A systematic review and empirical investigation of adjustment to cancer diagnosis:
Predicting clinically relevant psychosocial outcomes and testing Lazarus's
Transactional Model of Stress.

# Nicholas James Hulbert-Williams

Submitted in accordance with the requirements for the degree of Doctor of Philosophy

Department of Primary Care and Public Health
Cardiff University, School of Medicine

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#### THESIS SUMMARY

Cancer is one of the leading causes of death in the UK. The Cancer Reform Strategy (2007) highlighted the need for integration of psychological services into routine cancer care. Previous research into psychosocial aspects of adjustment is, however, inconsistent. This thesis opens with a background on cancer epidemiology and policy; the psychological impact of cancer; and, the shortcomings of previous intervention-based research. The Transactional Model is introduced as a potential framework for modelling adjustment. The thesis aimed to test this model for cancer patients in order to provide evidence to better inform the provision of psychological services for cancer patients.

A systematic review summarised the literature exploring the extent to which personality, appraisals and emotions were associated with psychosocial outcome. 68 studies were included. A number of small meta-analyses were performed using the Hunter and Schmidt method. Findings demonstrated a lack of consistency, and a number of research questions still unanswered. A methodological critique was provided based on systematic quality assessment.

The empirical study had two purposes: prediction of clinical outcome and theory development. 160 recently diagnosed colorectal, breast, lung and prostate cancer patients were recruited. Measures of personality, appraisal, emotion, coping and outcome (anxiety, depression and quality of life) were collected at baseline, three- and six-month follow-up. Analyses demonstrated that the data generally fitted the model but adaptations were proposed. Clinically, between 47 and 74% of variance in psychosocial outcome was explained by these predictor variables, with cognitive appraisals most predictive of all Transactional Model components. Statistical theory testing of cognition-emotion processes did not confirm the Transactional Model (Lazarus, 1999). These findings question the prescriptive nature of the theory and further testing is suggested, particularly in response to chronic stressors.

Guidelines for methodological improvements are provided. The thesis concludes with proposals for further research, including suggestions for theory-informed interventions.

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## Glossary of abbreviations

CHLC Chance Health Locus of Control

CRT Core Relational Theme

**CECS** Courtauld Emotional Control Scale

DHLC Doctor Health Locus of Control

**EORTC** European Organisation of Research in the Treatment of Cancer

FACT Functional Assessment of Cancer Therapy

GHLC God Health Locus of Control

**HADS** Hospital Anxiety and Depression Scale

HLoC Health Locus of Control

IHLC Internal Health Locus of Control

LoC Locus of Control

LOT Life Orientation Test

MAC Mental Adjustment to Cancer (scale)

MHLC Multidimensional Health Locus of Control (scale)

NHS National Health Service

NHSCRD National Health Service Centre for Reviews and Dissemination

OHLC General Other Health Locus of Control
PHLC Powerful others Health Locus of Control

RCT Randomised Controlled Trial

QoL Quality of Life

T1 Time one/baseline data collection

T2 Time two/three month follow up data collection

Time three/six month follow up data collection

TNM Tumour, Node, Metastasis (staging)

Note: Many other abbreviations are used with summary tables for the systematic review. These abbreviations are presented elsewhere in appendix 2.2

## Acknowledgments

This thesis has been challenging to say the least and I am indebted to the following people for helping me arrive at this completed work.

- My supervisors, Richard Neal, Val Morrison, and Clare Wilkinson: Thank you for giving me the opportunity to carry out this work.
- My friends and colleagues at Cardiff University, Bangor University and the University of Wolverhampton for their words of encouragement.
- Chris Whittaker for advice on meta-analysis.
- The North Wales Research Committee for financing data collection for the empirical study.
- Alison Roberts, Ann Gostage, Sandie Jones, Jenny Potts, Jan Mytton, Glenys Gee, Anne Francis-Jones, Mandy Neathy, Jennifer Jones, Lowri Jones and Dafydd Roberts: thank-you for your time, support and enthusiasm in recruiting patients into the empirical study. None of this would have been possible without you.
- Helen Lawrence, Caroline Tebbutt and Mark Johnson for assistance in collecting clinical and histology data.
- Matthew Makin, Julie Jones, and Jilly Wilcox-Jones for immensely useful advice and support.
- Daphne Russell for expert tuition and guidance using TeleFORM.
- My friend and colleague, Helen Dudley. Thank you for your input into the systematic review; it was wonderful to work with you again. I am fully aware of the boredom of the task that I asked of you and your contribution will never be forgotten. I owe you one!
- Kerry Hood, Paul Bennett, Adrian Edwards, Steve Rollnick and Claire Lane for your help and support, particularly over the last six months. I think I would have given up long ago had it not been for you all.
- My friends and family: many apologies for my absence at family gatherings and social events, particularly over the last two years. I did warn you that this would happen before I started. Thank you for your love, continued support and encouragement. Hopefully I can get back to having a life outside of work now!

Last, but by no means least, I thank my partner, Lee Hulbert-Williams. Your faith in me, your support and your love have carried me through this PhD. Thank you so much.

This work is dedicated to the memory of my grandmother,

Vera Dodd (1923-1996)

who made me aware of the impact that cancer has and who continues to inspire my work, each and every day.

"Nothing in life is to be feared, it is only to be understood.

Now is the time to understand more, so that we may fear less."

Marie Curie (1867-1934)

#### CHAPTER 1

#### **BACKGROUND LITERATURE REVIEW**

#### 1.1 CHAPTER OVERVIEW

This chapter will review some of the key theoretical and applied psychology literature that underpins the rationale for this thesis. After a brief summary of the relevant epidemiological literature (section 1.2) and a review of current cancer policy (section 1.3), an overview of psychological issues commonly faced by cancer patients will be presented (section 1.4). Together, these will help to delineate the need for increased psychological input into the care of cancer patients.

Published psychosocial intervention trials have had varying success and few have replicated the promising early effects on survival reported by Spiegel and his colleagues (e.g. Speigel, Bloom, Kraemer & Gottheil, 1989). Nonetheless, there is evidence that a variety of psychological variables are predictive of many short-term outcomes including distress and quality of life. Few studies have approached empirical investigation of cancer adjustment from a fully theoretical perspective. An overview of the relevant intervention literature is presented in section 1.5 including a summary of some of the methodological problems with these studies.

The second half of the chapter (sections 1.6-1.11) introduces personality and stress theory as potentially useful frameworks for understanding adjustment to cancer. Although some evidence is published linking a limited number of personality traits to outcome, there are many others which have simply not featured in previous research. Additionally, though not yet empirically tested in entirety, by incorporating cognitive, affective, and behavioural factors, underpinned by personality and individual differences, the Transactional Model of Stress holds promise for bringing together findings from the many disparate studies already conducted in this field. Two primary issues remain. First, in clinical application, it is not yet clear which aspects of the Transactional Model (Lazarus, 1999) are most predictive of outcome, and therefore which should be targeted in future research and clinical intervention. Second, theory-testing of the latest version of this model has not been sufficiently comprehensive to justify either the complexity of the model or the hypothesised nature of inter-variable relationships.

Herein lie the multifaceted aims of this thesis:

- To systematically review the literature to date in line with this theoretical framework
- To explore the utility of Transactional Model components in the prediction of clinically-relevant psychosocial outcomes in cancer patients
- To test the specific nature of Transactional Model with regards to theoretically hypothesised associations between cognitions and emotions.

The chapter concludes with a description of how each of these questions will be approached (section 1.12).

#### 1.2 CANCER INCIDENCE AND EPIDEMIOLOGY

Cancer remains the biggest threat to health in the UK accounting for 26% of all deaths (Department of Health, 2007). A disease most prevalent in the elderly (Geraci, Birch, Alston, Moran & Eden, 2007), of the 239,000 new diagnoses made in 2005, 26% were patients younger than 60 years of age (Office of National Statistics, 2008). There were 152,491 cancer-related deaths in the UK in 2005, of which, 47% resulted from a diagnosis of lung, colorectal, breast or prostate cancer. These still remain the most common cancer diagnoses made. Although incidence-proportional mortality rates remain higher in men than women, general trends of decreasing mortality for both genders are evident (Cancer Research UK, 2008). Despite this, five year survival rates for UK cancer patients remain significantly lower than most comparable European healthcare systems where the UK ranks 9<sup>th</sup> out of 28 for male survival and just 22<sup>nd</sup> out of 28 for female survival (Department of Health, 2007).

#### 1.2.1 Cancer site-specific incidence and epidemiology

In the UK, cancer diagnoses are staged using both cancer-type specific systems and generic tumour-node-metastases (TNM) systems. TNM staging provides a score from 0-4 for each of the three aspects to give a specific categorisation of the extent of disease. TNM scores are translated into a more generic cancer stages ranging from 0 to IV with higher staging indicating worst

prognosis (at its simplest level, stage IV represents metastatic spread to other parts of the body).

#### 1.2.1.1 Breast cancer

Breast cancer is the most commonly diagnosed cancer in the UK and agestandardised incidence is higher than in any other country worldwide (McPherson, Steel & Dixon, 2000). Twenty percent of diagnoses are made in the under 50 age group. Approximately 100 new diagnoses of female breast cancer are made every day, but just 300 new diagnosis of male breast cancer are made each year (Cancer Research UK, 2008). Fifty-five percent of breast cancer patients are diagnosed at Stage 0 (non-invasive lobular or ductal carcinoma in situ) or with early stage (I or II) invasive adenocarcinomas (85% ductal, 15% lobular) (Moorman, Jones, Millikan, Hall & Newman, 2001). A number of rarer diagnoses also exist, for example, Paget's disease and inflammatory breast disease (each diagnosed at incidence of 1-2%; Cancer Help UK, 2007). Due perhaps to increased symptom awareness and more accurate and available screening, diagnosis rates of stage III and IV (advanced) breast cancer have significantly decreased (Cancer Research UK, 2008). Most breast cancer patients will undergo surgery and many will also receive radiotherapy and/or hormone therapy. Chemotherapy is less commonly used, but can particularly improve survival when combined with treatments like Herceptin for some patient groups with advanced or aggressive breast cancer (Cancer Research UK, 2008). Eighty percent of patients survive beyond five years (Office for National Statistics, 2008), however, this varies significantly between those diagnosed at early or advanced stage (Miller, Ellis, Sainsbury & Dixon, 1994).

# 1.2.1.2 Lung cancer

Lung cancer is the most commonly diagnosed type of cancer worldwide, and remains second most common (after breast) in the UK (Office of National Statistics, 2008). Diagnosis is more common in men than women at a ratio of 7:5. The majority of diagnoses are of adenocarcinoma or squamous cell carcinoma. An additional 15-20% are diagnosed with small cell carcinoma which has a poorer prognosis (Blows, 2005). Other rare diagnoses include mesothelioma and large cell carcinoma (Cancer Help UK, 2007). Once again, cancer staging is based on TNM staging; over two thirds of patients are diagnosed at a late stage (Yoder,

2006) and just 7% survive beyond five years after diagnosis (Cancer Research UK, 2008). This survival rate drops even further for small cell carcinoma which carries a two year survival prognosis of just 2%. Surgical excision of the tumour is the only curative treatment available to lung cancer patients but this is suitable for fewer than 10% of diagnoses. Most patients without metastatic spread are offered combination treatments including surgery, radiotherapy and chemotherapy, which can increase five-year survival up to 20% (Cancer Help UK, 2007). Although the prognosis following a lung cancer diagnosis remains poor, rates of diagnosis are falling, and are expected to continue doing so with the recent significant decrease in smoking related behaviour (Cancer Research UK, 2008).

#### 1.2.1.3 Colorectal Cancer

Colorectal cancer has a higher incidence in the UK (third most common) in comparison to many other countries (Boyle & Langman, 2000). Of all UK diagnoses, two thirds originate in the colon, and one third in the rectum. Eighty three percent of cases are diagnosed in those over 60 years of age (Office of National Statistics, 2008). Ninety percent are diagnosed as adenocarcinomas, with adenomas accounting for the remaining 10%. Staging is made using TNM classification system or by using the colorectal-specific Dukes scale (Categories A -D where A represents best prognosis and D refers to advanced or metastatic cancer) (Midgley & Kerr, 2000). Just 10% of patients are diagnosed at an early stage (Dukes A) but those who are have an 85% chance of five-year survival (Cancer Research UK, 2008). Thirty percent are diagnosed with advanced (Dukes D) colorectal cancer (Cancer Help UK, 2007), one of the highest UK rates of advanced cancer at the point of diagnosis. Eighty percent of patients will be offered surgery for colorectal cancer, although this is not always with curative intent (Cancer Help UK, 2007). Chemotherapy is usually offered for all nonmetastatic cancers of the colon and has been shown to improve five-year survival by 6-7%. (Midgley & Kerr, 2000). Radiotherapy is typically used for treatment of rectal cancer, but can also be used as a form of palliative therapy and symptom control for advanced colon cancer (Cancer Help UK, 2007). Colorectal cancer is the second most common cause of cancer-related death in the UK (Office of National Statistics, 2007) but this is expected to significantly decrease since the

introduction of routine screening with colonoscopy for the over 60's in 2006 (Department of Health, 2005).

#### 1.2.1.4 Prostate cancer

Prostate cancer is the most commonly diagnosed male cancer in the UK accounting for 24% of all diagnoses, totalling around 35,000 diagnoses per year and a male lifetime risk of 1 in 14 (Office of National Statistics, 2008). Significantly increased diagnosis rates over the past 20 years have been concluded not to represent increasing incidence, but better detection following introduction of PSA (Prostate Specific Antigen) testing (Cancer Research UK, 2008). Sixty percent of all men diagnosed with prostate cancer are over 70 years of age (Cancer Research UK, 2008) but evidence shows that between 15 and 30% of all men over 50 show some symptoms of the disease (Cancer Help UK, 2007). This figure rises to 66% in over 75's (Dawson & Whitfield 1996) and continues to rise with increasing age. Extent of prostate cancer can be indicated in three ways. Whilst PSA levels are a good indicator of cancer presence, high levels do not always equate with worst prognosis (Cancer Help UK, 2007). TNM staging is more frequently used, as is the prostate specific Gleason classification. Where TNM staging indicates overall extent and spread of illness, Gleason scores are an indicator of tumour histology only. Scores range from 0-10, where scores above eight indicate the fastest growing tumours (Cancer Help UK, 2007). Very few men die from prostate cancer directly (approximately 4%; Cancer Research UK, 2008). The most common treatment options are active surveillance (monitoring of those who may, at a later date, benefit from curative radical treatment), watchful waiting (treating symptoms of those who are unlikely to benefit from radical treatment on an ad hoc basis) or hormone therapy, particularly where the illness is diagnosed in more elderly patients (Cancer Help UK, 2007; Neal, 2008). Radical therapy (radiotherapy or surgery) is also used for localised disease, with chemotherapy generally only reserved for cases of advanced cancer (Dawson & Whitfield, 1996).

#### 1.2.2 North Wales incidence

Six counties contribute to the geographical area of North Wales (Anglesey, Conwy, Denbighshire, Flintshire, Gwynedd and Wrexham) comprising a population of approximately 670,000 persons (Welsh Cancer Intelligence and Surveillance

Unit, 2006). Table 1.1 summarises total incidence, mortality, and survival statistics for this region between 1995 and 2000. These statistics are highly comparable with the summary data previously discussed for general UK trends, but not the improved incidence-related trends observed in many other European countries.

Table 1.1. Incidence, Absolute Survival and Mortality Statistics for breast, prostate, lung and colorectal cancers in North Wales (provided by the Welsh Cancer Intelligence and Surveillance Unit).

	Total Incidence (1995-2004)		1 Year Absolute Survival *				5 Year Absolute Survival *				<b>Total Deaths</b>	
			Male		Female		Male		Female		(1995-2004)	
	Male	Female	Relative Survival	95% CI	Relative Survival	95% CI	Relative Survival	95% CI	Relative Survival	95% CI	Male	Female
Breast		5368			92.0%	90.5, 93.3			79.3%	77.1, 81.3		1838
Lung	3270	2039	16.3%	14.5, 18.3	14.6%	12.4, 16.9	4.1%	3.1, 5.1	5.0%	3.7, 6.5	2704	1630
Colon	1577	1603	62.9%	58.6, 66.8	55.5%	51.1, 59.6	46.2%	41.5, 50.7	37.7%	33.3, 42.1	753	894
Rectum	1137	810	70.9%	66.2, 75.2	70.3%	64.5, 75.3	48.1%	42.7, 53.3	47.3%	40.9, 53.5	450	347
Prostate	4156		85.5%	83.2, 87.6			72.6%	69.0, 75.8			1300	

<sup>\*</sup> Based on diagnoses made 1995-2000 and followed up until 2005.

#### 1.3 CANCER GUIDANCE AND POLICY

Increasing incidence, high levels of mortality, and poor comparison in terms of survival statistics have ensured that cancer remained at the forefront of NHS policy during the last decade. The NHS Cancer Plan (Department of Health, 2000) set cancer as a health services priority and laid out a number of key aims including better co-ordination between primary and secondary care services, increased participation in clinical trials, and better end of life care, amongst others. It also stated the need for personalised support and individually tailored care for each patient, with a requirement to address inequalities in care over different social groups. The NHS Improvement Plan (Department of Health, 2004) also aimed to build upon previous success by increasing the quality and speed of treatment, and by proposing much more choice and decision-making responsibility for the patient.

Despite a large body of literature stressing the importance of quality of life, these latest two documents, in aiming for improvement of service delivery, tend to focus on the practicalities of cancer care and medically based treatments rather than psychosocial concerns. An earlier report by the Chief Medical Officers of England and Wales (A Policy Framework for Commissioning Cancer Services; Department of Health, 1995) gave more recognition to quality of life, and psychological support and care of cancer patients claiming survival to be of "...no means the only outcome of importance." (p.27). It also stated the likelihood of differing quality of life following different treatment programmes.

The Cancer Reform Strategy (Department of Health, 2007) builds upon earlier strategic documents and aims to illustrate "how by 2012 [English] cancer services can and should become among the best in the world." (p. 7). In addition to many suggestions regarding the organisation of medical care, the strategy lays out a clear role for psychological services in achieving this aim, recognising as it does, that support services are "as important as any other aspect of their treatment" (p.76). Despite this objective, the practicalities of implementing this are not clear; dedicated psychological services are not explicitly included under treatment improvements, nor are staff listed in summaries of the expanded cancer workforce since 2004 (also in the same report). Four levels of psychological input are suggested:

- Level one: Information and communication issues
- Level two: Problem solving interventions
- Level three: Counselling and theoretically driven interventions
- Level four: Specialist psychological and psychiatric interventions.

Of these, the first two, and possibly even the third are suggested to become a key component of the role of Clinical Nurse Specialist, thus requiring higher levels of training and support for these individuals.

The latest strategic policy in Wales, Designed to Tackle Cancer in Wales (Welsh Assembly Government, 2008), falls slightly short of the Cancer Reform Strategy by failing to explicitly outline the role of psychological services in ongoing cancer care improvement. Aims of the strategy do, however, include surveys of the experiences and needs of cancer patients and survivors which seems an obvious first step.

#### 1.4 PSYCHOLOGICAL OUTCOMES AND INTERVENTIONS IN CANCER CARE.

## 1.4.1 Incidence of psychological co-morbidity

A large body of multi-disciplinary literature is available (psychology, liaison psychiatry, nursing, social work, clinical oncology and so forth) demonstrating the psychological impact of a cancer diagnosis. Indeed, cancer is not unique among the chronic and terminal illnesses, with worsening physical health significantly associated with higher risk of developing psychological co-morbidity (G. Smith, 2003). Within oncology, the need to tackle such problems is clear (Ramirez, 1989; Pendlebury & Snars, 1996).

Following cancer diagnosis, and throughout treatment, few individuals are able to maintain previous levels of psychological health and well-being without at least some challenges. However, there are many inconsistencies in the literature concerning incidence levels and prognosis of such co-morbidity. In short, the process of, and long-term outcomes from, psychological adjustment to cancer are unpredictable and unknown.

Distress, a term used within the literature to encompass a broad range of negative psychological co-morbidity (Ridner, 2004), is reported to be problematic for in excess of 30% of patients (Zabora, Brintzenhofezoc, Curbow, Hooker & Piantadosi, 2001; Jacobsen, 2007; Mitchell, Kaar, Coggan & Herdman, 2008). In some cases, distress levels are reported as high as 75% (Galway, Black, Cantwell,

Cardwell, Mills & Donnelly, 2008). As such there is a growing movement within the field of psychosocial oncology for distress to be recognised as a sixth 'vital sign' in cancer care, alongside the more traditional physiological assessments of body temperature, pulse, blood pressure, respiratory rate, and pain (Bultz & Carlson, 2006).

Maguire (2000) reports that around one third of all patients diagnosed with cancer will develop one or more psychological co-morbidities, such as anxiety or depression. Anxiety is perhaps the most common of these (Missiha, Solish & From, 2003), but incidence rates at diagnosis are variable ranging from 10% (Ratcliffe, Dawson & Walker, 1995) to 41% (Glinder & Compas, 1999). Clinical depression appears less common, but nevertheless incidence is still considerable ranging from as low as 2% (Ratcliffe et. al., 1995) to 34% (Epping-Jordan, Compas, Osoweicki, Oppedisano, Gerardt, Primo et. al., 1999; Glinder & Compas, 1999). Such wide ranges of reported clinical psychological co-morbidity in cancer patients may be reflective of clinical, demographic and psychosocial variation between studies investigating such outcomes. There is relatively consistent evidence that postdiagnosis levels of depression and anxiety are related to both pre-illness psychological history and concurrent psychological factors (Robinson, Boshier, Dansak & Peterson, 1985). Anxiety and depression are not only common at the time of diagnosis: Sukantarat, Greer, Brett & Williamson (2007) claim that cancer is one of many illnesses in which patients show evidence of such co-morbidity many months—even years—after diagnosis.

Cancer can also have exceptional effects on an individual's quality of life, resulting in psychosocial, sexual and physical challenges and dysfunction (Fallowfield, 1995; Boini, Briançon, Guillemin, Galan & Hercberg, 2004). Alhama, Extremera, Mesa, Martin, Vizoso & Vico (1996) report that around 50% of newly diagnosed patients are dissatisfied with their quality of life, yet a study of breast cancer patients by Kessler (2002) suggests that patients reported better quality of life than they perceived the general population to have. A review by de Haes & van Knippenberg (1983) concluded that there was insufficient evidence to suggest that quality of life differences could be fully accounted for by differences in clinical presentation and treatment modalities and that, as in the case of anxiety and depression, psychological mechanisms are likely to be implicated. Although a

relatively old review paper, no empirical evidence has yet been published to the contrary.

# 1.4.2 The process of adjustment

In the case of illness, the term adjustment can be used to refer to the process of adaptation or return to 'normality' that ensues after a diagnosis. Many studies in the field of psychosocial oncology suggest that this process of adjustment commences very quickly after diagnosis for both distress (Trask, Paterson, Fardig & Smith, 2003; Deshields, Tibbs, Fan, Bayer, Taylor & Fisher, 2005) and quality of life outcomes (Felder-Puig, Formann, Mildner, Bretschneider, Bucher, Windhager et al., 1998; Chan, Ngan, Li, Yip, Ng, Lee et. al., 2001; Yan & Sellick, 2004). However, there is also a substantial literature which suggests that adjustment is far more complicated and that each different psychosocial outcome may follow different adjustment trajectories. Indeed, some studies seem to imply that over the course of illness, quality of life and distress are relatively stable (although differing in quantity between patient groups), and that it is not until after treatment has finished that they begin to improve (Bleiker, van der Ploeg, Ader, van Daal & Henriks, 1995; Nordin & Glimelius, 1998; Butow, Coates & Dunn, 1999). The linear relationship between high quality of life and low distress seem an obvious observation to make given the supportive literature, but this is important to note (D'Antonio, Long, Zimmerman, Peterman, Petti & Chonkich, 1998).

## 1.4.3 Psychological interventions to aid adjustment

Given the potential for poor psychological adjustment, and therefore, poorer long-term psychological well-being, it is no surprise that the need for psychological support for cancer patients is well documented (Spiegel, 1994). Attempts have previously been made to introduce psychological interventions to compliment physical therapies for cancer patients (e.g. Mermelstein & Holland, 1991; Spiegel, Morrow, Classen, Raubertas, Stott, Mudalier et al., 1999; Donelley, Kornblith, Fleishman, Zuckerman, Raptis, Hudis, et al., 2000). These have enjoyed varying success but few have replicated the promising early findings of Speigel and colleagues that such interventions may directly impact upon survival in cancer patients (e.g. Speigel, Bloom, Kraemer & Gottheil, 1989; Richardson, Shelter, Krailo & Levine, 1990); whilst both clinical and demographic factors are found to contribute to long-term disease-free survival, evidence for the role of psychological

variables is weak, if present at all (Cassileth, Walsh & Lusk, 1988; Smedslund & Ringdal, 2004).

Whilst Walker, Hayes & Eremin (1999) suggest that there is theoretical potential for improved survival from psychosocial interventions, the mounting criticism, predominately from Coyne and his colleagues, suggests otherwise. In the first of two commentary articles in response to publications of psychotherapeutic interventions, Palmer and Coyne (2004) suggest that methodological weaknesses are often apparent; namely sampling weaknesses and unclear justification for the intervention components. More so, they go on to suggest that in published reviews of interventions, publication biases and inappropriate comparison analyses between included studies falls below appropriate standards and so not even these conclusions can be trusted. In the second commentary (Coyne, Hanisch & Palmer, 2007) and two further review articles (Lepore & Coyne, 2006; Coyne, Stefanek & Palmer, 2007), the overall conclusion is that the lack of evidence to date is sufficient to abandon all claims of survival effects from psychological interventions, in favour of more subtle hypothesis testing of intervention effects on behavioural aspects of illness; experiences of and coping with side effects of treatment, treatment adherence, and follow-up care delivery, for example (Coyne, Hanisch et al., 2007).

Whilst Coyne et al's methodological critique is sound and has been echoed elsewhere in the literature (e.g. Edwards, Hulbert-Williams & Neal, 2008), their conclusion that interventions should not be aimed at survival, or indeed the many other important psychosocial outcomes, seems premature. Indeed, putting survival outcomes aside, there is evidence that intervention may have beneficial impacts upon psychosocial outcomes such as anxiety, depression, distress, perceived pain, information needs and so forth (Fallowfield, Ratcliffe, Jenkins & Saul, 2001).

Two recently published Cochrane reviews of psychological interventions within oncology samples further question the findings of individual studies; the first (Edwards *et al.*, 2008) explored of the impact of two types of psychological intervention (Cognitive Behavioural Therapy and Supportive-Expressive Group Therapy) on a variety of outcomes within metastatic breast cancer patients and the other (Akechi, Okuyama, Onishi, Morita, & Furukawa, 2008) focuses

specifically on psychotherapeutic interventions targeted at depression but in a range of palliative diagnoses. Edwards *et al.* (2008) concluded that whilst interventions can improve short-term psychological comorbidity, the small corpus of established literature offers little in terms of conclusive evidence for benefits on long term psychological or physical outcome. Akechi *et al.* (2008) conducted numerous meta-analyses which demonstrate that where effects on anxiety were non-significant, some ameliorating effect on depression was observed.

Whilst these two reviews focus upon those with metastatic illness, the findings are not just limited to these patient populations and similar findings are reported for those with less advanced illness (Trijsburg, can Knippenburg & Rijpna,1992; Jacobsen & Hann, 1998; Uitterhoeve, Vernooy, Litiens, Potting, Bensing & deMulder, 2004; Owen, Klapow, Hicken & Tucker, 2001; Schofield, Carey, Bonevski & Sanson-Fisher, 2006). As yet, no up-to-date systematic reviews of the effects of intervention for early cancer diagnosis has been published, although one is currently underway for quality of life outcomes (Galway et al., 2008). Given the ongoing debate on the efficacy of psychosocial intervention, the scope for a similar review for interventions aimed at psychological outcomes in patients with early stage diagnosis patients is clear. Despite the, albeit controversial, evidence from intervention studies for improvements in distress and quality of life, the practicality and cost-effectiveness of offering these to all patients is questioned given the reported benefits (Owen et al., 2001; Rehse & Pukrop, 2003). Bloom (2007, 2008) promotes the view that whilst intervention research has failed to establish a clear benefit for recurrence or survival, the shorter-term psychological benefits could result from an indirect effect of increased social support, a conclusion also drawn earlier by Llewelyn, Murray, Johnston, Johnston, Preece and Dewar (1999).

Other indirect benefits of psychosocial interventions have been reported, including the fostering of an environment conducive to emotional expression (Shrock, Palmer & Taylor, 1999), and the enhancement of psychophysiological immune functioning (Compass & Leuken, 2002). This latter finding has also been supported by growing research into the effects of mindfulness-based psychological therapies. Although it is perhaps too early to make any substantive claims from such research regarding disease progression and survival, promising results, both

in terms of short-term distress levels and psycho-neuroimmunological functioning, have been published (Mackenzie, Carlson & Speca, 2005).

Coyne et al.'s (2007) conclusion that the trialling of interventions should be tailored entirely to medical and behavioural outcome is neither universally accepted nor promoted in this thesis. What is clear, however, is that should psychological intervention ever be intended to impact upon clinical oncology in a significant way, more methodologically sound, theoretically based empirical research is needed (Ross, Boesen, Dalton & Johansen, 2002; Schofield et al., 2006). Furthermore, the methodology of the non-intervention based psychosocial oncology literature is also questionable and may well account for the inconsistency of findings. The use of randomised controlled trials and longitudinal designs over cross sectional surveys is becoming more important as a marker of good quality research (Yardley & Moss-Morris, 2007) and yet this remains a critical problem in psychosocial oncology. Furthermore, the effects of clinical variables and within sample bio-medical differences (Andersen, 1992; Edwards et. al., 2008) need to be considered with more methodological rigour.

Particular attention is also due to the many reviews (e.g. Cull,1990; Andersen, 1994) which suggest that the greatest weakness in the field arises from a lack of sound theoretical rationale (this critique of the literature is not new within health and clinical psychology; see Marteau & Johnston, 1987 for an early commentary on the potential of health psychology theory application). Basing future research on established and validated theory may improve the credibility of the findings.

It has long been suggested that research with a multidimensional focus is required (Baltrusch & Waltz, 1985). Rather than continued study of behavioural processes, a focus on the additional effects of individual differences, cognitive processes and emotional (or affective) reactions on patient outcome should be investigated as these may act to facilitate or impede psychosocial interventions (Folkman & Greer, 2000; Compas & Lueken, 2002). One attempt to model these complex variable interactions was proposed by Brennan (2001) in his Social-Cognitive Theory of adjustment. This process model of adjustment encompasses a broader range of psychosocial components primarily centred around the notion that distress results when the diagnosis (and its sequalae) require greatest re-

organisation of the patient's mental map (Brennan & Moynihan, 2004), a term used to refer to individual cognitive schema and experience of the world. Interventions encompassing such components (e.g. self-efficacy, self-regulation and outcome expectancies) have previously been reported to be efficacious in improving psychosocial outcome (Graves, 2003). However, the model requires further development and empirical support; specifically, its research and multi-disciplinary application beyond clinical psychology services is unclear.

Whilst Brennan's model is rooted in clinical psychology, the discipline of health psychology may offer useful alternatives. Self-Regulation Theory—based upon the work of Leventhal and his colleagues (e.g. Leventhal, Leventhal & Schaefer, 1989) and Carver & Scheier (e.g. Carver & Scheier, 1999)—has to date dominated research into cognitive aspects of illness adjustment, both within cancer and other illness groups. Self-regulation theory was in part developed from more generic stress and coping theory (Schroevers, Kraaij & Garnefski, 2008) in order to expand such theories to encompass goal-related cognitions. However, even this popular model has weaknesses, primarily that the longitudinal aspect of how the different components of self-regulation change over time and interact is under-developed and un-clear (Marks, Murray, Evans, Willig, Woodall & Sykes, 2005). As an alternative approach, recently expanded socio-cognitivemotivational models of stress (i.e. Lazarus's Transactional Model) may be considered well positioned to provide a theoretically developed and empirically supported model which could (but haven't yet in their fullness) be applied to oncology. The remainder of this chapter will focus on reviewing this theory and some of the relevant research.

#### 1.5 THE TRANSACTIONAL MODEL OF STRESS

Psychologists define stress as a fundamentally subjective transactional process involving appraisal of the potential stressor (the circumstance initiating the stress reaction) and perceived resources (the individual's ability to cope with, and deal with the stressor) (Lazarus & Folkman, 1987). Individual differences in response to similar stressors reflect cognitive appraisal variations (Lazarus, 1984). It is these variations in event and resource appraisal that make some individuals particularly vulnerable to stress. Appraisal occurs at both conscious and

unconscious levels and is influenced by situational, temporal, and personal factors. For example, an individual receiving a diagnosis may appraise it as a threat (e.g. to future goals), as a challenge (to overcome) or as a loss (e.g. loss of role). In turn these appraisals will vary depending upon the diagnosis made, the past experience of the patient, and even the age of the patient.

Coping represents the cognitive and behavioural efforts made by an individual to make the situation more manageable and less demanding or threatening, or what a person will do or think in order to meet the perceived challenge. Although numerous dichotomies of coping have been proposed within the literature—for example Folkman and Lazarus's (1988) Problem versus Emotion focussed coping, or Carver's Adaptive versus Maladaptive coping (1997)—it is perhaps the process and flexibility of the constructs which should be of importance, rather than the specific label assigned, which may (as in Carver's case) be misleading: a strategy perceived by one to be adaptive, may be perceived by another, or indeed that same person in a different situation, to be maladaptive. What is generally accepted within the coping literature is that coping is complex, flexible, dynamic, and more crucially, primarily dependent on cognitive appraisals. Furthermore, within a given stressful situation, individuals will often report using many different types of coping approach to handle the different demands associated with that stressor (Lazarus, 1993).

There is a significant body of empirical evidence concluding that coping is linked with event outcome. However, it has recently been suggested that it may be individual differences in the cognitive appraisals and affective processes which lie behind the coping effort that have most predictive value (Schneider, 2008). Lazarus's revised stress theory (1993, 1999), the Transactional Model, proposes that under threat of potential stress, the individual will not only appraise the situation/event, but will also make an assessment or appraisal of how one will cope with stressor and how the stressful experience will interfere with attainment of one's personal goals. It was also in these latter developments of the theory that appraisals were split into macro and micro components (see table 1.2). Lazarus refers to this former group as the core-relational themes, a summary perception of harms or benefits from the situation. Within a given situation, a specific core-relational theme is referred to as a relational meaning, and each is paired with one

of 12 core emotions (Smith & Ellsworth, 1985; Lazarus, 1999). It is interesting to note that where ten of these pairings are unique, there are two independent emotions (sadness and resignation) which, according to the literature, can result from the same core-relational theme (loss/helplessness). It is differing combinations of the individual appraisal components which produce varying perceptions of relational meaning (at the micro processing level). At this point, appraisal theory had moved away from a simple assessment of harm, loss and challenge, to a more complex interaction of motivational (relevance of the situation and how congruent this is to one's goals), situational (locus of accountability and coping expectations), and future-oriented (expected length of disruption due to the stressor and perceived long-term impact) appraisals (Lazarus, 1993).

Although the one-to-one relationships between emotions and relational meaning are well documented, the unique appraisal component contributions to each core-relational theme are less clear. For six so-called 'hot' cognitions (which underlie the emotions of anger, guilt, fear/anxiety, sadness, hope/challenge, and happiness), the entire process (an emotion-specific cognition model) is fully proposed. The remainder (these haven't yet been assigned a grouped sub-title within the literature), are less defined and a description of which appraisal components are (or aren't) involved has not been established. Indeed, there are some emotions, for example regret, for which even the unique relational meaning is not fixed due to the neutrality of the emotional state to which they are associated (Smith, 2006). Table 1.2 summarises which components are implicated for each emotional reaction according to the latest academic opinion (Smith and Lazarus, 1993; Lazarus, 1999; Smith, 2006).

Table 1.2. Hypothesised relationships between Transactional Model components.

Emotion	Core-Relational Theme	Appraisal Components
The 'Hot' Cognitions		
Anger	Other-blame	Motivational relevance
		Motivational incongruence
		Other accountability
Guilt	Self-blame	Motivational relevance
		Self accountability
Fear/Anxiety	Danger/threat	Motivational relevance
		Motivational incongruence
		Low Emotion focussed coping potential
Sadness	Loss/ helplessness	Motivational relevance
		Motivational incongruence
		Low Problem focussed coping potential
		Low Future expectancy
Hope/Challenge	Optimism	Motivational relevance
		Motivational incongruence
		Problem focussed coping potential
Happiness	Success	Motivational congruence
Other Cognition		
Surprise	Unexpectedness	Not specified
Resignation	Loss/helplessness	Not specified
Tranquility	Lack of concern	Not specified
Shame/Humiliation	Self consciousness	Not specified
Interest	Relevance	Not specified
Boredom	Irrelevance	Not specified
Relief	Threat removal	
Frustration	Not specified	Not specified
Self-Directed Anger	Not specified	Not specified
Regret	Not specified	Not specified

Over the course of the late 1980s and 1990s, the order of the linear process between components in this model changed numerous times. Some papers (e.g. Lazarus, 1991) placed both emotion and coping as concurrent outcomes from the appraisal process while others placed emotion before coping (e.g. Lazarus, 1999). In his 1999 text, Lazarus also comments that coping can even shape emotion, presumably by changing situational appraisals. Despite such inconsistencies, assessment of the interdependent role of each component—appraisal, emotion, and coping—has been concluded as imperative to best outcome prediction (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986; Lazarus, 1999; Storbeck & Clore, 2007). Figure 1.1 presents a diagrammatic summary of the model encompassing feedback loops between outcome and re-appraisal, and between coping and re-appraisal, to emphasise the ongoing and cyclical nature of the stress process.

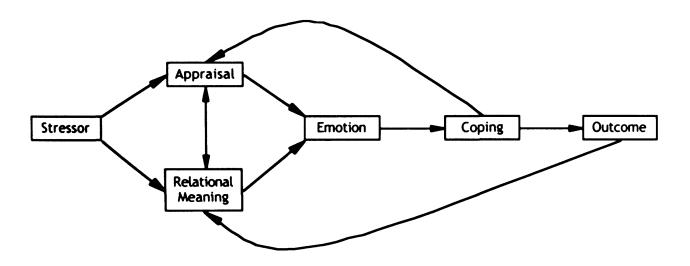


Figure 1.1. The Transactional Model of stress (adapted from Lazarus, 1999).

# 1.6 EMPIRICAL EVIDENCE FOR THE TRANSACTIONAL MODEL

Only a few published studies test the full complexity of the Transactional Model in sample of physically ill individuals (though there are some, for example Lowe, Vedhara, Bennet, Brookes, Gale, Munnoch et al. 2003; Bennet, Lowe & Honey, 2003). The majority of empirical support comes from laboratory-based, experimental studies by Lazarus and colleagues (Lazarus, 1993) and their published theoretically-based hypotheses, position papers, and textbooks. A distinction must be drawn here between the two categorisations of stress often made in health psychology; that between chronic stressors (high impact, ongoing stressors) and acute stressors (low impact, short lived stressors). In summarising previous methodological approachs to this subject, Lazarus (1999) suggests that most experimental studies have focussed primarily on short-term acute stressors (e.g. exam stress), vicarious stressors (e.g. responses to viewing stressful situations on film), or retrospective reflections on heterogenous stressors within the same sample (e.g. requiring participants to respond based on a recent stressful event of their choice). Few, if any, have successfully tested the Transactional Model within the context of chronic stressors (e.g. diagnosis of a life-threatening illness). Whilst the effect on the individual of each stressor type is thought to be quantitative rather than qualitative—in other words, that the same psychological and psycho-biological process may result, but at differing levels, with the potential for resultant outcomes to differ in both quantity and time-extent (Lazarus, 1999)—it is imperative that future empirical tests of this model focus on the homogenous experience of chronic stressors in addition to the lesser impacting acute stressors.

### 1.7 APPRAISAL, EMOTIONS, COPING AND ADJUSTMENT TO CANCER

Cancer diagnosis could theoretically operate at many levels of Lazarus's model (Jenkins & Paragament, 1988). For example, illness adjustment and outcome rely not only on personal coping, but also on personal appraisal and external intervention (e.g. treatment) which can pose a challenge to personal control of the situation. Additionally, illness frequently has major emotional implications and often challenges personal goals (Brennan, 2001). And yet, research testing specific components of the model in the adjustment process is

sparse. Chapter Two of this thesis will provide a systematic review of such evidence, however, an overview of some of the key research in psychosocial oncology is provided here to form the rationale for this research thesis.

# 1.7.1 Appraisals

In terms of cognitive appraisal, a variety of components have been studied, though few repeatedly enough to form sound conclusions. Costanzo, Lutgendorf, Bradley, Rose and Anderson (2005) found that strong internal attributions were associated with greater distress, as did Faller, Schilling and Lang (1995) and Gotay (1995). Where Jenkins and Paragament (1988) found only moderate predictive ability for appraisals on outcome, other studies report that primary appraisals relate to outcome more strongly than do secondary appraisals (Burgess and Haaga, 1998). In-keeping with the Transactional Model, Krietler, Chaitchik, Kreitler, Rapoport and Algor (1996) report findings which highlight the importance of motivation-related cognitions (assessment of how much impact the stressor will have on the achievement of current goals and activities) in adjustment to cancer, a factor virtually absent from current empirical literature and models of cancerspecific adjustment.

