&D Department for Cardiff & Vale NHS Trust

R&D Department for Cardiff University

Dr Z U Bhatti, Dept of Dermatology, Cardiff University, University Hospital of Wales, Heath Park, Cardiff, **CF14 4XN**

Professor S Salek, Welsh School of Pharmacy, Cardiff University, Redwood Building, King Edward VII Avenue, Cardiff, **CF10 3XF**

Appendix 2

NHS
WALES
GIG
CYMRU

Cardiff and Vale NHS Trust
Ymddiriedolaeth GIG Caerdydd a'r Fro

University Hospital of Wales
Ysbyty Athrofaol Cymru

Heath Park,
Cardiff CF14 4XW
Phone 029 2074 7747
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd CF14 4XW
Ffôn 029 2074 7747
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20743742
Fax: 029 20745311
Research.Development@cardiffandvale.wales.nhs.uk

From: Professor MF Scanlon
Trust R&D Director
Radnor House
University Hospital of Wales
Cardiff
CF14 4XW

18 June 2008

Professor Andrew Finlay
Department Of Dermatology
Cardiff University, Heath Park
Cardiff

Dear Professor Finlay

Project ID : 08/CMC/4212 : A cross–sectional prospective study to investigate the influence of chronic diseases on major life changing decisions

REC Reference: 08/WSE03/16
Amendment Number: 1
Amendment Date: 02/06/08

The above amendment has been received by the Joint Trust/University Peer and Risk Review Committee.

The documents reviewed were:-

Document	Version	Date
Protocol	1.1	18/03/08
NHS REC Application Form	1.1	undated
Revised Consent Form For Individual Interviews	1.1	15/05/08
Revised Consent Form For Focus Groups	1.1	15/05/08
Revised Consent Form For Postal Questionnaire Survey	1.1	15/05/08
Revised additional I S for focus group	1.1	15/05/08
Revised Invitation Letter for Focus Group Discussion	1.2	15/05/08
Revised Invitation Letter for individual interview	1.2	15/05/08
Revised Invitation Letter for postal questionnaire survey	1.1	15/05/08
Revised participant personal details	1.1	15/05/08
Revised PIS(FG)	1.2	15/05/08
Revised PIS(I INT)	1.2	15/05/08

Revised PIS(PQS)	1.2	15/05/08
Revised qualitative assessment sheets	1.1	15/05/08

I can confirm that the above support documentation has been approved and that you may continue with this study accordingly.

Please ensure that the appropriate Research Ethics Committee have a copy of this letter.

May I take this opportunity to wish you success with the project and remind you that as Principal Investigator you are required to:

- Inform the Trust R&D Office if any external or additional funding is awarded for this project in the future.
- Inform the Trust R&D Office of any further amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start / end dates.
- Complete any documentation sent to you by the Trust R & D Office or University Research & Commercial Division regarding this project.
- Adhere to the protocol as approved by the Research Ethics Committee.
- Ensure the research complies with the Data Protection Act 1998.

Yours sincerely,

pp **Professor MF Scanlon**
Chair of the Joint Trust/University Peer & Risk Review Committee

CC R&D Lead Dr Richard Motley
Chris Shaw, Research and Commercial Division, Cardiff University

C:\my documents\lisa\databases\study folders\4212\RD Letters\08-CMC-4212 Amendments After Approval 18-06-2008.doc

Appendix 3

Patients' details for postal survey

Name of speciality:

Note: For patient recruitment, please stick patient addressograph in the "Addressograph" column and write "broader disease description" and "disease severity" in relevant column s. Code numbers are allocated for each patient for identification. Thank you

Code No	**Addressograph**	**Broad disease description**	**Disease severity Mild/moderate /severe**	Dr Bhatti to Complete		
				Date Posted	Date 2^{nd}posting	Date Response Received

2

Appendix A

Freepost RRZA-ESKS-ATUE
Major Life Changing Decisions-Study Group
Department of Dermatology
3rd Floor Glamorgan House
University Hospital of Wales
Heath Park
Cardiff
CF14 4XN

Appendix B

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date:

Reminder

Study Title: A cross-sectional prospective study to investigate the influence of Long-term diseases on Major Life Changing Decisions

A few weeks ago we sent you a request to take part in a research survey. So far we have not received a reply from you. We realise that there may be many reasons for this. We are sending this reminder because your taking part in this research would be very helpful to the success of the study.

We would be extremely grateful if you could complete and return this at your earliest convenience.

Thank you for considering this.

Yours sincerely

Professor Andrew Finlay
Professor of Dermatology
Chief Investigator MLCD-Study Group

NHS
WALES
GIG
CYMRU

Appendix C

Cardiff and Vale NHS Trust
Ymddiriedolaeth GIG Caerdydd a'r Fro

University Hospital of Wales
Ysbyty Athrofaol Cymru

Heath Park,
Cardiff CF14 4XW
Phone 029 2074 7747
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd CF14 4XW
Ffôn 029 2074 7747
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Date: 11/08/2008
Version 1.2

Invitation for postal questionnaire survey

Dear Sir/Madam,

We would like to invite you to take part in a postal questionnaire survey as part of our research to understand the influence of long-term diseases on major life changing decisions. This postal survey would give you a chance to let us know about your experiences, especially about long-term diseases and whether they influence critical life changing decisions.

We enclose information about this survey to help you decide whether to take part in this research study.

Information sheet
Consent form (for postal questionnaire survey)
Personal details sheet
Qualitative assessment sheet

Please take time and make sure that you have read and understood these before making a decision. I am one of the researchers involved in this study. However, this study involves several departments and is being co-ordinated by the Department of Dermatology; hence all replies are going to the Dermatology Department for analysis. If you are willing to take part in this research, please sign the consent forms, complete the other sections and send them to the "Major Life Changing Decisions-Study Group" (MLCD-Study Group), Department of Dermatology using the enclosed pre-paid self addressed envelope. We would appreciate if you could send your reply within the next few weeks.

Your taking part in the study would help us to develop strategies for better healthcare in the future.

Thank you very much for considering taking part in this study.

Yours faithfully,

Name of researcher

Appendix D

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD
CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 11/08/2008
Version: 1.3

Participant Information Sheet
(For Postal Questionnaire Survey)

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Dear Participant,

We would like to invite you to take part in this study to help us understand how long-term diseases influence major life changing decisions. This "Participant Information Sheet" will provide you with in depth detailed knowledge about this research, such as aims and objectives, method, selection criteria, data protection and your rights. Please take your time to read and understand this information. Please do not hesitate to ask any question if you need further explanation of any aspect of this research.