### **1.7.2** Coping

Research relating coping to illness outcome is abundant compared with research into cognitions or affective responses. The majority of these papers however, demonstrate such relationships with only modest effect sizes (Felton & Revenson, 1984; de Ridder & Schreurs, 1996). Regardless of strength of effect, most replicate the transactional and fluid nature of coping demonstrated in the general health psychology literature (Gammon, 1993). For long-term illness adjustment, it is a general principle that escape or avoidant coping, excess denial, or emotion-focussed coping tend to be more strongly associated with higher distress than do active or problem-focussed coping (Zabalegui, 1999; McCaul, Sandgren, King, O'Donnell, Branstetter & Foreman, 1999). The latter should, according to Cohen (2002), be the focus of psychosocial interventions within this patient group. However, as defined earlier, coping responses are subjective and should not always be exclusively considered in this simplistic way. Some authors, for example, have compared coping responses between patient sub-groups

implying that these may be indirectly responsible for cultural, age, and gender differences in adjustment and outcome (e.g. Culver, Arena, Antoni & Carver, 2002). Furthermore, religious-specific coping is becoming an area of increasing research interest with preliminary results seeming to show some benefits (with regard to psychosocial outcome) for those using religious coping and reporting deeper spirituality (Gall, de Renart & Boonstra, 2000; Nairn & Merluzzi, 2003; Gall, 2004).

#### 1.7.3 Emotions

Varying levels of experienced emotion—sadness, fear, or hope, for example—have also been reported to influence psychosocial outcome in cancer patients (Grassi & Molinari, 1988; Watson, Greer, Rowden, Gorman, Robertson, Bliss et al., 1991; Longman, Braden & Mischel, 1999). Although published data on a wide range of specific emotional components is infrequent with most papers tending to focus on more generic affective disorders such as anxiety, depression or distress as primary outcome measures.

The concept of emotional control has been researched more often within cancer samples, primarily using Watson and Greer's Courtauld Emotional Control Scale (CECS; 1983) which assesses the extent to which an individual supresses to their anger, anxiety and depressive emotions. Numerous studies have demonstrated how in cancer patients, higher emotional repression correlates with anxiety (Pettingale, Watson & Greer, 1984), and more general adjustment (Classen, Koopman, Angell & Speigel, 1996; Sanderman & Ranchor, 1997; and Denollet, 1999).

#### 1.7.4 The Mental Adjustment to Cancer Scale

Much of the work of Watson, Greer and their various colleagues since the early 1980s has focussed on processes involved with cancer adjustment. This resulted in the creation of the Mental Adjustment to Cancer (MAC) Scale (Watson, Greer, Young, Inayat, Burgess, & Robertson, 1988). With a somewhat ambiguous title, the measure was originally created to assess coping strategies in people with cancer. However, there are features of this scale which not only relate to the construct of coping. When viewed in the context of stress models, the scale also seems to assess (whether purposely or not is unclear) cognitive appraisal and emotions. As such the scale seems suited to the development of social-cognitive-

motivational models of adjustment, if perhaps still requiring of further modification and clarification. Of the four main factor components of this scale, three are repeatedly found to be correlated with psychosocial outcome: helplessness/hopelessness (e.g. Greer, 1991), fatalism (e.g. Watson *et al.*, 1991; Kugaya, Akechi, Okamura, Mikami & Uchitomi,1999) and fighting spirit (Classen *et al.*, 1996; Gilbar, Or-Han & Plivazky, 2005; Watson, Homewood, Haviland & Bliss, 2005). Additionally, the role of hopelessness/helplessness has been shown to be implicated in disease-free survival (Watson, *et al.* 2005) but the wider impact of fighting spirit on such physical outcomes remains unclear (Coyne *et al.*, 2007). Nevertheless, Greer (2008) continues to promote the use of cognitive-behavioural therapy to enhance fighting spirit to reduced the risk of recurrence and improve survival chances.

In a relatively recent review, Ranchor & Sanderman (2006) further add to the confusion as to what is measured by the Mental Adjustment to Cancer Scale by referring to the concept of fighting spirit as a personality variable, going on to suggest that there is potential for research to explore how Five-Factor models of personality relate to this charcteristic. The Mental Adjustment to Cancer Scale, and particularly the notion of fighting spirit will be addressed at numerous points during this thesis. However, a discussion of the role of personality in cancer adjustment follows.

#### 1.8 PERSONALITY THEORY

Carver & Scheier (2000) define personality as "a dynamic organization, inside the person, of psychophysical systems that create the person's characteristic patterns of behaviour, thoughts, and feelings" (p.5). The overlap here with the Transactional Model is clear and numerous researchers including Lazarus and Folkman (1987) and O'Brien and DeLongis (1996) make a sound case for the hypothesis that person-related variables (e.g. locus of control) may act as causal antecedents to stress appraisals, emotions, and coping (the thoughts, feelings, and behaviours referred to by Carver & Scheier). Lazarus further clarified his position on this issue by writing that:

"...psychology has long been ambivalent about individual differences, opting for the view that its scientific task is to note invariances and develop general laws. Variations around such laws are apt to be considered errors of measurement, though they must be understood if reasonably accurate prediction is to be possible." (1993, p.3)

Related more explicitly to illness, Eysenck (1991; 1993) claimed personality and individual differences to be as equally important as the stressor and coping responses in determining final stress outcomes.

Personality is generally considered to consist of two distinct parts. 'State' attributes are those which are changeable: unstable and situation specific (e.g. Self-Efficacy). In addition, exists the concept of 'trait' personality characteristic—a label first coined by Cattell to replace the previously used term 'predisposition' (Pervin & John, 2001)—of which there are many different academic perspectives. including the psychoanalytic, behaviourist, and cognitive perspectives, for example. The dispositional perspective has become one of the most commonly researched and holds that individuals display long-term consistency and continuity in their cognitive and behavioural actions (Carver & Scheier, 2000). One popular model from this perspective is the Five-Factor Model (Costa & McCrae, 1992). This proposes that personality consists of five independent factors; extroversion, agreeableness, conscientiousness, neuroticism, and openness (note that other theorists within the dispositional perspective also propose five-factor models, the factor content of which being relatively equivalent, but with different labels attributed to each component. Out of all, Costa & McCrae's is perhaps the best known, and most cited in empirical research in health related fields).

#### 1.9 PERSONALITY AND ADJUSTMENT TO CANCER

A substantive proportion of the literature relating personality to health and illness has a very different focus to the proposal here outlined, in that personality was researched as a risk factor for onset of illness (Suls & Rittenhouse, 1990): the disease-prone personality (Friedman, 1990). However, the current focus is in the role that personality may play in prediction of illness outcome (Levy & Heiden, 1990; Levenson & Bemis, 1991; Vollrath, 2006).

No conclusive evidence is yet published for an association between personality and clinical outcomes such as cancer recurrence or survival (Canada, Fawzy and Fawzy, 2005; Nakaya, Tsubono, Nishino, Hosokawa, Fukudo, Shibuya, et al., 2005; Ranchor & Sanderman, 2006); these outcomes are assumed to be primarily biologically driven (Richardson, Zarnegar, Bisno & Levine, 1990). There is, however, some evidence for the influence of personality on some psychosocial outcomes, including for example, quality of life (Boini et al., 2004; Llewellyn, McGurk & Weinman, 2005), anxiety (Skarstein, Aass, Fossa, Skovlund, & Dahl, 2000; Montazeri, Jarvandi, Haghighat, Vahdani, Sajadian & Ebrahimi et al., 2001), and depression (White and Macleod, 2003). The process by which personality may influence these outcomes lacks substantive empirical support (Goldberg & Cullen, 1985); what evidence there is focuses almost exclusively on neuroticism, optimism, self-efficacy and locus of control.

Neuroticism in particular has been found to influence distress levels throughout, and after treatment (Millar, Purushotham, McLatchie, George & Murray, 2005). Temoshock (1987) and Sanderman and Ranchor (1997) also report strong evidence for a role of both neuroticism and introversion in illness adjustment when measured within the taxonomy of the so-called cancer-prone 'Type C' personality; a factor construction of personality variables also characterised by a tendency to suppress emotion, and to respond to stress with depressive or hopeless reactions, which is associated with not only adjustment, but also (tentatively) with cancer onset (Temoshock, 1987; Friedman, 1990; Eysenck, 1994).

The boundaries of what constitutes situational specific 'state' attributes are unclear and often overlap with concepts of health cognitions. Nonetheless, a review by Denollet (1999) suggests that there is clear evidence to support the inclusion of both state and trait measures in psychosocial oncology research. In making this statement, Denollet is drawing on the large body of literature which demonstrates outcome moderating effects of self-efficacy (Lev, 1997; Kreitler, Peleg & Ehrenfeld, 2007); health related locus of control (Andrykowski & Brady 1994); and, optimism (Carver, Pozo, Harris, Noriega, Scheier, Robinson *et al.*, 1993; Allison, Guichard, & Laurent, 2000; Carver, Smith, Antoni, Petronic, Weiss &

Derhagopian, 2005) in addition to trait-related findings. Some caveats to this are necessary.

Regarding control, distinction is often drawn between generic control, often referred to as Locus of Control, and situation-specific control, such as self-efficacy (Lyons & Chamberlain, 2008). Although support for the role of self-efficacy is virtually unanimous, findings related to generic, and even health-specific, locus of control are less consistent (Osoweicki & Compass, 1998). In those studies that have found significant effects, it is suggested that these could act by indirect mechansims of promoting health behaviours (Newsom, Knapp & Schulz, 1996), or by fostering a fighting spirit attitude (Watson, Greer, Pruyn & Van den Borne, 1990). The inconsistency in these results has been suggested, among other reasons, to be primarily a by-product of methodological differences, particularly in how the concept is operationalised and measured in research (DeBoer, Ryckman, Pruyn & Van den Borne, 1999).

The concept of optimism—a tendency to always expect positive outcomes (Pitts & Phillips, 1998)—also requires expansion. Although here listed as a state variable, there are some (e.g. Carver et al., 1993) whose measures claim to assess dispositional optimism, a more longitudinally stable, trait-like form of optimism. Pessimism is usually defined as a diametric opposite state to optimism. Whilst both have been found to influence illness outcome, there is ongoing debate about whether the two constructs exist at opposite ends of the same continuum, or indeed, whether they are separate factors requiring different measurement tools (Marshall, Wortman, Kusulas, Hervig & Vickers, 1992; Carver et al., 1994). It is, of course, feasible for individuals to have unrealistically optimistic beliefs. Whilst such unrealistic beliefs are not found to compromise psychological well-being (Taylor & Brown, 1994), Spiegel (2001) claims that within cancer samples, optimism is only beneficial if the future that is optimistically referred to is realistically achievable.

# 1.10 INTEGRATING PERSONALITY AND THE TRANSACTIONAL MODEL INTO CANCER ADJUSTMENT THEORY

Within the context of the Transactional Model, it was previously thought that the personality-outcome relationship operated via a mediating effect of coping,

and there is a good deal of supportive literature for this hypothesis (David & Suls, 1999; Aarstad, Aarstad, Bru & Olofsson, 2005; Semmer 2006). A recent review by Petticrew, Bell and Hunter (2002), however, concluded that coping may not be significant as an influencing factor over physical illness outcomes for cancer patients. These findings are in contradiction to the basic Transactional Model and thus further work is required to clarify the process by which the many factors interact to predict outcome.

There is limited empirical evidence explaining how personality may influence cognitive appraisals of a health threat. A recent study by Tong, Bishop, Enkelmann, Why, Diong, Ang et al. (2006), provided evidence that within non-clinical samples personality traits according to the Five Factor theory can explain variability in appraisals and emotions. Research also demonstrates that personality can affect symptom perception, illness self report, and outcome expectancies (Scheier & Carver, 1985; Deary & Frier, 1995; Millar et al., 2005). It seems, therefore, a reasonable assumption that these same effects could extend to cognitive appraisals in line with the Transactional Model.

In their recent meta-analysis, Franks and Roesch (2006) reported that coping is clearly related to appraisal: threat appraisal associated with problem-focused coping; harm/loss appraisal with avoidance coping; and, challenge appraisal with problem-focused and approach coping. In light of this, it is possible that it is not coping directly, but the appraisals themselves which form the coping response, which acts as the primary link between personality and illness outcome.

#### 1.11 SUMMARY AND THESIS RATIONALE

When considered as a whole, the individual studies contained in this overview may lead to a better understanding of how the Transactional Model can be applied to the study of cancer outcomes. Although many features are covered in other cancer specific adjustment models (particularly Brennan's Social-Cognitive Theory, 2001), many lack the in-depth motivation-related appraisals of Lazarus's later theory. Empirical findings demonstrate that both personality and each component of the Transactional Model are implicated in outcome prediction and some studies seem to show that the mechanism by which personality affects outcome may not be direct but rather through the effects of coping. This was not,

however, supported by Petticrew *et al.*'s (2002) review. Far less research has considered the possible role of cognition as the mediating variable, but the high correlation between cognition and coping may go some way to explaining the misplaced assumption that coping acts as a moderator. Therefore personality-cognition-outcome relationships are worthy of further research attention. If these are confirmed, a refined theory of adjustment may be possible which will enable development of both an improved understanding of the adjustment process and clinically applicable systems by which those most at risk of psychological distress or quality of life difficulties can be highlighted and treated at earlier illness stages.

# 1.12 THESIS QUESTIONS

In applying health psychology theory to cancer adjustment, this thesis has three aims: to systematically review the literature to date according to this theoretical framework; to explore the clinical applicability of the model in a pragmatic, empirical way; and to test the micro-level theoretical assumptions inherent in the Transactional Model.

The first of these aims has two important components: a review of findings, and a review of methodology. Therefore, a systematic review and meta-analysis will be performed on the psychosocial oncology literature to answer the following two questions.

Question 1: What evidence is there currently in the literature demonstrating associations between personality, cognitive appraisal, emotion, and psychosocial outcome for cancer patients?

Question 2: Since early reviews, has research methodology in this field improved? If not, what further steps need to be taken?

This review will address the need to consider findings within a fully theoretical context and improve on previous reviews which instead either focus on just part of the model or else stick to the method of a traditional non-systematic review without statistical meta-analysis. The review will summarise relevant findings of individual studies in a coherent way in order to understand the full application of

the model and identify potential gaps in the literature which could stimulate future research endeavour. Additionally, each study will be rigorously quality assessed and the overall methodological approach critiqued. This will allow analysis of the overall validity of previous claims that the literature has poor methodological quality, and whether this can be justifiably cited as a reason for inconsistent findings. Second, and perhaps more important, previous methodological reviews have merely claimed that methodology needs to be improved. By taking such a rigorous approach to quality assessment, this review will move one step further by specifying methodological problems and providing guidelines for precisely how quality can be improved in future studies.

A pragmatic approach will be taken to clinical application of this model to meet the second aim. An empirical study will follow the adjustment of newly diagnosed cancer patients and analyses will be conducted to attempt to identify which potentially modifiable variables are most predictive of short-term psychosocial outcomes. The purpose is not to thoroughly test the transactional model, nor is it to attempt to change components included in the model, but to explore correlation between components within it and clinically relevant psychosocial outcomes. This data can then be used to inform future empirical investigation (including theory-led interventions), and to demonstrate the extent to which such variables may prove indicative and predictive in clinical settings.

Question 3: What are the most important predictors of psychosocial outcome in newly diagnosed cancer patients, and leading from this, at what time point (baseline or three month follow-up) are these most predictive of longitudinal (three or six month) follow up?

Studies into psychological aspects of breast and prostate cancer in this field are numerous and this is reflected by the improved prognosis and availability of psychosocial support for these patient groups seen in recent years (Department of Health, 2007). However, a recent meta-analysis of psychosocial interventions has been highly critical of research in the field for over reliance on studies based solely on breast cancer samples (Rehse & Pukrop, 2003). Cancer patients are not a homogenous group in terms of either physiology and psychology and each type of

cancer presents particular challenges, varying levels of threat and different stressors to each individual patient.

Although there have been similar medical advances across all cancer diagnostic sites, expansion of research attention into these areas is vital. The field needs to establish if knowledge about breast and prostate disease is generalisable to other cancers and to gain understanding of site-specific problems, and how these impact upon each patient's individual psychosocial needs. In particular, the collective research focus must widen to also include, for example, colorectal cancer where incidence remains high, but wide variability in outcome and adjustment is observed, and lung cancer where the psychosocial wellbeing through the course of illness, and survival expectancy, remain poor.

The proposed study will recruit a sample of patients with cancer of various types, collecting both self-report data (psychosocial predictor and outcome variables), and secondary care clinical and histology data to attempt to control for such differences in the underlying physiological nature of the illness. This theory-driven study will test the rationale introduced within this chapter that adjustment could potentially be modelled using personality and stress theory. In keeping with methodological recommendations, this will be a longitudinal study. Patients will be recruited soon after diagnosis and followed up at three and six month time points. The theory in which this research is based lays emphasis on the transactional nature of appraisal over time, therefore, an ability to explore temporal changes in these variable relationships is paramount to provide the most informative evidence (Somerfield & Curbow 1992).

Clinically oriented findings will improve understanding of the psychological processes occurring following cancer diagnosis which could have important implications for non-medicine based treatments. And by using a sound theoretical basis, it should be evident how, and to what extent, clinical factors, personality, cognition and emotions interact to enable prediction of short-term psychosocial outcome.

The final aim, that of theory testing, directly matches the fourth thesis question. Using baseline data from the empirical study (see question three), theory testing will focus on the relationships between cognitive and affective components of the Transactional Model.

Question 4: Are the hypothesised associations between cognitive appraisals, core-relational themes, and emotions in Lazarus's Transactional Model supported in a sample of newly diagnosed cancer patients.

As previously outlined, this model has potential to explain the process of adjustment to cancer diagnosis. However, the theoretical basis of this model needs empirical development; namely, the complex associations between cognition and emotion variables needs testing in a homogenous sample of participants undergoing chronic, high impact stress. This will be used to evaluate the wider validity of findings reported from previous lab-based investigations, and those of heterogenous samples undergoing acute stress. Furthermore, these tests will expand beyond the 'hot' cognitions (to which most previous empirical investigations have been limited), to test the full range of affective outcomes outlined by Lazarus in the latest version (1999) of the theory.

#### **CHAPTER 2**

# PERSONALITY, COGNITIONS AND EMOTIONS AS CORRELATES OF ANXIETY. DEPRESSION AND QUALITY OF LIFE: A SYSTEMATIC REVIEW OF THE CANCER LITERATURE.

#### 2.1 CHAPTER OVERVIEW

Following the narrative theoretical review in Chapter One, this chapter presents a systematic review of a more focussed area of the literature. Few systematic reviews have been conducted in psychosocial oncology, and at present, no up to date review exists examining the application of the Transactional Model to adjustment in cancer patients. This theory encompasses a wide range of different psychological components (cognitions, emotions, and personality as an overall influencing factor). Whilst no studies have been conducted within the entire theoretical framework, many studies are expected to have relevance to one or other part of the theory. The review is important, therefore, not only to synthesise findings, but to attempt to contextualise each of these studies within a larger theoretical framework. The need for this type of review became apparent early on as scoping searches revealed a vast literature to be synthesised. This study was, therefore, planned in addition to a generic background review, to feature as a prominent part of the thesis as equally important as the later empirical work.

Three primary questions were asked of the data:

- 1) What is the association between personality and illness cognitions and emotions following cancer diagnosis?
- 2) What is the association between personality on psychosocial outcome for cancer patients?
- 3) What is the association between illness cognitions and emotions on psychosocial outcome for cancer patients?

Many studies highlighted in the review do not always use explicitly equivalent terminology, for example, illness appraisals and illness perceptions are both accepted terms for illness-related cognitions. Therefore, it was necessary to group different variables together such that the review could discuss findings in a more coherent way. Grouping of these studies was mainly theory-led, but also had

to be guided by the individual hypotheses being tested in each study. In line with theory, groupings used included personality (either state or trait), health control beliefs, illness cognitions (appraisals), emotional reaction to illness, and coping. Although the predictive effects of coping were not a primary focus of this review, data on this construct were essential in order to assess the full model. Therefore, coping studies were included if they related to interactions between any of the other predictor variables and an outcome variable.

Psychosocial outcome variables were categorised as either psychological comorbidity (anxiety, depression) or quality of life. A protocol amendment was made during data extraction to also include well-being and general distress as two separate but closely related outcome measures. For a number of reasons, primarily the lack of specifically relevant literature, question one (the association betweem personality on cognitions) was removed from the review after literature searches had been completed. The reasons and implications for this are discussed more fully in section 2.5.7. Therefore, although the methods section of this chapter will include reference to this research question, extraction and analysis were not conducted.

The review protocol was written in accordance with standard guidelines produced by the NHS Centre for Reviews and Dissemination (NHS CRD: Khan, Reit, Glanville, Sowden & Kleinjnen, 2001) and the Cochrane Collaboration (Higgins & Green, 2005), in addition to several methodological papers (e.g. Rosenthal, 1995; Egger, Smith & Altman, 2001; Papworth & Milne, 2001; and, Rosenthal & DiMatteo, 2001). Additionally, the protocol, and in particular the search strategy, were peer reviewed by the Cardiff University Support Unit for Reviews of Evidence (SURE). As recommended, and as a further check against bias and subjectivity, two reviewers worked independently at all stages of inclusion and quality assessment. For this purpose, Helen Dudley, a psychology graduate with some research experience in psychosocial oncology, was employed on a casual basis. Throughout this review Miss Dudley will be referred to as reviewer one and the candidate as reviewer two.

#### 2.2 BACKGROUND

# 2.2.1 Systematic reviewing

Traditional non-systematic reviews, although informative, are subjective and often prone to error and bias, both in selection of included studies and in data extraction (Egger et al., 2001). A systematic review, on the other hand, aims to take an objective, scientific approach to make the process and, therefore, conclusions, transparent and replicable (Egger et al., 2001). Not only can the process of non-systematic reviewing be prone to study selection bias, but also, descriptive summaries may not always make adjustments for within study bias; systematic reviews and meta analyses are better placed to take these biases into consideration when synthesising results (Petticrew & Gilbody, 2004).

### 2.2.2 Meta-analysis of effect sizes

The most complex and reliable method of data synthesis is a statistical metaanalysis. Meta-analysis combines the results of a number of related studies in order to "...impose order on chaos..." (Rosenthal & DiMatteo, 2001, p.80) and provide a weighted overall mean effect size ( $\bar{r}$ ). To avoid giving too much weight to small studies, study effect sizes are usually weighted by sample size in order that more adequately powered studies are given higher influence in determining the mean effect size than their similar under-powered equivalents (Field, 2001). Meta-analysis also attempts to overcome the limits of the size or scope of smaller studies by combining their findings together (Berman & Parker, 2002) for greater applicability. Despite superiority to the non-systematic review, Overton (1998) cautions against over-stating the findings of a systematic review; it is not an exact science. Despite aims of objectivity, each stage of the systematic review process is prone to the effects of subjective bias (albeit less than in an non-systematic review), for example in selection of relevant papers and thoroughness of data extraction. Furthermore, the size and significance of the findings will be different depending on the type of meta-analysis model selected (to be further explained later in this section).

The term 'effect-size' is sometimes misunderstood to mean only the calculation of a standardized mean difference between groups or condition in an experimental design. In fact, the term includes any measure of the magnitude of

relationship between two variables, for example, correlation coefficients, proportions, odds ratios, and so forth (Glass, 2000; Field, 2001; Field, 2003a). Type of effect size presented often differs, not only between study, but also between model of meta-analysis selected.

Meta-analysis assumes that the data are both substantially homogenous (in terms of sample, population and design) and follow a normal distribution (Egger et al., 2001). Although it is ideal to perform meta-analysis by using individual participant data from each study, this is rarely feasible and most statistical procedures allow for calculation of mean effect sizes from more commonly published summary statistics (Egger et al., 2001).

Within the meta-analysis methodology literature, it is often suggested that study designs should be ordered hierarchically, based primarily on the level of experimental control and manipulation researchers inherently have in the design. Randomised controlled trials (RCTs) are considered the best choice of design at the upper end of the hierarchy and observational studies and surveys at the lower end. There is some argument (see Egger et al., 2001) that meta-analysis should only be conducted on high quality studies. However, particularly within health and clinical psychological research where many research questions cannot be addressed using experimental designs, meta analysis of observational or prognostic (non-experimental) studies is becoming commonplace (Egger, Schneider & Smith, 1998; Stroup, Berlin, Morton, Olkin, Williamson, Ronnie et. al., 2005).

Meta-analysis of studies at the lower end of the evidence hierarchy remains highly controversial and problematic (Berman & Parker, 2002). Altman (2001) and Egger *et al.* (2001) list a number of potential hazards including: greater potential for publication bias; variation in designs, measures, and methods of data handling; inadequate methodological and outcome variable reporting; biased inclusion criteria; inappropriate timing of outcome data collection; retrospective data collection; and, last but not least, a lack of recognised quality assessment tools (see section 2.6.2).

Glasziou, Vandenbroucke and Chalmers (2004) provide a useful review of the application of design hierarchies concluding that their oversimplification leads to misconceptions and misuse rather than benefit. They further propose that the

current conceptualizations of such hierarchies should not be used without further development, or alternatively that they be abandoned altogether. In a further methodological paper, Gene Glass (the founder of the modern concept of meta-analysis) remains committed to his original intention for meta-analysis; that it should "...deal with all studies, good bad and indifferent, and that their results are only properly understood in the context of each other, not after having been censored by some *a priori* set of prejudices." (Glass, 2000, p.10). The most suitable design for answering the questions relevant to this review is that of correlation design; explorations of association between two observed variables. Thus, this review predominantly identifies survey based research studies.

Two dominant models of meta-analysis exist: fixed effect and random effect models (Field, 2001). A third model (mixed or conditionally-random effects) has been proposed, however, this is rarely used in preference of a more clearly defined fixed or random approach (Hedges & Vivea, 1998). Fixed effect statistical models assume homogeneity of effects across the studies being combined (assumed constancy of (unknown) effect sizes), that is, the true effect size has a common true value. In the summary effect sizes, therefore, only the variance of particular studies are taken into account (Hedges & Vivea, 1998). Random effect models, however, assume that all effect sizes are variable to some extent and that those being analysed are a sample of many possible effect sizes true to the population. This model, therefore, is often favoured where levels of between study heterogeneity are expected to be high; although they sometimes give more weight to smaller samples, they calculate error according to, not only within-study variance, but also between-study variance (Hedges & Vivea, 1998; Egger et al., 2001).

Hedges and Vivea (1998) state that choice between fixed or random effects models should not be based on study homogeneity (or lack of) alone; the proposed inference of the analysis is perhaps more important. To clarify, where the aim of a meta-analysis is to make conclusions limited only to its specific constituent studies only (conditional inferences), fixed effect methods are more than adequate. However, where the aim is to make inferences from the analysis which explicitly attempt to generalise to wider populations, random effects models should be used (Hedges & Vivea, 1998; Field 2001).

Hunter and Schmidt (2000) further point out that fixed effect models are substantially more likely to result in Type I error bias: wrongly rejecting the null hypothesis in favour of deeming an association significant. Furthermore, due to the calculation of narrower confidence intervals, they imply much greater degrees of precision than should be inferred given meta-analytical calculations.

Three main methods are proposed to compute meta-analyses. Whereas both the Hedges and Vivea (1998) and Rosenthal and colleagues approaches calculate the mean effect sizes via transformation of study effect sizes into a standard normalised value (Cohen's d) prior to study weighting, Hunter and Schmidt (also cited in Field, 2001) propose calculation of weighted mean effect sizes without prior data transformation. Proponents of transformation methods claim that such transformations (based on Fisher's transformation) are essential to eliminate within study bias occuring as a function of higher correlation coefficients (Field 2001). However, Hunter and Schmidt propose that in reality, the actual transformation eliminates comparatively little bias to justify the extra error that further data manipulation may introduce (cited in Field, 2001). Hedges's and Rosenthal's meta-analytic methodologies can be used in either fixed or random effect models as they claim that choice of model will be dependent on the purpose of meta-analysis and type of data relationships being synthesised. Conversely, Hunter and Schmidt propose only a random effects model in order to ensure that findings obtained using their method are always grounded in population generalisability principles.

Controversy exists about which method of meta-analysis should be used. In essence, both Hedges's and Rosenthal's methodologies are very similar and high convergence is reported between the results of the two (Johnson, Mullen & Salas, 1995). The method of Hunter and Schmidt is very different and findings can often be substantially different. So much so, according to Johnson *et al.*, (1995), that it violates conventional statistical frameworks and should be used with great caution. Schmidt and Hunter (1999) replied to this criticism by stating that in their calculations, Johnson *et al.* had used incorrect calculations of the standard error estimate of the mean effect size; when this was corrected for, the findings were comparable to both Hedges's and Rosenthal's. Field (2001) also reanalysed the

Johnson et al.'s (1995) methodological review and highlighted further criticisms of this paper.

In his own comparison of the methods, Field (2001) stated two important considerations. First, with regard to effect size calculations, he found that where studies were homogenous, Hedges's and Rosenthal's methods tended to overestimate the mean effect size. Conversely, the Hunter and Schmidt method tended to underestimate the effect size, and although this bias increased with larger mean effect sizes (particularly above r=.5), the bias was less severe than either Hedges's or Rosenthal's overestimation effect. Second, regarding the mean effect size significance estimates, Hedges's method best controlled for Type I error and the Hunter and Schmidt method was judged to be too liberal, claiming significance for far too many null results.

Field's more recent paper (2005) further compares the two methods and raises two additional important issues. First, he explored the interaction between inaccuracy in estimation of the mean effect size and the study effect sizes. Results showed that where effect sizes are above r=.30 and standard deviations are large (above .16) no difference was found between either Hedges's or Hunter and Schmidts method. However, with effect sizes lower than r=.30, Hedges's method resulted in far more inaccuracy of mean effect size calculation. Second, confidence interval estimates were reported to be far more accurate using Hedges's method. Neither Hedges's, Rosenthal's or the Hunter and Schmidt method were found to adequately predict the confidence intervals when only a small number of studies were meta-analysed.

### 2.2.3 Advanced and alternative meta-analytical techniques.

In addition to statistical weighted mean effect sizes, meta-analyses often present more sophisticated inferential statistics. Funnel plots are a way of identifying bias; where a normal distribution is not observed, the results of the meta-analysis must be treated with caution as they may be indicative of publication bias. Homogeneity analysis tests the assumption that all effect sizes are estimating the same population mean. This is calculated using variance estimates based on both the raw data (weighted mean) and inferred population variance estimates. Using sensitivity analysis, one can assess the robustness of the overall findings by conducting smaller meta-analyses comparing sub-groups of the

studies based between different study features, for example, study designs or between high versus low quality studies (Egger *et al.*, 2001).

To conduct these advanced statistics on a meta analysis based on few studies is of little practical and scientific value; the utility of graphical or statistical demonstrations of between study similarity are meaningless, for example, when only two or three studies are being compared. Similarly, to attempt to break down a meta-analysis into smaller analyses which are then compared is simply impossible when few studies are being meta-analysed in the first place.

Rosenthal's fail safe *n* statistic can be calculated to give an indication of how many studies with a negative result (i.e. one in which the direction of relationship is opposite to the weighted mean, or which are found to be non-significant) would be required to negate any overall effect size and to increase the *p* value beyond the alpha level (cited in Egger *et al.*, 2001). Where the fail safe *n* is high, one can have much more confidence in the findings of the meta-analysis than if the *n* was low. Once again, to attempt calculation of a fail safe *n*, when the original number of studies entered in a meta-analysis is low has little meaning; statistics are simply not necessary. It seems logically apparent that when weighted mean effect sizes are based on just two or three studies, even where sample sizes are large, that confidence in the findings should be low and that the introduction of just one small piece of empirical research could significantly change the significant, or even directional effect of the result.

Where the number of studies to be entered into a meta-analysis is low, a descriptive, or qualitative, data synthesis is recommended (Papworth & Milne, 2001). The minimum number of studies required before meta-analytical techniques become of dubious scientific validity is open to controversy. Rosenthal (1995) claims that although the techniques can be applied on as few as two individual studies, the results are very unstable and should be treated with caution. Papworth and Milne (2001) claim that within the social sciences, statistical meta-analysis is not suitable where "...approximately under 50..." studies are to be synthesised (p. 195). A comparative study of Hedges's, and the Hunter and Schmidt's method, demonstrated that the most accurate estimates of population means effect size are yielded using the Hunter and Schmidt method (Field, 2001), but that below a minimum of 20 studies, neither method can be

relied upon as estimates of population variances become more biased and inaccurate. Field (2003b) stated that in meta-analysis of less than 15 studies, the probability of encountering a Type I error is substantially increased.

Systematic reviews employing qualitative data synthesis are still encouraged to follow all of the stringent guidelines for study location, relevance screening, and extraction of data. According to Egger et al. (1998), systematic reviews of observational research are one particular occasion where advanced meta-analytical statistical procedures may be difficult to achieve both practically (due to data limitations and between study heterogeneity) and mathematically (the formulae are often found to simply not work with small data sets). Further, where such analysis is reported, they can produce misleading or overly generous conclusions. Whilst efforts should be made to make systematic reviews of observational studies as objective as possible, the meta-analysis should form only a small part of data synthesis with a substantial qualitative synthesis component being essential.

# 2.3 AIMS & OBJECTIVES

The original aim of this review was to systematically review published empirical research investigating associations between Transactional Model components (personality, cognitions and emotions) and psycho-social outcome (quality of life, anxiety and depression) in cancer patients. After searches had been completed, a review of the literature pertaining to personality was dropped from the review aims: this is further explained in section 2.5.7.

There were two main objectives. First, to provide a précis of the current literature: how this question has previously been addressed and the results to date. Second, assessment of the methodological quality of each individual study to enable a summary methodological critique of the literature.

It was predicted that the published evidence relevant to this review would be highly heterogenous. General trends were hypothesised between more positive personality domains (e.g. optimism, self efficacy as opposed to neuroticism, for example), positive cognitions (fighting spirit, challenge, optimistic treatment expectancies, and so forth), positive emotional reactions (e.g. hope as opposed to

anger), and better adjustment (lower anxiety and depression and higher quality of life) following cancer diagnosis.

The overall purpose was to summarise the findings of research to date in a coherent way to inform the direction of, and hypothesis setting for, future research, including the empirical work that follows in the remainder of this thesis.

#### 2.4 METHOD

#### 2.4.1 Identification of studies

### 2.4.1.1 Search string development

Although some organisations, such as the Cochrane Collaboration and NHS CRD, have developed some common search strings (for example, for identifying health economic evaluations or RCTs), given the vast scope of the literature potentially relevant to this review, none fitted the wide searching requirements. Instead, review-specific searches were developed based on content keywords, rather than methodological search terms.

Four search strings were developed: Cancer; Personality and Illness Beliefs; Appraisal and Emotions; and Psychosocial Outcome (Table 2.1). Inclusion of terms into each search string was determined by both theory (based on personality theory and the Transactional Model) and the overall thesis aims. For example, although a plethora of different personality terms exist, and indeed were to be included in the review, the primary model of trait personality was the Five Factor theory. Therefore, although search strings included general personality terms, additional terms specific to this model were also included. Similarly, for cognitive appraisals and emotions, although general terms were included, terms highly specific to the Smith and Lazarus's Appraisal Components and Emotion Themes Questionnaires (1993) were also included.

Systematic review searches require careful consideration to ensure that the balance between sensitivity or recall, the chance of finding the majority of relevant literature, is maximised without loosing feasible levels of specificity or precision, making the search unfeasibly large and unfocussed. The crucial factor here is that too specific searching can often result in low sensitivity.

Table 2.1. Terms used in the development of search strings.

Cancer	Personality / Illness Beliefs	Appraisal and Emotion	Outcome	
Oncology	Personality	Appraisal	Quality of life	
Neoplasm	Neuroticism	Attribution	Mental adjustment	
Cancer	Pessimism	Emotion	<b>Emotional adjustment</b>	
Carcinoma	Optimism	Shame	Life change	
Tumour	Life Orientation Test	Humiliation	Life Satisfaction	
Sarcoma	Hope	Interest	Anxiety	
Malignant	Positivism	Surprise	Depression	
Adenocarcinoma	Generalised Self-efficacy	Boredom	Well being	
Metastatic	Five Factor Inventory	Detachment	Fatalism	
Lymphoma	Big Five	Tranquillity	Hopelessness Helplessness	
Myeloma	Individual differences	Relief		
Leukaemia	Personality theory	Anger	Fighting spirit	
Teratoma	Extroversion	Frustration	Cognitive avoidance	
Seminoma	Introversion	Resignation	Anxious preoccupation	
Teratocarcinoma	Openness	Guilt	HADS	
Melanoma	Agreeableness	Fear	FACT Inventory	
Adenoma	Conscientiousness	Sadness	MAC Inventory	
Choriocarcinoma	NEO Inventory	Норе	MiniMAC	
Glioma	Helplessness	Challenge		
Astrocytoma	Hoplessness	Happiness		
Blastoma	Expectations	Coping		
(non-) Hodkins	Cognitive style	Core relational themes		
Craniopharyngioma	Internal/external	Relational meaning		
Ependymoma	Locus of Control	Emotion theme		
Esthesioneuroblastoma		Transactional		
Fibrosarcoma		Lazarus		
Lymphangioma				
Porocarcinoma				
Oliogodendroglioma				
Osteosarcoma				
Nephroblastoma				

Early scoping searches highlighted that this literature was vast and that there was little consistency between use of theoretical definitions (see also section 3.6.3). Therefore, in order to minimise the number of studies which may otherwise have been missed by a specific and focused search, a high frequency of search terms were used. Sensitivity was thereby maximised, albeit by increasing the total recall rate and reducing search precision. Programming commands and Boolean operators were then applied to each term, and translated for each database, to enable accurate searching of different spellings or truncations of terms.

Once terms were established, each was translated into an appropriate Subject Heading (for the psychologically based databases) or a MeSH Heading (a thesaurus based hierarchy developed by the National Library of Medicine used for the medically oriented databases) (Higgins & Green, 2005). Essentially, Subject Headings and MeSH Headings are equivalent; they are general terms or keywords used to describe each piece of published research held in a database, organised into a theoretical hierarchy of terms with links to 'narrower' (related, but more focused), terms. To demonstrate this complex organisation priniciple, figure 2.1 shows a hierarchy for both PsychINFO and MEDLINE when searching for the concept of personality.

By identifying and 'exploding' key terms, researchers are able to quickly and accurately identify any piece of research held on the database whose subject heading fits into any term in the hierarchy at, or below the level of the specific term entered. This search method further enables high sensitivity searching and is encouraged by both Cochrane guidance and the NHSCRD.

Search strings were then combined into three combinations, one for each of the questions described in this chapter overview:

- · 'Cancer' and 'Personality' and 'Appraisals and Emotions'
- 'Cancer' and 'Personality' and 'Outcome'
- 'Cancer' and 'Appraisals and Emotions' and 'Outcome'.

		PsychINFO					MEDLINE	
Perso	nalit	v	4816	Psych	niatry			
4			.010	Behaviour & behavioural mechanisms				
	•	Character			<b>-</b>		pation, Psychological	0 24595
	•	Disposition			•	Attit	, ,	8672
	•	Temperament			•	Beha	viour	4792
•	Nari	rower Terms			•	Chile	i rearing	863
	•	Inadequate personality	2		•		nse mechanisms	1849
	•	Personality traits [+nt]	8243		•	Emo	tions	9226
	•	Psychoanalytic personality factors	132		•	Hum	an characteristics	164
•	Rela	ited terms			•	Hum	an development	758
	•	Cognitive Style [+nt]	1677		•		tal competency	2950
	•	Coronary prone behaviour	218		•		vation	13642
	•	Egocentrism	175		•	Neu	robehavioral manifestations	
	•	Emotional adjustment [+nt]	3217		•		onality	4891
	•	Emotional states [+nt]	6829	1		•	Assertiveness	373
	•	Five factor personality model	919			•	Authoritarianism	349
	•	Gender identity [+nt]	1784			•	Character	415
	•	Human nature	861	ĺ		•	Creativeness	1465
	•	Individual differences	5076			•	Dependency	427
							(psychology)	
	•	Lifestyle [+nt]	1431			•	Empathy	4494
	•	Person environment fit	397			•	Individuality	2779
	•	Personality change	389			•	Intelligence	4381
	•	Personality correlates	846			•	Leadership	10236
	•	Personality development [+nt]	1794			<b>•</b>	Machiavellianism	122
	•	Personality disorders [+nt]	2583			•	Negativism	490
	<b>•</b>	Personality processes	393	1		•	Personality	2644
	4	[+nt]	1.420				development (+nt)	1461
	<u> </u>	Personality theory [+nt]	1438 515		<u>_</u>	Dame	Temperament	1461 899
		Predisposition				Socia	<del></del>	
	•	Psychodynamics	3003				discipline and activities	0
	•	Self actualization	274	•			orders	29783
	•	Self concept [+nt]	7893	•	proc	esses	ical phenomena and	0
	•	Self evaluation	1494	Biolo	gical S	Scienc	es	
	•	Self monitoring	145	l				
		(personality)						
	•	Self perception	3459	1				
	•	Somatotypes	32	]				
	<u> </u>	Teacher personality	50	<u> </u>				

Note: In PsychINFO, personality is the highest term in its appropriate Subject Heading Tree, however, in MEDLINE, personality appears as a narrower term under a higher MeSH Heading. Numbers refer to the number of article links for each term. [+nt] indicates that specific terms have hierarchical trees of their own which, if exploded, would all be included.