What is the Purpose of the study?

Long-term diseases have enormous Quality of Life impact on patients' lives and cause serious impact on day to day living. Decisions about the most important issues in life are often not easy. Long-term disorders may result in patients taking different decisions. Up to now, little is known about this. The main aim of this study is to identify the influences of long-term disease on major life changing decisions and a questionnaire will be created for future research.

What is the study procedure?

No drugs are being tested and there is no blood or other laboratory tests.

This research study consists of
A. Individual interviews
B. Group discussions
C. Postal survey

Patients with skin diseases will be invited either for individual interview or for a group discussion. The postal questionnaire survey will be used for patients who suffer from heart, joint, kidney, diabetes or chest problems.

What will happen to me if I take part?

You are only invited to take part in the postal questionnaire survey. Patients suffering from heart, joint, kidney, diabetes or chest problems will receive this postal survey pack. You will be asked to write any ways in which these conditions have had an influence on major life decision taking. Responses will be returned by post using an enclosed prepaid envelope.

Why have I been invited?

You fulfil our "inclusion criteria" for this research and so we have selected you to receive an invitation to take part in this study. Points of our inclusion criteria are as follows:

- Patients who have been suffering from long-term disease for more than one year
- 16 years of age and over
- Patients who can read and write in English
- Agree to protect the confidentiality of other focus group participants (if taking part in focus group discussion)
- Are willing to share personal experiences in a tape recorded focus group discussion (if taking part in focus group discussion)

Do I have to take part?

This research is absolutely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

How will I be treated if I do not take part?

Not taking part will not affect the standard of care that you receive.

What are the possible risk and benefits of taking part?

There are no harmful aspects of this study. This research is based on interviews/discussion and written responses. There is no clinical or medical risk. Your participation will help to develop a new patients' life changing decision taking questionnaire. This will enable health care providers to form appropriate strategies that would help patients with their long-term decision taking, resulting in improved Quality of Life.

Will my taking part in the study be kept confidential?

All the information gathered from you will be kept strictly confidential. Records of voice tape recording of individual interviews/focus groups and written postal replies will remain in a secure locked cabinet in the Department of Dermatology, University

Will my taking part in the study_be kept confidential?

All the information gathered from you will be kept strictly confidential. Records of voice tape recording of individual interviews/focus groups and written postal replies will remain in a secure locked cabinet in the Department of Dermatology, University Hospital of Wales. Every patient will be allotted a "code number" for identification. Responses will be transferred to a University computer without any personal details. Access to University Hospital computers is protected and only the researchers will have access to the participant's records. Immediately after the completion of this research, recorded material will be destroyed under the supervision of supervisors and other staff members. Patients will be informed once the data is destroyed. The name and address of participants will not be disclosed. Published results will not reveal any personal information.

What if there is a problem?

If you have any complaint, you can contact any of the following;

1. Professor Andrew Finlay	029 20744721
2. Professor Sam Salek	029 20876017
3. University Hospital of Wales Patient Advice and Liaison Service (PALS)	029 2074 2233

Who is organising and funding the research?

This research is funded and jointly organised by the School of Pharmacy and Department of Dermatology, School of Medicine, Cardiff University.

Who has reviewed the study?

This research has been examined and thoroughly reviewed by:

- Cardiff University (Research and Commercial Division)
- Cardiff and Vale NHS Trust Research and Development Office
- South East Wales Local Research Ethics Committee

What if I do have any questions?

If you have any questions about this study, the following investigators will be pleased to answer your questions.

1. Professor Andrew Finlay	029 20744721
2. Professor Sam Salek	029 20876017
3. Dr Zaheer Uddin Bhatti	029 20745875
4. Sister Anne Thomas	029 20742672

Appendix E

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 11/08/2008
Version 1.2

Centre: Cardiff and Vale NHS Trust
Code Number:

CONSENT FORM

(For Postal Questionnaire Survey)

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Name of Researcher: Professor AY Finlay

I confirm that I have read and understand the participant information sheet dated 11/08/2008 (Version 1.3) for the above study. I hereby give written consent to participate in the study that involves me completing a postal questionnaire pack.

Name of Patient	Date	Signature

Appendix F

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version 1.1

Code Number: ___________

Participant Personal Details

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Dear Participant,

Please complete the simple questionnaire and circle the appropriate answer. Thank you very much for your help.

Gender: Male/ Female

Marital Status: Single / Married / Divorced / Widowed

Education: School / College / University

Employment Status: Employed / Unemployed / Retired / Early retirement

If you are unemployed, retired or took early retirement, please state your reason

Long-term disease / other reasons

Age: Years _________

Diagnosis: ____

Duration of the disease: Years _________

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version 1.1

Code Number: __________

Exploratory Qualitative Assessment Sheet

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Over a lifetime, people take many major life decisions. Examples of major life decisions include marriage or relationship, divorce or separation, having a child, higher education, job and career, change of profession or early retirement, relocating to another city or country. Please write down **any ways in which your long-term disease has had a major influence on major life decisions**.

Thank you very much for your help.

1.

2.

3.

4.

Code Number: ____________

Exploratory Qualitative Assessment Sheet

5.

6.

7.

8.

9.

10.

Appendix H

NHS
WALES
GIG
CYMRU

Cardiff and Vale NHS Trust
Ymddiriedolaeth GIG
Caerdydd a'r Fro

University Hospital of Wales
Ysbyty Athrofaol Cymru

Heath Park,
Cardiff CF14 4XW
Phone 029 2074 7747
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd CF14 4XW
Ffôn 029 2074 7747
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Date:

Invitation for individual interview

We would like to invite you for an interview as part of our research to understand the influence of long-term diseases on major life changing decisions. This interview will give you a chance to let us know about your experiences, especially about skin diseases and whether they influence critical life decisions. We enclose information to help you decide whether to take part in this research study.

Information sheet
Consent form (for individual interview)
Personal details sheet

Please take time and make sure that you have read and understood these before making a decision. If you are willing to take part in this research study, please inform us within four working days either on telephone number **029 2074 5875** or alternatively you can tear of the bottom part of this letter and send it to the Department of Dermatology using the enclosed pre-paid self addressed envelope. We will let you know when and where the interview will be held. We will try to fix a time convenient for you. Taking part in the study would help us to develop strategies for better health care in the future.

Thank you very much for considering this matter.

Yours sincerely,

Professor Andrew Finlay
Professor of Dermatology

Note: Please do not send your consent form. We will ask you to sign it on the day of the interview.