Figure 2.1. Search term hierarchies in PsychINFO and MEDLINE.

### 2.4.1.2 Search strategy

As the subject of psychosocial oncology is multi-disciplinary, a wide range of electronic databases were used in literature searching spanning the fields of medicine, psychology, nursing and complementary health. The chosen databases represent international literature searching, including searching of the grey literature:

- Allied & Complementary Medicine Database (AMED)
- British Nursing Index (BNI)
- Cochrane Central Register of Controlled Trials (CENTRAL)
- Cochrane Database of Systematic Reviews
- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- Database of Abstracts of Review of Effects (DARE)
- EMBASE
- Health Management Information Consortium (HMIC)
- Health Technology Assessment Database (HTA)
- MEDLINE
- PsychINFO
- Social Science Citation Index (SSCI)
- System of Information on Grey Literature in Europe (SIGLE)

Systematic reviews often include searches of health service research registers (for example, the National Research Register or the Current Science Register of Controlled Trials); hand searching of conference abstracts from relevant professional societies; and/or, an email request to the key researchers within the field. Egger et al. (2001), for example, claim that only 50% of conference abstracts, and even fewer dissertations (around 30%), are ever published, therefore, searches purely limited to the published literature may miss relevant data. Typically though, unpublished studies are lower in methodological quality; inclusion, therefore, carries potential to introduce methodological bias into the review. The observation that publication of negative results is often much harder to achieve (therefore potentially biasing the direction of mean effect sizes in a statistical meta-analysis) further confuses matters on this issue.

Searching for non-published data can dramatically increase the length of time required to complete a review and is not always feasible. Whilst it is

acknowledged that to include searching of non-published works could have introduced extra information, due to the ongoing debate regarding their suitability, and for practical reasons relating to the time allocation for this part of the thesis, literature searching for this review focused on published literature only.

#### 2.4.2 Inclusion criteria

A priori specified inclusion criteria are important to ensure that no bias occurs when deciding upon which studies are relevant to the review to the question. Five categories of inclusion criteria were used.

# 2.4.2.1 Study Population

The review was concerned with patients who had been diagnosed with cancer. Inclusion encompassed any cancer site, and where applicable, different cancer sites were planned to be synthesised separately. Those which also recruited patients with recurrent cancer were excluded unless the primary cancer sub-samples were analysed separately: appraisals of a primary or recurrent diagnosis will be very different due the clinical variations of the diagnoses.

Advanced (terminal/palliative) cancers were included, but comparisons and data synthesis between studies recruiting early and advanced cancer patients are to be treated with caution. Any ethnic group or gender samples were included, however, child cancer samples were excluded: there is some evidence that personality does not stabilise until adulthood (Pervin & John, 2001), therefore, with personality being a key feature of the review, to include children may have skewed the results. Mixed illness samples (i.e. those recruiting generally unwell patients rather than, specifically, cancer patients) were excluded unless subsamples with cancer were analysed separately from other illnesses.

One of the key premises for this thesis was that cancer adjustment changes over time, and that psychological responses to early phases of illness are perhaps the most important indicators of longer term adjustment. A number of studies were found in which recruited samples demonstrated not only a wide range of time between diagnosis and recruitment into the study, but also with mean time periods since diagnosis of a great many years, after which treatment will have ceased and adjustment could generally be said to have stabilised.

A period of five years from diagnosis is considered a critical juncture for cancer patients; at this point, chance of continued survival for illness-free patients significantly increases. Only studies which reported an average time between diagnosis and recruitment of five years or less were to be included in this review.

#### 2.4.2.2 Study Design

Any type of published empirical research was included. This included any experimental (e.g. RCT, Intervention study etc.) or non-experimental (e.g. Survey) design study. Excluded records comprised commentary articles and narrative reviews, as these are primarily subjective pieces; systematic reviews, although these were noted for the purposes of writing the narrative thesis review (chapter one); conference abstracts; and, dissertations, although these were the subject of a further search (See section 3.5.3 for details). Qualitative research was also included; the importance of the integration of such data into systematic reviews has been cited elsewhere (see Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005; Dixon-Woods, Bonas, Booth, Jones, Miller, Sutton et al., 2006; and Jack, 2006). No studies adopting qualitative methodology were found to be directly relevant to the research question and the review, therefore, focuses exclusively on quantitative studies.

From early scoping searches, it was expected that most included studies would be non-experimental in design as these are the most applicable for the review question. It was also entirely feasible that some survey data may have been collected as part of larger psychosocial interventions or RCTs within a cancer population, and so such experimental designs were potentially important to include.

#### 2.4.2.3 Language of publication

Although it is acknowledged that psychosocial oncology research is conducted internationally (this is evidenced, for example, by prominence of the International Psycho Oncology Society), only those studies published in the English language were included in this review. Due to variations in access to translation services, foreign language papers were excluded. Full international expansion of this inclusion criterion would have required translation of data at all stages of the review (relevance screening, inclusion assessment, quality assessment, and data extraction) and this was not feasible.

#### 2.4.2.4 Variable measurement

For inclusion, studies had to measure at least one of the pre-defined predictor variables, in addition to at least one of the pre-defined outcome variables. Predictor variables included any personality measure; health control belief; cognitive appraisal or attribution measure; or, a measure of emotional reaction following illness. Outcome variables included any measure of anxiety, depression, or quality of life.

All measures were limited to those which are self-reported: any studies which reported on these variables using other-report (e.g. researcher observation, medical team or carer reported) were excluded as this review was concerned with patients directly, not subjective, proxy, reports of their behaviour.

#### 2.5 LITERATURE SEARCHING

# 2.5.1 Study Location

Electronic searches were carried out between December 2005 and the end of February 2006. To the candidate's knowledge, no studies have since been published in the major journals in the field that would invalidate the results published, although an updated systematic search at a future time-point would be beneficial.

#### 2.5.2 Deduplication of records

Electronic results from the searches were exported into EndNote referencing software. As anticipated, the searches yielded a high output, however, there was some overlap between each of the search strings. Once in EndNote, references were de-duplicated both using automatic EndNote functions, and also by manual methods (automatic de-duplication was found to be quite unreliable, perhaps as a result of the large number of records contained in each database, therefore, databases were sorted (by author, then by title), and visually searched for duplicates). This minimised multiple referencing of the same study between databases leaving a total of 59,395 individual references remaining. In later stages of the review procedure, further duplicates were highlighted; the flow chart of inclusion (figures 2.2 and 2.3) indicates at what stage these extra duplicates were removed.

# 2.5.3 Relevance screening and inclusion assessment

Titles and abstracts of each study were assessed by two independent reviewers for relevance to the review questions. The relevance lists of the two reviewers demonstrated around 40% overlap which although surprisingly low, can be accounted for by several reasons. These include potential insufficiency of training/experience of the reviewers, unclear inclusion criteria, or simply the number of search records to be screened. The latter of these is perhaps the most likely. Whatever the cause may be, this clearly demonstrates the importance of having two reviewers involved at this stage and corroborates with Petticrew and Gilbody (2004) who claim that one in every ten references can be missed per reviewer in relevance screening (an under-estimate given our data).

Those deemed relevant by one reviewer were discussed and agreement made as to the study's relevance. Where agreement could not be made, or any doubt regarding relevance remained, a third reviewer (Richard Neal; the main thesis supervisor) was asked to resolve the disagreement. This occurred very few times given the scope of the review. At this point, the three separate lists of relevant searches were merged and once again de-duplicated to safeguard against duplicate entry from different searches. Figure 2.2 presents a flow chart showing the narrowing of the literature through searching, deduplication and relevance screening.

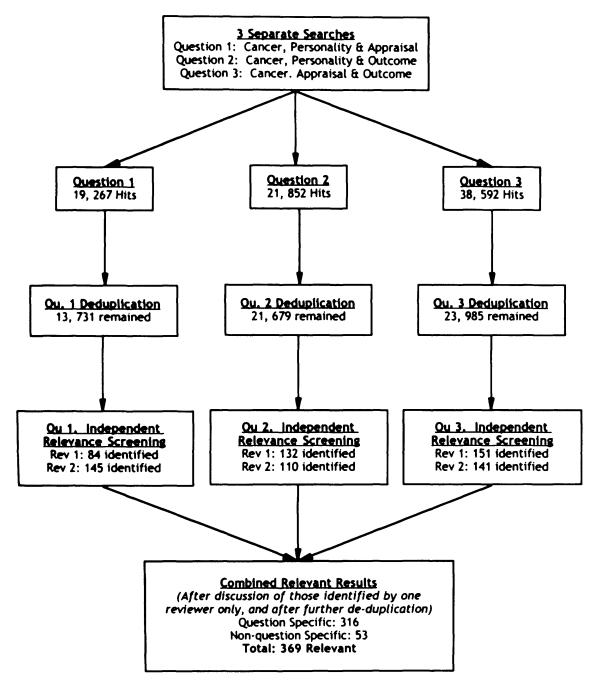


Figure 2.2. Flow chart presenting the numerical results of searching, deduplication and relevance screening (refer to section 2.5.7 for a note about the inclusion of question 1).

Three hundred and sixty nine records were identified for full inclusion assessment. Of these proposed relevant records, six were later found to be duplicates, four were unobtainable, and 117 were excluded; 44 of these exclusions were papers written in a language other than English, one was a book chapter, four were conference abstracts and 68 were dissertations. As a precaution against loss of important data from these dissertations, a further search using first author

names from each dissertation was conducted using PsychoINFO and MEDLINE databases. Relevance from this search was assessed by reviewer two and resulted in an additional eight records being identified for full inclusion assessment.

The remaining 250 papers were ordered for full article inclusion assessment (reviewer two only). Figure 2.3 further demonstrates how these 250 papers were further reduced to provide our final included sample of 68 studies.

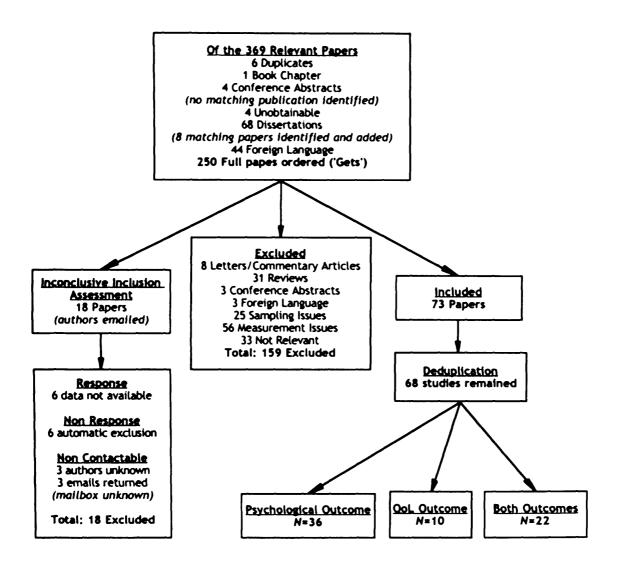


Figure 2.3. Flow chart presenting the results of study inclusion assessment.

One hundred and fifty nine records were excluded and the remaining 18 did not contain sufficient information for inclusion to be confidently assessed. The latter were subject to email requests for further information (see section 2.5.5).

# 2.5.4. Description of excluded papers

A high proportion of excluded studies was always expected given the scope of the literature search. In inclusion assessment, most papers were excluded because of low search specificity; use of key word searches resulted in many papers that were of a completely different subject matter and just very loosely related. For example, many of the original excluded studies were of a biomedical and genetic nature exploring causes, development, and treatment of cancer.

A summary of reasons for exclusion of the 159 papers excluded after fullarticle assessment is presented in table 2.2.

Table 2.2. Categories, and frequency, of exclusion for papers obtained for full paper assessment.

Reason	Number of studies
Foreign Language Publication	3
Letter/Commentary Article	8
Review Article	31
Conference Abstracts	3
Sampling Issues	
Not Cancer Specific (e.g. Cardiovascular disease patients, rheumatology patients, student samples)	6
Included recurrence without separate analysis	12
Mean time between diagnosis and recruitment greater than 5 years (or not stated and unable to confirm)	7
Inadequate Measurement	
Not self-report	1
Only met personality criteria	7
Only met outcome criteria	38
Only met appraisal/emotion criteria	4
No outcome measure included	6
Irrelevant to question (e.g. risk/onset prediction, measure creation/validation, screening/treatment trial study)	33

# 2.5.5 Studies with incomplete information to assess inclusion

Eighteen papers did not contain sufficient information to confidently assess inclusion, mainly with regards to the time since diagnosis criterion. Summary information on these studies is presented in appendix 2.1.

Attempts were made to trace and email corresponding authors to ask for clarity regarding inclusion. Three authors were untraceable using world-wide web searching; three emails were returned from 'unavailable mailboxes' (alternative email addresses could not be found); and, six authors did not respond to the email request. Of the six who did respond, all confirmed that the required data was not available, and therefore, these were also excluded.

#### 2.5.6 Included studies

Seventy-three records were identified for definite inclusion. Of these, there were three incidences where the same data was reported in two publications and one incidence where the same data was reported in three publications; in these cases, the records were merged and considered as the same study (a precaution against duplicate study weighting in meta-analysis). Sixty-eight studies thus remained. Of these 36 reported on psychological comorbidity outcomes (anxiety, depression, or overall distress); 10 reported on quality of life outcomes; and 22 reported on both quality of life, and psychological comorbidity. Table 2.3 summarises measures (predictors and outcomes) used and main findings from all include studies.

#### 2.5.7 Amendment of review objectives

Despite highlighting a large number of papers in the early stages, question one (that of association between personality and appraisal) was removed as a study objective at this stage. The objectives were initially reviewed because it was felt that the review had become too large to feasibly answer all research questions with sufficient clarity and quality. In exploring each question individually it became clear that question one was the weakest. There were two primary reasons. First, of the three review questions, the least amount of research had been conducted on question one and, therefore, it was felt more salient to review those that had been the focus of greater research effort. Reviews of this question will be important in due course. However, with the heterogeneity observed in this

field of research, the studies identified were not expected to be similar enough to be synthesised in an informative way. Instead, (as with many other excluded papers) the studies were used in the narrative review (Chapter One). Second, it was expected that in extraction of data relating to the remaining two questions, a partial (albeit not strictly systematic) answer to the association between personality and appraisal may be possible.

Although this modification to the study objectives did not dramatically reduce the literature size (ultimately, only six studies were removed as many of the other papers highlighted by this specific search were relevant to other research questions), by reducing the scope of the review it made data synthesis more straightforward and the findings more comprehensible.

Table 2.3. Publication details and variables measured for the 68 included studies.

				Relevant measures us	ed¹	_	
ID	Authors	Date	Title	Personality	Health Belief/ Cognition/ Emotion	Outcome	Summarised Main Findings
1	Aarstad, Aarstad, Heimdal & Oloffson	2005	Mood, anxiety and sense of humour in head and neck cancer patients in relation to disease stage, prognosis and quality of life.	<ul><li>Humour (SVQ)</li><li>Neuroticism (EPI)</li></ul>		<ul> <li>Anxiety (STAI-S)</li> <li>Depression (BDI)</li> <li>Quality of Life (EORTC)</li> </ul>	<ul> <li>Higher anxiety/lower depression than controls.</li> <li>Some clinical variables predict outcome.</li> <li>Sense of humour at diagnosis predicts QOL and depression at six year follow up.</li> </ul>
2	Ahmed, Kamal, Zahar & Sobhy.	2004	A study of some psychological variables in Egyptian patients with cancer bladder.	<ul> <li>Trait Anxiety (STAI-T)</li> <li>Neuroticism (EPI)</li> <li>Extroversion (EPI)</li> <li>Psychoticism (EPI)</li> </ul>		<ul><li>Depression (ZDI)</li></ul>	<ul> <li>Anxiety, depression and neuroticism higher in patients than controls.</li> <li>Concurrent anxiety and neuroticism predict depression in patients.</li> </ul>
3	Alhama, Extremera, Mesa, Martin, Vizoso & Vico.	1996	Quality of life in oncological patients. A study of 105 cases.		<ul><li>Locus of Control (MHLC)</li></ul>	<ul><li>Quality of Life (GRQLI)</li></ul>	<ul> <li>Co-morbidity and locus of control were strongly associated with QOL.</li> </ul>
4	Allison, Guichard & Gilain.	2000	A prospective investigation of dispositional optimism as a predictor of health-related quality of life in head and neck cancer patients.	• Optimism (FLOT)		<ul> <li>Quality of Life (EORTC)</li> </ul>	Pre- and post- treatment, optimists reported better QOL.

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title	Relevant measures use	ed¹	Summarised Main Findings
5	Andrykowski & Brady		<ul><li>Locus of Control (MHLC)</li></ul>	<ul><li>Distress (PAIS)</li><li>Depression (POMS)</li></ul>	<ul> <li>Disease severity and treatment moderate the relationship between LOC and distress (LOC has most effect on distress at low levels of perceived severity).</li> </ul>	
6	Andrykowski , Curran, Studts, Cunningham, Carpenter, McGrath, Sloan & Kenady.	1996	Psychosocial adjustment and quality of life in women with breast cancer and benign breast problems: a controlled comparison.	<ul> <li>Positive Affect         (PANAS)</li> <li>Negative Affect         (PANAS)</li> <li>Personal Change</li> </ul>	<ul> <li>Depression (POMS/CES- D)</li> <li>Quality of Life (PHQ)</li> </ul>	<ul> <li>Patients reported poorer physical health, functioning but greater psychosocial adaptation than controls (benign breast problem patients).</li> <li>No differences in distress between patients and controls.</li> </ul>
7	Badger, Braden, Mishel & Longman.	2004	Depression burden, psychological adjustment, and quality of life in women with breast cancer: Patterns over time.	<ul> <li>Negative Affect (NAS)</li> </ul>	• Well Being (IWB)	<ul> <li>Mood at diagnosis is predictive of mood at longitudinal follow-up.</li> <li>Greatest adjustment observed in those reporting perceived high depression burden in an intervention group.</li> </ul>
8	Baider, Andritsch, Uziely, Goldzweig, Ever-Hadani, Hofman, Krenn & Samonigg.	2003	Effects of age on coping and psychological distress in women diagnosed with breast cancer: review of literature and analysis of two different settings.	<ul> <li>Fatalism (MAC)</li> <li>Hopeless/Helples sness (MAC)</li> <li>Anxious Preoccupation (MAC)</li> <li>Fighting Spirit</li> <li>Thought Intrusion/Avoidance (IES)</li> </ul>	• Distress (PAIS)	<ul> <li>Cross-cultural differences in distress observed.</li> <li>Across all subsamples, age and distress were significantly associated (young women, more distress).</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title	R	elevant measures use	d¹	Summarised Main Findings
9	Bleiker, van der Ploeg & Ader.	1995	Personality traits of women with breast cancer: before and after diagnosis.	<ul> <li>Rationality (SAQ-N)</li> <li>Understandin g (SAQ-N)</li> <li>Optimism (SAQ-N)</li> <li>Anxiety (SAQ-N)</li> </ul>	<ul> <li>Emotional control (SAQ-N)</li> <li>Emotional expression-in (SAQ-N)</li> <li>Emotional expression-out (SAQ-N)</li> <li>Anti-emotionality (SAQ-N)</li> </ul>	• Depression (SAQ-N)	<ul> <li>Rationality and emotional expression differed between patients and controls.</li> <li>No significant depression differences.</li> </ul>
10	Bleiker, Pouwer, van der Ploeg, Leer & Ader.	2000	Psychological distress two years after diagnosis of breast cancer: frequency and prediction.	<ul> <li>Rationality (SAQ-N)</li> <li>Understandin g (SAQ-N)</li> <li>Optimism (SAQ-N)</li> <li>Anxiety (SAQ-N)</li> </ul>	<ul> <li>Emotional control (SAQ-N)</li> <li>Emotional expression (SAQ-N)</li> <li>Anti-emotionality (SAQ-N)</li> <li>Thought intrusion (IES)</li> <li>Thought avoidance (IES)</li> </ul>	• Depression (SAQ-N)	<ul> <li>16% still distressed, two years after diagnosis.</li> <li>Intrustive thoughts, anxiety and health complaints were best predictors of two year distress levels.</li> </ul>
11	Boer, Elving & Seydel	1998	Psychosocial factors and mental health in cancer patients: opportunities for health promotion.	<ul><li>Self-Efficacy (GSES)</li></ul>		• Quality of Life (RAND)	<ul> <li>Mental health in cancer survivors is lower than general population controls.</li> <li>Self-efficacy and loneliness were strong predictors of mental health.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	Summarised Main Findings	
12	Brown, King, 2000 Butow, Dunn & Coates.	Patterns over time in quality of life, coping and psychological adjustment in late stage melanoma patients: An application of multilevel models.		<ul> <li>Isolation (PAC)</li> <li>Minimisation (PAC)</li> <li>Anger (PAC)</li> <li>Perceived aim of treatment</li> <li>Perceived ability to cope with illness (PACIS)</li> <li>Coping (COPE)</li> </ul>	<ul> <li>Quality of Life (LASA/GLQ)</li> </ul>	<ul> <li>QOL fluctuates highly over time; mood remained stable.</li> <li>Well-being deteriorated over time</li> <li>Between patient variability accounted for 60%, 45%, and 44% of the total variance in effort to cope, mood and well-being respectively.</li> <li>Perceived treatment aims, minimization, anger, marital status and better QOL were significant independent predictors of survival.</li> </ul>	
	Butow, Coates & Dunn	1999	Psychosocial predictors of survival in metastatic melanoma.		,		
13	Carver, Pozo, Harris, Noriega, Scheier, Robinson, Ketcham, Moffat Jr. & Clark.	1993	How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer.	• Optimism (LOT)	• Coping (COPE)	• Distress (POMS)	<ul> <li>Optimism was significantly associated with distress (prior levels controlled for) at each time point.</li> <li>Several coping reactions (esp humour, denial and disengagement) are longitudinally predictive of lower distress levels.</li> </ul>
14	Carver, Pozo- Kaderman, Harris, Noriega, Scheier, Robinson, et	1994	Optimism versus pessimism predicts the quality of women's adjustment to early stage breast cancer.	• Optimism (LOT)	<ul> <li>Thought Intrusion</li> <li>Life Satisfaction</li> </ul>	<ul><li>Distress (POMS)</li><li>Quality of sex life</li></ul>	<ul> <li>Pessimism was significantly predictive of longitudinal well-being even when previous levels were controlled for.</li> <li>No effect of pessimism on quality of sex life or thought intrustions.</li> <li>Optimism-pessimism are adequately measured using single item scales.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	rd¹	Summarised Main Findings
15	Carver, Harris, Lehman, Durel, Antoni, Spencer & Pozo- Kaderman.	2000a	How important is the perception of personal control? Studies of early stage breast cancer patients. Study 1		<ul> <li>Cancer         Expectancy</li> <li>Recurrence         Control Beliefs</li> <li>Positive/Negative         Affect (ABS)</li> </ul>	• Distress (POMS)	<ul> <li>Perceived control over remaining cancer free was not associated with distress.</li> <li>Expectancy of remaining cancer free was associated with distress levels.</li> </ul>
16	Carver, Harris, Lehman, Durel, Antoni, Spencer & Pozo- Kaderman.	2000b	How important is the perception of personal control? Studies of early stage breast cancer patients. Study 2		<ul> <li>Cancer         <ul> <li>Expectancy</li> </ul> </li> <li>Recurrence         <ul> <li>control beliefs</li> </ul> </li> </ul>	<ul><li>Distress (POMS)</li><li>Depression (CES-D)</li></ul>	
17	Cohen, Moor & Amato	2000	The association between treatment-specific optimism and depressive symptomatology in patients enrolled in a phase I cancer clinical trial.	Treatment Specific Optimism		<ul><li>Depression (CES-D)</li><li>Distress (POMS)</li></ul>	<ul> <li>Treatment specific optimism was significantly associated with fewer depressive symptoms, lower mood disturbance, and fewer symptoms of distress (after demographic and clinical variables were controlled for).</li> <li>Clinically depressed patients reported significantly lower treatment specific optimism at diagnosis.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	ed¹	Summarised Main Findings
18	Cousson- Gelie	2000	Breast cancer, coping and quality of life: A semiprospective study.	• Anxiety (STAI-T)	<ul> <li>Perceived Stress (PSS)</li> <li>Locus of Control (CLoCS)</li> </ul>	<ul><li>Anxiety (STAI-S)</li><li>Quality of Life (WoC)</li></ul>	<ul> <li>Coping mediated the relationship between health status and QOL.</li> <li>Self-accusation and perceived stress mediated the relationship between trait anxiety and QOL.</li> <li>Perceived stress mediated the relationship between tumour status and QOL.</li> </ul>
19	De Valck & Vinck	1996	Health locus of control and quality of life in lung cancer patients.		<ul> <li>Locus of Control (MHLC)</li> </ul>	<ul><li>Quality of Life (DCL)</li></ul>	<ul> <li>Patients reported higher internally oriented LOC beliefs than controls.</li> <li>Fluctuations in QOL best explained by increasing physical complaints.</li> <li>No significant association between LOC and QOL.</li> </ul>
20	Dropkin	2001	Anxiety, coping strategies, and coping behaviours in patients undergoing head and neck cancer surgery.	• Anxiety (STAI-T)	• Coping (WoC/CBS)	• Anxiety (STAI-S)	Self-care was the only significant predictor of anxiety.
21	Epping- Jordan, Compas, Osowiecki, Oppedisano, Gerhardt, Primo & Krag.	1999	Psychological adjustment in breast cancer: processes of emotional distress.	Optimism	<ul> <li>Monitoring</li> <li>Thought Intrusion (IES)</li> <li>Thought Avoidance (IES)</li> <li>Coping (CSI)</li> </ul>	• Distress (SCL)	<ul> <li>At diagnosis, age and distress relationships were mediated by intrusive thoughts. Optimism – distress relationships were mediated by coping.</li> <li>At three month follow up, distress was only predicted by intrusive thoughts.</li> <li>Six month distress was predicted by optimism (mediated by coping).</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	ed¹	Summarised Main Findings
22	Evans, Thompson, Browne, Barr & Barton	1993	Factors associated with the psychological wellbeing of adults with acute leukaemia in remission.	<ul><li>Personality (PRF)</li></ul>	• Coping (CRI)	<ul><li>Distress (SDS)</li><li>Well-Being (GBI)</li></ul>	<ul> <li>Some differences in well being found to be associated with variability across a number of personality characteristics (endurance, affiliation, cognitive structure, autonomy, and nurturance).</li> </ul>
23	Faller, Bulzebruck, Drings & Lang.	1999	Coping, distress, and survival among patients with lung cancer.		<ul><li>Coping (FQCI)</li><li>Emotional Distress</li></ul>	<ul><li>Depression (DS)</li></ul>	<ul> <li>Depressive coping and emotional distress were both significant predictors of distress.</li> </ul>
24	Gallagher, Parle & Cairns	2002	Appraisal and psychological distress six months after diagnosis of breast cancer.		<ul> <li>Appraisals</li> </ul>	• Distress (GHQ)	<ul> <li>Psychological functioning was significantly related to psychiatric history, tumour grade and cognitive appraisals (esp. threat and self- efficacy).</li> </ul>
25	Glinder & Compas	1999	Self-blame attributions in women with newly diagnosed breast cancer: a prospective study of psychological adjustment.	• Self Blame (SBI)	• Coping (CSI)	• Distress (SCL)	<ul> <li>Behavioural self-blame was predictive of concurrent distress levels only; characterological self-blame was predictive of changes in distress over time.</li> </ul>
26	Golden- Kreutz & Andersen	2004	Depressive symptoms after breast surgery: relationships with global, cancer- related, and life event stress.	• Neuroticism (EPI)	<ul> <li>Perceived Stress (PSS)</li> <li>Thought Intrusion (IES)</li> <li>Thought Avoidance (IES)</li> </ul>	<ul> <li>Depression</li> </ul>	<ul> <li>Perceived stress and neuroticism both significantly predict depressive symptoms.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	d¹	Summarised Main Findings
27	Goodwin, 2 Ennis, Bordeleau, Pritchard, trudeau, Koo & Hood.	2004	Health-related quality of life and psychosocial status in breast cancer prognosis: analysis of multiple variables.		<ul> <li>Fatalism (MAC)         <ul> <li>Fighting Spirit</li> <li>(MAC)</li> <li>Anxious</li> <li>Preoccupation</li> <li>(MAC)</li> </ul> </li> <li>Hopelessness/Hel plessness (MAC)</li> <li>Emotional Control (CECS)</li> </ul>	<ul> <li>Distress         (POMS/PAIS)</li> <li>Quality of         Life (EORTC)</li> </ul>	<ul> <li>Psychosocial status and quality of life were not associated with medical outcome.</li> </ul>
28	Grassi & Molinari.	1988	Pattern of emotional control and psychological reactions to breast cancer: a preliminary report.		<ul> <li>Emotional Control (CECS)</li> </ul>	<ul><li>Anxiety (IBQ)</li><li>Depression (IBQ)</li></ul>	<ul> <li>Some associations between emotional control, hostility and psychosocial outcome were found.</li> </ul>
29	Green, Pakenham, Headly & Gardiner.	2002	Coping and health- related quality of life in men with prostate cancer randomly assigned to hormonal medication or close monitoring.	Self Efficacy	<ul><li>Threat appraisal</li><li>Coping (COPE)</li><li>Satisfaction with life</li></ul>	<ul> <li>Quality of Life (EORTC)</li> <li>Depression (DASS)</li> <li>Anxiety (DASS)</li> </ul>	<ul> <li>Patient groups did not differ on measures of distress, life satisfaction, cognitive function, physical symptoms, or social/role functioning.</li> <li>Hormonal treatments were associated with poorer psychosexual functioning, but improved physical symptoms.</li> <li>Threat appraisals and coping were predictive of longitudinal QOL.</li> </ul>
30	Hack & Degner.	2004	Coping responses following breast cancer diagnosis predict psychological adjustment three years later.		<ul> <li>Coping (CRI)</li> <li>Preference for decision making</li> <li>Anger Expression (AEI)</li> </ul>	• Distress (POMS)	<ul> <li>Baseline depression and cognitive avoidance and minimal use of approach based coping strategies were associated with poorer adjustment at three years.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title	1	Relevant measures use	d¹	Summarised Main Findings
31	Hassanein, Musgrove & Bradbury  Hassanein, Musgrove & Bradbury.	2001	Functional status of patients with oral cancer and its relation to style of coping, social support and psychological status. Psychological outcome of patients following treatment of oral cancer and its relation with functional status and coping mechanisms.		<ul> <li>Fatalism (MAC)</li> <li>Fighting Spirit (MAC)</li> <li>Anxious         Preoccupation (MAC)</li> <li>Hopelessness/Hel plessness (MAC)</li> </ul>	<ul> <li>Quality of Life (UWQOL/EO RTC)</li> <li>Anxiety (HADS)</li> <li>Depression (HADS)</li> </ul>	<ul> <li>25% of patients had anxiety/or depression.</li> <li>Poorer functioning was associated with many clinical and demographic variables.</li> <li>Functionality was also associated with anxiety, depression, coping style (support and fighting spirit were only very weakly associated).</li> <li>Anxiety and depression were only weakly correlated with socio-demographics and medical variables.</li> <li>Anxiety and depression were highly correlated with cancer specific QOL.</li> <li>MAC scores were strongly associated with psychosocial outcome.</li> </ul>
32	Hee, Kim, Eremenco & Han	2005	Quality of life in colorectal cancer patients with colectomy and the validation of the functional assessment of cancer therapy-colorectal (FACT-C)	<ul> <li>Extroversion (EPI)</li> <li>Neuroticism (EPI)</li> <li>Psychoticism (EPI)</li> </ul>		<ul> <li>Quality of Life (FACT/FLIC)</li> <li>Distress (POMS)</li> </ul>	<ul> <li>FACT C is a valid tool for measuring QOL in cancer patients.</li> </ul>
33	Helgeson, Snyder & Seltman	2004	Psychological and physical adjustment to breast cancer over 4 years: identifying distinct trajectories of change.	Self Esteem (RSE)	<ul> <li>Illness ambiguity (MUIS)</li> </ul>	• Quality of Life (SF-36)	<ul> <li>Age, self-image, perceived control, and social resources all distinguished between different trajectories of adjustment.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	ed¹	Summarised Main Findings
34	Helgeson & Lepore	2004	Quality of life following prostate cancer: the role of agency and unmitigated agency.	<ul><li>Agency</li><li>Self Esteem (RSE)</li><li>Self Esteem (GSES)</li></ul>		<ul><li>Quality of Life (SF-36)</li><li>Depression (CES-D)</li></ul>	<ul> <li>Agency was associated with indicators of good QOL.</li> <li>Unmitigated agency was associated with intrusive thoughts, depressive symptoms and poorer mental functioning.</li> <li>Role of agency was related to self-efficacy.</li> </ul>
35	Iwamitsu, Shimoda, Abe, Tani, Okawa & Buck	2005	Anxiety, Emotional Suppression, and psychological distress before and after breast cancer diagnosis.		<ul><li>Emotional Control (CECS)</li></ul>	<ul><li>Anxiety (MAS)</li><li>Distress (POMS)</li></ul>	<ul> <li>Pre surgery anxiety and emotional suppression were associated with distress pre- and post- surgery.</li> </ul>
36	Kessler	2002	Contextual variables, emotional state, and current and expected quality of life in breast cancer survivors.		<ul> <li>Affects (PANAS)</li> <li>Satisfaction with life</li> </ul>	• Quality of Life	<ul> <li>Affect was associated with both life satisfaction and QOL.</li> <li>Survivors reported greater comparative life satisfaction and life satisfaction future expectancies.</li> </ul>
37	Koopman, Angell, Turner-Cobb, Kreshka, Donnelly, McCoy, et al.	2001	Distress, coping and social support among rural women recently diagnosed with primary breast cancer.		<ul> <li>Coping</li> <li>Fatalism (MAC)</li> <li>Fighting Spirit (MAC)</li> <li>Hopelessness/Hel plessness (MAC)</li> <li>Anxious Preoccupation (MAC)</li> </ul>	• Distress (POMS)	Distress and hopelessness/helplessness were both reported at very high levels.

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	ed¹	Summarised Main Findings								
38	Laubmeier, Zakowski & Bair	Zakowski &	2004	2004	•	2004	2004	2004	2004	2004	The role of spirituality in the psychological adjustment to cancer: a test of the transactional model of stress and coping.		<ul> <li>Perceived Life Threat</li> </ul>	<ul><li>Quality of Life (FACT)</li><li>Well being (SWBS)</li></ul>	<ul> <li>Spirituality was associated with less distress and better QOL regardless of levels of perceived life threat.</li> <li>Existential, but not religious well being accounted for most variance in QOL.</li> </ul>
39	Lehto, Ojanen & Kellokrumpu -Lehtinen	2005	Predictors of quality of life in newly diagnosed melanoma and breast cancer patients.		<ul><li>Coping (WoC)</li><li>Anger Expression</li></ul>	<ul> <li>Distress (RSCL)</li> <li>Depression (DEPS)</li> <li>Quality of Life (EORTC)</li> </ul>	<ul> <li>Psychosocial factors were the strongest predictors of QOL (when compared with cancer and treatment types).</li> <li>Breast cancer patients received far more social support than melanoma patients.</li> <li>Adjuvant treatment may comprimise the beneficial role of psychosocial factors that enhance QOL.</li> </ul>								
40	Lewis	1982	Experienced personal control and quality of life in late-stage cancer patients.	• Self Esteem (RSE)	<ul> <li>Purpose in Life (PLT)</li> <li>External Locus of Control (HLCS)</li> </ul>	• Anxiety (ZAS)	<ul> <li>Perceived meaning (but not control) of the illness was associated with anxiety and self- esteem.</li> </ul>								
	Lewis	1989	Attributions, experienced meaning, and psychosocial wellbeing in patients with advanced cancer.												

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	thors Date Title		,	Relevant measures use	d¹	Summarised Main Findings
41	Lloyd, 1984 Parker, Ludlam & Maguire	1984	Emotional impact of diagnosis and early treatment of lymphomas.	<ul> <li>Extroversion (EPI)</li> <li>Neuroticism (EPI)</li> <li>Psychoticism (EPI)</li> </ul>		<ul> <li>Risk of psychiatric disorder (SPI)</li> </ul>	<ul> <li>No age or treatment associations with outcome.</li> <li>Female patients were more likely to meet psychiatric disorder criteria.</li> <li>Neuroticism was strongly associated with dissatisfaction with communication with medical staff.</li> </ul>
42	Longman, Braden & Mishel	1999	Side-effects burden, psychological adjustment, and life quality in women with breast cancer: pattern of association over time.		Affect (PANAS)	<ul> <li>Quality of Life (CLQoL)</li> <li>Well-Being (IWB)</li> <li>Anxiety (SEC)</li> <li>Depression (SEC)</li> </ul>	Affect was associated with anxiety and depression, but not quality of life.
43	Lowery, Jacobsen & DuCette	1993	Causal attribution, control, and adjustment to breast cancer.		<ul> <li>Attributions</li> <li>Cancer Control (CSC)</li> <li>Thought Intrusion /Avoidance(IES)</li> <li>Locus of Control (MHLC)</li> </ul>	• Distress (PAIS)	<ul> <li>'Why me?' attributions, perceived loss of control, and higher impact of event scores were associated with both poorer adjustment and prediction of psychological distress.</li> </ul>
44	Malcarne, compass, Epping- Jordan & Howell	1995	Cognitive factors in adjustment to cancer: attributions of self-blame and perceptions of control.	Self Blame	Personal Control     Perceptions	• Distress (BSI)	<ul> <li>Self blame was associated with longitudinal distress (four months), but not concurrent distress levels.</li> <li>Perceptions of control had no direct or mediating effects for distress.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title	,	Relevant measures use	ed¹	Summarised Main Findings
45	Marks, Richardson, Graham & Levine	1986	Role of health locus of control beliefs and expectations of treatment efficacy in adjustment to cancer		<ul> <li>Illness         perceptions</li> <li>Locus of Control         (MHLC/I-E Scale)</li> </ul>	• Depression (ZDS)	<ul> <li>Perceived control mediated the relationship between perceptions of disease severity and depression.</li> </ul>
46	Miller, Manne, Taylor, Keates & Dougherty	1996	Psychological distress and well-being in advanced cancer: the effects of optimism and coping.	• Optimism (LOT)	• Coping (WoC)	<ul><li>Distress (MHI)</li><li>Well-Being (MHI)</li></ul>	<ul> <li>Optimism and coping were both associated with adjustment, even after controlling for functional status and prior adjustment measures.</li> <li>Optimism was positively associated with well-being, and negative associated with distress.</li> </ul>
47	Morris, Greer, pettingale & Watson	1981	Patterns of expression of anger and their psychological correlates in women with breast cancer.	<ul> <li>Extroversion</li> <li>Neuroticism (EPI)</li> <li>Psychoticism (EPI)</li> <li>Anxiety (STI)</li> </ul>	<ul> <li>Anger Expression</li> </ul>	• Anxiety (STAI-T)	<ul> <li>Anger expression was higher in patients than controls.</li> <li>Of all personality traits, only neuroticism differed between patients (higher) and controls (lower neuroticism).</li> <li>No age – anxiety association.</li> </ul>
48	Nakada, Nagao, Takiguchi, Tatsumi & Kuriyama	1996	Quality of life and anxiety before and after lung cancer chemotherapy: relationship to patient's personality.	<ul><li>Personality EGOGRAM</li><li>Anxiety (STAI-T)</li></ul>		<ul><li>Anxiety (STAI-S)</li><li>Quality of Life (JQLI)</li></ul>	Two out of five EGO states were highly correlated with QOL scores.
49	Naus, Price & Peter	2005	The moderating effects of anxiety and breast cancer locus of control on depression.		<ul> <li>Health Locus of Control (MHLC)</li> </ul>	<ul><li>Depression (BDI)</li><li>Anxiety (BAI)</li></ul>	<ul> <li>Demonstrated an interactive effect between some locus of control scores and anxiety in the prediction of depression.</li> <li>Suggest that those loci of control assumed to be adaptive in the general population may, in fact, be maladaptive in early stage cancer survivors.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title	Relevant measures use	ď	Summarised Main Findings
50	Nelson, Friedman, Baer, Montague, Lane & Smith	1994	Subtypes of psychosocial adjustment to breast cancer.	<ul><li>Coping (CRI)</li><li>Affect (ABS)</li></ul>	<ul> <li>Distress (PAIS)</li> <li>Anxiety (HADS)</li> <li>Depression (HADS)</li> </ul>	<ul> <li>Of four patient profile clusters, only one demonstrated high distress and global maladjustment.</li> <li>The remainder all had normal affect levels, but differed on various QOL/functioning subscales.</li> <li>Suggests that even non-emotionally distressed patients have varying adjustment trajectories and may all benefit from intervention.</li> </ul>
51	Nordin & Glimelius	1998	Reactions to gastrointestinal cancer-variation in mental adjustment and emotional wellbeing over time in patients with different prognoses.	<ul> <li>Fatalism (MAC)</li> <li>Fighting Spirit (MAC)</li> <li>Anxious         Preoccupation (MAC)</li> <li>Hopelessness/hel plessness (MAC)</li> </ul>	<ul><li>Anxiety</li><li>Depression</li><li>Quality of Life</li></ul>	<ul> <li>Fighting spirit was associated with emotional well-being; hopeless/helplessness and anxious preoccupation was not.</li> <li>MAC scores were generally stable over time.</li> <li>Marked differences observed between HADS clinical/non clinical subsamples.</li> </ul>
52	Osowiecki & Compas	1998	Psychological adjustment to cancer: control beliefs and coping in adult cancer patients.	<ul> <li>Perception of Control</li> <li>Coping (CSI)</li> <li>Thought Intrusion (IES)</li> <li>Thought Avoidance (IES)</li> </ul>	<ul><li>Anxiety (BSI)</li><li>Depression (BSI)</li></ul>	<ul> <li>Problem focussed coping was associated with low anxiety/depression; emotion focussed coping with more symptoms.</li> <li>Interactions between PF coping and control were predictive of lower anxiety and depression at baseline, but not four months later.</li> </ul>
53	Osoweicki & Compas	1999	A prospective study of coping, perceived control, and psychological adaptation to breast cancer.	<ul><li>Perceptions of Control</li><li>Coping (CSI)</li></ul>	<ul><li>Anxiety (SCL)</li><li>Depression (SCL)</li></ul>	<ul> <li>PF coping associated with lower distress near diagnosis.</li> <li>EF disengagement coping associated to distress at 6 months controlling for earlier levels.</li> <li>No main effects for perceived control.</li> <li>Interaction between coping and control significant at baseline only, not longitudinally.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title	1	Relevant measures use	d¹	Summarised Main Findings
54	Padilla, Mishel & Grant	1992	Uncertainty, appraisal and quality of life.	Mastery	<ul><li>Illness uncertainty (MUIS)</li><li>Appraisal (AS)</li><li>Coping (WoC)</li></ul>	<ul><li>Quality of life (MQOLS-CA)</li><li>Distress (POMS)</li></ul>	<ul> <li>Mood, illness ambiguity, mastery and danger focussed appraisal are all key predictors of QOL, explaining far more variance than clinical factors.</li> <li>Coping was not predictive of QOL.</li> </ul>
55	Perczek, Burke, Carver, Krongrad & Terris	2002	Facing a prostate cancer diagnosis: who is at risk for increased distress?	• Optimism (LOT)	<ul><li>Coping (Brief COPE)</li></ul>	• Distress (POMS)	<ul> <li>Avoidance was predictive of increased distress; optimism, cancer status, and all other coping strategies weren't.</li> <li>Interactions between optimism and coping weren't significant predictors either.</li> </ul>
56	Ranchor, Sanderman, Steptoe, Wardle, Miedema & Ormel	2002	Pre-morbid predictors of psychological adjustment to cancer	<ul><li>Neuroticism (EPI-N)</li><li>Self Efficacy (GSES)</li></ul>		• Distress (GHQ)	<ul> <li>High neuroticism was associated with high distress in short, and long term analyses.</li> <li>Higher social support was associated with higher distress.</li> </ul>
57	Ratcliffe, Dawson & Walker.	1995	Eysenck personality inventory L-Scores in patients with Hodgkin's disease and non-Hodgkin's	• Lie (EPI)		<ul><li>Anxiety (HADS)</li><li>Depression (HADS)</li></ul>	<ul> <li>L-Scores (reflecting the cancer prone personality) were high at diagnosis and associated with risk of death at 5 years.</li> <li>Depression was also an independent 5 year survival risk factor.</li> </ul>
58	Rondorf- Klym & Colling	2003	Quality of life after radical prostatectomy.	<ul><li>Self-Esteem (RSE)</li></ul>	<ul> <li>Symptom         <ul> <li>appraisals (PCI)</li> </ul> </li> <li>Anger Expression         <ul> <li>(AEI)</li> </ul> </li> <li>Health Locus of         <ul> <li>Control (MHLC)</li> </ul> </li> </ul>	<ul><li>Depression (CES-D)</li><li>Quality of Life (QLS)</li></ul>	<ul> <li>Perceived support, self-esteem, and health locus of control were all significant predictors of QOL.</li> <li>Urinary function appraisal was mediated by locus of control.</li> <li>Anger suppression and depression were not significant predictors of QOL.</li> </ul>
59	Schnoll, Knowles & Harlow.	2002	Correlates of adjustment among cancer survivors.	<ul><li>Optimism (LOT)</li></ul>	<ul><li>Life Purpose (PLT)</li><li>Coping (COPE)</li></ul>	<ul><li>Quality of life (PAIS)</li></ul>	Higher social support, optimism, high perceived meaning in life and lower avoidant coping were associated with better adjustment.