……

Please state if you would like to take part in an individual interview. Yes / No

Name: ---------------------------------- Signature: ----------------------------------

Address: --

-------------------------------------Telephone Number: (optional) ------------------------

Date: 15/05/2008
Version 1.2

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version: 1.2

Participant Information Sheet

(For Individual Interview)

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Dear Participant,

We would like to invite you to take part in this study to help us understand how long-term diseases influence major life changing decisions. This "Participant Information Sheet" will provide you with in depth detailed knowledge about this research, such as aims and objectives, method, selection criteria, data protection and your rights. Please take your time to read and understand this information. Please do not hesitate to ask any question if you need further explanation of any aspect of this research.

What is the Purpose of the study?

Long-term diseases have enormous Quality of Life impact on patients' lives and cause serious impact on day to day living. Decisions about the most important issues in life are often not easy. Long-term disorders may result in patients taking different decisions. Up to now, little is known about this. The main aim of this study is to identify the influences of long-term disease on major life changing decisions and a questionnaire will be created for future research.

What is the study procedure?

No drugs are being tested and there is no blood or other laboratory tests.

This research study consists of
A. Individual interviews
B. Group discussions
C. Postal survey

Patients with skin diseases will be invited either for individual interview or for a group discussion. The postal questionnaire survey will be used for patients who suffer from heart, joint, kidney, diabetes or chest problems.

What will happen to me if I take part?

You are only invited to take part in a individual interview. This will be carried out in the dermatology out-patient department. You would be asked about the ways in which your skin condition has had a major influence on major life changing decision taking. The interview will be recorded using a tape recorder. The interview will not take more than 40 minutes.

Why have I been invited?

You fulfil our "inclusion criteria" for this research and so we have selected you to receive an invitation to take part in this study. Points of our inclusion criteria are as follows:

- Patients who have been suffering from long-term disease for more than one year
- 16 years of age and over
- Patients who can read and write in English
- Agree to protect the confidentiality of other focus group participants (if taking part in focus group discussion)
- Are willing to share personal experiences in a tape recorded focus group discussion (if taking part in focus group discussion)

Do I have to take part?

This research is absolutely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

How will I be treated if I do not take part?

Not taking part will not affect the standard of care that you receive.

What are the possible risk and benefits of taking part?

There are no harmful aspects of this study. This research is based on interviews/discussion and written responses. There is no clinical or medical risk. Your participation will help to develop a new patients' life changing decision taking questionnaire. This will enable health care providers to form appropriate strategies that would help patients with their long-term decision taking, resulting in improved Quality of Life.

Will my taking part in the study_be kept confidential?

All the information gathered from you will be kept strictly confidential. Records of voice tape recording of individual interviews/focus groups and written postal replies will remain in a secure locked cabinet in the Department of Dermatology, University Hospital of Wales. Every patient will be allotted a "code number" for identification. Responses will be transferred to a University computer without any personal details. Access to University Hospital computers is protected and only the researchers will have access to the participant's records. Immediately after the completion of this research, recorded material will be destroyed under the supervision of supervisors and other staff members. Patients will be informed once the data is destroyed. The name and address of participants will not be disclosed. Published results will not reveal any personal information.

What if there is a problem?

If you have any complaint, you can contact any of the following;

1. Professor Andrew Finlay	029 20744721
2. Professor Sam Salek	029 20876017
3. University Hospital of Wales Patient Advice and Liaison Service (PALS)	029 2074 2233

Who is organising and funding the research?

This research is funded and jointly organised by the School of Pharmacy and Department of Dermatology, School of Medicine, Cardiff University.

Who has reviewed the study?

This research has been examined and thoroughly reviewed by:

- Cardiff University (Research and Commercial Division)
- Cardiff and Vale NHS Trust Research and Development Office
- South East Wales Local Research Ethics Committee

What if I do have any questions?

If you have any questions about this study, the following investigators will be pleased to answer your questions.

1. Professor Andrew Finlay	029 20744721
2. Professor Sam Salek	029 20876017
3. Dr Zaheer Uddin Bhatti	029 20745875
4. Sister Anne Thomas	029 20742672

Appendix J

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version 1.1

Centre: Cardiff and Vale NHS Trust
Code Number:

CONSENT FORM

(For Individual Interviews)

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Name of Researcher: Professor AY Finlay

Please initial box

1. I confirm that I have read and understand the participant information sheet dated 15/05/2008 (Version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I am willing to take part in a tape recorded interview. ☐
4. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the Cardiff and Vale NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
5. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of Patient	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version 1.1

Code Number: ____________

Participant Personal Details

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Dear Participant,

Please complete the simple questionnaire and circle the appropriate answer. Thank you very much for your help.

Gender:	Male/ Female
Marital Status:	Single / Married / Divorced / Widowed
Education:	School / College / University
Employment Status:	Employed / Unemployed / Retired / Early retirement

If you are unemployed, retired or took early retirement, please state your reason

Long-term disease / other reasons

Age: Years ________

Diagnosis: ______________________________

Duration of the disease: Years ________

NHS
WALES
GIG
CYMRU

Cardiff and Vale NHS Trust
Ymddiriedolaeth GIG
Caerdydd a'r Fro

University Hospital of Wales
Ysbyty Athrofaol Cymru

Heath Park,
Cardiff CF14 4XW
Phone 029 2074 7747
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd CF14 4XW
Ffôn 029 2074 7747
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Appendix L

Date:

Invitation for focus group discussion

Dear

We are organising an open "focus group" discussion as part of our research to understand the influence of long-term diseases on major life changing decisions. This discussion meeting will give you and other participants a chance to talk about your experiences, especially about long-term skin diseases and whether they influence critical life decisions. We enclose information about the focus group discussion to help you decide whether to take part in this research study.

■ Information sheet ■ Additional information for focus groups ■ Consent Form (for focus group) ■ Personal details sheet

Please take time and make sure that you have read and understood these before making a decision. If you are willing to take part in this research study, please inform us within four working days either on telephone number **029 2074 5875** or alternatively you can tear off the bottom part of this letter and send it to the Department of Dermatology using the enclosed pre-paid self addressed envelope. We will let you know when and where the focus group discussion will be held. We will try to fix a time convenient for you. Participants will be reimbursed travel expenses in attending the focus group discussion. Taking part in the study would help us to develop strategies for better health care in the future.

Thank you very much for considering this matter.

Yours sincerely,

Professor Andrew Finlay
Professor of Dermatology

Note: Please do not send your consent form. We will ask you to sign it on the day of a focus group discussion.