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	ed¹	Summarised Main Findings
60	Schou Ekeberg, Ruland, Sandvik & Karesen.	2004	Pessimism as a predictor of emotional morbidity one year following breast cancer surgery.	• Optimism (LOT)	<ul> <li>Positive         expectations</li> <li>Fatalism (MAC)</li> <li>Fighting Spirit         (MAC)</li> <li>Hopelessness/Hel         plessness (MAC)</li> </ul>	<ul> <li>Anxiety (HADS)</li> <li>Depression (HADS)</li> <li>Quality of Life (EORTC)</li> </ul>	<ul> <li>Prevalence of emotional morbidity was significantly higher among pessimists.</li> <li>Pessimism was the strongest predictor of one year anxiety and depression.</li> <li>Optimists and pessimists have different coping approaches which may interact to predict outcome.</li> </ul>
	Schou, Ekeberg & Ruland.	2005a	The mediating role of appraisal and coping in the relationshp between optimism-pessimism and quality of life		<ul> <li>Anxious         Preoccupation             (MAC)     </li> <li>Treatment             decision making</li> <li>Primary             Appraisals (VASA)</li> <li>Treatment</li> </ul>		<ul> <li>Optimism had both a direct and a mediated (via fighting spirit and hopeless/helplessness) effect on QOL.</li> <li>Relationships between predictors and outcomes were also mediated by threat appraisals at the time of diagnosis.</li> <li>Compared to general population controls, at diagnosis patients reported lower emotional,</li> </ul>
	Schou, Ekeberg, Sandvik, Hjermstad & Ruland.	2005Ь	Multiple predictors of health-related quality of life in early stage breast cancer. Data from a year follow-up study compared with the general population.		decision making		<ul> <li>cognitive and social functioning.</li> <li>Cognitive and social functioning disparity continued until one year post surgery.</li> <li>Breast conservation surgery a chemotherapy were predictive of functioning one year after surgery.</li> <li>Throughout, optimism was associated with better QOL and fewer symptoms.</li> </ul>
61	Stanton, Danoff-Burg, Cameron, Bishop, Collins, Kirk, Sworowski & Twillman	2000	Emotionally expressive coping predicts psychological and physical adjustment to breast cancer.		<ul><li>Hope</li><li>Coping (COPE)</li><li>Perceived Health</li></ul>	<ul> <li>Quality of Life (FACT)</li> <li>Distress (POMS)</li> </ul>	<ul> <li>Emotionally expressive coping was associated with fewer cancer related medical appointments, enhanced health and vigour, and decreased distress at three month (age, coping and initial levels controlled for).</li> <li>Relationships between emotionally expressive coping and QOL were mediated by social receptivity.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	r <b>d</b> 1	Summarised Main Findings
62	Taylor, Lamdan, Siegel, O'Connor, Moran, Lunch & Hrywna	1999	The role of coping in the psychological adjustment of African American women with early- stage breast cancer.		<ul> <li>Thought Intrusion (IES)</li> <li>Thought avoidance (IES)</li> <li>Coping (COPE)</li> </ul>	<ul> <li>Distress (MHI)</li> <li>Well Being (MHI)</li> <li>Quality of Life (CARES)</li> </ul>	<ul> <li>Avoidant coping was associated with psychological distress, particularly in younger patients.</li> </ul>
63	Timko & Janoff- Bulman	1985	Attributions, vulnerability, and psychological adjustment: the case of breast cancer.	• Self-Esteem	<ul><li>Emotional Reactions (EES)</li><li>Attributions</li></ul>	• Depression (BDI)	<ul> <li>Relationships between illness attributions and adjustment were mediated by perceived vulnerability beliefs.</li> </ul>
64	Trunzo & Pinto	2003	Social support as a mediator of optimism and distress in breast cancer survivors.	• Optimism (LOT)		<ul><li>Distress (POMS)</li></ul>	<ul> <li>Affective social support mediated the relationship between optimism and distress at baseline and 6 month follow up, but not at 1yr follow up.</li> <li>Confident social support did not mediate the optimism-distress relationship at any point.</li> </ul>
65	Urcuyo, Boyers, Carver & Antoni	2005	Finding benefit in breast cancer: relations with personality, coping, and concurrent well-being.	• Optimism (LOT)	<ul> <li>Threat sensitivity (BIS/BAS)</li> <li>Illness Concerns</li> <li>Coping (Brief COPE)</li> </ul>	<ul><li>Distress</li><li>Depression (CES-D)</li><li>Quality of Life</li></ul>	<ul> <li>Benefit finding was associated with optimism, positive reframing, religious coping, and emotional distress.</li> </ul>

Table 2.3. Publication details and variables measured for the 68 included studies (continued).

ID	Authors	Date	Title		Relevant measures use	d¹	Summarised Main Findings
66	Watson, Greer, Rowden, Gorman, Robertson, Bliss & Tunmore	1991	Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients.		<ul> <li>Emotional Control (CECS)</li> <li>Fatalism (MAC)</li> <li>Fighting Spirit (MAC)</li> <li>Anxious         Preoccupation (MAC)         Hopelessness/hel plessness (MAC)     </li> </ul>	<ul><li>Anxiety (HADS)</li><li>Depression (HADS)</li></ul>	<ul> <li>Emotional control and fatalism were highly significantly associated.</li> <li>Anger control was associated with helplessness.</li> <li>Psychological morbidity was related to type of adjustment reported.</li> </ul>
67	Yamaoka, Shigehisa, Ogoshi, Haruyama, Watanabe, Hayashi & Hayashi	1998	Health-related quality of life varies with personality types: a comparison among cancer patients, non-cancer patients and healthy individuals in a Japanese population.	<ul> <li>Extroversion (EPI)</li> <li>Neuroticism (EPI)</li> <li>Psychoticism (EPI)</li> <li>Optimism (LOT)</li> </ul>		• Quality of Life (HRQoL)	Optimism was a mediator between eating ability and quality of life, particularly physical and social well-being.
68	Yu, Fielding & Chan	2003	The mediating role of optimism on post-radiation quality of life in nasopharyngeal carcinoma.	<ul> <li>Extroversion (EPI)</li> <li>Neuroticism (EPI)</li> <li>Psychoticism (EPI)</li> </ul>		• Quality of Life	<ul> <li>High extroversion, low neuroticism, and high psychoticism were associated with higher QOL.</li> </ul>

<sup>&</sup>lt;sup>1</sup> Where validated scales are used, abbreviations are shown in brackets. (For full measure titles see appendix 2.2)

# 2.6. PROCEDURE OF DATA EXTRACTION, QUALITY ASSESSMENT, & SYNTHESIS

#### 2.6.1 Data extraction

Data were extracted from all included studies using standardised forms.

These were independently piloted by two reviewers on a random selection of five papers during protocol development.

Study content and results were extracted by reviewer two only; whilst duplicate extraction would have been preferable resources were not available to enable this extra step of methodological validation. Data extraction included:

Basic Study Information. Authors, date of publication, and an allocated study identification code.

Sample. Sample size, gender ratio, age range/mean, cancer site, cancer stage, recruitment rate, and follow up attrition.

*Methodology*. Design, timing of follow up data collection (if appropriate), main study research question, and measures used.

*Results.* Statistics of relevant findings, descriptions of associated results, and poignant comments made in the discussion.

Comments. Any additional comments on the study made by the reviewer.

### 2.6.2 Quality assessment

Study quality significantly varied between design with prognostic, epidemiological, or observational designs usually demonstrating most variance and often the poorest standards of methodological rigour (Altman, 2001).

Assessment of quality is important to enable objective assessment of the individual contribution of each study to the field as a whole. As such, quality assessment data can be used in numerous ways. First, data can be synthesised qualitatively to give a methodological critique of a specific field of research; second, as a grouping variable for sensitivity analysis; and, third, many reviews will often use low quality scores as a basis for study exclusion as their inclusion can often obscure the true nature of variable relationships (Altman & Lyman, 1998). Rosenthal (1995) warns against use of quality scores as an exclusion variable as scores are prone to the bias of the individual(s) who conducted the quality assessment. Rather, Rosenthal promotes using the data to investigate the moderating role of study

quality in the mean effect size (i.e. in sensitivity analysis) or as an alternative study weighting variable in meta-analysis.

Despite substantial criticism against doing so, many reviews continue to discount non-RCT designs and as such, numerous quality assessment tools currently exist for RCTs; the Delphi List (Verhagen, de Vet, de Bie, Kessels, Boers, Bouter et al., 1998) and the GRADE approach (Atkins, Briss, Eccles, Flottorp, Guyatt, Harbour et al., 2005) for example. As an alternative to quality assessment scales, the Cochrane Collaboration encourage the use of risk of bias lists which promote evaluation based on sub-domains of quality rather than calculation of total quality scores (Higgins & Altman, 2008). Like many of the other tools, however, this method is biased towards assessment of the RCT and not all aspects are relevant to other methodological designs. The increasing number of such tools makes it difficult to distinguish between them and select the most suitable (Altman, 2001).

Fewer tools exist for use in assessing the quality of qualitative studies. The protocol stated that had qualitative studies been included, their quality would be assessed using the well-validated Mays and Pope (1996) tool (these criteria will not be detailed here as no qualitative studies were ultimately included, however, they are readily available: see Mays and Pope, 1996; Kahn *et. al.* 2001).

Converse to the number of experimental design quality assessment tools, there are no widely accepted quality criteria for studies of observational or non-experimental research. To use experimental quality criteria would be invalid as many features are simply not suitable for theses design specific quality indicators. Therefore, many review teams create their own, usually citing NHS CRD guidance, the Cochrane Handbook and methodological papers (see, for example, Downs & Black (1998) and Papworth & Milne, 2001) for their development. This has given rise to a number of largely invalidated measures in the literature which are rarely used on more than one or two occasions (Altman, 2001).

An alternative approach is proposed by Edwards, Russell and Stott (1998): the signal to noise ratio. These authors advocate that to exclude designs lower in the evidence hierarchy is inappropriate as such designs are more feasible and appropriate to many questions. Edwards *et al.* (1998) propose that in addition to quality assessment, the 'noise' component, an assessment should also be made

about the potential value added by the study, the 'signal' component, to the literature. Resultant scores are then presented as a ratio representing study value rather than quality *per se*.

For this review it was necessary to select a method which was relevant to the highest number of possible designs, to allow for direct comparisons to be made. Whilst the signal to noise method could have been selected, the more straightforward and arguably more objective checklist approach was favoured. As such, the Kmet, Lee and Cook (2004) tool was selected.

Some modification to this quality assessment tool was necessary to meet the specific requirements of this review. Based on the assumption that longitudinal designs are more informative for explorations of variable association and prediction, three items of quality assessment were added relating to such designs. Specifically, these items assessed: (1) the suitability of timing between baseline and follow-up collection (i.e. long enough for outcomes to have emerged); (2) the sufficiency of explanation of sample attrition between baseline and follow up data collection; and, (3) whether statistical adjustments were made in the analyses based on different lengths of follow-up.

The modified tool used the same scoring instructions recommended by Kmet et al. (2004). The standardised form is applied to each study individually and assesses the quality, clarity and suitability of the stated aims, hypotheses, design, sample, methodology, analysis, reporting of results, and validity of the conclusions drawn from the data. Each paper is awarded one of four scores (2=yes/good; 1=partial; 0=no/poor; X=not applicable) for each of the 19 quality criteria. The total (out of 38) is then converted into a percentage indicator of quality. Quality assessment was conducted by both reviewer one and reviewer two independently and an overall mean score calculated per study. A copy of the quality assessment form (including scoring guidelines) is included in appendix 2.3.

Whilst potentially creating some level of confound into data synthesis, studies with low quality assessment scores were not excluded (see section 2.2.2). This decision was reached based on two observations. First, due to the subjectivity inherent in quality assessment checklist, and second, because scoping searches had already highlighted that poor quality was an ongoing issue in this field. One of the review objectives was to systematically critique methodology in addition to

synthesising findings. To exclude some studies based on low methodological scores would have rendered this objective redundant. Whilst total mean scores were calculated for each study, domain specific evaluation (as suggested by the Cochrane Collaboration) was conducted and in-depth descriptive discussion of various aspects of quality are presented in addition to summary scores.

In addition to quality scoring each individual study, Russell, Di Blasi, Lambert and Russell (1998) propose a scoring system for systematic reviews themselves. No systematic reviews are currently available on this topic and as such scoring systems were not relevant to data extraction, however, this tool was used in the review evaluation (section 2.8.3).

## 2.6.3 Data synthesis

This review had two objectives. First, to provide a methodological critique of the literature to investigate whether claims of poor methodology are valid (for example, see Cull, 1990; Altman & Lyman, 1998) and potentially responsible for the low impact of research in the field. Second, results were synthesised in order to (a) explore if similar studies report corroborative or opposing findings and (b) to identify any research gaps to guide future research.

Data were extracted with the aim of conducting numerous small-scale statistical meta-analyses; scoping searches previously established that large-scale meta-analyses for each outcome were not viable. The method of meta-analysis chosen was a random effects model using the Hunter and Schmidt (1999) method. A random effects model was selected as the ultimate goal was unconditional inference of the findings; generalisability to the population in order to generate both research and clinical practice implications. Further, fixed effect models are more likely to commit Type I error. As data were presented in a correlation coefficient format, it was deemed unnecessary to introduce extra bias into the calculation by transformation of these scores; the Hunter and Schmidt method is the only one of the three which combines these statistics directly.

Both Hedges's and Rosenthal's methods are reported to produce overestimates of effect sizes and are found to be particularly inaccurate where effect sizes fall below  $\bar{r}$  =.3, which they did in many cases in this review. Therefore, the comparatively stringent Hunter and Schmidt method was more appropriate. In response to claims that it may be poor at accurately detecting true significance, the

more stringent two-tailed probability test was used; still, given low numbers of included studies, reported significance levels should be treated with caution.

Effect sizes were weighted by sample size. Although Rosenthal (1995) promotes further weighting of studies by quality score, this was inappropriate due to the differences in scores obtained between reviewers, possibly indicative of bias in either the scorer or the scoring system (for further detail see section 2.7.2.1).

In preparation for potential meta-analysis, during data extraction and synthesis, variables were categorised into either: one of five predictor variable groupings, including, personality, health control beliefs, illness cognitions/appraisals, emotional reaction to illness and coping; or, into one of five outcome variable groupings, including anxiety, depression, distress, quality of life and well-being. These groupings were structured around theoretical concepts and studies were matched based on an analysis of the content of the specific measures used. Care was taken to ensure categorisation was done systematically and theoretically rather than basing simply on the title of the selected measure (which can often be misleading) or on the stated purpose in each study (which may not always be the validated and appropriate use). In most cases this was clear, but for others, categorisation was less explicit as usage was found to be inconsistent.

Within this review, the heterogeneity of constructs assessed, and the different measures used between studies to assess those constructs was much greater than anticipated. Although meta-analysis aims to group similar studies this is not always feasible or straightforward; many measures of similar psychosocial variables not only have different numbers of factor loadings, but very different subscale content. For example, within the final number of included papers, 17 different measures of quality of life were used. Although more recent research seems to be focusing on use of standard measures such as the FACT or EORTC, to accurately match subscales from each of these scales is no simple task.

Even more problematic was inconsistency in the application of measures. Whilst it is relatively easy to group different measures of the same construct, there were a number of occasions where one single measure was used to assess different constructs between studies. There are two examples of this. First, the Impact of Events Scale was sometimes used as both cognitive predictor variable for psychosocial outcome (e.g. a predictor of quality of life), but also as an outcome

itself (e.g. stress as an outcome). Within the theoretical model adopted for this review (where distress and quality of life were the standard outcomes), the IES most suitability fits in the cognition category. The result of this is that studies which used only the IES as an outcome did not necessarily meet review inclusion criteria and were thus excluded.

Even more confusing was application of the Mental Adjustment to Cancer (MAC) Scale. Watson et al. (1988) claim that this is a measure of adjustment where adjustment is defined as comprising appraisals and their ensuing reactions. Many studies, in fact, use this scale not as an adjustment (outcome) measure, but as an assessment of coping (particularly where the mediating role of coping is being investigated). The reason for this could possibly be the lack of clarity for what adjustment actually is, and that the nature of psychological response to illness is dynamic: cyclical and not fixed. Schou et. al. (2004) also raise this problem of definition and when comparing the measure to theoretical literature decide that it is best suited to measure 'cognitive coping'. Nelson et. al. (1994) claim that at least two of the sub-scales, anxious preoccupation and hopelessness/ helplessness, should be classed as 'mental attitudes' rather than adjustment indicators or coping. Content analysis of the subscales for the purpose of this review concluded that the measure was, indeed, more related to cognitive processes rather than coping or adjustment. Therefore, in this review, the MAC was considered a health cognition and appraisal construct.

This is an issue, not limited to psychosocial oncology, but to much of health psychology. Health psychology is still a young discipline having been independently established less than 25 years ago and UK based psychosocial oncology was established soon after. Therefore, much of the research has been exploratory, leading to many competing theories and multiple assessment tools. An ideal goal would be for the field to become standardised, and over time, this seems likely to happen. However, it is imperative that in preparing new protocols, researchers are clear about (1) which theoretical model they are basing their research around; (2) how they choose to define different constructs; (3) that important (possibly confounding, mediating or moderating) constructs are not missed out from their chosen model; and, most importantly (4) that assessment

tools are carefully selected to validly assess the desired construct within the chosen theory.

#### 2.7 RESULTS

Data were synthesised primarily according to the guidance of Egger *et al.* (1998) due to their heterogenous nature. Therefore, the results that follow contain a qualitative synthesis of the included studies, a description of why most did not fit in with standard requirements for meta-analytic procedures, and a number of small meta-analyses which should be treated with caution. Advanced statistical procedures (e.g. sensitivity analysis) were not possible due to the limited size of the meta-analysis. Additionally, the disproportional number of studies in each cancer group meant that synthesis of findings specific to each patient group was not possible. Results were synthesised with regard to cancer as a group of illnesses, but where differences in site may be important, these are highlighted and possible causes for such discrepancy discussed.

Results are presented according to the two objectives. Therefore, the methodological critique and results of the quality assessment exercise are presented first. Appreciation of the methodological issues raised is critical to understand the descriptive results which follow thereafter. Results of the statistical meta-analysis are presented between the methodological critique and the descriptive data synthesis of the main findings from individual studies, into which, relevant meta-analytic findings are integrated and discussed.

Due to the number of studies reviewed, it was not possible to discuss methodological differences for each study. However, attention is drawn to summary information presented in table 2.3 (measures used) and table 2.4 (clinical descriptors, design features, and summary quality assessment scores). The main findings from each study are also presented in table 2.3. Throughout the results section, where reference is made to significance of result, this pertains to a standardised alpha level of p<.05.

## 2.7.1 Description of included papers

The clinical, demographic, and design characteristics of the 68 included studies are shown in table 2.4. Included papers ranged in date of publication from 1981 to 2005.

Thirty eight of the sixty-eight included studies were carried out in North America. Twenty-one were carried out in Europe (of which, four recruited in the Netherlands, four in Scandinavia, and six in the United Kingdom); five in Asia; three in Australasia; and just one in Africa. The final study was a cross sectional analysis comparing Israeli and Austrian cancer patients.

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers.

							Sample	e Size	l l	nder %)	A	ge	Qua Assess Scores	ment
Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line•	F/U <sup>s</sup>	M	F	Mean (sd)	Range	Mean	Diff
Cross Se	ectional Studies													
2	Ahmed	2004	Egypt	Bladder (Not specified)	n/a	Diagnosis	148	n/a	82	18	48.6		63.6	9.1
3	Alhama	1995	Spain	Lung (14); Breast (31); Colorectal (27); Head/Neck (28) <i>(All)</i>	n/a	Treatment	105	n/a	55	45	55.6		65.9	4.5
5	Andrykowski	1994	North America	Leukaemia (All)	n/a	21.5 months month post diagnosis (SD=15.9)	69	n/a	55	45	35.9 (8.8)		84.1	4.5
6	Andrykowski	1996	North America	Breast (I-IIIa, In remission)	n/a	28.2 months month post diagnosis (SD=15.1, R: 6-57)	80 (81- 86%)	n/a		100	53.9 (9.3)	35-79	90.1	0
8	Baider	2003	Austria / Israel	Breast (I-II, Survivors)	n/a	1 - 5 years post diagnosis	22 <b>4</b> (37.3%)	n/a		100		30-80	88.6	13.6
11	Boer	1988	Nether- lands	Gynaecological (11); Breast (53); Lung (8); Somach/Intestinal (12); Prostate (16) (Not Specified)	n/a	2.5 years post diagnosis	480	n/a	29	71	60.6 (11.8)	20-80	77.3	9.1

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	M	F	Mean (sd)	Range	Mean	Diff
16	Carver	2000 b	North America	Breast (I-II)	n/a	Diagnosis; 3, 6, or 12 month post diagnosis	202 (80%)	n/a		100	53.8 (12.8)	27-87		
22	Evans	1993	Canada	Leukaemia (Not Specified)	n/a	24 months post diagnosis (R: 3-91)	40 (71.4%)	n/a	21	19	47.0	16-82	75.0	4.5
26	Golden- Kreutz	2004	North America	Breast (I-III)	n/a	36.3 days post surgery (SD=16.89)	210	n/a		100		20-85	86.2	0.4
31	Hassanein  And  Hassanein	2001	United Kingdom	Oral (All)	n/a	23 months post treatment end (R: 6months-6yrs)	68 (88.3%)	n/a	69	31	58	28-86	87.5	8.3 0.8
35	lwamitsu	2005	Japan	Breast (Not Specified)	n/a	Pre-Diagnosis	23	n/a		100	45.5 (9.6)	25-72	85.4	4.8
36	Kessler	2002	North America	Breast (Not Specified)	n/a	3.5 years post diagnosis (SD=3.61, R:0.1-19 yrs)	1 <b>4</b> 8 (71%)	n/a		100	52. <del>4</del> (11.6)	28-80	74.6	32.6
37	Koopman	2001	North America	Breast (0-111)	n/a	6 months post diagnosis	100	n/a		100	58.6 (11.6)	31-82	84.1	22.7
38	Laubmeier	2004	North America	Prostate (23); Breast (16); Ovarian (14); Endrometrial (11); Other (36) (All)	n/a	3 months to 5 years post diagnosis	95 (92.3%)	n/a	33	67	58.5 (10.8)	27-84	90.9	0

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	М	F	Mean (sd)	Range	Mea n	Diff
39	Lehto	2005	Finland	Melanoma; Breast (All)	n/a	3 - 4 months post diagnosis	175 (83.3%)	n/a	21	79	54.5	28-71	81.8	18.2
40	Lewis And	1982	North America	Lung (23); Breast (24); Ovarian (11); Lymphatic (9); Other (23);	n/a	Treatment (2/3rds within 1 year of treatment)	57	n/a	37	63	54	21-79	72.7	0
	Lewis	1989		Unknown Primary (10) (Metastatic)		ŕ		•			(13.3)		75.0	13.7
43	Lowery	1993	North America	Breast (All)	n/a	13.9 months post diagnosis (R:1-60 months)	195	n/a		100	53	•	81.8	18.2
45	Marks	1986	North America	Heamatological (All)	n/a	Diagnosis	137	n/a	66	34		18-86	79.5	4.5
47	Morris	1981	United Kingdom	Breast (T <sub>0-2</sub> , N <sub>0-1</sub> , M <sub>0</sub> )	n/a	Pre-Diagnosis	17 (68%)	n/a		100	56		82.8	7.2
48	Nakada	1996	Japan	Lung (All)	n/a	Diagnosis	50	n/a			58	35-78	65.9	13.6
49	Naus	2005	North America	Breast (I, II)	n/a	4.3 years post diagnosis	109	n/a		100	53.2 (8.2)	32-79	84.1	4.5
50	Nelson	1994	North America	Breast (Not Specified)	n/a	3 years post diagnosis (R:1-255 months)	122 (68.6%)	n/a		100	52.7		84.1	4.5

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	М	F	Mean (sd)	Range	Mean	Diff
54	Padilla	1992	North America	Gynaecological (All)	n/a	5.1 months post diagnosis (SD=3.5, R: 1- 14 months)	100 (80.6%)	n/a		100	52.9 (15.9)	20-81	90.9	9.1
58	Rondorf- Klym	2003	North America	Prostate (I, II)	n/a	12 - 24 months post treatment end	88 (66.6%)	n/a	100	. <b></b> .	66		79.5	31.8
59	Schnoll	2002	North America	Breast (65); Prostate (22); Other (13) (Not Specified, Survivors)	n/a	61 months post diagnosis (SD=68.7)	109 (100%)	n/a	24	76	60.3 (11)		81.8	9.1
62	Taylor	1999	North America	Breast (All)	n/a	Sample 1: 4 months post diagnosis Sample 2: 2.5 months postdiagnosis	93 (62.8%)	n/a		100	53.7 (12.2)	26-85	90.1	9.1
63	Timko	1985	North America	Breast (Not Specified)	n/a	8.9 months post diagnosis	42 (95.4%)	n/a		100	53.4	23-81	86.4	0
65	Urcoyo	2005	North America	Breast (0-11)	n/a	< 1 year post surgery	230 (80%)	n/a		100	53.5 (12.3)	27-87	90.2	3.2
66	Watson	1991	United Kingdom	Breast (0-11)	n/a	1 - 3 mo post diagnosis	360 (95%)	n/a		100	55.8 (10.6)	25-75	95.4	0

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	M	F	Mean (sd)	Range	Mean	Diff 6
67	Yamaoka	1998	Japan	Stomach (Not Specified, Survivors)	n/a	R: 34d-19.8yr	207	n/a	68	32	57.5	32-831	77.3	18. 2
RCTs														
17	Cohen	2001	North America	Renal; Melanoma (Metastatic)	3 week	Treatment	46	46 (100%)	70	30	54.9 (8.9)	36-76	89.3	21. 4
29	Green	2002	Austra- lia	Prostate (Not Specified)	6 month	Diagnosis	77 (93.9%)	65 (84.4%)	100		69.2 (6.3)	56-86	84.2	5.3
Longitu	ıdinal Studies			, ,			` ,	,						
1	Aarstad	2005	Norway	Head &Neck (All)	6 year	Diagnosis	79	79 (100%)	100		59.9 (1.3)		72.5	16. 5
4	Allison	200	France	Upper aero- digestive (All)	3, 12, 24 month	Diagnosis	101 (99%)	88 (87.1%)	93	7	58.2 (11.6)		84.0	3.6
7	Badger	2004	North America	Breast (All)	3, 6 month	Diagnosis	169	169 (100%)		100	55.6 (12.8)	25-82	74.3	1.3
9	Bleiker	1995	Nether- lands	Breast (All)	19.5 month s	Pre-Illness	25 (78%)	25 (100%)		100	62.5 (10.3)		60.7	0
10	Bleiker	2000	Nether- lands	Breast (T <sub>1-4</sub> N <sub>0-3</sub> M <sub>o</sub> )	18 month	2 mo post surgery (SD=0.8)	244 (77%)	170 (69.7%)		100	51.9 (10.5)	29-75	89.3	21. 4
12	Brown	2000	Austra- lia	Melanoma (IV)	3, 6, 9, 12, 15,	234 days post diagnosis							87.0	4.7
	And				18, 21,	(SD=371)	125	44	60	40	55.0			
	Butow	1999			24 month		(54%)	(35.2%)			(14.0)		91.6	14. 0

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>t</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	М	F	Mean (sd)	Range	Mean	Diff
13	Carver	1993	North America	Breast (I-II)	1, 10 days, 3, 6, 12 month	Diagnosis	59	59 (100%)		100	58.0 (10.8)	33-72	85.0	8.5
14	Carver	1994	North America	Breast (I-II)	3,6,12 month	Diagnosis	70	54 (77.1%)	. <b></b>	100	58.2 (11.2)	32-75	85.2	1.1
15	Carver	2000	North America	Breast (I-II)	3,6, 12 month	Diagnosis	147 (85%)	126 (85.6%)		100	55.8	28-78	75.9	20.9
18	Cousson- Gelie	2000	France	Breast (Early)	3 week, 2 year	Pre-Diagnosis	75	59 (78.7%)	· <b></b>	100	48.3 (10)	30-70	69.8	31.9
19	DeValck	1996	Belgium	Lung (Not Specified)	20 week	Pre-Diagnosis	16	16 (100%)	88	12	58		61.9	7.1
20	Dropkin	2001	North America	Head & Neck (Not Specified)	4,5,6 day	Diagnosis	75	75 (100%)	70	30	61	37-82	69.7	6.1
21	Epping- Jordan	1999	North America	Breast (All)	3, 6 month	10.8 days post diagnosis	110	80 (72.7%)		100	54.8 (10.3)		85.6	21.2
23	Faller	1 <b>9</b> 99	Germ- any	Lung (All)	7-8 year	Diagnosis (within 3 days)	152	103 (67.8%)	83	17	59.0 (9.0)	32-84	76.8	25.0
24	Gallagher	2002	Austra- lia	Breast (1-111)	6 month	2 months post diagnosis	195 (71.7%)	195 (100%)		100	57.0	25-90	85.4	13.7
25	Glinder	1999	North America	Breast (All)	3,6, 12 month	10.8 day post diagnosis	76 (69.1%)	64 (84.2%)		100	54.8 (9.8)		90.8	10.1

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	М	F	Mean (sd)	Range	Mean	Diff
27	Goodwin	2004	North America	Breast (T <sub>0·3</sub> , N <sub>0·1</sub> , M <sub>0</sub> )	12 month	9.7 weeks post diagnosis : 0.5-35)	378 (95%)	323 (85.4%)		100	52.0 (9.9)	26-74	87.0	<b>4</b> .7
28	Gr <b>a</b> ssi	1988	Italy	Breast (T <sub>L</sub> N <sub>o-L</sub> ,M <sub>o</sub> )	1 week, 6 month	Pre-Diagnosis	32 (91.4%)	12 (37.5%)		100	52.0 (6.4)	29-70	69.2	0
30	Hack	2004	Canada	Breast (I-II)	3 year	90.3 days post diagnosis (R: 1.5-6 mon ths)	70	55 (78.%)		100	55.6 (10.1)		92.3	15.4
32	Hee	2005	Korea	Colorectal (All)	1,6 month	Diagnosis	98	52 (53.1%)	59	41	59.7 (11.7)		91.3	4.9
33	Helgeson	2004 (a)	North America	Breast (I-III)	7, 13, 19, 31, 55 month	Treatment	363 (81.6%)	271 (74.7%)		100	48.3 (9.8)	27-75	83.2	9.0
34	Helgeson	2004 (b)	North America	Prostate $(T_{1-3}N_{0}M_{0})$	2, 8, 14 month	47 days post treatment start (SD=22)	93 (77%)	81 (87.1%)	100	·	65	49-80	80.1	13.7
41	Lloyd	1984	United Kingdom	Lymphoma (All)	6 month	Diagnosis	40 (90.1%)	31 (77.5%)	63	37	43.6 (18.5)	19-77	69.2	38.5
42	Longman	1999	North America	Breast (All)	3, 6 month	Diagnosis	53	53 (100%)		100			714	14.3

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	М	F	Mean (sd)	Range	Mean	Diff
44	Malcarne	1995	North America	Breast (40); Gynaecological (22); Heamatological (10); Brain (10); Lung (6); Testicular & Prostate (4); Skin (3); Other (4) (All)	4 month	9.75 weeks post diagnosis (SD=7.34)	98 (77.7%)	72 (73.5%)	21	79	42.5 (7.5)		90.8	3.0
46	Miller	1996	North America	Gastrological (77); Breast (13); Lung (3); Ovarian (1); Unknown Primary (4) (Metastatic)	2, 4 month	10.2 months post diagnosis	121 (89%)	75 (62.0%)	35	65	55.4 (11.5)	35-75	88.9	0.8
51	Nordin	1998	Sweden	Gastrological (Not Specified)	3, 6, 12 month	Within 12 weeks post diagnosis	139	55 (39.6%)	53	47	66		94.5	3.3
52	Osoweicki	1998	North America	Breast (40); gynaecological (22); Haematological & Lymphoma (8); brain (10); Lung (2); Testicular (6); Gastrological (5); Melanoma (4); other (3) (All)	4 month	10 weeks post diagnosis (SD=5.84)	83 (75%)	62 (74.7%)	18	82	41.5 (7.5)	21-61	82.1	0

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2.3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	M	F	Mean (sd)	Range	Mean	Diff
53	Osoweicki	1999	North America	Breast (1, 11, 111)	3, 6 month	10.8 days post diagnosis (R:0-43 days)	70	70 (100%)		100	54.9 (10.0)	36-80	89.7	2.4
55	Perczek	2002	North America	Prostate (Not Specified)	2 week	Pre-Diagnosis	172 (88.7%)	101 (58.7%)	100		66.6 (7.5)	46-87	92.3	0
56	Ranchor	2002	Nether- lands	Lung (8); Breast (16); Prostate (14); Gastrological (31); Colorectal (16); Other (14) (All)	2, 6, 12 month	Pre-Illness	167 (50.3%)	99 (59.3%)	58	42	71.8 (6.5)		96.4	7.1
57	Ratcliffe	1995	United Kingdom	Lymphoma (All)	5 year	Within 48 hours post diagnosis	63	36 (57.1%)	56	44		19-73	82.2	28.0
60	Schou And	2004	Norway	Breast (I, II, III)	3, 12 month	12 days post diagnosis (R: 2-21d)							96.4	7.1
	Schou	2005 (a)					195 (80%)	165 (84.6%)		100	56 (10.3)	21-78	92.7	6.8
	And	(a)					(00%)	(04.070)			(10.3)			
	Schou	2005 (b)											90.8	3.0

Table 2.4. Summary information on demographic, clinical, design, sampling and quality assessment for all included papers (continued).

Study ID.	Authors	Date	Country	Cancer Site <sup>1</sup> (Staging at diagnosis)	Follow -up	Timing of Recruitment 2,3	Base- Line <sup>4</sup>	F/U <sup>s</sup>	М	F	Mean (sd)	Range	Mean	Diff
61	Stanton	2000	North America	Breast (I, II)	3 month	Within 20 weeks of treatment start	122 (83%)	92 (91%)		100	51.56 (10.3)	28-76	91.1	3.6
64	Trunzo	2003	North America	Breast (I-II, Survivors)	3, 6, 12 month	247 days post diagnosis (SD=106.6)	69	69 (100%)		100	57.5 (13.2)		87.5	3.6
68	Yu	2003	China	Nasopharyngeal (All)	4, 8 month	20 days post diagnosis (SD=48d)	211 (45%)	187 (88.6%)	74	26	49.7 (12.2)		91.0	10.4

Numbers in parentheses refer to percentage of overall sample represented by cancer site sub-sample.

Pre Illness = Before emergence of symptoms; Pre Diagnosis = Pre communication of diagnosis to patient; Diagnosis = between communication of diagnosis and treatment start; treatment = receiving active treatment.

Numerical values refer to sample means except where otherwise stated. Value in brackets refers to the standard deviation of time where provided.

Sample stated is the number of participants used in analysis (not necessarily the number consenting to participate). Percentage figure reported in parentheses refers to the proportion of patients that this sample represents from the original population sampled from (where stated or calculation was possible).

Percentage figure reported in parenthesis refers to the proportion of patients analysed at follow up from the originally analysed baseline sample.

<sup>6</sup> Difference in quality assessment scores (%) between reviewer one and reviewer two.

# 2.7.2 Methodological summary and critique of the included studies

### 2.7.2.1 Quality assessment scores

As discussed in section 2.6.2, quality assessment is an important exercise in which distinction can be made between studies, and through which the contribution of an individual study to the overall field can be evaluated.

Concordance between reviewer scores on the modified Kmet *et al.* (2004) assessment tool was lower than expected; only 10 out of the 68 studies were given the same quality score by both reviewers. Of the remainder, 11 studies had a greater than 20% difference in quality scores. Mean and between-reviewer differences in quality scores are presented in table 2.4.

High and low scores approached equivalence between reviewers, but these were attributed to different studies. Reviewer one awarded scores ranging from 50% to 100%: Lloyd et al. (1984) was scored at the lower end and Bleiker et al. (2000), Hack et al. (2004) and Cohen et al. (2001) at the top end of the scale. Scores from reviewer two ranged from 54% to 100%. However, the Cousson-Gelie (2000) was scored lowest and both Ranchor et al. (2002) and Schou, et al. (2004) highest. Differences in quality score become of most concern when comparisons are made on lowest scoring studies. Although reviewer one awarded just 50% quality to the Lloyd (1984) paper, reviewer two awarded this same paper 88%. Similarly, whereas reviewer two awarded Cousson-Gelie (2000) 86%, reviewer one gave the same paper just 54%. Such differences may be attributed to the level of critical evaluation experience of the reviewers; reviewer two being the candidate and reviewer one a psychology graduate. Alternatively, these differences may indeed reflect a lack of clarity in scoring and interpreting the quality criteria. Figure 2.4 shows the distribution of mean quality scores.

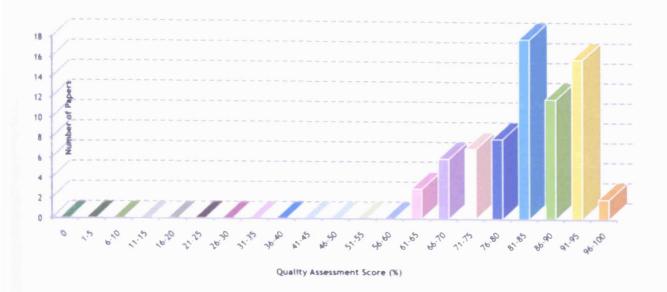


Figure 2.4. Bar chart representation of mean quality assessment scores (mean of reviewer one and review two scores) for included studies.

Mean quality scores were all over 61%. When quality scores are analysed separately, reviewer one awarded slightly greater spread of scores (all, however, remained above 50%) but with slight positive skew when compared to those scores awarded by reviewer two. Means and standard deviations were, however, comparable (reviewer one: M=83%, SD=10.5%; reviewer two: M=82%, SD=11.4%).

Following Cochrane Collaboration guidance (Higgins & Altman, 2008), each area of quality will be discussed in turn. To ensure clarity references for all methodological comparisons are not made. Instead, the general trends and themes are discussed and all such detail is provided in previous summary tables and where pertinent examples are worth note, these will be highlighted.

## 2.7.2.2 Study designs

Twenty-nine studies used a cross sectional design; 37 employed longitudinal designs; and, two presented baseline statistical associations between variables for patients recruited into randomised controlled trials (Cohen *et al.*, 2001; Green *et al.*, 2002). Of the 37 longitudinal designs, two recruited patients at a pre-symptom

stage (the sample formed a sub-sample from larger general population surveys) and seven recruited patients between first consultation and confirmatory diagnosis.

Cross sectional research is not necessarily a design weakness; often it can be the most appropriate methodology, and being less complex, is often a far more economically efficient way to collect data. However, such designs lack the ability for inferences of causality and prediction to be drawn. Within this set of cross sectional studies, the same information was found to be repeatedly presented. Up to date surveys tended to reproduce findings from earlier studies, with few methodological improvements. This is despite earlier conclusions that more research effort should be concentrated on longitudinal research. Illness adjustment is usually considered to be a process and, therefore, whilst cross sectional findings may be informative (to inform of immediate impact of diagnosis, or follow-up psychosocial status, for example), their impact is limited. Higher quality research and subsequent implementation into practice is reliant on gaining an understanding of the temporal processes involved and this is simply not achievable using single time point data collection.

One final study is important to note. Carver *et al.* (2000b) recruited a number of groups of breast cancer patients at different illness time-points and compared the effect of time since diagnosis. A longitudinal design would have been far more appropriate here: not only would this have improved the comparable quality, but would also have minimised the effects of individual differences and confounding variables, thus allowing for more sophisticated analysis.

### 2.7.2.3 Timing of recruitment

Longitudinal studies which recruited pre-diagnosis (e.g. deValck & Vinck, 1996; Perczek et al., 2002) were considered superior in quality as these gain better indications of baseline scores. Obviously, those within this category that recruit pre-symptom (Bleiker et al., 1995; Ranchor et al., 2002) are best as these acheive true baseline measurement. Two studies collected baseline data between first consultation and communication of diagnosis (Morris et al., 1981; Iwamitsu et al. 2005). Both pre-illness, and pre-diagnosis recruitment enable prospective investigation of the full impact of this diagnosis, comparing to pre-morbid

psychosocial status. Such recruitment is obviously not always possible as it necessitates recruitment of a large healthy sample and longer term follow up until sufficient numbers develop illness. However, the common compromise of recruiting post-symptom / diagnosis and using retrospective self-report is far more prone to inaccuracy.

In these studies, a huge range of between study time periods between diagnosis and recruitment were reported. Whilst this may not affect some research questions, it seems logical when researching illness adjustment to strive to recruit patients as close to diagnosis as possible. In particular, this becomes an issue when considering event appraisals and attributions; such variables are dynamic and as such can change with very slight circumstantial alteration. Furthermore, due to the on-going nature of psychological response to illness, reappraisals of an event at a later date have potential to provide very different, and sometimes misleading, results.

A related issue is the within study range of time between diagnosis and recruitment where large mean time differences were apparent between study. In other words, recruitment inclusion criteria were too non-specific for generalisable. homogenous samples to be recruited. Andrykowski et al. (1996), for example, report a range of time between diagnosis and recruitment of 6 to 57 months. Evans et al. (1993) had a range of 87 months; Hassanein et al. (2005), a range of up to five and half years; Lowery et al. (1993) of 60 months; Nelson et al. (1994) of 255 months; and studies by both Kessler (2002) and Yamaoka et al. (1998) had ranges of time since diagnosis of 19 years. These samples present results where those who have only just recently received a diagnosis are grouped with those who may have been disease free for up to fifteen or more years. The experiences of these patients will be very different due to changed clinical circumstance (active treatment versus remission for example); where time increases, patients will have had longer to adjust, are unlikely to be receiving active or invasive treatment and their uncertainties and fears will have, largely, been addressed. Where studies compare between groups, this is not an issue, provided that adequate sub-sample sizes are achieved for each group. However, when presenting general, all-sample correlation data, samples should be relatively homogenous in terms of their clinical circumstances. The scientific validity of the studies is highly questionable;

the changing needs and stress demands throughout the illness process create anything but a homogenous sample. To recruit a range of patients including primary diagnoses, secondary diagnoses, recurrent diagnoses, and survivors significantly limits the usefulness and theoretical generalisability of these findings.

# 2.7.2.4 Timing of follow-up

Timing of follow up between longitudinal studies was, on the whole, standardised. Standardised follow up is important in this research field due to the rapidity at which these psychosocial variables fluctuate; it is very difficult to draw comparisons between dissimilar time points in studies. Due to the differences in timing of original recruitment, when considered as time-points through the illness process rather than point of follow-up from recruitment, much more variability emerges. What at first may appear to be a vast wealth of comparable research, may in fact, not be so.

# 2.7.2.5 Sampling issues

Sample sizes ranged from 16 to 480 amongst cross sectional studies. Longitudinal study baseline samples ranged from 32 to 278, with follow up samples ranging from 12 to 271. Of all included studies, 11 scored an inadequate sample size in quality assessment. Of those providing sufficient information (39 out of 68; 57%), response rates appear high; only five studies indicated response rates of less than 30% and 17 (44%) reported over 81%. Of more concern though, almost half presented unclear or inconsistent information relating to the recruitment procedures, response rates, and completion rates. An accurate picture of true response (and, therefore, the potential generalisability of the findings) is impossible to attain. It is possible that this discrepancy may hide poor recruitment strategies or low response rates.

Five studies recruited specifically male samples; four of which recruited only prostate cancer patients, and one was a head and neck cancer study (Aarstad *et al.*, 2005) with no explanation given for why a male-only sample was recruited. Twenty nine studies recruited purely female samples and these constitute all of the breast cancer research; no studies included in this review recruited male breast cancer patients. This is perhaps representative of the low male to female breast cancer diagnosis ratio. However, despite low incidence, male breast cancer

research remains an important area of study. The 34 remaining studies recruited both males and females although gender ratios differed greatly; the most unequal was 82% female biased (Osoweicki & Compas, 1998). The effect of gender difference on the findings will be further explored in sections 2.7.3.2 and 2.7.3.4, but this issue may be best not considered a cancer site issue rather than a gender issue. In other words, gender biases exist because researchers limit inclusion to gender exclusive cancer diagnoses.

All of the major cancer diagnoses were represented, although the number of studies focusing on breast cancer was disproportional to other cancers (n=43%). This is perhaps best explained by both a historical trend for more dedicated funding for this type of cancer, and the typical demographics of breast cancer patients; typically younger, female, and thus more likely to respond to research invitations (Edwards, Roberts, Clarke, DiGuiseppi, Prataap et al., 2002). Of those recruiting mixed cancer diagnoses, between two and eight different cancers were comprised in samples. Two studies did not specify the breakdown of cancer site categories and in those that did, varying sub-group sizes were reported. In all, a female bias was again evident with higher participation from breast and gynaecological cancer patients.

With respect to stage of illness, 21 (30.8%) studies recruited only those patients with non-advanced cancer (i.e. without metastases and limited lymph node involvement). Five studies (7.4%) recruited only patients with advanced cancer and four studies (5.9%) comprised of survivors only (stage of prior illness was not specified, but assumed to be relatively non-advanced given the recovery observed in these patients). Twenty six studies (38.2%) recruited cancer patients at any stage of illness. Typically, these studies were those which reported the longest mean times between diagnosis and recruitment into the research. The remaining 12 studies (a high 17.6%) did not specify any illness-stage inclusion criteria and so are assumed to have included any stage of illness.

#### 2.7.2.6 Data collection

This issue has already been covered in part in section 2.6.3. Aside from the issue raised there regarding confusion in construct definition and usage of validated measures, two other important points should be noted. First, three studies (Aarstad *et al.*, 2005; Bleiker *et al.*, 1995; Bleiker *et al.*, 2000) seem to imply

that they defined a measure of anxiety and/or depression as a personality variable. Second, a large proportion of the longitudinal studies seemed not to repeat all measures at all time points meaning that full concurrent, or longitudinal relationships are not always obtainable. Such practices are quite commonplace, and whilst they are not un-scientific and do have value for the field, in the case of very focused review questions such as this, the findings are not always useful.

A number of studies did not use questionnaire data collection methods; instead, patients were interviewed using structured or semi-structured schedules. It is commonly reported in these studies, that rather than using validated measures, researchers use abbreviated, or single-item questions to assess the same constructs. To do so can prevent direct comparability with other studies and often results in low quality assessment scores; neither the questions, nor responses, are clearly defined and categorised, nor corroborated by reliability and reproducibility statistics.

# **2.7.2.7** Control of confounding variables

Inclusion of many different cancer sites has advantages and disadvantages. On the one hand it is a positive move away from the gender and clinically biased research base in breast cancer. Clinical differences (e.g. stage of illness and treatment received) between individual cases of cancer lead to different levels of morbidity and mortality. It seems sensible to assume, and has been stated in the literature, that such differences may be associated with, or influence, variables of relevance to this review. Similarly, individual demographic differences (e.g. age or gender) are also found to influence psychosocial variables across many types of research. In recruitment of samples which may necessitate control of a greater number of confounding variables, bigger sample sizes are required and greater emphasis should be placed on in-depth testing, and controlling, of the effects of differences in sample demographics or clinical variables. Statistical analysis should ideally include not only the reporting of descriptive data, but also an analysis of how these are related to variables of primary interest. This method should be used to assess which variables should be controlled in more complex analyses.

For this review the following information was deemed to be potentially important:

Demographic Gender (in mixed gender recruitment)

Age

Education

**Employment Status** 

Income/Socio-Economic Status

Children/Dependants

Marital status

Clinical Cancer site (in multi-site recruitment studies)

Cancer stage

Time since diagnosis

Treatment received.

Five of the included studies only partially controlled for potential confounding clinical and demographic data. Twenty-three did not report on any testing of the effects of potential confounders, or confounder controlled analysis.

Of greater concern, particularly when considering only the multi-site studies which require even greater control for clinical variables, only 60% of studies appeared to fully address this issue.

Further, 27 of all included studies (39.7%) did not contain any information beyond a basic descriptive analysis. Because no analysis was mentioned, it is unclear whether these variables were not actually analysed, or were analysed, but found to be non-significant and thus not presented. Without knowing this information, it is not possible to ascertain whether adequate confounding variable control has been made during analysis.

Nine papers made general statements that no associations were found between background demographic or clinical variables and psychosocial variables included in the studies. Although informative to a limited extent, and suitable explanation for why multivariate analysis did not include clinical or demographic information, these papers lacked detail about which specific background information was collected and how possible confounding relationships were tested.

Three papers stated that statistical controls were made for the effects of demographic or clinical data, however, no statistical information was reported about the significance of direction relationships between variables.

The remaining 35 papers made explicit statements about statistical relationships between clinical and/or demographic information and psychosocial variables. In some cases it was not clear whether all of the potentially important confounding variables were assessed and not reported on, or whether in fact, only partial assessment and statistical control of potentially confounding was made. In all cases, where significant associations or differences were established, adequate controls were made by the authors in subsequent analysis. These specific findings are detailed further in section 2.7.3.1 to 2.7.3.4.

# 2.7.2.8 Appropriateness of statistical analysis

Further concern was raised by studies which presented unclear hypothesis-driven statistical tests and appear to use simply inferential or descriptive statistics to compare between clinical or demographic groups (e.g. Andrykowski et al., 1996; Dropkin, 2001). Additionally, a number simply used multivariate testing, without any inferential, univariate or bivariate preliminary tests being reported (e.g. Boer et al., 1998; Cohen et al., 2000; Stanton et al., 2000). Although complex multivariate tests are considered to be the highest quality statistical analysis due to their ability to control for confounding variables and to fully assess variable interaction effects, presentation of bivariate statistics is helpful in the interpretation of the complex models.

A small number of studies did not present individual correlation effect sizes for each bivariate relationship, but rather presented a range of effect sizes (Hee et al., 2005; Schou et al., 2004, 2005; Osoweicki & Compas, 1998, 1999), without specifying where within this range that each particular variable relationship associations lies nor the level of significance attributable to each relationship.

### **2.7.2.9** Transformed outcome scores

A final statistical issue raised by the quality assessment was the alternative use of psychological measures either in the form of a dichotomous split, rather than continuous scale, or as a composite score.

From the 68 studies in this review, 15 (22.1%) did not report on the specific outcome measured, but combined them into more generalised variables, for example the repeated combination of anxiety and depression subscales into composite scores of distress. Of the 14 found to score measures in this way, 13 created composite outcome scores, and one created a composite of mental adjustment (based on MAC subscales).

Using composite scores can be convenient; they minimise the number of findings reported thus clarifying understanding and their application. However, to truly understand complex psychosocial processes, individual subscale analysis is also useful, at least to a certain level. For example, there is evidence that anxiety and depression have both different predictors, different long-term trajectories of change over time, and are reportedly non-overlapping psychological constructs (Stavrakaki & Vargo, 1986); such differences are lost by testing only a distress composite score.

Where composite scores are required, it is considered good science to calculate them using standardised and validated methods. Four studies (Osoweicki & Compas, 1998; Epping-Jordan *et al.*, 1999; Glinder & Compas, 1999; and Osoweicki & Compas, 1999) created composites using standardised t-score normalization methods on the Brief Symptoms Inventory.

Three studies justified their use of a composite score based on a factor analysis of their data (Carver et al., 1994; DeValck & Vinck, 1996; and Miller et al., 1996); on finding that all outcomes loaded onto just one factor, composite scores were created. Given that sample sizes for these studies did not rise above 75 participants, it is not surprising that the results loaded in this way; factor analysis was simply not suitable for these small sample sizes and their use of the composite outcome measure is questionable. Carver et al. (1994) based their composite scores on highly correlated variables.

The remainder (Andrykowski & Brady, 1994; Carver et al., 2000; Stanton et al., 2000; Hassanein et al., 2001; Green et al., 2002; and, Hassanein et al., 2005) are to be treated with greatest caution, as within their respective publications, they did not clearly specify the justification for, and/or method by which composite scores were obtained.

# 2.7.3 Synthesis of results

A descriptive overview of data related to clinical and demographic variables will be presented first, followed by the results of statistical meta-analysis and indepth discussion of findings related to the importance of the predictor variables for each outcome included. Possible moderation or mediation effects presented within the included studies are also reviewed.

# 2.7.3.1 Prevalence and stability: Predictor Variables

Cohen et al. (2001) reported that greater than 80% of their sample were optimistic about the effects of treatment on their illness in spite of the fact that they had all received diagnoses of metastatic cancer. Lowery et al. (1993) reported that only 45% of their participants claimed to feel somewhat or high internal control over their illness; 56% reported that other people had highest control over their illness. Control beliefs (Osoweicki & Compas 1999) and optimism (Miller et al., 1996) were both stable over time (in longitudinal studies) supporting trait theories of these constructs.

Emotional expression was significantly higher in breast cancer patients compared to RCT control groups (Badger et al., 2004). Morris et al. (1981) report that control participants (benign breast problems) were less neurotic and less able to control anger expression (CECS-Anger) than breast cancer patients. Bleiker et al. (2000) state that only 15% and 20% of their sample were above the clinical cutoffs for thought avoidance and intrusion respectively, and that although these caseness figures decreased with time, one fifth of patients were still suffering from clinical levels of intrusive thought at two years post diagnosis. Green et al. (2002) reported significant decreases in threat appraisals beyond the initial period of diagnosis. According to Koopman et al. (2001), 70% reported high levels of perceived stress.

## 2.7.3.2 Prevalence and stability: Outcome variables

Anxiety was significantly higher in patients than controls in studies by both Aarstad et al. (2005: control participants were benign or treated tumours) and Ahmed et al. (2004). However, only the former found a significant difference for depression. This is not surprising given that matched family members formed the control group in the latter study. Reported anxiety caseness ranged from 10%

(Ratcliffe et al., 1995) to 41% (Glinder & Compass, 1999). Cross-sectionally, mean rates of anxiety yielded caseness of 29.8% at baseline, 19.3% at around three months post diagnosis, 21% at six months post diagnosis, 16.7% at 12 months, and 16% at two years post diagnosis, possibly implying an overall trend of decreased anxiety over time. However, some between site differences should be noted. Diagnosis anxiety was reported to be much lower in non-breast cancer samples (comparisons possible only at time shortly after diagnosis and one year follow up). It is unclear whether differences are, therefore, related to clinical or gender variation. Although the differing clinical characteristics must not be ruled out, a gender difference in anxious responses to stress (higher in females) has been repeatedly demonstrated in the literature.

A similar trend is also observed for depression above the clinical cut-off. Greatest differences were reported at the time of diagnosis, where they ranged from 2% (Ratclife et al., 1995) to 34% (Epping-Jordan et al., 1999; Glinder & Compass, 1999). Taking a mean across these studies, 25% were potentially within the clinical range. However, once again, there were vast site differences; studies of breast and gastrointestinal cancer patients report equivalently high rates (<30%), however, lymphoma patients scoring much lower (the earlier reported 2% figure). Nordin and Glimelius's (1998) sample of gastric cancer patients had a relatively even gender split, therefore the between cancer site difference here cannot be accounted for by gender; rather, it seems that depression reactions are, at least in part, dependant on the site of cancer diagnosis made. Cross sectional mean depression levels differed by only 6% between diagnosis and two years follow up time points. Interestingly, in studies of breast cancer patients, an increase in caseness of depression at six months was reported.

Two studies reported percentage risk of developing a psychiatric disorder at or above clinical cut-off levels, rather than focusing specifically on levels of anxiety or depression as individual outcome constructs (Lloyd et al., 1984; Gallagher et al., 2002). In these longitudinal studies, diagnosis risk was reported at 37% (Lloyd et al., 1984: mixed recruitment) to 43% (Gallagher et al., 2002: breast patients), decreasing to 26-27%, six months later. An interesting note here, is that although breast cancer patients were at significantly worse risk at diagnosis, by six months, this was not distinguishable from the mixed cancer sample.

Considering longitudinal studies only, anxiety and depression were more stable than implied by analysing cross sectional time differences (Bleiker *et al.* 1995, Nordin & Glimelius, 1998; Brown *et al.*, 2000; Butow *et al.*, 1999). Quality of life, on the other hand, was found to fluctuate more (Yu *et al.*, 2003; Hee *et al.*, 2005), but with a general trend towards improvement (Schou *et al.* 2004, 2005).

Alhama et.al. (1995) reported that during treatment, 50% of patients sampled reported dissatisfaction with their quality of life. Strangely, however, Kessler (2002) found that patients reported better quality of life than they perceived for the general population. Both Hee et al. (2005) and Schou et al. (2004/05) reported significant decreases in well-being over time.

### 2.7.4 The effect of demographic and clinical differences

Due to inherent difference in the aims and hypotheses being tested in individual papers, not all studies presented findings relevant to this section. Those that did, are summarised in table 2.5. Age is by far the most commonly explored demographic variable, however, interesting trends are highlighted for other demographic and clinical sample characteristics. Meta-analysis was not conducted on this data as this was not the primary focus of this review. As such exact effect sizes are not reported the data are presented simply to help contextualise the later findings and to provide an overview of the samples recruited into the included papers.

Table 2.5. Significance of reported associations between demographics, clinical data, and predictor variables.

Predictor	Finding Reported				
Age	Significant	Non-Significant			
Optimism	Schou et al. (2004)	Perczek et al. (2000)			
Self-efficacy	Ranchor et al. (2002)				
Lie Score	Ratcliffe et al. (1995)				
Neuroticism	Morris et al. (1981)				
	Ranchor et al. (2002)				
Thought intrusion	Carver et al. (1993)	Bleiker <i>et al.</i> (2000)			
· ·	Osoweicki & Compass (1998)	(2222)			
	Epping-Jordan et al. (1999)				
Thought avoidance	Bleiker et al. (2000)	Osoweicki & Compas (1998)			
_	Baider et al. (2003)	Epping-Jordan et al. (1999)			
Treatment Expectancy	Marks et al. (1986)				
Locus of control	Marks et al. (1986)				
Норе	Stanton et al. (2000)	Morris <i>et al.</i> (1981)			
Mental Adjustment	Baider <i>et al.</i> (2003)				
Gender	•				
Neuroticism	Ranchor et al. (2002)				
Self-efficacy	Ranchol et al. (2002)	Ranchor et al. (2002)			
Self-ellicacy		Ranchol et al. (2002)			
Family Support					
Optimism	Schou <i>et al.</i> (2004)				
Educational Status					
Optimism	Epping-Jordan et al. (1999)				
•	Schou et al. (2004)				
Thought avoidance	Epping-Jordan et al. (1999)				
Self-efficacy	Ranchor et al. (2002)				
Neuroticism		Ranchor et al. (2002)			
Socio-Economic Status					
Locus of Control	Marks <i>et al.</i> (1986)				
Illness Perceptions	Marks et al. (1986)				
imess refceptions	Marks et al. (1700)				
Disease severity					
Though intrusions	Carver et al. (1994)				
Negative affect	Kessler (2002)				
Time since diagnosis					
Thought intrusion	Lowery <i>et al.</i> (1993)				
Thought avoidance	Lowery et al. (1993)				
Locus of control	Lewis (1982/1989)				
Positive affect	Kessler (2002)				
Self-esteem		Lewis (1982/1989)			
Purpose in life		Lewis (1982/1989)			

Faller et al. (1999) and Perczek et al. (2000) reported that age had no significant impact on any psychosocial variables measured. However, other studies report that younger patients were more self-efficacious, more optimistic, and scored lower on Eysenck lie-scores. Three papers reported that younger patients were significantly more likely to experience intrusive thoughts although one paper reported non-significance of effect. Whilst two also found that younger patients were significantly more likely to report though avoidance, two did not support such hypotheses. Older patients were significantly more likely to have negative treatment expectancies and higher beliefs in chance locus of control. Contradictory findings were reported for associations between age and hope. Measured on the MAC, Baider et al.'s (2003) Austrian sample showed positive associations between age and higher fighting spirit, but also, contradictorily, increased hopelessness/helplessness and fatalistic acceptance. These findings were not replicated in the Israeli comparison sample.

Gender comparisons were far more infrequently reported, presumably due to the dominance in the field of single-sex recruitment frameworks; only the Ranchor *et al.* (2002) paper presented relevant statistics. Family support (being married or having children) was found to be associated with higher levels of optimism.

Higher educational status was associated with optimism, thought avoidance and self-efficacy, but not neuroticism. No specific associations were reported for employment status although socio-economic status was negatively associated with change and doctor locus of control, and increased perceptions of illness severity.

From a clinical perspective, disease severity and time since diagnosis were found to be associated with a range of variables including affect, thought intrusion, thought avoidance, and increased personal control beliefs. Where lower selfesteem and lower purpose in life perceptions were also found to be correlated with time since diagnosis, neither reached significance.

**Table 2.6.** Significance of reported associations between demographics, clinical data and **outcome** variables.

Outcome	Finding Reported				
	Significant	Non-Significant			
Age					
Depression	Lehto <i>et al.</i> (2005) Baider <i>et al.</i> (2003)	Faller <i>et al.</i> (1991) Rondorf-Klym & Colling (2003)			
Anxiety	Baider <i>et al.</i> (2003)	Morris et al. (1981)			
Distress	Osoweicki & Compas (1998) Stanton et al. (2000) Carver et al. (1993) Epping-Jordan et al. (1999) Padilla et al. (1992) Miller et al. (1996)	Andrykowski <i>et al.</i> (1996) Glinder & Compas (1999) Osoweicki & Compas (1999)			
Clinical risk		Gallagher et al. (2002)			
Functional impairment	Hassanein <i>et al.</i> (2001) Rondorf-Klym & Colling (2003)				
Quality of Life	Schou <i>et al.</i> (2005)	Alhama <i>et al.</i> (1996) Schnoll <i>et al.</i> (2002) Lehto <i>et al.</i> (2005)			
Well-being	Padilla <i>et al.</i> (1992) Carver <i>et al.</i> (1994) Miller <i>et al.</i> (1996)				
Gender					
Distress	Lehto <i>et al.</i> (2005) Ranchor <i>et al.</i> (2002)	Osoweicki & Compas (1998)			
Functional impairment Quality of Life	Hassanein et al. (2001)	Lehto <i>et al.</i> (2005)			
Marital Status Quality of Life	Schnoll et al. (2002)				
Educational Status Distress		Andrykowski & Brady			
Quality of Life	Glinder & Compas (1999)	(1994) Padilla et al. (1992) Alhama et al. (1996) Osoweicki & Compas (1998) Osoweicki & Compas (1999) Schnoll et al. (2002)			
Income					
Satisfaction with QoL	Alhama <i>et al.</i> (1996) Schnoll <i>et al.</i> (2002) Yu <i>et al.</i> (2003)				
Employment status Distress	Padilla <i>et al.</i> (1992)				

**Table 2.6.** Significance of reported associations between demographics, clinical data and outcome variables (continued).

Outcome	Findi	ng Reported
	Significant	Non-Significant
Cancer Site		
Quality of Life		Brown <i>et al.</i> (2000)
Sexual Adjustment	Schnoll <i>et al.</i> (2002)	0.11.1.1.1.00000
Clinical Risk Satisfaction with QoL		Gallagher <i>et al.</i> (2002)
Disease Severity	Significant	Non-Significant
Clinical Risk	Gallagher et al. (2002)	G
Distress	Trunzo & Pinto (2003)	Faller <i>et al.</i> (1999) Glinder & Compas (1998)
		Osoweicki & Compas (1998)
Depression		Timko <i>et al.</i> (1985)
Quality of Life	Padilla <i>et al</i> . (1992) Yu <i>et al</i> . (2003)	Hee <i>et al.</i> (2005)
Time since diagnosis		
Distress	Lowery <i>et al.</i> (1993)	Andrykowski & Brady (1984)
Anxiety	Lewis (1982/89)	•
Quality of Life	Kessler (2002)	Schnoll et al. (2002)
	Hee et al. (2002)	
	Green <i>et al.</i> (2002)	
Treatment		
Di <b>s</b> tress	Carver <i>et al</i> . (1993)	
	Hee et al. (2002)	
Quality of Life	Schou et al. (2004)	
	Nakada <i>et al.</i> (1996)	
	Padilla <i>et al.</i> (1992)	

The effects on outcome were far less consistent. Whilst there is general consensus that outcomes are worse in younger patients (with the exception of the Schou et al. (2005) study) these effects are not always significant. Some gender differences were reported which seem to indicate that female patients report not only greater distress, but also more functional impairment. In the Ranchor et al (2002) study, such effects were consistently significant over time. Those patients who were married were also found to report better quality of life.

Whilst educational status was largely non-significantly associated with outcome, both employment, and higher family income were significantly

associated with lower distress and greater satisfaction with current levels of quality of life respectively.

Differences in both sexual adjustment and satisfaction with quality of life were found between patients with illness at different sites (prostate cancer patients were better sexually adjusted than breast cancer patients but breast cancer patients were more quality of life satisfied than colorectal cancer patients). Quality of life was not found to significantly differ between cancer site, nor was clinical psychiatric disorder risk. This latter variable was, however, higher in those with more advanced illness. Disease severity was further associated with poorer quality of life (in two of three studies), and higher follow-up level (Trunzo & Pinto, 2003) but not concurrent baseline levels of distress. Associations between time since diagnosis and distress are contradictory in terms of significance but in both studies, longer time was associated with decreased distress. Associations between time since diagnosis and quality of life are inconsistent, not only in terms of significance, but also direction of effect; where Kessler (2002) and Hee et al. (2002) found that longer time since diagnosis associated with better quality of life, Green et al. (2002) found the opposite direction of effect. Few studies reported the effects of treatment differences on these outcomes, but those that did reported significant effects. The evidence in this review suggests that multiple types of treatment, particularly if they involve chemotherapy lead generally to poorer outcome.

#### 2.7.5 Meta Analysis

#### **2.7.5.1** Associations between predictors and outcomes

Having discussed the type of study included in this review and some of the background demographic and clinical patterns in results, attention will now be focussed on discussion of associations between the predictor variables—personality, cognitions, and emotions—and the outcome variables—anxiety, depression, and quality of life. Two types of results will be discussed. First, the results of the statistical meta-analysis are presented; far fewer analyses were possible than were expected and so these findings should be treated with caution. Second, an in-depth descriptive analysis is presented which not only describes

those findings included in the meta-analysis, but also the significance and effects of those that were not included.

# 2.7.5.2 Potential for meta-analysis.

Large scale meta analysis of the predictors for anxiety, depression, and quality of life was not possible. At first thought to be feasible (despite a vast number of different measures being used, a large overlap in underlying constructs was measured between studies), during data extraction and synthesis, the extent of study heterogeneity became apparent and three primary barriers to large-scale meta-analysis were identified: measurement, recruitment and statistics.

It is important that high levels of homogeneity in measurement and samples exist between studies to be meta-analysed; they must claim to measure the same construct using comparable measures, and only data from similar time-points can be meta-analysed between studies. Such requirements were met by very few studies within this review.

Similarly, meta-analysis should only be performed on similar statistical information, for example, meta-analysis should not be performed on both correlation and comparative tests. Additionally, r values in correlations cannot be meta-analysed together with regression effect sizes; regressions can be separately 'meta-regressed', but such procedures were not possible in this review as different variables were entered into analysis between various studies. For this reason, meta-analysis focussed on correlation data only.

Despite this focussed approach, a larger problem existed: data were not presented in all cases where it was expected. Not all studies measuring the same predictor-outcome constructs presented usable information. The most likely reason for this is related to the high number of differing research questions and hypotheses being set; studies accrued masses of data that were not particularly relevant to individual research questions, therefore the data were not analysed. An alternative explanation could be that analyses were conducted, but on the finding of null results, the analyses were not published: the 'file drawer' problem, a common issue in systematic reviewing (Egger et al., 2001).

Inadequate reporting of statistics ruled a number of other studies out of statistical meta-analysis. Three studies reported ranges of effect sizes (Hee et al., 2005; Schou et al., 2004, 2005; Osoweicki et al., 1998, 1999); Osoweicki and

Compas (1998, 1999) converted raw scores into normalised t-scores and presented correlations using only these, and not raw data; and, three studies (Allison *et al.*, 2000; Iwamitsu *et al.*, 2005; and Schou *et al.*, 2004/05) converted raw scores into median split, bivariate scales, thus preventing the use of correlation statistics.

Furthermore, the number of studies which presented data in comparison to control groups, rather than inter-correlating variables within the cancer sample (e.g. Aarstad et al., 2005; Ahmed et al., 2004; Bleiker, van der Ploeg, & Ader, 1995; and Yamaoka et al. 1998), or which used the variables of interest to this review for the purposes of mediation testing (e.g. Baider et al. 2003) rather than looking at direct associations, further minimised the amount of data that was available for meta-analysis. This should not be read to detract from the importance of such research questions, but their unsuitability for the current purposes.

A number of small-scale meta-analyses were possible, each comprised of two or three studies. These analyses were, as planned, calculated using Hunter and Schmidt's method. Due to the small number of studies in each analysis, only basic level statistical techniques were performed. As discussed in section 2.2.3, although weighted mean effect size calculations, and calculations based on estimations of variance from this statistic (e.g. z-scores and their conversion into a probability statistic) are feasible, those procedures which involve estimation of population variance (e.g. calculation of between study homogeneity of variance and confidence intervals for the mean effect size) are prone to error and were, therefore, concluded to be inappropriate. Additionally, calculation of fail safe 'n' statistics was deemed to be unnecessary given the low number of studies entered into each meta-analysis.

#### **2.7.5.3** Meta-analysis procedure.

Meta-analyses were conducted using Field's guidance (2001) whereby formulae were programmed into Microsoft Excel. A random sample of calculations were further checked using hand calculation (see appendix 2.4 for a breakdown of the formulae used, and an example of the hand calculation corroboration exercise). To further protect against human error in either the programming or interpretation of these results, the meta-analyses were audited by an independent statistician.

In order to calculate *p*-values, a modulus of each *z*-score was taken. MiniTab statistical software was then used to provide observed significance levels according to normal curve distributions. The values were then doubled to account for significance according to the more stringent two-tailed hypothesis test procedures.

# 2.7.5.4 Meta-analysis results

Results of the meta-analyses are shown in table 2.7, and will be discussed at relevant sections of the following data synthesis. Of the 21 meta-analyses calculated, all were significant at the  $p \le 0.05$  (or greater) alpha level, except for the analysis of Emotional Anxiety and Depression; a p-value of .054 was obtained which lies just outside of the standard alpha boundary. The lack of significance is probably best explained by the variance amongst the effect sizes which were being meta-analysed (n=356, r=.07; n=32, r=.31).

Two notes of caution must be made. First, due to the high number of tests conducted, a Bonferroni adjustment is often employed to correct for inflation of the alpha ( $\alpha$ ) level (Field, 2005). Such adjustment essentially involves considering  $\alpha$  at a much higher or more precise level. There is an argument against using Bonferonni adjustment (see Pergner, 1998, for example) as the chance of committing a Type II error increases instead, however, in this case it was simply not necessary; most meta-analyses were significant at p<.001 and so even with Bonferonni correction the overall pattern of results did not change. Furthermore, as has previously been noted (see section 2.2.2), the Hunter and Schmidt method has a poor ability to distinguish between true significance and null results anyway and so the primary focus should instead be on the magnitude of effect sizes

Effect size confidence intervals were not calculated as none of the current methods of meta-analysis are accurate in estimating these where the number of studies in the analysis is small.

Table 2.7. Study effect sizes and meta-analysis statistics for each meta-analysis calculated.

	n	r	<u>_</u>	SD,	$SE_{\bar{r}}$	z	p
1) Self-Efficacy & Distre Ranchor, 2002 Green, 2002	ess 167 65	33 01	240	.144	.102	-2.365	.018
2) Optimism & Distress Carver, 2003 Epping-Jordan, 1999 Miller, 1996	54 80 75	56 50 53	526	.021	.014	-38.413	<.001
3) Optimism & Well-Bei Miller, 1996 Carver, 1993	ing 75 54	.69 .53	.623	.079	.056	11.163	<.001
4) Anxious Preoccupati Watson, 1991 Nordin, 1998	on & An 356 139	.60 .67	.620	.031	.022	27.857	<.001
5) Hopelessness/Helple Watson, 1991 Nordin, 1998	ssness & 356 139	Anxiety .44 .55	.471	.049	.035	13.471	<.001
6) Fatalism & Anxiety. Watson, 1991 Nordin, 1998	356 139	.23 .16	.210	.031	.022	9.456	<.001
7) Fighting Spirit & And Watson, 1991 Nordin, 1998	356 139	17 39	232	.099	.070	-3.315	<.001
8) Control of Emotional Watson, 1991 Grassi, 1988	356 32	.04 01	.036	.014	.010	3.689	<.001
9) Control of Emotional Watson, 1991 Grassi, 1988	356 32	.13 .11	.132	.006	.004	33.840	<.001
10) Control of Emotion Watson, 1991 Grassi, 1988	356 32	.11 .15	.113	.011	.008	14.562	<.001
11) Anxious Preoccupa Watson, 1991 Nordin, 1998	356 139	.43 .57	.469	.063	.044	10.549	<.001
12) Hopelessness/Helph Watson, 1991 Nordin, 1998	356 139	& Depre .40 .67	ssion .476	.121	.086	5.546	<.001
13) Fatalism & Depress Watson, 1991 Nordin, 1998	356 139	.22 .24	.226	.009	.006	35.500	<.001
14) Fighting Spirit & Do Watson, 1991 Nordin, 1998	epressio 356 139	n 29 53	357	.108	.076	-4.686	.006

**Table 2.7.** Study effect sizes and meta-analysis statistics for each meta-analysis calculated (continued).

	<u>n</u>	<u>r</u>	<u>r</u>	SD,	$SE_{\bar{r}}$	Z	p
15) Control of Emotion	al Angei	. & Depre	ession				
Watson, 1991	356	.09		020	024	2 502	. 001
Grassi, 1988	32	02	.081	.030	.021	3.782	<.001
16) Control of Emotion	al Anxie	ty & Dep	ression				
Watson, 1991	356	.07		044	0.47	1 022	054
Grassi, 1988	32	.31	.090	.066	.047	1.923	.054
17) Control of Emotion	al Depre	ession &	Depression	1			
Watson, 1991	356	.12	•		200	2.500	. 001
Grassi, 1988	32	.32	.136	.055	.390	3.509	<.001
18) Though Intrusion &	& Distres	S					
Baider, 1999§	324	.29					
Epping-Jordan, 1999	80	.46	.350	.092	.053	6.600	<.001
Osoweicki, 1999	62	.52					
19) Thought Avoidance	e & Distr	ess					
Baider, 1999§	324	.43					
Epping-Jordan, 1999	80	.20	.402	.097	.056	7.190	<.001
Osoweicki, 1999	62	.52					
20) Total Self-Blame &	Distress	5					
Glinder, 1999	64	.33	.314	.015	.011	29.670	<.001
Malcarne, 1995	72	.30	.514	.015	.011	27.070	<b>\.001</b>
21) Fatlism & Total Qu	ality of l	Life					
Nordin, 1998	139	14	194	.050	.035	-5.515	<.001
Schou, 2005	165	24	7,137	.030		-3.313	

n = Sample Size; r = Effect Size;  $\bar{r}$  = Weighted Mean Effect Size [MES];  $SD_r$  =

Standard deviation of the mean;  $SE_{\tilde{r}}$  = Standard error of the MES; z = Z-Score; p = 2-tailed significance statistic.

A full discussion of the results of these meta-analyses will be integrated with the narrative data synthesis that follows.

# 2.7.5.5 Associations between personality and outcome

Although personality has received a lot of research attention in psychosocial oncology, it was surprising how few studies matched all criteria for inclusion in this review. The findings from those that did are synthesised in table 2.8.

Both higher levels of optimism and self-esteem were found to significantly correlate with lower levels of anxiety; in the case of the Schou *et al.* (2004) paper, a number of these medium effect sizes remained at follow-up. However, the

<sup>§</sup>Overall effect sizes were not published, but a weighted mean effect size was calculated (and total sample size summated) from the sub-group effect sizes reported.

remaining results reported very low, and non-significant effect sizes. Meta-analysis of the two studies reporting correlations between Eysenck Lie Score and anxiety was not possible due to time of self-report; Morris et al. (1981) report pre-diagnosis correlations whilst Ratcliffe et al. (1995) report post-diagnosis correlations. This methodological difference may go some way to explaining the conflicting direction of effect, but this finding should not be heavily weighted due to the small effect sizes reported.

Effect sizes for correlations with depression tended to be higher than those reported for anxiety and most were reported to be significant; depression correlated with low self-esteem, low optimism, lower self-reported humour, and higher agency (defined by Aarstad et al. (2005) as an exclusive self-focus). Unlike for anxiety, lie scores were not strongly associated. Meta-analysis of the two corroborating findings for self-esteem was not possible due to differences in when self-reports were made; nine-month as opposed to 12-24 months post diagnosis.

Seven studies reported relevant results on associations between personality and distress. Scores of the monitoring personality style (those individuals who are constantly attending to stress and threat; Morrison & Bennett, 2006) were not associated with distress. However, neuroticism scores were associated with distress across both a range of diagnoses and timepoint. Conflicting results were found for both the effects of optimism and self-efficacy. In all cases, higher scores were associated with lower levels of distress, but effect sizes were much greater for optimism. Even though correlations between optimism and distress were reported over a number of time-points (and, indeed remained, even when earlier levels were statistically controlled for), only baseline scores from each study could be meta-analysed (meta-analysis 1). The overall results indicate a highly significant (p<.001), large effect size ( $\bar{r}$  =-.53). A smaller, but still significant overall effect size for self-efficacy (meta-analysis 2) was found;  $\bar{r}$  =-.24, p<.05.