……

Please state if you would like to take part in a focus group discussion. Yes / No

Name: --------------------------------- Signature: ------------------------------------

Address: --

------------------------------------Telephone Number: (optional) -----------------------------

Date: 15/05/2008
Version 1.2

Appendix M

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version: 1.2

Participant Information Sheet
(For Focus Group Discussion)

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Dear Participant,

We would like to invite you to take part in this study to help us understand how long-term diseases influence major life changing decisions. This "Participant Information Sheet" will provide you with in depth detailed knowledge about this research, such as aims and objectives, method, selection criteria, data protection and your rights. Please take your time to read and understand this information. Please do not hesitate to ask any question if you need further explanation of any aspect of this research.

What is the Purpose of the study?

Long-term diseases have enormous Quality of Life impact on patients' lives and cause serious impact on day to day living. Decisions about the most important issues in life are often not easy. Long-term disorders may result in patients taking different decisions. Up to now, little is known about this. The main aim of this study is to identify the influences of long-term disease on major life changing decisions and a questionnaire will be created for future research.

What is the study procedure?

No drugs are being tested and there is no blood or other laboratory tests.

This research study consists of
A. Individual interviews
B. Group discussions
C. Postal survey

Patients with skin diseases will be invited either for individual interview or for a group discussion. The postal questionnaire survey will be used for patients who suffer from heart, joint, kidney, diabetes or chest problems.

What will happen to me if I take part?

You are only invited to take part in a group discussion. The group will consist of 10 patients. The investigator will lead the group discussion and patients will share their experiences with other participants. The discussion will be recorded using a tape recorder. Please make sure that you have read and understood the attached separate "Additional information sheet for focus group". The focus group session will take about 2 hours.

Why have I been invited?

You fulfil our "inclusion criteria" for this research and so we have selected you to receive an invitation to take part in this study. Points of our inclusion criteria are as follows:

- Patients who have been suffering from long-term disease for more than one year
- 16 years of age and over
- Patients who can read and write in English
- Agree to protect the confidentiality of other focus group participants (if taking part in focus group discussion)
- Are willing to share personal experiences in a tape recorded focus group discussion (if taking part in focus group discussion)

Do I have to take part?

This research is absolutely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

How will I be treated if I do not take part?

Not taking part will not affect the standard of care that you receive.

What are the possible risk and benefits of taking part?

There are no harmful aspects of this study. This research is based on interviews/discussion and written responses. There is no clinical or medical risk. Your participation will help to develop a new patients' life changing decision taking questionnaire. This will enable health care providers to form appropriate strategies that would help patients with their long-term decision taking, resulting in improved Quality of Life.

Will my taking part in the study be kept confidential?

All the information gathered from you will be kept strictly confidential. Records of voice tape recording of individual interviews/focus groups and written postal replies will remain in a secure locked cabinet in the Department of Dermatology, University Hospital of Wales. Every patient will be allotted a "code number" for identification. Responses will be transferred to a University computer without any personal details. Access to University Hospital computers is protected and only the researchers will have access to the participant's records. Immediately after the completion of this research, recorded material will be destroyed under the supervision of supervisors and other staff members. Patients will be informed once the data is destroyed. The name and address of participants will not be disclosed. Published results will not reveal any personal information.

What if there is a problem?

If you have any complaint, you can contact any of the following;

1. Professor Andrew Finlay	029 20744721
2. Professor Sam Salek	029 20876017
3. University Hospital of Wales Patient Advice and Liaison Service (PALS)	029 2074 2233

Who is organising and funding the research?

This research is funded and jointly organised by the School of Pharmacy and Department of Dermatology, School of Medicine, Cardiff University.

Who has reviewed the study?

This research has been examined and thoroughly reviewed by:

- Cardiff University (Research and Commercial Division)
- Cardiff and Vale NHS Trust Research and Development Office
- South East Wales Local Research Ethics Committee

What if I do have any questions?

If you have any questions about this study, the following investigators will be pleased to answer your questions.

1. Professor Andrew Finlay	029 20744721
2. Professor Sam Salek	029 20876017
3. Dr Zaheer Uddin Bhatti	029 20745875
4. Sister Anne Thomas	029 20742672

Appendix N

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version: 1.1

Additional Information Sheet for Focus Groups

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

This information sheet will provide you with step by step information about focus groups.

What is a focus group?

A focus group is a group of people who meet with a meeting leader and discuss the meeting topic.

What are focus groups for?

Focus groups are organised in order to let researchers understand better through that the members of the groups know about it.

Who is in the planned focus group?

10 people, who have long-term skin disease, will be included in each focus group.

Who will lead the focus group?

One of the researchers (Dr. Bhatti) will conduct the focus group discussion; along with the researcher the Dermatology specialist research sister will also be present.

What is the procedure of this focus group discussion?

At the start, the focus group members will introduce themselves. Dr. Bhatti will open the discussion by suggesting a topic. Dr. Bhatti will encourage people to share their views about the influence of their skin condition on their lives. First, there will be a general discussion. Secondly, Dr Bhatti will encourage people and will direct discussion to more specific areas. Conversation will be recorded using a tape recorder.

Duration of focus group?

Each focus group session will last for up to 2 hours. Actual discussion will last for 1 hour and 30 minutes.

Where will the focus group discussion be held?

The discussion will be held in Glamorgan House, Department of Dermatology, University Hospital of Wales, Heath Park, CF14 4XN. Participants will be reimbursed travel expenses in attending the meeting.

Appendix P

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version 1.1

Centre: Cardiff and Vale NHS Trust
Code Number:

CONSENT FORM
(For Focus Groups)

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Name of Researcher: Professor AY Finlay

Please initial box

1. I confirm that I have read and understand the participant information sheet dated 15/05/2008 (Version 1.2) and the additional information sheet for focus groups dated 15/05/2008 (Version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I am willing to share personal experiences in a tape recorded group discussion. ☐

4. I agree to protect the confidentiality of other focus group participants. ☐

5. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the Cardiff and Vale NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

6. I agree to take part in the above study. ☐

Name of Patient	Date	Signature
Name of Person taking consent	Date	Signature

Appendix Q

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
Years Blynedd

Cardiff University
Prifysgol Caerdydd

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version 1.1

Code Number: __________

Participant Personal Details

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Dear Participant,

Please complete the simple questionnaire and circle the appropriate answer. Thank you very much for your help.

Gender: Male/ Female

Marital Status: Single / Married / Divorced / Widowed

Education: School / College / University

Employment Status: Employed / Unemployed / Retired / Early retirement

If you are unemployed, retired or took early retirement, please state your reason

Long-term disease / other reasons

Age: Years _________

Diagnosis: ____

Duration of the disease: Years _________

Appendix R

Version 1
Date: 29.01.2010

Stage 3: Content validity of a new questionnaire

"Questionnaire Items Rating Sheets"

Name:
Speciality:

Guidelines for panel members

Introduction: The developmental version of the questionnaire (version 1, date 29.01.2010) requires content validity. For this purpose member of a panel of judges must rate each item for its language clarity, completeness, relevance and scaling. For standardisation, all panel members should have the same understanding of these criteria. It is important that all members consider the following criteria for content validation process:

A. Language clarity: the sentences and wording should be clear, understandable, straightforward and simple. Make sure phrases and wordings should be unambiguous and jargon free and should be understood by a person who has a mental aptitude of a 12 year old child.

B. Completeness: The sentences should be complete and not broken and should end properly.

C. Relevance: Each item should be relevant to subject area and targeted population.

D. Scaling: 4 point Adjectival scale is used for scaling system, starting from 0 to 4 (0=No influence, 1=Slight influence, 2=Moderate influence, 3=Strong influence, 4=A very strong influence). Panel members should rate the scaling system as to whether the response option fit the question (i.e. statement/item) or not.

Appendix S

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 04.02.2010
Project ID: 08/CMC/4212
Ethics ID: 08/WSE03/16

Project Title: A Cross-Sectional Prospective Study to Investigate the Influence of Chronic Diseases on Major Life Changing Decisions.

Dear Dr

Major Life Changing Decisions Study Group

Thank you for your continuing efforts with the study. We are enclosing following documents related to our next stage of the study "stage 3: face and content validity".

1. Developmental version of the new questionnaire (version: 1, date 29.01.2010)
2. Content validation rating sheets

Please rate each questionnaire item for its language clarity, completeness, relevance and scaling. Documents are self explanatory and you can also put your suggestions for more detailed discussion on Thursday 25 February 2010 meeting. Dr Bhatti will also provide you another similar set of documents for your member of staff (specialist nurse) for their input. On completion please ask them to contact Dr Bhatti on 02920745875 Email: bhattizu@cardiff.ac.uk for collection. Contact details are also available in the end of the content validation rating sheets.

The meeting will be held on **Thursday, 25 February 2010** from **12:00 to 2:00 pm** in the Department of Dermatology Library, Top floor, Glamorgan House, Heath Park, UHW. (With sandwiches as usual)

The draft meeting agenda is enclosed.

Many thanks

Professor Andrew Y Finlay
Department of Dermatology
School of Medicine
Cardiff University
Heath Park
Cardiff CF14 4XN
Tel: 029 2074 4721
Email: finlayay@cf.ac.uk

Professor Sam Salek
Centre for Socioeconomic Research
Welsh School of Pharmacy
Cardiff University, Redwood Building
Cardiff CF10 3NB

Tel: 029 2087 6017
Email: salekss@cf.ac.uk

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 09.04.2010
Version: 1.4

Participant Information Sheet
(For Questionnaire Survey)

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Dear Participant,

We would like to invite you to take part in this study to help us understand how long-term diseases influence major life changing decisions. This “Participant Information Sheet” will provide you with in depth detailed knowledge about this research, such as aims and objectives, method, selection criteria, data protection and your rights. Please take your time to read and understand this information. Please do not hesitate to ask any question if you need further explanation of any aspect of this research.

What is the Purpose of the study?

Long-term diseases have enormous Quality of Life impact on patients’ lives and cause serious impact on day to day living. Decisions about the most important issues in life are often not easy. Long-term disorders may result in patients taking different decisions. Up to now, little is known about this. The main aim of this study is to identify the influences of long-term disease on major life changing decisions and a questionnaire will be created for future research.

What is the study procedure?

No drugs are being tested and there is no blood or other laboratory tests. The questionnaire survey will be used for patients who suffer from skin, heart, joint, kidney, diabetes or chest problems.

What will happen to me if I take part?

You are invited to take part in the questionnaire survey. Patients suffering from skin, heart, joint, kidney, diabetes or chest problems will receive this survey pack.

Why have I been invited?

You fulfil our "inclusion criteria" for this research and so we have selected you to receive an invitation to take part in this study. Points of our inclusion criteria are as follows:

- Patients who have been suffering from long-term disease for more than one year
- 16 years of age and over
- Patients who can read and write in English

Do I have to take part?

This research is absolutely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

How will I be treated if I do not take part?

Not taking part will not affect the standard of care that you receive.

What are the possible risk and benefits of taking part?

There are no harmful aspects of this study. This research is based on interviews/discussion and written responses. There is no clinical or medical risk. Your participation will help to develop a new patients' life changing decision taking questionnaire. This will enable health care providers to form appropriate strategies that would help patients with their long-term decision taking, resulting in improved Quality of Life.

Will my taking part in the study be kept confidential?

All the information gathered from you will be kept strictly confidential. Records of voice tape recording of individual interviews/focus groups and written replies will remain in a secure locked cabinet in the Department of Dermatology, University Hospital of Wales. Every patient will be allotted a "code number" for identification. Responses will be transferred to a University computer without any personal details. Access to University Hospital computers is protected and only the researchers will have access to the participant's records. Immediately after the completion of this research, recorded material will be destroyed under the supervision of supervisors and other staff members. Patients will be informed once the data is destroyed. The name and address of participants will not be disclosed. Published results will not reveal any personal information.

What if there is a problem?

If you have any complaint, you can contact any of the following;

1. Professor Andrew Finlay	029 20744721
2. Professor Sam Salek	029 20876017
3. University Hospital of Wales Patient Advice and Liaison Service (PALS)	029 2074 2233

Who is organising and funding the research?

This research is funded and jointly organised by the School of Pharmacy and Department of Dermatology, School of Medicine, Cardiff University, in partnership with the Welsh Heart Research Institute, Department of Nephrology and Transplantation, Department of Rheumatology, Department of Respiratory Medicine, Adult Cystic Fibrosis Services and Diabetes and Endocrinology Department. This research group is also known as "Major Life Changing Decisions-Study Group" (MLCD-Study Group).

Who has reviewed the study?

This research has been examined and thoroughly reviewed by:

- Cardiff University (Research and Commercial Division)
- Cardiff and Vale NHS Trust Research and Development Office
- South East Wales Local Research Ethics Committee

What if I do have any questions?

If you have any questions about this study, the following investigators will be pleased to answer your questions.