Table 2.8. Summary of reported associations between personality and psychosocial outcome.

	Finding Reported						
	Significan	t	Non-Significant				
Inxiety							
Optimism	Schou <i>et al.</i> (2004)	r=36 to .43					
Extroversion			Morris <i>et al.</i> (1981)	r=07			
Lie Score			Morris <i>et al.</i> (1981)	r=.10			
			Ratcliffe et al. (1995)	<i>r</i> =01			
Neuroticism		77	Morris <i>et al.</i> (1981)	<i>r</i> =07			
Psychoticism			Morris <i>et al.</i> (1981)	<i>r</i> =.10			
Trait anxiety			Morris <i>et al.</i> (1981)	r=03			
Self-esteem	Lewis (1982 / 89)	r=30					
epression							
Lie Score			Ratcliffe et al. (1995)	r=03			
Self-esteem	Rondorf-Klym & Colling (2003)	r=55					
	Timko & Janoff-Bulman (1985)	r=41					
Agency	Helgeson & Lepore (2004)	r=.49					
Optimism	Schou <i>et al.</i> (2004)	r=41 to .51					
Humour	Aarstad et al. (2005)	r=.54					
Distress							
Monitors			Epping-Jordan et al. (2006)	r=.15 to 17			
Optimism*	Carver <i>et al.</i> (1993)	r=56 to62	Yu et al. (2003)	r=4			
	Miller <i>et al</i> . (1996)	<i>r</i> =50 to61					
	Epping-Jordan et al. (1999)	<i>r</i> =40 to55					
Neuroticism	Ranchor <i>et al.</i> (2002)	r=27 to33					
Self-efficacy*	Ranchor et al. (2002)	r=24 to33	Green <i>et al.</i> (2002)	<i>r</i> =01 to11			
Clinical Risk							
Neuroticism	Lloyd <i>et al.</i> (1984)	r=.49					

Table 2.8. Summary of reported associations between personality and psychosocial outcome (continued).

		Finding Reported			
	Significa	ınt	Non-Significant		
General Quality of Life					
Optimism	Schou <i>et al</i> . (2005)	r=.29  to  .43			
Self-esteem	Rondorf-Klym et al. (2003)	r=.67			
Humour	Aarstad <i>et al.</i> (2005)	r=44			
Extroversion	Yamaoka <i>et al</i> . (2003)	r=26 to29			
Neuroticism	Yamaoka <i>et al.</i> (2003)	r=13 to24			
Psychoticism	Yamaoka <i>et al.</i> (2003)	<i>r</i> =.18 to .27			
Physical aspects of Quality of	of Life				
Optimism	Schou et al. (2005)	r=.14  to  .21			
Agency	Helgeson & Lepore (2004)	r=.02 to .07			
Self-efficacy	Green et al. (2002)	r=(+/-).09 to .05			
Mastery	Padilla et al. (1992)	r=.46			
Psycholosocial aspects of Qu	uality of Life				
Optimism	Schnoll <i>et al.</i> (2002)	r=.49			
•	Schou <i>et al.</i> (2005)	r=.29 to .55			
Mastery	Padilla et al. (1992)	r=.48			
Agency	Helgeson & Lepore (2004)	r=.14			
Self-efficacy			Green <i>et al.</i> (2002)	<i>r</i> =.00 to .21	
Humour	Aarstad <i>et al</i> . (2005)	r=44			
Well-being					
Various traits ***	Evans <i>et al.</i> (1993)	r=.32  to  .52	Evans <i>et al.</i> (1993)	r=.09 to .27	
Optimism*	Carver et al. (1993)	r=.11 to .72			
•	Miller <i>et al.</i> (1996)	r=.58 to $.73$			

Findings were also meta-analysed: see table 2.7
 Range of correlations presented for different longitudinal comparisons
 Various range of personality characteristics reported, not congruous with standard trait types; some results were significant, others were not.

Just one study reported correlation between personality and risk scores for psychiatric disorder; the high effect size reported by Lloyd *et al.* (1984) indicates a significant association between higher levels of neuroticism and increased scores of clinical risk.

Quality of life and a measure of personality were concurrently measured in 14 studies. On the whole, associations were significant, although they range in effect size from the relatively small (agency: Helgeson & Lepore (2004), r=.14) to the considerably large (self-esteem: Rondorf-Klym  $et\ al.$ (2003), r=.67). Comparison of associations between predictors and both general and sub-scales of quality of life demonstrate consistency of effect; that higher qualify of life was associated higher self-esteem, extroversion, self-efficacy, agency, mastery, optimism and lower scores of neuroticism. A few inconsistent findings should be noted. First, psychoticism and quality of life appear to be positively correlated; second, that humour and quality of life were negatively correlated; and finally, that self efficacy correlated significantly with physical quality of life, but non-significantly with psychological quality of life, despite both results achieving only small effect sizes. Due to the unexpected direction of these effects, findings should be treated with caution until empirical replication and explanation become available.

Meta-analysis of optimism and well-being correlations (meta-analysis 3) yielded the highest of all mean effect sizes ( $\bar{r}$  =.62, p<.001); these two studies also present data longitudinally, and although this could not be meta-analysed, it is clear that higher optimism is strongly and consistently correlated with well-being. Evans et al. (1993) explored correlations across a range of personality variables on the PRF; results indicated a range of effect sizes, only some of which were significant.

# 2.7.5.6 Associations between cognitions, emotions and outcome

Many more correlations were reported between cognition or emotion variables and outcomes than were for personality variables. Not surprisingly perhaps, there was also far more inconsistency in the direction and effect sizes of these findings. Table 2.9 presents all relevant information extracted from the included papers.

Anxiety was very strongly correlated with both thought intrusion and thought avoidance; confrontative attitudes towards illness also correlated at equally high effect sizes, but a self report perception of purpose in life correlated far more weakly, albeit still significantly. Where Naus et al. (2005) found associations between locus of control and anxiety to be both weak and non-significant, Lewis (1982 / 89) presents inconsistent findings; using a pre-validated measure, significant medium effect sizes were reported, but using a single item control measure, non-significance was once again reported.

Two studies reported on associations between MAC components and anxiety; large differences in effect sizes were reported, but the majority were significant. Exceptions included associations with fatalism, where small effects sizes were found to be contradictory but significant, and fighting spirit, where an additional study (Hassanein *et al.*, 2005), reported a non-significant result. This latter study did, however, assess this correlation at a much later timepoint. Meta-analysis of each MAC component revealed significant effects; anxiety associated with higher anxious preoccupation (meta-analysis 4  $\bar{r}$ =.62), higher hopeless/helplessness (meta-analysis 5  $\bar{r}$ =.47), higher fatalism (meta-analysis 6  $\bar{r}$ =.21) and lower fighting spirit (meta-analysis 7  $\bar{r}$ =-.23). Nordin *et al.*'s (2005) follow-up analysis reported that where both fighting spirit and fatalism tended to decrease over time, the remaining two MAC scales remained stable throughout treatment and recovery.

Table 2.9. Associations between cognitions, emotions and psychosocial outcome.

		Finding Reported					
	Significa	ant	Non-Significant				
nxiety							
Thought intrusion	Nordin & Glimeius (1998)	<i>r</i> =.75					
Thought avoidance	Nordin & Glimeius (1998)	<i>r</i> =.56					
Locus of Control	Lewis (1982/89)	r=3	Naus et al. (2005)	r=.02 to .11			
Confrontative attitude	Nordin & Glimeius (1998)	r=71					
Purpose in Life	Lewis (1982 / 89)	<i>r</i> =3					
MAC: Anxious	Nordin & Glimeius (1998)	<i>r</i> =.67		TO THE CONTRACT OF THE CONTRAC			
Preoccupation*	Watson <i>et al.</i> (1991)	<i>r</i> =.6					
MAC: Fatalism*	Watson et al. (1991)	<i>r</i> =.16	Nordin & Glimeius (1998)	r=.23			
MAC: Fighting spirit*	Nordin & Glimeius (1998)	<i>r</i> =39	Hassanein <i>et al.</i> (2005)	r=14			
	Watson et al. (1991)	r=17	•				
MAC:	Nordin & Glimeius (1998)	<i>r</i> =.55					
Hopeless/helplessness*	Watson et al. (1991)	r=.44					
Negative affect	Longman <i>et al.</i> (1999)	r=.34 to .46					
Positive affect	Longman <i>et al.</i> (1999)	<i>r</i> =05					
Anger expression			Morris et al. (1981)	r=.02			
CECS: Anxiety*	Watson <i>et al.</i> (1991)	r=.13	Grassi <i>et al.</i> (1988)	r= (+/-).02 to .15			
CECS: Anger*	Watson et al. (1991)	r=.4	Grassi <i>et al.</i> (1988)	r=1 to37			
CECS: Depression*	Watson et al. (1991)	r=.11	Grassi <i>et al.</i> (1988)	r= (+/-).15 to .45			
epression							
Thought intrusion	Nordin & Glimeius (1998)	r=.60					
	Bleiker et al. (2000)	r=.32					
Thought avoidance	Nordin & Glimeius (1998)	r=.53	Bleiker <i>et al.</i> (2000)	r=.19			
Locus of Control			Rondorf-Klym & Colling (2004)	r=18			
			Naus <i>et al.</i> (2005)	r=.01  to  .17			
			Marks et al. (1986)	r = (+/-).05  to.09			

Table 2.9. Associations between cognitions, emotions and psychosocial outcome (continued).

		rinaing kep	Finding Reported			
	Significan	<u>t</u>	Non-Significant			
Pepression (cont.)						
Perceived Severity	Rondorf-Klym & Colling (2004) Marks et al. (1986)	r=.38 r=.38				
Treatment expectancy		The second secon	Marks et al. (1986)	<i>r</i> = ·.05		
Confrontative attitude	Nordin & Glimeius (1998)	<i>r</i> =67				
Self-Blame	Timko & Janof-Bulman (1985)	r= (+/-) .05 to .30				
MAC: Anxious	Nordin & Glimeius (1998)	r=.57				
preoccupation*	Watson <i>et al.</i> (1991)	r=.43				
MAC: Fatalism*	Watson et al. (1991)	r=.22	Nordin & Glimeius (1998)	r=.24		
MAC: Fighting spirit*	Nordin & Glimeius (1998)	<i>r</i> =53				
	Watson et al. (1991)	r=29				
	Hassanein et al. (2005)	r=27				
MAC:	Nordin & Glimeius (1998)	r=.67				
Hopeless/helplessness*	Watson et al. (1991)	r=.40				
<b>Emotional Expression</b>	Faller <i>et al.</i> (1991)	<i>r</i> =.55				
Negative affect	Timko & Janoff-Bulman (1985)	r=.62				
	Longman (1999)	r=.38				
CECS: Anxiety*	Watson et al. (1991)	r=.07	Grassi et al. (1988)	r=.04 to .31		
CECS: Anger*	Watson et al. (1991)	r=.09	Grassi et al. (1988)	r = (+/-).10  to  .42		
CECS: Depression*	Watson et al. (1991)	<i>r</i> =.12	Grassi et al. (1988)	r= (+/-) .02 to .66		
Distress						
Thought intrusion	Baider <i>et al.</i> (2003)	<i>r</i> =.09 to .58				
	Osoweicki & Compass (1998)	r=.46				
	Epping-Jordan et al. (1999)	r=.48 to .70				
Thought avoidance	Baider <i>et al.</i> (2003)	<i>r</i> = .07 to .48	Epping-Jordan et al. (1999)	r=.20  to  .23		
	Osoweicki & Compass (1998)	<i>r</i> =.52				

Table 2.9. Associations between cognitions, emotions and psychosocial outcome (continued).

		Finding R	Reported		
	Significan	t	Non-Significant		
Distress (cont.)	• <del></del>				
Locus of Control			Osoweicki & Compas (1999) Andrykowski <i>et al.</i> (1994)	r=07 to .08 r=.04 to .22	
Threat appraisals	Green <i>et al</i> . (2003)	r=.52 to .67			
Perceived Severity		The second secon	Andrykowski et al. (1994)	<i>r</i> =.19	
Self-blame	Glinder & Compass (1999)	r=.26 to .53	Malcarne et al. (1995)	<i>r</i> =.30 to .33	
MAC: Anxious preoccupation	Baider <i>et al.</i> (2003)	r=.1 to .46			
MAC: Fatalism	Baider <i>et al.</i> (2003)	<i>r</i> =.15 to .27			
MAC:	Baider et al. (2003)	r=.13 to .64			
Hopeless/helplessness					
MAC: Fighting spirit			Baider <i>et al.</i> (2003)	r = (+/-).01  to  .25	
Clinical Risk					
Threat appraisal	Gallagher <i>et al</i> . (2002)	r=38			
Confidence in support	Gallagher <i>et al.</i> (2002)	r=27			
Health care confidence General Quality of Life			Gallagher et al. (2002)	<i>r</i> =.08	
Thought intrusion	Nordin & Glimelius (1998)	r=33			
Thought avoidance	Nordin & Glimelius (1998)	r=33			
Locus of Control	Rondoft-Klym & Colling (2005)	r=.21	DeValck & Vink (1996)	r=(+/-).12  to  .34	
Minimisation	Butow et al. (1999)	r=.47			
Treatment perceptions	Butow et al. (1999)	r=.15			
Confrontational attitude	Nordin & Glimelius (1998)	r=.36			
MAC: Fighting spirit	Nordin & Glimelius (1998)	r=.33			
MAC: Anxious preoccupation	Nordin & Glimelius (1998)	r=29			

Table 2.9. Associations between cognitions, emotions and psychosocial outcome (continued).

		Finding Reported					
	Significan	t	Non-Significant				
General Quality of Life (cont.)							
MAC:	Nordin & Glimelius (1998)	r=42					
Hopeless/helplessness							
MAC: Fatalism*	Schou et al. (2005)	r=24	Nordin & Glimelius (1998)	<i>r</i> =14			
Anger expression	Butow <i>et al.</i> (1999)	r=48					
Anger suppression	Rondorf-Klym & Colling (2005)	r=41					
Negative affect	Kessler <i>et al.</i> (2002)	r=66					
Positive affect	Kessler et al. (2002)	<i>r</i> =.32					
Physical Quality of Life							
Locus of control		aan oo dagaan ah seemaan oo oo see see reesaan oo	DeValck & Vink (1996)	r = (+/-).09  to  .40			
Information perception	Padilla <i>et al.</i> (1992)	r=27					
Illness unpredictability	Padilla <i>et al.</i> (1992)	r=28					
Illness ambiguity	Padilla <i>et al.</i> (1992)	r=38					
Threat appraisal	Padilla <i>et al.</i> (1992)	<i>r</i> =35					
	Green <i>et al.</i> (2002)	<i>r</i> =38 to .50					
Challenge appraisal	Padilla <i>et al.</i> (1992)	r=.30					
Symptom aspects of Quality of I	Life						
Threat appraisal	Padilla <i>et al.</i> (1992)	r=42					
Challenge appraisal	Padilla <i>et al.</i> (1992)	r=.23					
Illness unpredictability			Padilla <i>et al.</i> (1992)	r=16			
Illness ambiguity	Padilla et al. (1992)	r=40					
Illness uncertainty	Padilla et al. (1992)	r=39					
Information perception	Padilla <i>et al.</i> (1992)	r=33					
Emotional aspects of Quality of	Life						
Confrontational attitude	Nordin & Glimelius (1996)	r=67					
Challenge appraisal	Schou <i>et al.</i> (2005)	r=.22 to .24					
Thought intrusion	Nordin & Glimelius (1996)	r=.64					

Table 2.9. Associations between cognitions, emotions and psychosocial outcome (continued).

Finding Reported			
Significant		Non-Significant	
ife (cont.)			
Nordin & Glimelius (1996)	r=41		
Nordin & Glimelius (1996)	<i>r</i> =.70		The state of the s
Nordin & Glimelius (1996)	r=55		
Nordin & Glimelius (1996)	r=47		
` ,			
		Nordin & Glimelius (1996)	r=07
		,	
Green et al. (2002)	r=53 to56		
of Life			
•		DeValck & Vink (1996)	r = (+/-).08  to  .15
Padilla et al. (1992)	r=54		
Padilla et al. (1992)	r=.48		and the second s
Padilla et al. (1992)	r=26		
Padilla et al. (1992)	<i>r</i> =50		
Padilla et al. (1992)	r=48		
Padilla et al. (1992)	r=42		
	Nordin & Glimelius (1996) Nordin & Glimelius (1996) Nordin & Glimelius (1996) Nordin & Glimelius (1996)  Nordin & Glimelius (1996)  Green et al. (2002)  f Life  Padilla et al. (1992)	Nordin & Glimelius (1996)   r=41     Nordin & Glimelius (1996)   r=.70     Nordin & Glimelius (1996)   r=55     Nordin & Glimelius (1996)   r=47     Oreen et al. (2002)   r=53 to56     Of Life   r=54     Padilla et al. (1992)   r=54     Padilla et al. (1992)   r=48     Padilla et al. (1992)   r=50     Padilla et al. (1992)   r=50     Padilla et al. (1992)   r=48	Nordin & Glimelius (1996)   r=41     Nordin & Glimelius (1996)   r=.70     Nordin & Glimelius (1996)   r=55     Nordin & Glimelius (1996)   r=47     Nordin & Glimelius (1996)   r=47     Nordin & Glimelius (1996)     Green et al. (2002)   r=53 to56     of Life   DeValck & Vink (1996)     Padilla et al. (1992)   r=54     Padilla et al. (1992)   r=48     Padilla et al. (1992)   r=26     Padilla et al. (1992)   r=50     Padilla et al. (1992)   r=48

<sup>\*</sup> Findings were also meta-analysed: see table 2.7

\*\* Range of correlations presented for different longitudinal comparisons

Both positive and negative affect were found to be significantly correlated with anxiety, although the latter to a much reduced extent. Non-significant associations between anger expression and anxiety, and inconsistent findings for each of the CECS sub-scales were reported. Although both Watson *et al.* (1991) and Grassi *et al.* (1988) reported similar (small) effect sizes, only the former found these to be significant. Meta-analysis demonstrated that all were significant but minimally correlated; higher suppression of anger, anxious and depressive emotions correlated with higher levels of anxiety (Meta-analyses 8-10,  $\bar{r}$  =.04,  $\bar{r}$  =.13, and  $\bar{r}$  =.11 respectively).

Associations between predictor variables and depression were equally mixed. Again, thought intrusions were associated with increased depression (effect continuing beyond a two-year follow up) but contradictory findings were reported for thought avoidance; although these were not viable for meta-analysis, the significant findings related, not surprisingly, to much higher effect sizes. No significant effects of locus of control were reported and effect sizes for these relationships were small and varied over time.

Illness severity perceptions, self-blame attributions, and greater confrontative attitude towards illness were all significantly correlated with depression. Treatment expectancy did not. Associations between MAC components and depression were once again, reported with medium to large effect size, and in all but one case to be significant. Meta-analysis found that higher depression was associated with higher anxious preoccupation, higher hopeless/helplessness, increased fatalism, and decreased fighting spirit (meta-analyses 11-14,  $\bar{r}$  = .47,  $\bar{r}$  = .48,  $\bar{r}$  = 23, and  $\bar{r}$  = -.35 respectively).

Two studies reported associations between negative affect and depression; with both reporting medium to large significant effects. These could not be meta-analysed due to high variance in the timing of variable measurement. Faller  $et\ al.$  (1991) further report a high correlation between emotional expression and depression. Patterns of association between CECS subscales and depression reflect those also found for anxiety; both the Watson  $et\ al.$  (1991) and Grassi  $et\ al.$  (1988) studies report very small effect sizes, differing in significance. Meta-analysis found that Anger suppression ( $\bar{r}=.08$ ) and depression suppression ( $\bar{r}$ 

=.14) were highly significant, but the anxiety-suppression mean effect size ( $\bar{r}$  =.09) was marginally insignificant at the p<.05 level.

Associations with distress were also inconsistent. The three studies reporting associations between thought intrusion and distress found varying levels of, but consistently significant effects; meta analysis (18) found this to be highly significant,  $\bar{r}$  =.35. Only two of these studies found associations with thought avoidance to be significant; overall meta-analysis (19) concluded a highly significant association between higher avoidance and higher distress,  $\bar{r} = .40$ . Conversely to depression, perceived severity was found not to be significantly associated, as was locus of control (at various time-points). Threat appraisals remained significantly and highly associated. Associations between self-blame and depression were also meta-analysed (20) finding a highly significant medium mean effect size of  $\bar{r}$  =.31. MAC components were only correlated with distress in one study; effect sizes were variable across the many participant subsamples; overall, all but fighting spirit were significantly correlated. Gallagher et al. (2002) additionally explored associations with clinical risk for psychiatric disorder; both higher threat appraisal and lower confidence in family in support significantly correlated with higher risk (medium effect sizes), but confidence in health care was did not.

There was far less replication of findings for associations between cognitions, emotions and quality of life. A range of cognition variables including thought intrusion, thought avoidance, minimisation, confrontational attitude and treatment perceptions were significantly correlated with general quality of life, mostly at medium effect sizes. One study reported significant, and one reported non-significant, associations with locus of control, although due to timing differences, these could not be meta-analysed. Three out of four subscales of the MAC were found to be significantly correlated (although this is based on just one study), but opposing effects were reported for fatalism in other studies. Meta-analysis (21) found this to be overall significant,  $\bar{r} = -.19$ , p < .001.

Negative affect was correlated with much higher effect sizes than positive affect. Strangely, both anger expression and anger suppression were negatively correlated with quality of life.

Padilla et al. (1992) explored associations between six appraisals and subscales of quality of life. For psychological and physical subscales, all were significantly correlated: all but unpredictability were significant for symptom subscales. Locus of control was not significantly correlated with either physical nor psychological subscales despite reporting of larger effect sizes for the former. Though these studies indicated lack of effect on quality of life, Alhama et al. (2002) report that those high in internal control are more satisfied with their current quality of life. Higher threat appraisals were significantly correlated with both physical and social subscales of quality of life at medium to large effect sizes, with effect continuing to various longitudinal follow-ups, but differences in timing prevented meta-analysis. In a similar pattern of results, emotional sub-scales of quality of life were found to be strongly correlated with lower thought intrusion, lower thought avoidance, less confrontation, higher challenge appraisals and three of the four MAC subscales (all but fatalism).

## 2.7.5.7 Inter-correlations between the predictor variables

Although the specific research question pertaining to the associations between the two sets of predictor variables was removed from the protocol, some relevant associations were highlighted during data extraction. Caution must be applied, however, as neither the means by which these data were included, nor extracted, were as systematic as the remainder of the review.

Optimism was repeatedly found to be significantly associated with various cognition variables in a variety of cancer samples: high perceived control (Carver et al., 2000), high treatment expectations, low perceived threat, and challenge based appraisals (Schou et al., 2004/05). Neuroticism and self-efficacy beliefs were significantly correlated (Ranchor et al., 2002); as were agency and thought intrusions (Helgeson & Lepore, 2004); life satisfaction and positive affect (Kessler, 2002); and, low perceived control and high levels of thought intrusion and avoidance (Osoweicki & Compas, 1998)

# 2.7.5.8 Reported results from multivariate analyses: Moderation and mediation effects

Thirty-one studies conducted multivariate tests that were relevant to this review. In longitudinal designs, by far the most significant predictor of psychosocial outcome is measurement of that same variable at an earlier time

point (Bleiker et al., 1995; Malcarne et al., 1995; Gallagher et al., 2002; Green et al., 2002; Badger et al., 2004). In other words, the most highly associated variable for quality of life at, say, three months, is quality of life scores at diagnosis. Similarly, the most highly correlated variable of follow up distress, is baseline distress level (also see Carver et al., 1993; Ranchor et al, 2000; Aarstad et al., 2005). The most likely explanation for this effect is that these outcomes are fairly resilient to change, particularly where the situation has altered very little; follow-up times in these studies were reasonably short and so one might expect that situational appraisals and the environment remained relatively constant. Whilst some studies find that this strength of association is limited to only outcomes of the same type (i.e. functional status is related to earlier functional status, but not psychological outcome, and vice versa), this is not substantiated in all research; Hassanein et al. (2001, 2005), Rondorf-Klym and Colling (2003), and Schou et al. (2004/05) found significant correlation between quality of life and psychological outcomes.

Although stability of the outcome variable is perhaps the most likely explanation for this finding, other possibilities must be explored. One much discussed theory that might be of relevance is the Hawthorne Effect. The Hawthorne Effect occurs when participants' scores on a psychological measure are affected by mere completion of that measure, rather than the measure assessing a true underlying psychological phenomenon (Chiesa & Hobbs, 2008). For example, applied to the current study, it could be that anxiety at baseline is highly correlated with anxiety at follow up, not due to stability of anxiety, but because of an underlying cognitive bias in response to questionnaires. Individual participants may vary in their proneness to the Hawthorne Effect. The methodological implication of the Hawthorne Effect is that whilst the measure may not be able to identify absolute values of the anxiety (to continue the example), where the focus of analysis is on association between variables, the error introduced is minimal (O'Sullivan, Orbell, Rakow & Parker, 2004). The use of the Hawthorne Effect as an explanatory mechanism is contentious (Adair, 1984) but where self-report measures are taken it seems plausible that some error may be introduced. This could represent an issue, not only relevant to this review, but to all research using participant self-report.

A related finding reported by numerous researchers (e.g. Miller et al., 1996; Schou et al., 2004/05) was that positive predictor variables are more highly correlated, and more significantly predictive of positive outcome; conversely, negative predictors are more highly correlated with negative outcome. For example, bigger effect sizes and more significant prediction are found between optimism (+ve) and well being (+ve) than they are for optimism (+ve) and anxiety (-ve): neuroticism (-ve) is more predictive (and more strongly associated with) levels of distress (-ve) than well-being (+ve). Such associations were not reported in all multivariate analyses, but are worthy contenders for an explanation of the process by which these variables have effect.

Table 2.10 summarises the main conclusions from those analyses in which independent effects of the predictor variables were still evident after controlling for potential confounds (e.g. clinical, demographic variables).

**Table 2.10.** Summary of studies demonstrating significant independent prediction of personality, cognitions and emotions.

Predictor Variable	Relationship to outcome			
Optimism	QoL (Ahmed et al., 2004)			
	Depression (Cohen et al., 2000)			
	Distress (Epping-Jordan et al., 1999)			
Lie score	Anxiety (Ratcliffe et al., 1995)			
Neuroticism	Distress (Ranchor et al., 2002; Golden-Kreutz & Anderson, 2004			
Appraisals	QoL (Brown et al., 2000; Butow et al., 1999)			
Self-Efficacy	Distress (Helgeson & Lepore, 2004; Gallagher et al., 2002)			
	QoL (Helgeson & Lepore, 2004)			
Perceived Threat	Anxiety (Laubmeier et al., 2004)			
	Depression (Laubmeier et al., 2004)			
	Distress (Gallagher et al., 2002)			
Thought intrusion	Distress (Osoweicki & Compass, 1998; Epping-Jordan et al.,19 Hack & Degner, 2004)			
Self-blame	Distress (Malcarne et al., 1995)			
Perceived stress	QoL (Cousson-Gelie (2000)			

Those retaining significant independent prediction in regression models include optimism, lie scores, neuroticism, self-efficacy, self-blame, perceived threat, thought intrusion, perceived stress, and some components of cognitive appraisal (perceived treatment aims and minimisation). Other variable effects, for example agency (Helgeson & Lepore, 2004), were lost when confounding variables were controlled for in these analyses. Some, but not all, of these relationships were longitudinally predictive: for example, future distress levels were reportedly predictable by both earlier levels of thought intrusion (Hack and Degner, 2004) and self-blame appraisals (Malcarne *et al.*, 1995).

A small proportion of studies reported findings pertaining to moderation and mediation effects resulting from multivariate analyses; table 2.11 summarises these results.

Whilst only one study reported a moderation relationship (of optimism on both stage of illness and illness cognitions over distress), many more mediation relationships were reported. Appraisals, for example, were found to reduce, and by a twelve-month follow-up to completely eliminate, the association between optimism and quality of life. Epping-Jordan et al. (1999) make an interesting observation that where at three month follow up, thought intrusion and avoidance act only as mediators between age and optimism, analysis of data three months later demonstrates that both of these cognition variables and optimism acted as independent predictors for psychosocial outcome. Although Malcarne et al. (1995) found no evidence of locus of control mediating the relationship between selfblame appraisals and distress, a number of other studies reported such mediation effects. Far more in fact report mediation effects than reported significant bivariate correlations; it is possible that whilst control may not directly predict outcome, it may influence the way in which patients cope with their appraisals (i.e. it isn't control per se which is important, but an interaction of (a) where control is located, (b) whether control is personally desired and (c) how control may help to alleviate negative appraisals).

**Table 2.11.** Summary of studies demonstrating moderation and mediation effects of personality, cognitions and emotions.

Predictor Variable	Relationship to outcome		
Moderation relationsh	nips		
Optimism	Stage of Illness on distress (Carver et al., 1993)		
	Cognitions on distress (Carver et al., 1993)		
Mediation relationship	ps .		
Appraisals	Optimism on QoL (Schou et al., 2004/05)		
Fatalism	Optimism on anxiety (Schou et al., 2004/05)		
	Hoplessness/helplessness on depression (Schou et al., 2004/05)		
Perceived Stress	Symptoms on QoL (Cousson-Gelie, 2000)		
Appraisal	Trait anxiety on QoL (Cousson-Gelie, 2000)		
Control	Illness severity on distress (Alhama et al., 1994; Marks et al., 1986)		
	Trait anxiety on depression (Naus et al., 2005)		
	Appraisals on QoL (Rondorf-Klym & Colling, 2003)		
Self-efficacy	Appraisals on QoL (Rondorf-Klym & Colling, 2003)		
Social Support	Self-efficacy on distress (Ranchor et al., 2002)		
	Perceived health on quality of life (Schnoll et al., 2002)		
	Optimim on QoL (Schnoll et al., 2002)		
	Optimism on distress (Trunzo & Pinto, 2003)		
Coping	Optimism on distress (Carver et al., 1993)		
	Optimsm on QoL (Shnoll et al., 2002)		
	Perceived health on QoL (Schnoll et al., 2002; Cousson-Gelie, 2000)		
	Control on distress (Osoweicki & Compas, 1998)		
	Illness stage and optimism (Epping-Jordan et al., 1999)		
	Illness stage and distress (Epping-Jordan et al., 1999)		
Thought intrusion/avoidance	Age on optimism (Epping-Jordan et al., 1999)		

Not surprisingly given the previous literature, a number of studies reported the mediating effects of social support and coping on associations between the variables relevant to this review. Last but not least, Osoweicki and Compas (1998) report that coping mediates the relationship between locus of control and distress; a mismatch (i.e. preference for problem focussed coping and perception of low control) results in highest distress levels.

#### 2.8 DISCUSSION

This is one of few systematic reviews in the field of psychosocial oncology. It aimed to assess associations between personality, cognitions, and emotions as correlates of anxiety, depression and quality of life outcome variables. As expected, heterogeneity between study and a number of quality assessment issues prevented large scale meta analysis. However, a number of smaller analyses, and a full descriptive data synthesis, including methodological critique were presented.

## 2.8.1 Summary methodological critique

Methodological quality was good across all studies (mean score >60%) with a majority scoring between 81 and 85%. This seems particularly high compared with quality scores reported by similar reviews (e.g. Goodwin, Higginson, Edwards, Finlay, Cook, Hood *et al.*, 2002) and perhaps highlights a validity weakness in the quality assessment method (to be discussed later in section 2.8.3).

A substantial proportion of studies used a cross sectional design; although these have provided some interesting baseline findings, the general consensus across the field is toward longitudinal research in order to better assess temporal changes in adjustment. Only two studies recruited pre-symptom; where possible this should be aimed at in future research to gain a fully prospective insight into the impact of diagnosis. Standardised timing of follow-up should also be encouraged and researchers should ideally repeat data collection of most psychosocial variables under investigation, at each time point; selective measurement at different time-points may compromise the full complexity of potential analyses (by missing or underestimating the effects of tertiary psychological and clinical variables) and their implications.

Perhaps one of the most pertinent issues was regarding the time between diagnosis and recruitment into research. As most studies in this review aimed to assess the impact of cancer diagnosis, the process of adjustment, or psychosocial outcomes; it seems imperative that patients are recruited during early stages of illness. The only exception would be cross sectional assessment of outcome, although such designs are not recommended due to the added benefit of preoutcome (i.e. during treatment) stage longitudinal data collection. This was not the case though; not only were times between diagnosis and recruitment variable, but within study time ranges of up to 19 years were reported. The findings are,

therefore, questionable; attention is drawn to the possible effects of confounding variables between patients with varying clinical profiles. Additionally, the Transactional Model (on which this thesis is based) asserts the dynamic and changing nature of psychological responses to stress including feedback loops and stressor re-appraisals. The unstable nature of cognition and emotion variables highlighted in this review provides evidence for the importance of temporally homogenous samples. Furthermore, the effects of post-cancer re-appraisals and error in retrospective self-report over these longer periods of time may introduce bias into the results of many of the studies.

Substantial sample biases existed; the research field is dominated by breast cancer studies, and, therefore, male responses to cancer are highly underrepresented. It is recommended that future research should aim to minimise both gender and cancer site biases so that findings can be more readily applied to general cancer populations.

Although only 11 out of the total 68 studies were deemed to have an inappropriate sample size for the analyses they conducted, very few studies explicitly stated sample size calculations with regard to planned analyses. A clearer explanation of recruitment strategies are recommended; recruitment and response rates are important criteria by which to assess the generalisability of the findings. Without such information, findings must always be treated with caution. Where reported, response rates are on average high, although the actual range was from 37.3% to 100%. Those attaining highest response rates, and those not providing such information were judged to provide the vaguest information regarding sample recruitment. It is likely that the more conservative estimates are reflected in the better quality studies.

Several of the measures used in psychosocial oncology research have been purported to measure different underlying psychosocial constructs by different researchers. The findings raise concerns about the coherence and definitions of some psychosocial constructs and their measurement highlighted in this review.

Choice of statistical analysis was also questionable in a number of papers. Of particular note are those studies which present merely descriptive data, or in which correlation effect sizes are presented in a 'range' format rather than specific bivariate associations. Further, when comparing the vast number of measures

used with the actual statistics presented in each paper, it became clear that some information is simply missing; although it is likely that much of this was due to irrelevance to the specific research question (in which case, the ethical consequences of measuring data which was not analysed are to be considered), it is equally possible that these data were not included due to the finding of null or negative results. Publication of these data would have enabled much more indepth meta-analyses and would help to develop more theoretical models of adjustment which consider the influence of a great many sources of variable changeability.

Findings are often difficult to interpret as some authors chose not to report individual outcome findings, but rather merge many outcomes into one variable. This is not always helpful when trying to understand the full complexity of the results. Numerous authors give neither justification of why, or explanation of how, such composite measures were created. Some researchers have used factor analysis as the justification, though the failure of a factor structure to emerge in their data is unsurprising given the small samples sizes used.

One final important point pertains to the difference between poor science and poor reporting of research. Whilst these are interconnected (and in many cases inseparable), this highlights an important point regarding publication. Whilst inappropriately designed and analysed research is essentially the responsibility of the authors, much of the critique presented in this review also pertains to lack of clarity and insufficient depth in the reporting of such research. When information is missing or covered only briefly, it must not necessarily be assumed that this is indicative of poor science, but may also be caused (in part at least) by submission length restrictions imposed by journal editorial teams.

## 2.8.2 Summary of main findings

Many significant associations were reported between demographic factors and variables of interest in this review. Age was inconsistently associated with personality but seemed to be significantly associated with cognitions and emotions, with older patients tending to report more positive appraisals, but more negative emotional reactions. Although the evidence suggests that younger patients tend towards poorer psychological adjustment, significance of these effects between study were inconsistent. Female patients were reported to be

both more neurotic and to report higher distress levels. Higher educational level was associated with more positive personality dimensions, but associations with outcome were predominantly non-significant.

Reported associations between clinical variables and psychological variables were inconsistent; many associations were un-corroborated (or, indeed, opposed) by those presented in other studies. No significant correlations were reported between personality and clinical variables. Cognitions and emotions were most consistently and significantly correlated with psychosocial outcomes. The limited evidence seems to suggest that stage of illness, time since diagnosis, and treatments received are most pertinent.

Where reported, personality seemed stable (as would be expected), despite the major stress and life adjustment that follow a cancer diagnosis. Only dispositional optimism is significantly associated with anxiety. Many more significant associations were reported between aspects of personality and depression; between personality and distress; and, between personality and both total, and subscales of, quality of life. The only exceptions were associations between mastery and symptom-related quality of life, and between self-efficacy and social quality of life. Deeper exploration of subscales of quality of life also shows an interesting pattern; personality is more consistently associated with psychosocial dimensions, but not physical and illness dimension of quality of life. Meta-analysis found the relationship between self-efficacy and distress to be overall significant, but with a low effect size. Medium effect sizes were found for the meta-analyses between optimism and both well-being and distress.

The evidence for associations between personality variables and cognitions seems to imply medium, or highly significant, effect sizes, particularly where optimism and neuroticism are concerned. In multivariate analysis, aspects of personality remained independent predictors of both distress and quality of life in nine separate studies. In seven others, its effect was reported to be mediated by a number of tertiary variables including clinical variables, appraisals, coping, social support, and locus of control (see section 2.7.5.8).

Emotions were also associated with all psychological outcomes, but not with quality of life. Specifically, negative affect was associated with worse psychological outcome (and vice versa for positive affect). Both anger suppression and anger

expression were significantly related to higher levels of both quality of life and depression. Meta-analyses between the incongruent findings on the CECS and both anxiety and depression yielded small, albeit highly significant, mean effect sizes.

Thought intrusion and avoidance were reported to be significant influences on levels of anxiety, depression, distress and quality of life. Meta-analysis of associations between the Impact of Events Scale and distress yielded highly significant, small effect sizes. Illness perceptions and cognitive appraisals (including, for example, threat, challenge, perceived severity and so forth) were, on the whole significantly associated with both psychological outcome (four studies p<.05; two studies p>.05) and quality of life (nine studies p<.05). Self blame was significantly associated with both depression and distress: a meta-analysis for the latter revealed a small, but highly significant effect size (p<.001) where self blame leads to poorer outcome. According to Butow  $et\ al$ . (1999) and Brown  $et\ al$ . (2000), the importance and reported significance of these cognitive variables is that they are not only measures of cognition, but also an indication of positive dimensions of personality.

Confrontational attitudes towards illness were found to be significantly beneficial for both quality of life and anxiety. Meta-analysis of the sub-components of the MAC scale yielded highly significant, small effect sizes between all components and both anxiety and depression; where better outcome was associated with lower hopelessness/helplessness, lower anxious preoccupation, lower fatalistic appraisals, and increased levels of fighting spirit. Incongruent findings were reported between MAC components and quality of life, but a small effect size (p<.001) was found in meta-analysis of the relationship between fatalism and quality of life.

Of all cognitions, locus of control appeared to be the most inconsistently correlated variable of all with equal evidence for and against significance; the net effect seems to be toward no influence on psychological outcome. However, the role of control may be more complex than apparent in this review: Carver et al., (2000) claim that control per se is not important in terms of correlation or prediction of psychosocial outcome, but that best outcome is dependent on high concordance between illness expectancies and control beliefs. Andrykowski et al.,

(1994) also makes similar claims of variable interaction; control has greatest effect when illness and treatment perceptions are most negative.

In multivariate analysis, only four studies reported a significant independent cognitive predictor of outcome; perceived social support was found to mediate the effects of health perception on quality of life, fatalism mediated between hopelessness/helplessness and distress, and coping mediated between control and distress.

Whereas the predictive validity of personality seemed stable over time, the predictive validity and significance of association based on cognitive and emotional factors seemed more changeable. Some of the strongest predictors of longitudinal adjustment identified in these studies are earlier levels of anxiety, depression and quality of life.

Although not specifically analysed in this review, a brief summary must be given for coping due its role in the transactional model. Direct associations between coping and both psychosocial predictors, and psychosocial outcomes, were inconsistently reported both in terms of which strategies were most beneficial, at different time points of illness, and in terms of statistical significance. Consistency was reported, however, in the mediating role of coping over numerous cognitions and appraisals (although cognitions also remain independently significant predictors), and numerous personality variables typically at high levels of effect size and significance. As such, the findings are clearly concordant with the Transactional Model.

A final point about longitudinal analysis. The methodological critique clearly stated that longitudinal designs are superior to cross-sectional designs and approximately 50% of the included studies, did indeed, collect some follow up data. Yet, it will be obvious from this data synthesis that very few longitudinal analyses are presented or discussed; data was simply not sufficiently analysed to do so within the individual included papers. Longitudinal analysis was largely limited to multivariate tests which were not the main focus of this review.

Correlation analyses were largely limited to cross-sectional data only. The use of cross-lagged correlations may be beneficial in future research.

#### 2.8.3 Review evaluation

The general area of research into which this review fits is vast. Whilst many related concepts are discussed, and single relevant variables measured, to have included every vaguely related psychosocial oncology study would have been infeasible on both a practical and an interpretative level. Therefore, a focussed question was planned exploring only those which had direct relevance to this thesis. Many more important questions have been addressed in psychosocial oncology research (e.g. religiosity, sexual adjustment, social support) and are equally deserving of systematic review, but beyond the scope of this thesis.