1. Professor Andrew Finlay	029 207 44721
2. Professor Sam Salek	029 208 76017
3. Dr Zaheer Uddin Bhatti	029 207 45875
4. Sister Anne Thomas	029 207 42672

Appendix U

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 09.04.2010
Version 1.3

Centre: Cardiff and Vale NHS Trust
Code Number:

CONSENT FORM

(For Questionnaire Survey)

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Name of Researcher: Professor AY Finlay

I confirm that I have read and understand the participant information sheet dated 09.04.2010 (Version 1.4) for the above study. I hereby give written consent to participate in the study that involves me completing a questionnaire.

______________________	______________	__________________
Name of Patient	Date	Signature

Appendix V

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date: 15/05/2008
Version 1.1

Code Number: ____________

Participant Personal Details

Study Title: A cross-sectional prospective study to investigate the influence of long-term diseases on major life changing decisions.

Dear Participant,

Please complete the simple questionnaire and circle the appropriate answer. Thank you very much for your help.

Gender: Male/ Female

Marital Status: Single / Married / Divorced / Widowed

Education: School / College / University

Employment Status: Employed / Unemployed / Retired / Early retirement

If you are unemployed, retired or took early retirement, please state your reason

Long-term disease / other reasons

Age: Years ________

Diagnosis: ______________________________________

Duration of the disease: Years ________

Department of Dermatology
Head of Department Professor A Y Finlay
Yr Adran Dermatoleg
Pennaeth Adran Yr Athro A Y Finlay

1883-2008
125
YEARS BLYNEDD

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Cardiff University
3rd Floor
Welsh Institute of Dermatology
Heath Park
Cardiff CF14 4XN
Wales UK

Tel *Ffôn* +44(0)29 2074 4721
Fax *Ffacs* +44(0)29 2074 4312
E-mail *E-bost* FinlayAY@cardiff.ac.uk
www.dermatology.org.uk

Prifysgol Caerdydd
3ydd Llawr
Sefydliad Dermatoleg Cymru
Mynydd Bychan
Caerdydd CF14 4XN
Cymru DU

Date:
Patient ID:

Major Life Changing Decisions Profile

(MLCDP)

Please give us your views about the questionnaire you have just filled in by answering the following six questions. The MLCDP is a newly designed questionnaire and your opinion will greatly help its further development.

1. How long (in minutes) did it take you to complete the questionnaire?

______ Minutes

2. Did you find the questionnaire easy to complete?

Yes ☐ No ☐

3. Did you find the response options for the statements in questionnaire straight forward?

Yes ☐ No ☐

4. In general, how clear and understandable were the instructions and statements?

Very clear ☐ Clear ☐ Not clear ☐ Very unclear ☐

5. Did you find the statements comprehensive enough to measure your disease influence on important life decisions?

Yes ☐ No ☐

6. If your answer to question 5 is "No", please write down below the life aspects you think should be added to the questionnaire.

____

____

____

Thank you very much for your help

Appendix X: Correlation matrix for the 34 items of the MLCDP (version 1a)

	A1	A2	A3	A4	B1	B2	B3	B4	B5	B6	B7	B8	B10	C1	C2	C4	C5
A1	1.000	.228	.346	.230	.179	-.022	.039	.175	.007	.096	.117	.129	.123	.141	.222	.201	.043
A2	.228	1.000	.442	.236	.154	.155	.243	.005	.296	.265	.092	.286	.066	.236	.022	.316	.020
A3	.346	.442	1.000	.193	.140	.032	.198	-.037	.158	.222	.030	.098	.065	.390	.068	.257	-.048
A4	.230	.236	.193	1.000	.302	.243	.329	.042	.207	.118	.141	.177	-.006	.201	-.065	.533	.058
B1	.179	.154	.140	.302	1.000	.416	.592	.062	.190	.488	.257	.174	.245	.216	.114	.188	.038
B2	-.022	.155	.032	.243	.416	1.000	.459	.390	.332	.211	.227	.256	.452	.164	.178	.199	.246
B3	.039	.243	.198	.329	.592	.459	1.000	.076	.275	.452	.244	.142	.213	.163	.139	.200	.067
B4	.175	.005	-.037	.042	.062	.390	.076	1.000	-.003	-.128	.158	.057	.319	-.035	.065	.044	.281
B5	.007	.296	.158	.207	.190	.332	.275	-.003	1.000	.317	.168	.480	.163	.156	.055	.201	.016
B6	.096	.265	.222	.118	.488	.211	.452	-.128	.317	1.000	.288	.380	.099	.182	.117	.090	-.009
B7	.117	.092	.030	.141	.257	.227	.244	.158	.168	.288	1.000	.175	.023	-.003	.148	.011	.016
B8	.129	.286	.098	.177	.174	.256	.142	.057	.480	.380	.175	1.000	.055	.139	.164	.177	-.027
B10	.123	.066	.065	-.006	.245	.452	.213	.319	.163	.099	.023	.055	1.000	.239	.252	.188	.191
C1	.141	.236	.390	.201	.216	.164	.163	-.035	.156	.182	-.003	.139	.239	1.000	.414	.294	.125
C2	.222	.022	.068	-.065	.114	.178	.139	.065	.055	.117	.148	.164	.252	.414	1.000	.078	.027
C4	.201	.316	.257	.533	.188	.199	.200	.044	.201	.090	.011	.177	.188	.294	.078	1.000	.001
C5	.043	.020	-.048	.058	.038	.246	.067	.281	.016	-.009	.016	-.027	.191	.125	.027	.001	1.000
C6	.126	.119	.269	.188	.069	.103	.075	.130	.004	-.012	-.021	-.018	.156	.340	.093	.250	.226
C7	.502	.157	.136	.278	.171	.090	.091	.347	.001	-.016	.070	.043	.158	.069	.061	.238	.105
D1	.077	-.014	.088	.022	.076	.166	.184	.112	.241	.078	.129	.079	.272	.156	.088	.106	.154
D2	.027	-.059	-.109	-.027	.068	.165	.051	.230	.095	.006	.144	.031	.160	.000	.048	.079	.165
D3	.130	.068	.026	.117	.093	.109	.131	.185	.078	.024	.087	.098	.122	.113	.010	.175	.165
D4	.298	.062	.172	.235	.236	.142	.110	.126	.161	.160	.153	.131	.175	.158	.185	.280	.094
D5	.049	-.013	.000	.202	.168	.224	.058	.245	.116	.105	.082	.074	.227	.116	-.030	.237	.201
D8	.104	.374	.351	.316	.163	.165	.226	.016	.212	.105	.169	.170	.042	.236	.071	.297	.049
D9	.081	.281	.262	.306	.153	.307	.160	.041	.215	.128	.043	.182	.165	.226	.115	.513	.092
D10	.002	.105	.123	.204	.024	.142	.052	.064	.253	.111	.206	.141	.094	.129	-.064	.066	.086
D11	.011	.125	-.009	.074	.224	.252	.221	.121	.137	.097	.132	.101	.152	.069	.048	.043	.182
D12	.137	.076	.052	.053	.120	.172	.190	.125	.114	.111	.092	.197	.248	.154	.104	.148	.171
D13	.111	.026	.091	.138	.182	.185	.194	.209	.135	.142	.165	.144	.173	.134	.121	.128	.193
D14	.213	.045	.015	.171	.096	.081	.049	.096	.060	.155	.190	.259	.065	.068	.241	.186	.104
E1	.115	.117	-.003	.186	.277	.268	.262	.090	.196	.216	.030	.227	.205	.156	.088	.092	.049
E2	.113	.090	.075	.074	.221	.344	.277	.198	.224	.206	.135	.184	.297	.090	.019	.066	.121
E3	.035	.120	-.024	.102	.226	.144	.129	-.056	.126	.144	.208	.090	-.012	.049	-.009	.064	-.030

Appendix X: Continuation of Correlation Matrix (34 Items)

C6	C7	D1	D2	D3	D4	D5	D8	D9	D10	D11	D12	D13	D14	E1	E2	E3
.126	.502	.077	.027	.130	.298	.049	.104	.081	.002	.011	.137	.111	.213	.115	.113	.035
.119	.157	-.014	-.059	.068	.062	-.013	.374	.281	.105	.125	.076	.026	.045	.117	.090	.120
.269	.136	.088	-.109	.026	.172	.000	.351	.262	.123	-.009	.052	.091	.015	-.003	.075	-.024
.188	.278	.022	-.027	.117	.235	.202	.316	.306	.204	.074	.053	.138	.171	.186	.074	.102
.069	.171	.076	.068	.093	.236	.168	.163	.153	.024	.224	.120	.182	.096	.277	.221	.226
.103	.090	.166	.165	.109	.142	.224	.165	.307	.142	.252	.172	.185	.081	.268	.344	.144
.075	.091	.184	.051	.131	.110	.058	.226	.160	.052	.221	.190	.194	.049	.262	.277	.129
.130	.347	.112	.230	.185	.126	.245	.016	.041	.064	.121	.125	.209	.096	.090	.198	-.056
.004	.001	.241	.095	.078	.161	.116	.212	.215	.253	.137	.114	.135	.060	.196	.224	.126
-.012	-.016	.078	.006	.024	.160	.105	.105	.128	.111	.097	.111	.142	.155	.216	.206	.144
-.021	.070	.129	.144	.087	.153	.082	.169	.043	.206	.132	.092	.165	.190	.030	.135	.208
-.018	.043	.079	.031	.098	.131	.074	.170	.182	.141	.101	.197	.144	.259	.227	.184	.090
.156	.158	.272	.160	.122	.175	.227	.042	.165	.094	.152	.248	.173	.065	.205	.297	-.012
.340	.069	.156	.000	.113	.158	.116	.236	.226	.129	.069	.154	.134	.068	.156	.090	.049
.093	.061	.088	.048	.010	.185	-.030	.071	.115	-.064	.048	.104	.121	.241	.088	.019	-.009
.250	.238	.106	.079	.175	.280	.237	.297	.513	.066	.043	.148	.128	.186	.092	.066	.064
.226	.105	.154	.165	.165	.094	.201	.049	.092	.086	.182	.171	.193	.104	.049	.121	-.030
1.000	.426	.061	-.010	.103	.384	.183	.205	.419	.022	.027	.164	.183	.003	.036	.116	.062
.426	1.000	.066	.094	.110	.267	.193	.068	.185	.008	.037	.139	.124	.181	.087	.077	.011
.061	.066	1.000	.286	.285	.098	.052	.088	.192	.087	.079	.373	.279	.164	.085	.227	.113
-.010	.094	.286	1.000	.202	.060	.095	.035	.093	.005	-.031	.151	.256	.027	.044	.214	.128
.103	.110	.285	.202	1.000	-.007	.104	.155	.214	.116	.182	.520	.405	.113	.287	.237	.048
.384	.267	.098	.060	-.007	1.000	.380	.120	.268	-.032	-.028	.182	.169	.053	.092	.222	.065
.183	.193	.052	.095	.104	.380	1.000	.105	.224	.227	.028	.094	.142	.007	.093	.239	.021
.205	.068	.088	.035	.155	.120	.105	1.000	.400	.251	.198	.128	.104	.108	.041	.088	.166
.419	.185	.192	.093	.214	.268	.224	.400	1.000	.179	.132	.265	.206	.174	.073	.131	.212
.022	.008	.087	.005	.116	-.032	.227	.251	.179	1.000	.051	.029	.014	.019	.109	.036	.099
.027	.037	.079	-.031	.182	-.028	.028	.198	.132	.051	1.000	.404	.330	.313	.388	.434	.194
.164	.139	.373	.151	.520	.182	.094	.128	.265	.029	.404	1.000	.625	.222	.450	.460	.174
.183	.124	.279	.256	.405	.169	.142	.104	.206	.014	.330	.625	1.000	.306	.471	.476	.198
.003	.181	.164	.027	.113	.053	.007	.108	.174	.019	.313	.222	.306	1.000	.233	.182	.076
.036	.087	.085	.044	.287	.092	.093	.041	.073	.109	.388	.450	.471	.233	1.000	.575	.315
.116	.077	.227	.214	.237	.222	.239	.088	.131	.036	.434	.460	.476	.182	.575	1.000	.364
.062	.011	.113	.128	.048	.065	.021	.166	.212	.099	.194	.174	.198	.076	.315	.364	1.000