The review was designed to be robust and of high quality by following the guidance of both NHSCRD and the Cochrane Collaboration. Positive peer review of the protocol reflects the importance of the research and suitability of the approach to answering the question. In order to assess whether robustness and quality were achieved, Russell *et al.*'s (1998) quality checklist for systematic reviews was applied. Table 2.12 presents the criteria and scores attained.

This scoring exercise highlights two primary weaknesses of the review: literature searching and data extraction. The search strings used were highly sensitive, perhaps too much so, given the high output from our searches. It is likely that this resulted in some studies being omitted from inclusion (this is, in part, demonstrated by the lack on concordance between the inclusion lists of the two reviewers). However, the fact that a second inclusion assessor was used minimised this risk substantially.

Table 2.12. Scoring the quality of the systematic review.

	Criteria	Score	Comment		
1.	Specifying the objectives?  Scores: (2) precise (1) vague (0) implicit	2			
2.	Searching the literature?	0	Due to feasibility issues,		
	Methods: electronic, handsearching journals, reference lists, authors, industry		only electronic searching was conducted		
	Scores: (2) 4+methods (1)2 or 3 (0) 0 or 1				
3.	Selecting relevant studies?	2			
	Scores (2) 2+ reviewers (1) 1 reviewer (0) selection implicit				
4.	Selecting valid studies?	2			
	Scores: (2) 2+ reviewers (1) 1 reviewer (0) selection implicit				
5.	Extracting the data?	1	Limited resources		
	Scores: (2) 2+ reviewers (1) 1 reviewer (0) extraction implicit		available (see main text		
6.	Synthesising the data?	2			
	Methods: rigorous qualitative overview, meta- analysis rigorous or rejected				
	Scores: (2) both (1) only one (0) implicit				
7.	Writing the report?	2			
	Components: table of included studies, table of excluded studies, discussion of robustness, implications for health care, implications for research				
	Score: (2) 4+ components (1) 2 or 3 (0) 0 or 1				
To	Total		11 (Out of possible 14)		

With regard to searching sources, although a vast range of electronic databases were searched (in order to reflect the multi-disciplinary nature of this review), this was limited by publication bias. Given the additional time and resources necessary to extend the search to also include non-published sources, it was not considered feasible to do so for the purpose of this thesis. The final inclusion rate as a proportion of search results was low; further searching was assumed unlikely to dramatically increase the number of included papers. This aspect of the review is undoubtedly a methodological weakness. However, it is worth noting that in data synthesis a surprisingly high number of non-significant results and a number of methodologically inferior publications are included which

may indicate *against* publication bias, to an extent at least. A future update of this review should consider more extensive searching (including follow-up searching of reference lists and key journals), if only to rule out the possibility of any further data being available and to be able to make more confidant claims against publication bias. Such review replication is not, however, recommended for some time: given the heterogeneity of the field, further research needs to be conducted before informative and clinically implicative meta-analysis is possible.

Due to resource restrictions, a second reviewer was only available for the paper selection phase and quality assessment, not for extraction of data from included papers. Whilst single-person data extraction can lead to bias or error, compromises were necessary due to limited staffing resources. It was thought that of the three areas where multiple reviewers are recommended, this was least crucial to the overall quality. In future replications, it would be beneficial to ensure that resources are sufficient to fully enable this.

Going beyond Russell *et al.*'s (1998) criteria, two further points are considered important for judging the quality of this review: validity of the quality assessment tool used and a cautionary word about the meta-analyses presented.

Independent quality assessment by two reviewers was conducted using a pre-validated (but slightly amended) tool applicable to all quantitative research designs. Low concordance in scores between quality assessor highlights concern that either bias existed in assessment, or in the clarity of scoring guidelines for the tool. Although mean quality scores give an indication of overall good methodological quality, the descriptive quality critique presented in section 2.7.2 was more negative on the whole. This discordance between quality score and an in-depth descriptive critique indicates possible weakness in the quality assessment tool used. Future research should consider the use of alternative scoring methods and thorough validation of the Kmet *et al.* (2005) tool. The limited scope of the meta-analysis did not allow for sensitivity analysis based on quality scores. Additionally, mean effect size weighting based on quality was not appropriate for the meta-analytical methodology used.

Due to between study variability, data synthesis was limited primarily to qualitative (non-statistical) data analysis. Many different models of meta-analysis were explored and the Hunter and Schmidt, random effects model was selected as

being most appropriate for the 21 small meta-analyses. Although (on the whole) highly significant effect sizes ranging from small to medium levels resulted from the statistical analyses, it is important that these findings are considered with caution; inference of the implications of findings any more statistically advanced than mean effect sizes are of minimal validity.

#### 2.8.4 Recommendations for future research

The findings of this review demonstrate that whilst personality, cognitions and emotions are associated with distress and quality of life after cancer diagnosis, little directly comparative research has been conducted. More research is clearly required. In particular, there is a need for more longitudinal, theory-based research of the relationships between all components of the transactional model (appraisals, emotional reactions, coping and outcome) to establish which are the most influential components. The question of how personality may complement or better predict outcome cannot confidently be answered using findings from this review. The limited evidence available, however, does seem to imply that appraisals are more useful indicators of adjustment. Whilst personality and quality of life are associated, correlations with psychological outcomes were more variable. Cognitive appraisals and emotions were more consistently associated with both psychological and quality of life outcomes. Further theory-based research using complex designs is essential though before this claim can be fully validated.

Future work must also improve in terms of methodology. First, theoretical constructs and the use of various psychological instruments need clarification and standardisation. Second, many important issues have been raised regarding temporal differences and recruitment into studies which should be considered more fully in planning future research. Improvements in sampling and recruitment strategies are imperative for optimal confidence in the generalisability of individual study findings. Third, more generic cancer research (rather than clinical site-specific) controlling for the effects of possible clinically confounding variables is required in a move away from the current breast cancer-biased literature. Finally, a number of statistical limitations were raised. Each of these should be carefully considered in the planning of new research protocols in this field.

## 2.8.5 Implications for policy making and clinical practice

The findings clearly point to the (varying) importance of individual differences, cognitive variables and emotions in adjustment to cancer diagnosis (specifically distress and quality of life). This is inkeeping with policy recommendations (e.g. the Cancer Reform Strategy, 2007) which call for, amongst other targets, better psychosocial support mechanisms, increased personalised support, and individually tailored care for the patient.

There is a strong argument for the stability of many personality characteristics (there are of course some exceptions, for example optimism) and so application of these findings into practice may be limited, however, there could be a case for using such information to highlight individuals who may be particularly at risk of adjustment difficulties at earlier time points in order refer to specialist psychosocial services. Perhaps of more pertinence is the strength of evidence found for many of the role of cognitive variables which are infinitely less stable than personality, and therefore more likely to be responsive to intervention. Although some appraisals are inherent in a cancer diagnosis (e.g. illness unpredictability), others are more reflective of individual reactions (e.g. self blame and thought intrusion). Therefore, interventions could focus upon both changing the way patients appraise their illness, and also the way in which the patient responds to, and acts upon these appraisals. There is a clear need to further empirically (and rigorously) investigate associations between these variables and outcomes to inform intervention research, but the potential contribution of these early findings is clear.

The high level of psychological distress reported in these studies is reflective of the potentially devastating impact that cancer can have. Although data were not available in these studies on how frequently patients had been referred to specialist oncology-based psychological support teams, the potential importance of such services is clear in both identifying those in distress and in helping patients to deal with and alter unhelpful responses to cancer diagnosis.

## 2.8.6 Concluding summary

Theoretical models of adjustment describe a complex interaction between many psychosocial and clinical factors. The implications (both theoretical and clinically applied) of studies that fail to address, or report statistical findings

relating to the full complexity of all psychosocial constructs, is unclear. Biased recruitment, occasionally incoherent measurement, missing analysis and a general lack of theoretical grounding all contribute to perceptions of poor quality within this field of research. However theoretically or clinically interesting study findings may be, poor quality studies will not result in improved clinical practice. Many researchers in this field are inadvertently limiting both the applicability and credibility of research findings in an area so heavily rooted in evidence based medicine and influenced by the application of theory to clinical practice.

Considered together though, some interesting findings do emerge. Using improved methodology it is possible that such findings may prove crucial to the development of successful interventions and clinical support systems for cancer patients.

#### 2.9 INTRODUCTION TO STUDY TWO

Although this systematic review was conducted in parallel to the empirical part of this PhD thesis, the conclusions are in keeping with the predictions made from early scoping searches. Reflecting methodological improvements, the study planned was longitudinal (data collected at diagnosis, three month and six month follow up) and aimed to recruit a mixed cancer sample of 160 patients with otherwise homogenous clinical disease characteristics. The study was theory-based and measured a more coherent set of variables including personality, appraisal, emotion, coping, health beliefs and psychosocial outcomes. The results of the empirical research build upon the research base synthesised in this review. However, through improved methodology it is hoped that the findings may contribute more to the field both in terms of theoretical and clinical implication.

## **CHAPTER 3**

## **EMPIRICAL STUDY: METHOD**

#### 3.1 CHAPTER OVERVIEW

The following sections of the thesis (Chapters Four to Six) pertain to the empirical application of the Transactional Model to explain adjustment in a sample of newly diagnosed cancer patients. The current chapter presents information about the purpose and aims of the study, the development of the protocol, and a detailed description of the method used for data collection.

The study was originally designed as an investigation of associations between personality, components of the Transactional Model, and psychosocial outcome in newly diagnosed colorectal cancer patients recruited from four Welsh NHS Trusts. The target sample size was 156 patients. A number of practical issues hindered recruitment into the study. Primarily, a number of procedural delays in setting up the study postponed the start of patient recruitment. Furthermore, the largest of the Trusts planned to be involved was not, in the end, able to assist with recruitment. Without this Trust, recruitment proved far slower than expected and achievement of the sample target became infeasible given the time and funding restraints of the project.

Consequently, recruitment was temporarily suspended whilst a period of study re-design and re-development was carried out and approved by the relevant committees. Following this, recruitment was extended to also include breast, prostate and lung cancer patients, and focused on three Welsh NHS Trusts.

One hundred and sixty patients were recruited in total. Recruitment rates were low (35%), but expectedly so, and comparable to a number of related studies (see section 2.7.2.5 of the systematic review for comparison studies). A high retention rate of 77% was achieved. The chapter ends with an overview and justification of the proposed statistical analyses which are presented in Chapter 4. These include both theory testing of the Transactional Model in addition to clinically relevant regression analyses to identify the most important predictors of psychosocial outcome within this population. Longitudinal analyses included data from the 123 patients who completed all three time points of the study.

#### 3.2 STUDY PURPOSE

#### 3.2.1 Aims

The aim of this study was to investigate personality, cognitive appraisals, emotions, and psychosocial adjustment in a cohort of newly diagnosed cancer patients. It was designed to address the third and fourth thesis questions (see section 1.7). In summary, these questions were:

- What are the most important predictors of psychosocial outcome in newly diagnosed cancer patients, and leading from this, at what time point (baseline or three month follow-up) are they most predictive of subsequent (three or six month follow-up) outcome?
- 4) Are the hypothesised associations between cognitive appraisals, core-relational themes, and emotions in Lazarus's Transactional Model supported in a sample of newly diagnosed cancer patients?

## 3.2.2 Objectives

- To identify the most important psychological predictors of anxiety, depression and quality of life at three and six month time-points after cancer diagnosis.
- 2) To identify at what time-period (baseline, three or six month follow up) predictor variables best predict each of the outcomes at three and six month follow-up.
- 3) To examine whether associated components of the Transactional model (cognitive appraisal, core-relational themes, emotion themes, and coping) vary equivalently over time.
- 4) To test the hypothesised associations between specific cognitive appraisals, core-relational themes, and emotion themes (i.e. the 'exclusively' linked components) in relation to cancer diagnosis.

## 3.2.3 Hypotheses

## 3.2.3.1 Objective One

Personality differences, and variation in appraisals, emotion, and coping are, at both baseline and short term follow-up, expected to contribute to statistical models predicting levels of anxiety, depression and quality of life, three and six

months after diagnosis (Hypothesis one). Health locus of control beliefs are not expected to account for any such variance in outcome (Hypothesis two).

## 3.2.3.2 Objective Two

Statistical tests are expected to yield varying levels of outcome prediction between regression models. Those predicting outcome six months prospectively are hypothesised to explain lower total  $R^2$  variance explained than those predicting outcome three months prospectively (Hypothesis three). Additionally, variance explained by three month predictor variables is hypothesised to be higher than that explained by baseline variables as this initial period may be too unstable and traumatic for accurate predictions to be made (Hypothesis four); although quite a general hypothesis given that strength of longitudinal relationship is often dependent on the specific nature of the variables in question, this hypothesis is based on the findings for similar studies in the field which indicate a more general trend toward better prediction over shorter time-periods.

## 3.2.3.3 Objective Three

Components of the Transactional Model are hypothesised to fluctuate with time (Hypothesis five) and the extent and direction of change between them to be equivalent for each theoretically associated component (Hypothesis six).

## 3.2.3.4 Objective Four

For the six so-called 'hot' cognitions (see Smith & Lazarus, 1993; Lazarus, 1991, 1999; also refer to section 1.5 for a breakdown of which cognitions this term refers to), unique patterns of association are hypothesised between the stated specific appraisal, core relational theme and emotion components. (Hypothesis seven). These associations are demonstrated in figure 3.1.

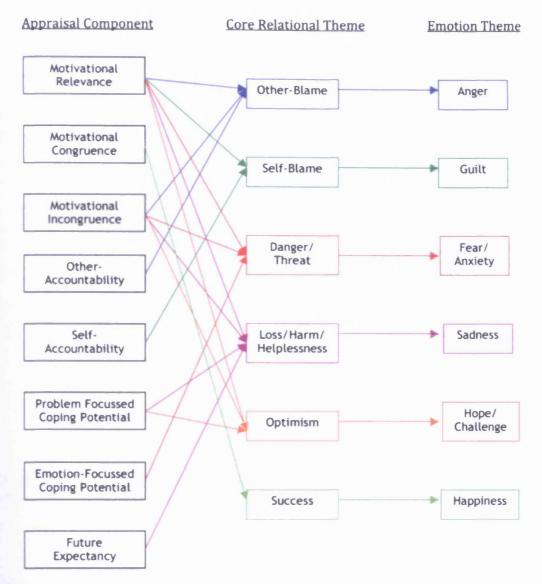


Fig 3.1. Associations between appraisal components, core-relational themes and emotion themes for the 'hot' cognitions.

For a further seven cognitive appraisals, uniquely significant associations are hypothesised (by Smith & Lazarus, 1993) between the following core relational themes and emotions (Hypothesis eight).

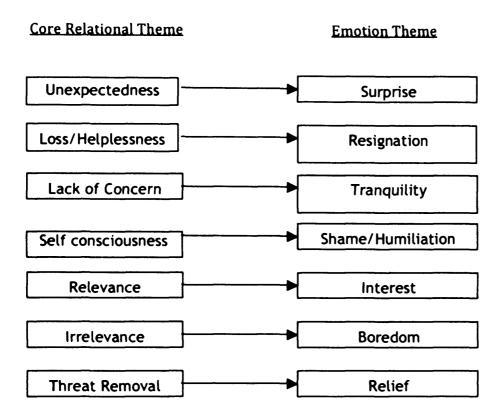


Figure 3.2. Unique core-relational themes for the emotions of surprise, resignation, tranquility, shame/humiliation, interest, boredom and relief.

Theory testing, therefore, only extends so far as to test these unique relationships. An exploratory approach will be taken to identify which unique appraisal components will also be associated.

Additionally, for the remaining three emotion themes described in the Transactional Model—frustration, self-directed anger, and regret—no appraisal components or core-relational themes are proposed in the model. Once again, therefore, an exploratory, rather than hypothesis-driven approach will be taken to investigate which unique cognitive patterns may precede these emotional reactions.

#### 3.3 STUDY DESIGN

#### 3.3.1 Overview

Limited clinical implication and application can be drawn from cross sectional designs (see section 2.7.2.2), therefore, a longitudinal cohort study was designed. Data were collected from newly diagnosed cancer patients by means of questionnaire at three separate time points during treatment. Patients were recruited from three NHS hospitals in Wales (here after referred to as Centres A, B and C).

Most data were quantitative in nature. Predictor variables assessed were personality, illness appraisals, emotions, and coping. Outcome variables were anxiety, depression and quality of life. Predictor and outcome data were collected in a repeated measures design, at each time point. Data were also collected on demographic and clinical variables which were identified as possible confounding variables; this information was obtained at diagnosis only but with regard to some clinical data, included prospective and retrospective elements. Some qualitative data were also collected. Content analysis of these data were used to clarify and add further meaning and depth to the main quantitative analysis.

## 3.3.2 Study Development

#### 3.3.2.1 Funding application and research sponsorship

During the development of the protocol for this research, a successful application for small grant funding was made to the North Wales Research Committee. A sum of £5000 was awarded for printing costs, data collection costs, and conference dissemination (see appendix 3.1). Sponsorship for the study and liability cover were provided by Cardiff University (appendices 3.2 and 3.3)

## 3.3.2.2 Consultation with clinical teams

Before the study could begin, consultation and negotiation with each clinical team was necessary. First, approval from the lead consultant for each cancer team was obtained. Second, clinical nurse specialists were approached as these individuals were proposed as the key members of the clinical team to be involved with recruitment. Provided that both the lead consultant and nurses were willing to assist, the research was presented to the remainder of the clinical team at one of the weekly multidisciplinary team (MDT) meetings. MDT meetings usually consist

of administrative staff, representatives from Trust Cancer Services, clinical nurse specialists, surgeons, oncologists, radiologists, pathologists and members of the palliative care team. Data collection was only possible following full MDT approval.

## 3.3.2.3 Piloting of the questionnaire with service user representatives

A pilot version of the questionnaire was distributed by the local Cancer Patient Expert Group Network via the Local Health Board. Ten patients were consulted, all of whom had previously been treated for colorectal cancer. Each patient was asked to complete the questionnaire and to answer a short survey about their experience of participation. A unanimously positive opinion of the research was obtained from the five who replied. Four out of the five conveyed that they would have been prepared to complete it at the time points which were proposed for this study. Two also commented that they would have found completing the questionnaire beneficial in order to clarify their thoughts and feelings. One commented that the results of the study would be of great value to medical staff to increase awareness of patient emotions. No negative feedback was received on the questionnaire layout or language used. One commented that the questionnaire was definitely too long and that this would be off-putting. It was a surprise that more members of the pilot group did not make comments along these line. Although the remainder did state that it was a long and at times complex questionnaire, the length would not have put them off participating had they been approached whilst undergoing treatment. Of course, no comments were received from the five pilot group non-responders and it is was possible that this sub-group who found the questionnaire too long. Regardless, when compared with response rates reported in the systematic review, the 50% response rate at this stage appeared reasonable.

## 3.3.2.4 Ethics, research governance approval and honorary contracts

Whilst attending MDT meetings and piloting the questionnaire, paperwork was completed in order to apply for NHS Ethical Approval (one multi-site application made via COREC: The Central Office of Research Ethics Committees) and Trust Research Governance (Research and Development / R&D) approval (individual applications for each Trust involved). Copies of approval letters can be

found in appendices 3.4 to 3.7. Once Ethical and Trust R&D approvals were finalised, honorary contract applications were made. Such contracts were required from each Trust where patients were to be recruited from, and also permitted the use of, and data extraction from, secondary care medical records and clinical databases.

## 3.3.2.5 Initial recruitment problems

The original intention was to recruit colorectal cancer patients from five NHS Hospitals, spread across four NHS Trusts. The most current at the time incidence rates of colorectal cancer for each Trust were obtained from the Welsh Cancer Intelligence and Surveillance Unit (WISCU; see table 3.1)

**Table 3.1.** Colorectal cancer incidence in four Welsh NHS Trusts, 2002-2003. (Source: WISCU, 2004).

Trust	Usanital		Incidence		
Hust	Hospital		2002	2003	Mean
Trust 1	Centre A		112	133	112.5
Trust 2	Centre B		175	151	163
Trust 3	Centre C		117	135	126
Trust 4	Centre D		132	128	130
Trust 4	Centre E		71	86	78.5
	Te	otal	607	613	610

Projected recruitment times were calculated as follows. From the total mean incidence across both years, an estimated 25% was deducted to account for those diagnoses which were estimated not to match our inclusion criteria (leaving 457.5 patients). By observing response rates in similar studies identified in our early scoping searches, we estimated a recruitment rate of approximately 40%. Therefore, it was anticipated that 183 patients were potentially recruitable over each year. As the sample size calculations yielded a required sample of 156 participants (see section 4.5.2), this was calculated to take approximately 10.5 months of continuous data collection. Recruitment was planned, therefore, to last for 11 months.

Initiation of recruitment was staggered and began in Centre A. Recruitment was initially slower with both eligibility and response rates being lower than expected. Furthermore, an unexpected ten week delay was encountered in gaining R&D approval and honorary contracts from the other two Trusts, primarily due to

long delays in the application of Criminal Records Bureau checks. Such delays are actually common and a paper published shortly after this study was approved indicates that 150 days is usual for R&D alone (Elwyn, Seagrove, Thorne & Cheung, 2005). Of greater concern was that even after concerted efforts (emails, telephone calls, and in-person meetings) with clinical staff at Trust Four, this site was dropped from the study as the clinical teams reported that high levels of sickness absence precluded them from committing time to aid with recruitment (a constraint of our ethical approval was that recruitment could only be done in collaboration with the clinical team due to the practical limitations of honorary contracts). This resulted in the loss of Centres D and E: both are in the same NHS Trusts which would have potentially referred the highest number of patients into the study.

## 3.3.2.6 Study re-design

After three months of slow referral from clinical nurse specialists and low recruitment into the project, the design was altered. Had these changes not been made it would have been unfeasible to complete the project within the time limitations of a PhD. Within the first three months of recruitment, only 16 patients were assessed as suitable for inclusion, a far lower number than originally anticipated. Given that just 31% of these patients returned completed questions, projected figures for total recruitment were estimated to be in excess of five years.

Care was taken to ensure that these changes were not detrimental to the aims of the PhD or clinical applicability of the study, therefore both theoretical and clinical issues were considered. Theoretical advice on these changes was provided by the candidate's supervision team, and from further review of the relevant literature. A number of academics and NHS based clinicians were consulted, including Dr Matthew Makin (Consultant in Palliative Medicine and Clinical Lead for Cancer Services), North East Wales NHS Trust), Prof Nick Stuart (Professor of Cancer Studies, North West Wales NHS Trust), Dr Simon Gollins (Consultant Clinical Oncologist, Conwy and Denbighshire NHS Trust), and Dr Peter Rutherford (Caldicott Guardian and Chair of the Local Ethics Committee for the North East Wales NHS Trust).

First, the eligibility criteria were altered. Previously, recruitment focussed only on colorectal cancer patients. However, the findings were anticipated to be

equally relevant to all types of cancer patients. To focus on one individual cancer site would have made analysis somewhat less complicated, however, obtaining an appropriate sample size was a more important issue. Additionally, findings from our systematic review demonstrated that conclusions from multi-site studies could be equally valuable (in some cases more valuable than single-site studies due to increased generalisability), provided that good methodology was employed.

Therefore, new inclusion criteria extended to patients with new diagnoses of breast, prostate, and lung cancer, thus representing recruitment of the four most commonly diagnosed cancers in the UK (CRUK, 2008). Including other diagnoses also had the advantage that comparisons could be drawn between patients with different types of illness. Although attrition by mortality was expected to be substantially higher in lung cancer (and therefore, far fewer were expected to reach the final follow-up) exclusion of this largely understudied patient population based on mortality alone could not be justified.

The second change was to the questionnaire itself. In including other diagnoses, the titles and wording of the introduction to the questionnaire and supplementary materials needed to be changed. The quality of life measure also had different subscales for each cancer type resulting in four cancer site-specific questionnaires. Finally, in response to feedback regarding the length of the questionnaire (particularly from the Ethics Committee and North Wales Research Committee), the length of the questionnaire was reduced as follows:

- 1) The Generalised Self-Efficacy scale (Jerusalem & Schwarzer, 1992) was removed. This measures similar health beliefs to the Multidimensional Health Locus of Control scale which remained in the study. Although the extra information may have had some small theoretical benefit, from a clinical perspective, it was not essential as the constructs overlapped.
- 2) The format of presentation of the Appraisal Components Questionnaire was also altered. All items were still included, however, instead of being answered individually, participants responded to a set of grouped statements. This reduced the number of items for participants to respond to, and also had the effect of appearing shorter and, therefore, less burdensome on the participants. This method has been used

- successfully in many other studies using cancer samples (for example, Griner & Smith, 2000; and Bennet, Lowe & Honey, 2003).
- 3) The originally selected coping measure (Ways of Coping Questionnaire, Folkman & Lazarus, 1985) is very lengthy (64 items), and was replaced with Carvers's (1997) Brief COPE (28 items). This alternative scale is thoroughly validated for use with cancer patients (see section 4.4.5).

Third, the final follow-up questionnaire was changed from nine months after baseline, to six months. As all outcome measures are psychosocial in nature rather than, for example, survival or disease progression, there was no concern regarding whether or not these outcomes could be measurable, and of clinical relevance, at six months. By reducing this time-frame, although losing some depth of data regarding longer-term adjustment, the shorter time investment per participant enabled a longer initial recruitment window, and increased the chances of more patients (i.e. those with lung cancers) surviving to final follow up. Also, the systematic review identified that most published longitudinal studies collected follow-up data at three and six months. This change rendered the study more comparable with these published data.

The final amendment concerned recruitment procedures. Ethical approval only allowed for the clinical team to carry out initial patient invitation. Therefore, cancer nurse specialists assisted by applying the inclusion/exclusion criteria and introducing the study to the patients in person using a standardised study description. If patients agreed to be contacted, the nurse specialist filled in a referral sheet. On receipt of signed referral sheets, questionnaire packs including information sheets, consent forms, and the questionnaire itself were sent to the patient via the postal system. The failure of this mode of recruitment was reportedly through pressure of work on the part of the nurse specialists. A new recruitment method was developed whereby questionnaire packs were distributed without prior verbal consent (see section 3.6.1.1 for details). Not only did this new method reduce NHS staff time commitment, but also further safeguarded against recruitment bias by ensuring that nurses had a more standardised route of patient invitation rather than introducing the study on an ad-hoc basis.

All of these changes were re-submitted to, and approved by, all relevant Ethics and R&D committees. The remainder of this methodology section (Measures and Procedure) relates only to the amended questionnaire and procedures.

#### 3.4 MEASURES

The same questionnaire pack was used at each time point. For each, questions were anchored to having received a cancer diagnosis rather than specific features of the cancer experience (e.g. treatment) in order to gain a more general overview of the whole cancer experience rather than a focussed part of it. By anchoring all questions to this one stressor, the study was designed to enable investigation of not only the predictive value of each variable, but also temporal changes through the cancer experience. Although there was some concern about measuring cognitive variables (appraisals, core-relational themes) retrospectively (delayed event appraisals could be affected by post-hoc reinterpretations or recreations of meaning, and similarly, reports of emotions could reflect these reinterpretations, rather than the appraisal of the actual event) when anchored to recall of a specific event, this has been promoted as valid way of collecting such data in this field, especially over numerous time-points (Bennett et al., 2003).

Participants were not asked to provide detailed clinical information; to prevent extra patient burden, and to yield more accurate information, these data were extracted from clinical records and databases (see section 3.4.3) with their consent.

#### 3.4.1 Quantitative Measures

The bulk of the questionnaire included validated quantitative measures. The measures used are detailed below.

## 3.4.1.1 Demographic and personal information

The first section assessed basic demographics including age, socio-economic status, presence of a significant other, number of dependents, employment status and highest educational qualification held (see appendix 3.8). This information was intended for use as a basis for conducting comparative analysis as previous research has demonstrated some effects of each of these variables on both predictor and outcome variables measured (see section 2.7.4). Patients were also

asked to provide contact details for their General Practitioner (GP) to enable prefollow up mortality checks to be made. Further, patients were asked to provide brief details of treatments received to date, although some of this information was later found to be inconsistent with clinical data, and not always specific or precise enough to be used in a constructive manner.

## 3.4.1.2 Personality measures

Dispositional optimism was assessed using the Life Orientation Test-Revised (LOT-R) (Scheier, Carver & Bridges, 1994), the latest version of one of the most popular forms of optimism assessment (appendix 3.9). Of the 14 studies measuring optimism within the systematic review, ten of these employed either the revised version, the original LOT (Scheier & Carver, 1985), or the French language validated FLOT (Allison et al., 2003). The scale has also been validated into a number of other languages and for other participant groups including Chinese, Japanese, and Portugese and an adolescent scale (the YLOT: Ey, Hadley, Allen, Palmer, Klosky, Deptula et al., 2005) to name but a few. The LOT-R is repeatedly demonstrated to have high internal consistency, good test-retest reliability, and adequate levels of validity (see Scheier et al., 1994; Weinman, Wright & Johnston, 1995; and Schou et al., 2005, for example).

Ten items, such as "In uncertain times, I usually expect the best" (including four filler items) are assessed using five-point Likert style scales with high total scores representing high optimistic beliefs. Although there have been some claims that the LOT-R contains two factors—optimism and pessimism (see, for example, Robinson-Whelan, Kim, MacCallum & Kiecolt-Glaser, 1997)—an equal number support the idea that only optimism is measured by the scale (e.g. Vautier, Rafaste & Cariou, 2003). Therefore, in this study, the measure is used as intended by the authors. The range of scores ranges from 0 to 24.

Two models of trait personality are most prominent within the health psychology literature: Eysenck's EPQ model (Eysenck & Eysenck, 1975) and the 'Big Five' model. For the purposes of this study, the latter model was selected.

Most studies in this area of literature have found inconsistent and contradictory findings when measuring the EPQ model. There could be three reasons for this: the model could be inapplicable or unimportant to illness adjustment, the measure could be invalid, or, the model could be too specific in grouping participants on just

three main personality dimensions. The Five Factor model, conversely, categorises personality on five dimensions, a number of which have not yet been explored within this specific area of psychosocial oncology research.

In order to assess the Five Factor personality traits of extroversion, neuroticism, openness, agreeableness and conscientiousness, the NEO-Five Factor Inventory (NEO-FFI) was used (appendix 3.10). This scale was originally developed by Costa and McCrae (1992) and has many formats; the NEO-FFI Form S was used here, a shorter, revised, self-report version of the original NEO-PI R (Costa & McCrae, 1989, 1992). The NEO inventory has wide usage, particularly in clinical and health psychology, and behavioural medicine (Costa & McCrae, 1992) and demonstrates 'excellent psychometric properties' (O'Brien & Delongis, 1994). The inventory manual reports good internal consistency ratings ( $\alpha$  in excess of .56 for individual facet scales); high retest reliabilities (N  $\alpha$ =.87, E  $\alpha$ =.91, O  $\alpha$ =.86, A  $\alpha$ =.66, C  $\alpha$ =.92), particularly over longer periods of time; and satisfactory levels of content, criterion , convergent and discriminate validity (Costa & McCrae, 1992).

Sixty items, for example "I try to perform all the tasks assigned to me conscientiously" or "I tend to be cynical and sceptical of others' intentions", are assessed on a five-point Likert scale. Total scores can then be obtained for each of the five main factors of personality: Neuroticism, Extroversion, Openness, Agreeableness, and Conscientiousness. Total scores for each subscale range from 0 to 48. Normative data mean scores are as follows: Neuroticism = 24.56, Extraversion = 30.49, Openness = 27.82, Agreeableness = 30.14, and Conscientiousness = 30.71, although variability is demonstrated in the literature (e.g. Furham & Bramwell, 2006).

## **3.4.1.3** Appraisals, core-relational themes, and emotion themes

This next set of questions enabled testing of the Transactional Model.

Although a number of studies claim to assess appraisals (often using un-validated, single item scales created for the purposes of their studies), only one measure exists which address each of the three factors of the Transactional Model (cognitive appraisal, core-relational themes, and emotion themes). It is later versions of this measure that have been used to develop later versions of the theory. Smith and Lazarus's measure is rarely used in its entirety, with many researchers instead choosing to focus on just the appraisals and core-relational

themes associated with only six emotions; the so called 'hot' cognitions described more fully in section 1.5.

Three main versions of this measure exist. The original lists eight single item appraisal components, each assessed on a Likert scale ranging from 1-11, which can be distinguished as falling into either primary or secondary appraisal; 54 statements pertaining to thoughts and feelings about the stressor, each assessed on a Likert scale ranging from 1 to 9, which are then grouped into 14 core relational theme subscales; and 50 statements pertaining to emotional reactions, again assessed on a Likert scale ranging from 1 to 9, which are then grouped into 18 emotion themes. For the six hot cognitions, published figures of internal consistency ( $\alpha$ ) for core-relational themes ranged from .71 to .95, and those for their associated emotion themes ranged from .75 to .90.

In a later modification of the scale, Griner and Smith (2000) alter the presentation of the measure. The main appraisal components were not changed, but reworded to suit the particular stressor in question. Additionally, rather than presenting core-relational themes and emotion themes as individual response questions, those statements pertaining to each theme were grouped together and participants were required to provide just one Likert style response to each cluster. A similar approach was later used by Bennett et al. (2003) however, this included an extra eight appraisal questions. Most subscales are equivalent with two exceptions; motivational congruence and motivational incongruence were merged into one component, and an extra item of situational relevance was added, although the authors acknowledge that this related more to what is at stake, rather than an appraisal per se. Test-retest reliability is presented in the 2003 paper and demonstrates high reliability for all but one appraisal component (congruence) and all but two core-relational themes (irrelevance and optimism). Test-retest reliability for the emotion themes was reported to be satisfactory (Bennett et al., 2003).

No study exists in the literature which compares the utility of the three versions, therefore a pragmatic approach was taken and the measure was presented in the least time-consuming manner for participants which is most comparable to that used by Griner and Smith (2000): Appraisal components were presented in the eight single-item format, however, slightly reworded to anchor

the question directly to the cancer event as a stressor (appendix 3.11); and, core relational themes (appendix 3.12) and emotion themes (appendix 3.13) were presented in the later clustered format.

Whereas previous research has tended to limit use of these questionnaires to investigate only the 'hot' cognitions, this study explored a much fuller range. Only two emotions were excluded—affection and sympathy—as these were perceived to be irrelevant to the research question. Therefore, all subscales of appraisal components were used (Primary Appraisals: Motivational Relevance, Motivational Incongruence, Motivational Congruence. Secondary Appraisals: Self-Accountability, Other Accountability, Problem-Focussed Coping Potential, Emotion-Focussed Coping Potential, Future Expectancy); 12 core relational themes were assessed (Other-Blame, Self-Blame, Threat, Loss/Helplessness, Effortful Optimism, Success, Self-Consciousness, Relevance, Unexpectedness, Irrelevance, Lack of Concern and Removal of Threat); and, 15 emotion themes were assessed (Surprise, Guilt, Resignation, Tranquility, Frustration, Self-Directed Anger, Challenge/Hope, Regret, Sadness, Shame/Humiliation, Interest, Happiness, Boredom/Detachment, Anxiety/Fear, Anger and Relief). See section 3.2.3 for theoretical and hypothesised associations between the components.

As these scales often result in a large number of variables, the emotion variables were grouped into two sub-scales: positive and negative emotions.

Again, this made the study more comparable with the literature presented in the systematic review.

## **3.4.1.4** Health control beliefs

Numerous locus of control measures exist which are best compared according to the types of scores created. Whereas some of the early, generic locus of control scales (see for example, Rotter, 1966) were analysed in terms of a continuum representing how internally or externally focused a person's locus was, more recent measures tend to further sub-categorise externality into more independent dimensions. Rather than using a generic locus of control scale, for the purposes of this study a health-oriented scale was selected.

Therefore, the Multi-dimensional Health Locus of Control (MHLC) (Wallston, Wallston & DeVellis, 1978) was chosen to assess how the individual perceives the influence of various sources of control over their own health (appendix 3.14).

Anchored towards the illness specifically, questions such as "Whatever improvement occurs with my condition is largely a matter of good fortune", are comleted using a six-point Likert responses. Total scores for the sub-scales of Internal Health Locus of Control (IHLC), Chance Health Locus of Control (CHLC), Powerful Others Health Locus of Control (PHLC) Doctor Health Locus of Control (DHLC), and General Others Health Locus of Control (OHLC) are obtained, which typically demonstrate alpha levels ranging from 0.67 to 0.77 (Wallston, Malcarne, Flores, Hansdottir, Smith, & Stein et al., 1999). In effect, DHLC and PHLC are further subcategories of OHLC. Into this scale has been added Wallston et al.'s (1999) God Locus of Health Control (GLHC) scale. This component adds a further six items to the questionnaire, for example "God is directly responsible for my condition getting better or worse", and has high internal consistency (0.87 to 0.94) over a range of different illnesses (Wallston et al., 1999).

## 3.4.1.5 Coping

Coping is an important feature of the Transactional Model as it is thought to play a mediating role between cognitive stages of the model and outcome. A more traditional approach comprising problem versus emotion focused coping (e.g. Lazarus & Folkman, 1987) was not adopted for this study. Instead, the Brief COPE was chosen (Carver, 1997) (appendix 3.15). Developed from the much longer COPE (Carver, Scheier & Weintraub, 1989), this short version scale consists of 28 items, each assessed on a four-point Likert scale. The scale has good reliability and validity data with Cronbach alphas ranging from .50 to .90 (Carver, 1997).

Individual items are grouped into 14 subscales ranging in score from 0 to 6 (0-3 per item contributing to each subscale): active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement and self-blame. In accordance with other uses of the Brief COPE, individual subscales can then be merged into two further subscales (based on the results of previous factor analysis), those of adaptive coping and maladaptive coping (score ranges: adaptive, from 0 to 24; maladaptive, from 0 to 18). Please refer to section 1.5 for a discussion of these conceptual categorizations of coping.

#### 3.4.1.6 Current health status

The Short Form 12 General Health Survey (SF-12: Ware, Kosinski & Keller, 1996) is a widely used measure to assess current health status (appendix 3.16). Rather than being a multi-dimensional measure of quality of life, like its predecessor, the SF-36 (McHorney, Ware, Raczek, 1993), the SF-12 aims to provide a generic measure of health status, and despite its brevity, the same dimensions are assessed with similar accuracy (Jenkinson, Layte, Jenkinson, Lawrence, Peterson, Paice et al., 1997). Extensive testing and confirmation of reliability and validity have been reported elsewhere (Ware et al., 1996). Twelve items relating to health perceptions and functional ability during the previous four weeks are assessed using tick box responses. These questions refer to eight-dimensions: Physical functioning; Role limitations due to physical problems; Role limitations due to emotional problems; Social functioning; Mental health; Energy/Vitality; **Pain**; and, General Health Perception. In a rather complex scoring system, scores are weighted, totalled, and added to constant values in order to calculate both an overall physical health component score, and an overall mental health component score.

## 3.4.1.7 Illness specific cognitions

The Mental Adjustment to Cancer Scale (MAC; Watson, Greer & Bliss, 1989) is a very common measure within psychosocial literature. The debate regarding its usage has already been covered in section 2.6.3 and the scale remains worthy of further independent research studies in order to establish the true content validity of the measure. In accordance with the conclusions drawn in the systematic review, for the purposes of this study, the scale was included as a measure of illness specific cognitive appraisals. In contrast to Smith and Lazarus's appraisal components questionnaire which was designed to elucidate appraisals of generic stress, the MAC is constructed to directly ask about the cancer experience. Once again, rather than using the full measure, the short form version, the MiniMAC (appendix 3.17), was used (Watson, Law, dos Santos, & Greer, 1994). The scale has been translated into a number of languages, all of which have good psychometric properties (e.g. Grassi, Buda, Cavana, Annunziata, Torto & Varetto, 2004).

The scale consists of twenty-nine items, for example "I see my illness as a challenge" and "I've had a good life, what's left is a bonus". Each item is assessed

by four-point Likert style responses to calculate total scores (range of scores for each given in parentheses) for five subscales: Helplessness/hopelessness (8 to 32); Anxious Preoccupation (8 to 32); Fighting Spirit (4 to 16); Cognitive Avoidance (4 to 16); and, Fatalism (5 to 20).

## 3.4.1.8 Quality of life

As concluded in the systematic review, a plethora of quality of life measures are available for use; some generic, others cancer-specific. For the purposes of this study, a cancer specific measure was deemed to be most clinically informative. Of the numerous measures available, two stand out as being the most popular, the Functional Assessment of Cancer Therapy (FACT-G: Cella, Tulsky, Gray, Sarafian, Linn, Bonomi et al, 1993) and that devised by the European Organisation of Research in the Treatment of Cancer (EORTC QLQ-C30: Aaronson, Ahmedzai & Bullinger, 1991). Although a recent comparison of the FACT-G and the EORTC QLQ-C30 (Rodary, Pezet-Langevin, Garcia-Acosta, Lesimple, Lartholary & Kaminsky, 2004) claimed the QLQ-C30 to be a slightly more acceptable measure, the results also demonstrated that overall patient preference was relatively equal to each scale. At the time of proposal the FACT had validated cancer-specific component sub-scales for cancer types included in this study, whereas those for the EORTC were still in development. Therefore, the FACT was chosen (appendix 3.18).