Appendix Y: Correlation matrix for 29 items of the MLCDP

	A1	A2	A3	A4	B1	B2	B3	B4	B5	B6	B7	B8	B10	C1	C4
A1	1.000	.228	.346	.230	.179	-.022	.039	.175	.007	.096	.117	.129	.123	.141	.201
A2	.228	1.000	.442	.236	.154	.155	.243	.005	.296	.265	.092	.286	.066	.236	.316
A3	.346	.442	1.000	.193	.140	.032	.198	-.037	.158	.222	.030	.098	.065	.390	.257
A4	.230	.236	.193	1.000	.302	.243	.329	.042	.207	.118	.141	.177	-.006	.201	.533
B1	.179	.154	.140	.302	1.000	.416	.592	.062	.190	.488	.257	.174	.245	.216	.188
B2	-.022	.155	.032	.243	.416	1.000	.459	.390	.332	.211	.227	.256	.452	.164	.199
B3	.039	.243	.198	.329	.592	.459	1.000	.076	.275	.452	.244	.142	.213	.163	.200
B4	.175	.005	-.037	.042	.062	.390	.076	1.000	-.003	-.128	.158	.057	.319	-.035	.044
B5	.007	.296	.158	.207	.190	.332	.275	-.003	1.000	.317	.168	.480	.163	.156	.201
B6	.096	.265	.222	.118	.488	.211	.452	-.128	.317	1.000	.288	.380	.099	.182	.090
B7	.117	.092	.030	.141	.257	.227	.244	.158	.168	.288	1.000	.175	.023	-.003	.011
B8	.129	.286	.098	.177	.174	.256	.142	.057	.480	.380	.175	1.000	.055	.139	.177
B10	.123	.066	.065	-.006	.245	.452	.213	.319	.163	.099	.023	.055	1.000	.239	.188
C1	.141	.236	.390	.201	.216	.164	.163	-.035	.156	.182	-.003	.139	.239	1.000	.294
C4	.201	.316	.257	.533	.188	.199	.200	.044	.201	.090	.011	.177	.188	.294	1.000
C5	.043	.020	-.048	.058	.038	.246	.067	.281	.016	-.009	.016	-.027	.191	.125	.001
C6	.126	.119	.269	.188	.069	.103	.075	.130	.004	-.012	-.021	-.018	.156	.340	.250
C7	.502	.157	.136	.278	.171	.090	.091	.347	.001	-.016	.070	.043	.158	.069	.238
D2	.027	-.059	-.109	-.027	.068	.165	.051	.230	.095	.006	.144	.031	.160	.000	.079
D3	.130	.068	.026	.117	.093	.109	.131	.185	.078	.024	.087	.098	.122	.113	.175
D5	.049	-.013	.000	.202	.168	.224	.058	.245	.116	.105	.082	.074	.227	.116	.237
D8	.104	.374	.351	.316	.163	.165	.226	.016	.212	.105	.169	.170	.042	.236	.297
D9	.081	.281	.262	.306	.153	.307	.160	.041	.215	.128	.043	.182	.165	.226	.513
D11	.011	.125	-.009	.074	.224	.252	.221	.121	.137	.097	.132	.101	.152	.069	.043
D12	.137	.076	.052	.053	.120	.172	.190	.125	.114	.111	.092	.197	.248	.154	.148
D13	.111	.026	.091	.138	.182	.185	.194	.209	.135	.142	.165	.144	.173	.134	.128
D14	.213	.045	.015	.171	.096	.081	.049	.096	.060	.155	.190	.259	.065	.068	.186
E1	.115	.117	-.003	.186	.277	.268	.262	.090	.196	.216	.030	.227	.205	.156	.092
E2	.113	.090	.075	.074	.221	.344	.277	.198	.224	.206	.135	.184	.297	.090	.066

Appendix Y: Continuation of Correlation matrix (29 Items)

C5	C6	C7	D2	D3	D5	D8	D9	D11	D12	D13	D14	E1	E2
.043	.126	.502	.027	.130	.049	.104	.081	.011	.137	.111	.213	.115	.113
.020	.119	.157	-.059	.068	-.013	.374	.281	.125	.076	.026	.045	.117	.090
-.048	.269	.136	-.109	.026	.000	.351	.262	-.009	.052	.091	.015	-.003	.075
.058	.188	.278	-.027	.117	.202	.316	.306	.074	.053	.138	.171	.186	.074
.038	.069	.171	.068	.093	.168	.163	.153	.224	.120	.182	.096	.277	.221
.246	.103	.090	.165	.109	.224	.165	.307	.252	.172	.185	.081	.268	.344
.067	.075	.091	.051	.131	.058	.226	.160	.221	.190	.194	.049	.262	.277
.281	.130	.347	.230	.185	.245	.016	.041	.121	.125	.209	.096	.090	.198
.016	.004	.001	.095	.078	.116	.212	.215	.137	.114	.135	.060	.196	.224
-.009	-.012	-.016	.006	.024	.105	.105	.128	.097	.111	.142	.155	.216	.206
.016	-.021	.070	.144	.087	.082	.169	.043	.132	.092	.165	.190	.030	.135
-.027	-.018	.043	.031	.098	.074	.170	.182	.101	.197	.144	.259	.227	.184
.191	.156	.158	.160	.122	.227	.042	.165	.152	.248	.173	.065	.205	.297
.125	.340	.069	.000	.113	.116	.236	.226	.069	.154	.134	.068	.156	.090
.001	.250	.238	.079	.175	.237	.297	.513	.043	.148	.128	.186	.092	.066
1.000	.226	.105	.165	.165	.201	.049	.092	.182	.171	.193	.104	.049	.121
.226	1.000	.426	-.010	.103	.183	.205	.419	.027	.164	.183	.003	.036	.116
.105	.426	1.000	.094	.110	.193	.068	.185	.037	.139	.124	.181	.087	.077
.165	-.010	.094	1.000	.202	.095	.035	.093	-.031	.151	.256	.027	.044	.214
.165	.103	.110	.202	1.000	.104	.155	.214	.182	.520	.405	.113	.287	.237
.201	.183	.193	.095	.104	1.000	.105	.224	.028	.094	.142	.007	.093	.239
.049	.205	.068	.035	.155	.105	1.000	.400	.198	.128	.104	.108	.041	.088
.092	.419	.185	.093	.214	.224	.400	1.000	.132	.265	.206	.174	.073	.131
.182	.027	.037	-.031	.182	.028	.198	.132	1.000	.404	.330	.313	.388	.434
.171	.164	.139	.151	.520	.094	.128	.265	.404	1.000	.625	.222	.450	.460
.193	.183	.124	.256	.405	.142	.104	.206	.330	.625	1.000	.306	.471	.476
.104	.003	.181	.027	.113	.007	.108	.174	.313	.222	.306	1.000	.233	.182
.049	.036	.087	.044	.287	.093	.041	.073	.388	.450	.471	.233	1.000	.575
.121	.116	.077	.214	.237	.239	.088	.131	.434	.460	.476	.182	.575	1.000