The FACT-G consists of 28 items. Questions include, "I am bothered by side effects of treatment" and "I am losing hope in the fight against my illness" are assessed using five-point Likert style scales. The FACT-G is multi-dimensional, and therefore, the total score can also be divided into four sub-scales: Physical well being, social/family well being, emotional well being, and functional well being. For each different cancer site, the appropriate domain 'additional concerns' will be added: FACT-C (colorectal), FACT-P (prostate), FACT-B (breast), and FACT-L (lung) (appendices 3.19 to 3.22 respectively). Alpha levels for the individual scales are upwards of .66 in a range of different samples, with a total scale alpha level reported at .85 to .91 (Ward, Hahn, Mo, Hernandez, Tulsky & Cella, 2004).

### 3.4.1.9 Anxiety and depression

The Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) is perhaps the most commonly used measure of assessment of anxiety and depression within clinical populations both in primary and secondary care (appendix 3.23). Not only does the measure perform well in generic medical research but it is specifically successful when used within samples of cancer patients (for example, see Nelson et al., 1994; Skarstein et al., 2000; Hassannein et al., 2001, 2005). Although the systematic review (Chapter 2) highlighted a number of other measures of anxiety and depression, some of which were used more than the HADS, in respect to clinical applicability the HADS was deemed better; not only is it used more commonly in medical based research than, for example the Profile of Mood States (POMS: McNair, Lorr, Droppleman, 1971), but also has guidance for standardised and validated clinical cut offs. Cronbach alphas are reported at levels up to .76 for the anxiety sub-scale, and .60 for the depression sub-scale (Zigmond & Snaith, 1983). The questionnaire is also demonstrated to have good validity against psychiatric assessment of these conditions (Bowling, 2001).

The HADS consists of 14 items (7 anxiety, 7 depression) for example, "I feel tense or wound up" and "I have lost interest in my appearance". Each item is assessed using Likert style response (0 to 3) and total scores calculated ranging from 0 to 21. Scores of seven or less are considered to be within the 'normal' range; those between eight and ten are considered doubtful, these are those individual that show some signs, but not a clear clinical pattern; scores ranging from 11 to 21 are considered definite clinical cases (Zigmond & Snaith, 1983).

### 3.4.2 Qualitative Component

The nature and length of the questionnaire had potential to cause significant emotional reactions from the participants. Furthermore, when asking such emotive questions in the restrictive ways imposed by Likert scales, there was an anticipation that participants may not have a chance to communicate all that they wanted to. Therefore, participants were given extra space at the end of the questionnaire to make any additional comments which they felt were relevant.

Patients were invited to make comments with the following instruction:

Please use this space below to make any additional comments that you feel are relevant to this study. This may be a more detailed response to particular questions (if so, please try to indicate which one), a description of how answering the questionnaire made you feel, or anything else at all regarding your cancer diagnosis that you may feel to be important to this study, and you would like to share with us. If nothing else, you may wish to simply record how you are feeling to get things off your mind. As with the reminder of the questionnaire, anything that you write here will be kept entirely confidential, so please do feel able to speak freely about any of your thoughts, feelings, and emotions.

This also allowed the participant an opportunity to write about their feelings and emotions following questionnaire completion. Acting in part as an emotional debriefing session (in absence of the presence of a member of the research team), this section was also anticipated to be beneficial to both the patient's psychological wellbeing following participation, and to the researchers in analysis of possible reasons why certain patterns of answers were given. Furthermore, it was expected that some comments would be made regarding more methodological issues which were anticipated to be useful for analysis of drop-out from the current study, and in planning future research.

Answers to this question were not expected to be sufficiently detailed to allow the use of complex interpretative methodologies such as grounded theory (Strauss & Corbin, 1990) or interpretative phenomenological analysis (J. Smith, 2003). A simple content (thematic) analysis was planned.

#### 3.4.3 Clinical Data

The following clinical data were collected for each participant:

- 1. Specific cancer cell type
- 2. Tumour stage at diagnosis
- 3. Treatment plan at diagnosis
- 4. Type of referral (Urgent suspected cancer (USC)/Non USC)
- 5. Date of histological diagnosis
- 6. Waiting time to treatment

Inclusion of items one, two, three and five was based primarily on the results of systematic review (Chapter 3). By including similar data to other studies, findings will be comparable with the literature. Additionally, as the review had highlighted the possibility that these may act as tertiary variables, attempts to fully control for the effects of them was intended. Items four and six were not explored within those studies in the review. However, given that the other clinical data may have a tertiary effect, then it is reasonable to assume that type of referral made and waiting time to treatment may have similar effects.

Due to smaller numbers, for those recruited from Centres B and C, the data were provided by the nurse specialists involved with recruitment. For the much larger sub-sample of patients recruited from Centre A, data were collected by the candidate with assistance from Trust Cancer Services. Using demographic data provided in questionnaires, unique patient identification numbers were identified using the Trust PAS (Patient Administration Service) Database. From these, staff in Cancer Services were able to use the CANISC database to extract type of diagnosis (4) and treatment delay (6). Cancer Services were able to provide researchers with access to MDT meeting minutes from which type of diagnosis (1), stage of diagnosis (2) and treatment plan at diagnosis (3) could be extracted. Finally, the Histology Department in the Trust were able to provide access to the T-PATH database from which exact dates of histological diagnosis were extracted.

### 3.4.4 Questionnaire design

Questionnaire-based surveys are known to suffer from poor response, especially within a population as vulnerable as those with an illness as potentially life threatening as cancer. In order to increase response rate to this study, the questionnaire was designed in accordance with findings from a meta-analysis of postal survey response rates (Edwards et al., 2002). Thus, questionnaires were printed on pale yellow paper; the length was minimised as much as possible without threatening content; letters were personalised and printed on Trust headed paper; envelopes were addressed by hand; pre-paid reply envelopes were provided for return of questionnaires; reminders were posted four weeks after initial approach, at each time point; demographic items (those easiest to answer) were presented first; and, the study was introduced to potential participants by CNSs (an individual familiar to the patient). Edwards et al. (2002) also list a

number of other factors which may be influential in improving response rates including the giving of incentives, postal by recorded or hand delivery, and making contact before delivery of questionnaires. The first two issues were discounted from this study for practical financial reasons; regarding the latter factor, precontact was not possible until consent was provided and to have added another stage, whilst possibly improving response rate, would have substantially lengthened the time taken to recruit the sample, thus reducing the number of people that we were able to follow-up within the time constraints of the project.

### 3.4.5 Psychometric properties

Although the selection of measures used in this study was based in large part on the reliability data in the published literature, statistical tests were carried out to test the internal consistency of all psychological measures used. Such tests allow investigation of anomalies in how these measures performed within the current sample. Table 3.2 summarises this data which can be compared with the published data in section 3.4.1.

Table 3.2. Cronbach alpha reliability statistics calculated from the current data set.

Measure (subscale)	Reliability
Life Onionation Test (Desired)	alpha
Life Orientation Test (Revised)	.74
NEO-FFI	
Neuroticism	.81
Extroversion	.78
Openness	.66
Agreeableness	.64
Conscientiousness	.80
Conscientiousness	.00
Emotion Themes	
Negative	.83
Positive	.70
GD 40 (II - II) G:	
SF-12 (Health Status)  Mental	.55
Physical	.33 .70
r nysicui	./0
MHLoC Scale	
Internal	.73
Chance	.72
General Others	.63
Doctor	.38
Other People	.63
God	.91
MAC Cools	
MAC Scale	.78
Hopelessness/helplessness	.90
Anxious Preoccupation	. <del>5</del> 0
Fighting Spirit	.36 .72
Cognitive Avoidance	.72 .46
Fatalism	.40
Brief Cope	
Active	.69
Planning	.73
Positive reframing	.73
Acceptance	.42
Humour	.83
Religion	.93
Emotional support	.72
Instrumental support	.73
Self-distraction	.55
Denial	.70
Venting	.54
Behavioural disengagement	.56
Self blame	.71
Substance use	.81
Adaptive	.68
Maladaptive	.52

FACT-G Quality of life Scale	
Physical	.82
Functional	.86
Social	.85
Emotional	.80
FACT Cancer specific quality of life Subscales	
Colorectal	.02
Breast	.45
Lung	.35
Prostate	.31
Hospital Anxiety and Depression Scale	
Depression	.85
Anxiety	.89

Most of these statistics compare favourably with those in the published literature and represent sufficient levels of reliability for the current study. LOT reliabilities are equivalent and of a good level and NEO-FFI statistics, whilst slightly lower than those in the scale manual, are of an acceptable to high level. Cronbach alphas for the two emotion theme subscales are high, but as these are newly created scales, there are no published comparison statistics. Subscales of the MHLC scale were lower than those in the literature, but the God Locus of Control scale had reliability equal to the highest published value. The range of alpha values found for the Brief COPE were slightly more dispersed than published values, however, only one subscale (acceptance) fell below the lowest published level. Whilst reliability for the adaptive scale was high, the reliability of the maladaptive subscale was disappointingly low.

With regard the SF-12, the mental health component had a low reliability, but the physical health component scale was more than adequate. Three out of five subscales of the MAC were below published levels, particularly in the case of fighting spirit and fatalism.

Reliabilities for the subscales of the FACT-G were much higher than those previously reported. Those for the additional concerns were found to be less reliable (α all under .45) and, indeed, much lower than published reliability statistics for the FACT-B (Brady, Cella, Bonomi, Tulsky, Lloyd, Deasy et al, 1997), FACT-L (Cella, Bonomi, Lloyd, Tulsky, Kaplan & Bonomi, 1995) and FACT-P (Esper, Mo, Chodak, Sinner, Cella & Pienta, 1997) subscales. The FACT-C (Ward, Hahn, Mo, Hernandez, Tulsky & Cella, 2004) subscale performed especially poortly with a

Cronbach alpha of just .02, By observing alpha statistics in our data, no particular item was responsible for reducing the reliability of these subscales within the current data set and, therefore, scale reliability could not be improved. These subscales were not used in the analysis; quality of life measures were taken from just the FACT-G and it's associated subscales for physical, social, functional, and emotional quality of life.

Reliability on both anxiety and depression subscales of the HADS were higher than published data.

### 3.5 PARTICIPANTS

## **3.5.1** Sample size calculation

Sample size calculations are necessary to ensure that analyses are adequately powered. Power refers to the probability that the proposed analyses will correctly distinguish between the null and experimental hypotheses (Rossi, 1990). A null hypothesis is always one of equilibrium, in other words, that there will be no effect **found (where effect could be an association, difference, regression coefficient etc.)** (Field, 2009). Where a null hypothesis is wrongly rejected, or where an effect is **concluded** to exist where it actually doesn't, it is said that a Type I error has been committed; a Type II error is one where a significant effect is concluded, where in fact, this isn't the case (Rosnow & Rosenthal, 1989; Loftus, 1996). The Greek letter  $\alpha$  is used to represent the probability of a Type I error occurring and the letter  $\beta$  is used to represent the probability of a Type II error occurring. Within psychology, **standard** levels of  $\alpha$ =.05 and  $\beta$ =.20 are used. Power calculations are more strongly geared to minimisation of a Type II error, therefore, a power level of .80 (1- $\beta$ ) is considered acceptable. (Loftus, 1996). Power is determined by three factors: sample size, effect size, and alpha level (Rossi, 1990). Given that  $\alpha$  and  $\beta$  are known entities, estimates of effect sizes from previous research can be used to calculate the required sample size for new research (Wilkinson, 1999). Sample size calculations are typically based on the analysis requiring highest sample size pertinent to the primary outcome variables.

In this study, each of the three outcomes (anxiety, depression and quality of life) were given equal weighting in terms of importance but the theory testing element was considered secondary to this aim. As regression analyses were

planned for this question, study sample size calculations were based on the minimum number of participants required to sufficiently power multivariate linear regressions. It was estimated that fewer than 20 variables would be entered into each analysis after prior selection based on correlation data (for more detail, see section 3.6.3). External advice on sample size calculations and the proposed analyses was sought from both statistical and health psychology experts.

Simultaneous entry of all assessed variables into a regression would be impossible due to collinearity and potential loss of power. In two cases (emotions and coping), the use of grouped variables were planned; although composite scores lose depth of data (as reported in the systematic review), in this case it seemed justifiable as neither grouped variable was a primary outcome variable. Rather, with regard to coping, instead of using scores from each coping subscale, the larger maladaptive and adaptive categories were used (perhaps not an ideal scenario (see section 1.5) but a necessary compromise). Similarly, rather than considering each emotional reaction, grouped totals of positive and negative emotion were used. Initial analysis was proposed to consist of a number of correlation analyses between all predictor and outcome variables. Those variables found to be significantly related with outcome (at p < .01) were then to be entered into regression models (see section 4.5.1.3 for further details of the statistical plan). Although minimising the number of variables to be entered into regression is not the most statistically ideal method (Cohen 1988, cited in Green 1991), it is a pragmatic method often used within psychological research (Tabachnick & Fidell, 2000). Where data collection from large samples is not possible, to enter all possible predictors into regressions, whilst being ideal, would be pointless as regression models would become too saturated and would simply fail. Therefore, some statistical compromise is necessary whilst continuing to address substantial research questions in a meaningful and contributory way.

There is a tradition within the behavioural sciences to use standard 'rules of thumb' for estimates of sample sizes required for regression analyses, where average ratios of five data cases to one variable are required (see for example, Gravetter & Wallnau, 2000; Maxwell, 2000; Tabachnick & Fidell, 2000). Many other rules of thumb have been suggested, some as high as a ratio of 25:1 (Schmidt, 1971, cited in Green, 1991). Green (1991), however, criticises these

methods of sample size calculation because they fail to take into account anticipated effect sizes. In this same paper, Green provides the reader with a list of power analysis calculations for various regression scenarios of differing levels of effect size, and various numbers of predictor variables. The calculations are based on Cohen's statistical tables and in his paper, Green compares these to standard rule of thumb calculations. Green provides an unequivocal argument for superior use of power analysis based sample size calculations.

Due to the proposed method of pre-selection of predictor variables, the number, and specific nature, of predictor variables relevant to the regressions was unknown until analysis began. As an *a priori* estimation, however, the total number were estimated to range between 15-20 variables. Previous research (see Chapter two) typically reports some small, but usually medium effect sizes for these type of predictor variables and it was not expected that this study would differ substantially from this. Therefore, using Cohen's power based calculations (1988, cited in Green, 1991, and Field, 2009), it was deduced that to find a medium effect size ( $R^2 = 0.13$ ), at a power level of .80 (80% chance of detecting an effect within the sample if one truly exists), between 138 and 156 participants (for 15 or 20 predictor variables respectively) would be required. The greater of these figures was, therefore set for the target sample size to ensure that the calculation remained as flexible and conservative as possible.

By observing participation rates in similar studies (e.g. Lowe *et al.*, 2003; Osoweicki & Compass, 1998) it was possible to calculate an estimated response rate in the region of 40%. Accordingly, it was deemed necessary to approach in excess of 390 patients. Considering that 25% of patients were expected to be excluded from the study, the total number of diagnoses needed to achieve this sample size was estimated at approximately 520 new cancer diagnoses.

# 3.5.2 Participant inclusion/exclusion criteria

All patients diagnosed with colorectal, breast, prostate or lung cancer from three North Wales NHS Hospitals (where clinical teams agreed to collaborate with recruitment) were considered for inclusion into the study.

Although any stage of diagnosis was included, any individuals perceived to have advanced disease or a very poor life expectancy at diagnosis (i.e. close to

**death)** were excluded. Exclusion criteria also prevented the following individuals **from** being approached for the study:

- Those who had been diagnosed with cancer, but whom their consultant hadn't yet informed, or who don't seem to understand the implications of their diagnosis.
- Those diagnosed with recurrent cancer.
- Those who had a poor understanding of the English language.
- Those concurrently suffering from any severe developmental,
   learning, or psychiatric conditions which may have impaired their understanding of the questionnaire.
- Any individuals unable to provide consent.
- Any individuals perceived to be at particular vulnerability or distress
  risk through participation (i.e. those perceived by the direct care
  team to have reacted to diagnosis with unusually high distress levels,
  to whom receiving this questionnaire may have a negative impact
  upon their ability to deal with their illness).
- Any individuals diagnosed more than six weeks prior.

Inclusion was determined by the CNS using a standardised inclusion matrix prior to referral into the study (appendix 3.24). This procedure was conducted in the presence of the researcher to minimise selection bias and a reason was recorded for each individual excluded from the study. Reasons for patient exclusion are discussed in section 3.6.5.

# 3.6 PROCEDURE OF RECRUITMENT, DATA COLLECTION AND ANALYSIS

### 3.6.1 Recruitment of participants

# 3.6.1.1 Standardised recruitment procedure

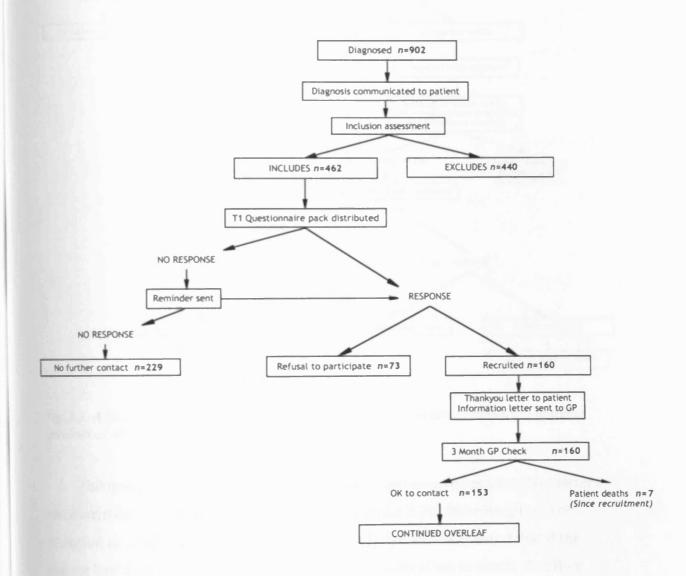
Following the period of project development (see section 3.3.2), and obtaining all relevant ethical and Trust approvals, participant recruitment and data collection became standardised across each clinical team involved in the research.

Initial patient identification. On a fortnightly basis, the researcher met with each nurse specialist team and the previous multi-disciplinary team meeting patient lists were consulted. These lists are a record of all new cancer diagnoses for each cancer site, at each hospital. Participation eligibility was assessed by cancer nurse specialists according to the previously outlined inclusion criteria. Eligible patients were sent questionnaire packs through the post. This comprised an invitation letter (appendix 3.25) introducing the study and research team (signed by the nurse specialist, and printed on Trust headed paper), an information sheet (appendix 3.26), consent form (appendix 3.27), questionnaire pack and a freepost return envelope. All documents sent to participant (with the exception of the pre-validated questionnaire pack) were produced bilingually in both English and Welsh. Translation of the questionnaire pack was not possible as this would have involved a lengthy process of re-validation of the new measures. No patient invited to participate would have been disadvantaged by this as a good understanding of English was stated as inclusion criteria (see section 3.5.2).

**Participants** were asked to provide consent and return the completed **questionnaire** (approximately 30 minutes completion time) directly to the **candidate** at the university. Each nurse specialist retained a list of patients who **had been** approached for the study each fortnight. This list was checked against a **list of** participants (and refusers) in order to identify non-responders. After four **weeks**, a further questionnaire pack was posted to non-responders to act as a **reminder**. For all questionnaires returned, a letter of receipt was sent giving **information** about follow up dates (appendix 3.28). At the request of the ethics **committee**, letters were also written to each participants' GP informing them of **their** patient's participation (appendix 3.29). This advance information about

their patients' participation was also important to expedite later contact with the GP to check whether the patients were still alive pre-follow.

A flow chart of the recruitment process with total recruitment figures at each stage (table 3.2 presents these figures further broken down by both centre and cancer type) is presented in figure 3.3.



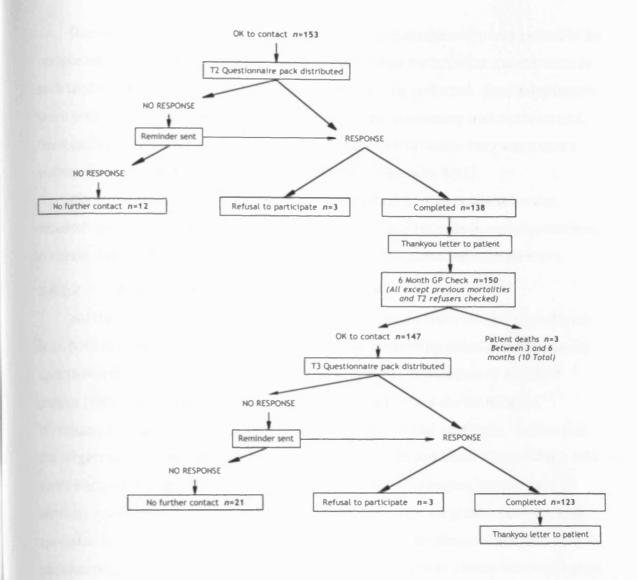


Fig. 3.3. A flow chart diagram of the recruitment process with total numbers of patients involved at each stage.

Follow-up data collection. Prior to sending follow-up questionnaires letters were written to each participant's GP (see appendix 3.30) informing them of intention to send a further questionnaire. The letter also requested that if the patient had died within the past three months, or was close to death, that they inform the research team to avoid any unnecessary upset and distress for families of deceased participants caused by receipt of the questionnaire pack (appendix 4.8). This system worked extremely well and in just two cases, following non-response from the GP, a follow-up questionnaire was sent to a deceased patient. Fortunately, the patient's families were not overtly distressed by this and in each case wrote to inform us of the death. Letters of condolence and apology were returned by the research team.

One week prior to the date of the follow-up, a questionnaire was posted to be completed and returned using the same procedure as for baseline questionnaires such that three and six month follow-up data could be collected. Reminder letters were sent two weeks after this if the completed questionnaire was not returned.

Once each participant had completed their final questionnaire they were sent a written debrief sheet with their letter of thanks (appendix 3.31).

Clinical data collection. Each patient was asked to give consent for the research team to consult their secondary care medical records in order to retrieve accurate data on their clinical condition. All patients provided such consent.

### 3.6.1.2 Clinical teams involved in recruitment

All three centres recruiting patients into the study were similar in that each is an NHS funded district general hospital (DGH) providing acute and community care in North Wales. North Wales has a largely rural population of 674,498 people (Office of National Statistics, 2006), and comprises the counties of Wrexham, Flintshire, Conwy, Denbighshire, Gwynedd and Anglesey. Centre A is the largest of the hospitals and has a total of 697 inpatient beds. Centre B has 684 acute beds whilst and Centre C has just 468. Within this region, cancer care services are currently spread across all three DGHs with surgical, oncology, and specialist nurse teams housed in each. Although some treatments are provided in each hospital, one (Ysbyty Glan Clwyd) is a specialist cancer centre which takes on some treatment of patients from across the entire region. All clinical teams (colorectal, breast, lung and prostate) in Centre A participated in recruitment, however, recruitment of lung cancer patients was temporarily suspended, for a period of four months, whilst the nurse was absent on compassionate leave. A short suspension of recruitment of prostate cancer patients also took place; quite early on in the project it became apparent that two patients had been sent questionnaire packs before receiving a formal diagnosis from the consultant. As this caused great distress for the patient, their family, and (indirectly) both the dinical and research teams, we investigated how this had happened with the assistance of the Trust R&D department. The first inclusion criterion was that patients had to have both received, and seemed to understand, their diagnosis, and this had been met. The situation should have been avoidable. It transpired that the error was due mainly to communication problems within the clinical team. For other cancer sites the nurse specialist was present during a diagnosis consultation but this was not the case with the prostate team. The nurse specialist simply referred all suitable patients on the multi-disciplinary team meeting list after a time delay when one might assume that formal diagnosis had been communicated. The ethics committee were informed and consulted with in order to slightly modify the recruitment procedure. From this point onwards, before sending questionnaire packs to suitable patients, the nurse specialist obtained copies of letters which had been sent from the Trust to the patient's GP confirming that diagnosis had taken place and that the patient had been fully informed of this. The problem did not arise again and thus seemed to have been an isolated incident.

In Centre B, only one clinical team participated (Colorectal). The lung cancer team did not feel that the study was suitable for their patient group and they felt it would cause both too much distress for their patients, and too much additional work for their staff. The breast care team were unable to commit their time to the study due to a large backlog of work following long term sick absence of one of the nurses. Similarly, the prostate nurse took a period of six month sickness leave shortly after the project was set up within this trust. On her return, with only a few months of recruitment left, it was decided not to pursue recruitment here.

For the colorectal team involved, some problems were experienced regarding recruitment, and therefore, in the early stages, recruitment levels were comparatively lower. After many discussions with the team, it became clear that the nurse specialists felt incredibly uncomfortable trying to recruit patients at this early timepoint. They perceived their patients to be too vulnerable so soon after diagnosis. On confirmation that patients could be approached up to four weeks post diagnosis, the nurse specialists began leaving a slightly longer delay before approaching patients, which seemed to improve both their attitude towards their role in the research, and the actual recruitment rates.

In Centre C, the breast care nurses did not have capacity for any further research collaboration due to ongoing commitments. Additionally, we were unable to include the prostate team due to a high level of staff turnover amongst nurses.

## 3.6.2 Participant recruitment rates

Recruitment into this study was challenging. Although this was expected given the nature of the both the study and patient group, the conservative sample recruitment estimates were still realistic. Recruitment from particular teams was especially difficult and many more patients were unsuitable for the study than had originally been anticipated. The initial response from patients who had been sent a questionnaire pack was 5% lower than estimated: the final response percentage was 34.6%. To achieve recruitment in excess of our target sample (156 patients were to be initially recruited), therefore, 462 patients were invited compared to the estimated figure of 390 study invitations. Perhaps of greatest hindrance to recruitment was the number of patients whom nurse specialists excluded from the study: patient inclusion rates were estimated at 75%, however, final figures show that only 51.2% of all patients were eligible for inclusion. Main reasons given by nurse specialists for exclusion are presented in table 3.3. The total number of patients diagnosed required therefore increased from an estimated 700 to a much higher, 902 diagnoses.

Inclusion rates varied substantially between clinical team (ranging from 34.7% to 76.0%). It is possible that this could be due to varying impacts of different diagnoses (i.e. some diagnoses may be perceived to be more serious, or cause greater potential for distress). However, even within cancer type, inclusion rates were variable—colorectal cancer inclusion ranged from 34.7% to 62.0% and lung cancer inclusion ranged from 38.5% to 61.1%—although clear inclusion guidelines were provided, it can be assumed from this variability that inclusion decisions may have been subjectively biased by nurses. Recruitment figures broken down by both clinical team and cancer type are presented in table 3.4 (a simplified version of these, in flow chart format, has already been presented; figure 3.3).

Tab. 3.3. Reasons given by clinical nurse specialists for patient exclusion.

Reason	Number Excluded
Palliative at diagnosis	85
Multiple/other reason	79
Recurrent illness	76
Advanced illness	60
Died before recruitment	32
Too unwell	26
Dementia	17
Private patient	15
Too distressed/Vulnerable	11
Very old/frail	11
Learning disabled/Illiterate/non English speaking	9
Refused treatment/entry into research	6
Physical co-morbidity	5
Psychological co-morbidity	5
Un-communicated diagnosis	2
Blind	1
TOTAL EXCLUDED	440

The combination of both underestimated rates of inclusion and response, in addition to numerous recruitment problems and temporary suspensions, resulted in a much longer recruitment period than anticipated. Had our original estimates been correct, recruitment was expected to take approximately 11 months.

Eighteen months were eventually required, thus moving our recruitment end date from October 2006 to May 2007. Collection of follow-up data was attempted from all those initially recruited who hadn't (a) dropped out of the study, (b) died, or (c) were close to death (judged by their GP). Of 147 approached (by December 2007), 123 contributed to this final stage of data collection.

Tab 3.4. Diagnosis, recruitment and follow up statistics.

		Cent	tre A		Centre B	Cent	re C	Total
	C'Rectal	Breast	Lung	Prostate	C'Rectal	C'Rectal	Lung	10141
Diagnosed	274	269	72	100	59	50	78	902
Excluded	179	108	28	24	34	19	48	440
% of all diagnoses suitable	34.7%	59.9%	61.1%	76.0%	42.4%	62.0%	38.5%	51.2%
Invited	95	161	44	76	25	31	30	462
Refused	19	20	4	21	1	7	1	73
Non Response	46	<b>72</b>	24	36	15	19	17	229
Total Recruited	30	69	16	19	9	5	12	160
% recruitment (of suitable diagnoses)	31.6%	42.9%	36.4%	25.0%	36.0%	16.1%	40.0%	34.6%
Three month follow up:		• • • • • • • • • • • • • • • • • • • •	• • • • • • • • • • • • • • • •	•••••		••••••		
Died	0	2	3	0	0	0	2	7
Sent	30	67	13	19	9	5	10	153
Drop out	0	3	0	0	0	0	0	3
Non response	4	0	2	0	2	0	4	12
Response	26	64	11	19	7	5	6	138
% completed	86.6%	95.5%	84.6%	100%	77.7%	100%	60%	90.2%
Six month follow up								
Died	1	0	2	0	0	0	0	3
Sent	29	64	11	19	9	5	10	147
Drop out	0	2	0	1	0	0	0	3
Non response	3	5	1	2	2	2	6	21
Response	26	57	10	16	7	3	4	123
% completed	89.7%	89.0%	90.1%	84.2%	77.7%	60.0%	40.0%	83.7%
Summary								
Total Invited	95	161	44	76	25	31	30	440
Total Recruited	30	69	16	19	9	5	12	160
Total Died	1	2	5	0	0	0	2	10
Total Drop out	0	5	0	1	0	0	0	6
Total 6 mo responses	26	57	10	16	7	3	4	123
% 6 mo retention	86.6%	82.6%	62.5%	84.2%	77.7%	60.0%	33.3%	76.8%

# 3.6.3 Plan of statistical analyses

# 3.6.3.1 Data input and preparation

All questionnaires were scanned directly into SPSS (v.11) databases using Teleform software and facilities at the University of Wales, Bangor. Once inputted, a random sample (one in every eight datasets) was manually checked against paper questionnaires. No errors accountable to Teleform input were detected. Clinical data was entered by hand directly into SPSS with 20% double checked for accuracy.

Missing data were identified and dealt with using standardised methods detailed in scoring and professional manuals for each respective measure. For the NEO, missing data was replaced using the neutral response category; for the MAC and FACT, mean substitution was used provided that no more than 1 item per subscale was missing. For the SF12, no missing data substitution was applied in compliance with scoring guidelines (Ware et al., 1996). For the LOT and HADS, no missing data guidance is provided and so mean substitution was used, provided that no more than 1 item from each subscale was missing. As the COPE and the appraisal components and core-relational themes questionnaires were assessed using single-item or two-item scales, missing data substitution would have been invalid, and was thus not done.

Where necessary, variables were recoded and respective items reverse scored. Component sub-totals were then calculated and renamed before the databases for each timepoint could be merged to form a single, longitudinal dataset.

#### 3.6.3.2 Initial data checks

Initially, exploratory statistics were calculated for each variable to ensure normality of data, thus defining whether parametric, or non-parametric statistics could be used. Most clinical data were approximately normally distributed except treatment waiting time; various data transformation (e.g. inverse, logarithmic) did not improve the normality of this data, therefore, it was converted into a categorical variable with data divided into quintiles (very short wait, short wait, medium wait, long wait, very long wait). All personality variables were Normally distributed, as were components of locus of control. God Health Locus of Control appeared to demonstrate a half distribution only. Following visual analysis of raw

data and qualitative comments (see section 4.5.3), it was concluded that, in many cases, this scale was only completed by non-religious individuals leading to the irregular distribution. Therefore, for statistical analyses, this scale was excluded.

The majority of appraisal components, core-relational themes, and emotion themes were not normally distributed. This may, in part, be because these were single-item psychometric measures. Emotion subtotals (total positive and total negative) were normally distributed. Similar transformations were carried out on the non-Normally distributed individual coping subscales, but once again, total scores (maladaptive and adaptive) represented Normal distributions. Sub-total scores on the MiniMAC demonstrated near Normal distributions.

Individual FACT subscales were not normally distributed, however, total FACT-G scores were. HADS scores were converted into categorical data using recommended clinical cut-off scores (Zigmond & Snaith, 1984). These scores were used for descriptive analysis. However, for richness of data, raw HADS data was also used in its original format as only a marginal positive skew was evident.

### 3.6.3.3 Data analysis

Initial descriptive statistics on demographic and clinical variables were performed to provide an accurate sample description. Univariate tests were conducted between clinical, demographic and psychological variables using a variety of tests including *t*-tests and Analysis of Variance (ANOVA); their non-parametric equivalents, Mann-Whitney U tests, and Kruskal-Wallis tests; and, Chi squared cross tabulation analyses. Comparative analysis was also performed between responders and non-responders, and also those who died during the six months of study. Paired-samples statistical tests and ANOVA were also used to investigate changes in outcome scores over time in order to gain an accurate clinical representation of the sample.

Objectives one and two. Bivariate correlations (Pearson's parametric and Spearman's Rho non parametric where relevant) were performed between all potential psychological predictor variables (personality and components of the Transactional model) and all outcome variables (anxiety, depression and total quality of life) to determine which factors were significantly associated. Those found to be significantly associated (p<.05) were then entered into a series of regression models (one for each outcome variable). Highly inter-correlated

predictor variables were not selectively excluded from the model; instead, for each model multi-collinearity statistics were obtained and will be discussed. Multiple regression analyses were employed to test longitudinal predictive relationships: time one predictor variables and time two outcomes; time one predictor variables and time three outcomes; and, time two predictors and time three outcomes.

Substantial consideration was given to the method of data entry into these regression analyses. To recap, the primary purpose of these analyses was not full theory testing, but instead a pragmatic approach to identify which potentially modifiable variables could potentially contribute to future intervention research and clinical application.

Although given due consideration, the use of stepwise regression was avoided; due to it's atheorectical, mathematically defined, approach to variable inclusion (Osborne, 2000), these techniques are recommended to be primarily reserved for analyses aimed at exploratory model building (Field, 2009). There is also an argument that stepwise techniques require a much higher sample size to variable ratio, therefore, disregarding this method likely improved the overall power of the study.

Hierarchical regression was also considered, but there is ongoing debate in the literature regarding the specific order in which variables should be entered into analysis, particularly where theory is so influentially used in data collection as was the case in this study. Tabachnick & Fidell (2007) provide a summary of the different standpoints on this issue. The first is that variables should be entered based on proximity to the outcome variable; in this case coping would therefore be entered first moving backwards through the model. The second is that they should be entered based on causality, meaning that in this case, appraisals would be entered into the regression first, because the appraisal is formed before the coping response in this model. This latter approach reflects the method most closely applied in similar studies (Folkman *et al.*, 1986 and Bennett *et al.*, 2003, for example).

Further confusing this issue is the state of empirical evidence behind the Transactional Model; as stated previously, although a well-defined theory, evidence for its valid applicability is lacking. Furthermore, there is ongoing conflict between which order some components (primarily emotions and coping)

should appear (see chapter one for further discussion). Choosing to enter variables into the regression based entirely on theory was concluded, therefore, to be potentially misinformed at this stage of empirical development.

Concurrent entry of all variables at the same time was also avoided; Tabachnick and Fidell (2007) further state that where the aim of regression is to identify which modifiable predictor variables can best predict a modifiable outcome variable, then some distinction should be made between modifiable and non-modifiable (e.g. demographic, clinical or control) variables from the outset.

As a best compromise between all of these methods, therefore, a two-block multiple hierarchical regression model was used, as suggested in Field (2009). In the first block, all non-modifiable and control variables were entered (demographics, clinical variables, health status, previous levels of outcome and trait personality). The residual level of outcome variable from this block (i.e. the proportion of variance not already explained by variables that cannot be changed or modified) was entered as the outcome variable for a second regression block including those predictor variables which were potentially modifiable (health control beliefs, appraisals, emotion, coping etc.). Although there is some ambiguity as to what the MAC measures, consensus within the literature implies that components of the MAC are modifiable and so these were entered into the second block of the regression.

Once again, although some predictor variables were not Normally distributed, and additionally, some outcome measures demonstrated skewed distributions, analysis of residual outputs demonstrated that hierarchical linear regression was an appropriate methodology to use.

Two other forms of regression analysis were considered; first, the use of predictor change scores (i.e. changes between T1 and T2 scores rather than single-point measurement) to predict T3 outcomes, and combinations of both T1 and T2 variables to predict T3 variables. Neither of these options were considered relevant for these specific research questions as previously discussed. Although a model requiring predictor variables to be assessed at two time-points may have the potential to be more statistically powerful, this would not necessarily infer that such a model would be clinically better. Indeed, such forms of multiple-time point predictive assessment may be clinically unfeasible as they require more intensive

psychological monitoring of individual patients over time. Instead, the goal of the chosen analysis was to identify individual combinations of variables at discreet time-points that would have statistical significance and clinical implementation feasibility. In addition to this, changes in predictor variables were furthermore considered unnecessary as initial statistical tests demonstrated there was little statistical change in these variables over the course of the study.

Objective three. To test whether associated components of the Transactional Model vary equivalently over time, correlation analyses were conducted. First, change scores were calculated for each variable (between baseline and 6 month follow-up). The change scores for associated components were then correlated (using Spearman's correlation due to non-normality of the data) in order to explore the size and direction of associated change. Bonferroni corrections were applied to this data to limit Type I error (Rosnow & Rosenthal, 1989; Perneger, 1998).

Objective four. In order to investigate theoretical associations between appraisal components, core-relational themes, and emotion themes, a series of multivariate regression analyses were planned. The concept for these tests was based on a modified version of Bennett et al.'s (2003) testing of the 'hot' cognitions. Bennett et al. conducted three step hierarchical regression analyses for each emotion whereby theoretically relevant appraisal components were entered at step one and theoretically relevant core relational themes were entered at step two. As a test of exclusivity of the model, all other appraisals and core relational themes were entered using stepwise procedures at step three.

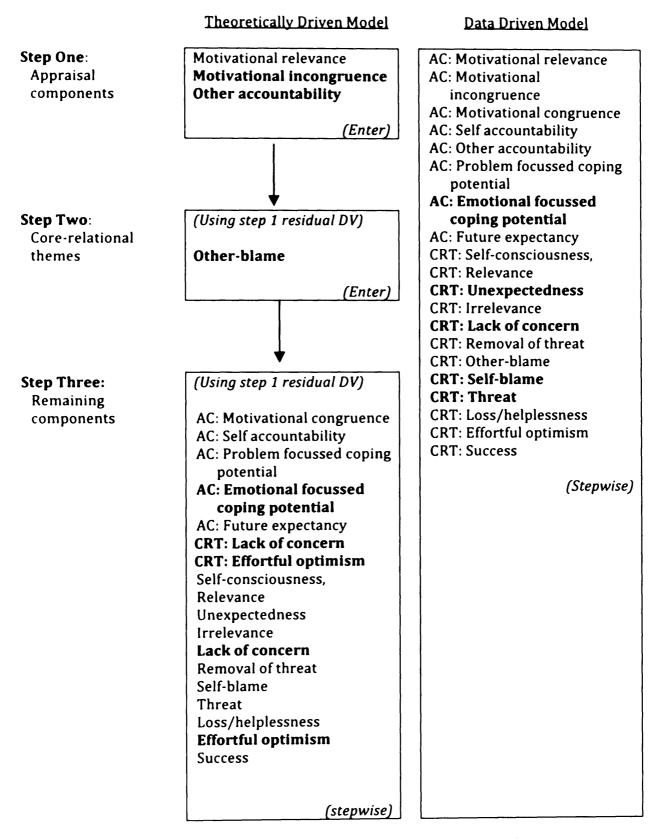
It could be argued that the approach of Bennett *et al.* is statistically biased as initial steps in the regression were 'forced' based on the assumptive theory to be tested. That is, the analyses were not data-driven, but restricted by the theory. Although the final step does test the exclusivity of each model, this may well be biased due to this early 'forced' steps of the regression analysis. A more appropriate approach could have used forward stepwise hierarchical regression to explore the true relationships provided by the raw data, and then comparing these to a further theoretically based regression. This was the approach taken in the current study. Of course there are disadvantages to a data-driven approach too, primarily that the analyses may become too specific to this particular group of

participants and so a replication study would find entirely different results. The respective advantages of each approach are, therefore, considered in the study discussion chapter (Chapter 5).

As with Bennett *et al.'s* (2003) approach, theory tests involved a series of three regressions per emotion. In block one, only those appraisals theoretically relevant to that specific emotion were entered. The residual level of emotion was used as the dependent variable for block two. In this block, the uniquely paired core-relational theme was entered. Again a residual dependent variable was calculated. This was then used as the dependent variable for block three in which all other appraisals and core-relational themes were entered using a forward stepwise approach such that the exclusivity of the theory (blocks one and two combined) could be explored. The data driven approach had just one block of regression whereby all appraisal components and core-relational themes were entered concurrently in a forward stepwise approach. For both stepwise regressions, the criterion for entry was p=.05 and the criterion for exclusion was p=.10). An example of this method (for anger) is presented in figure 3.4.

Overall theoretical and data-driven models were then compared in two ways. First, those variables found to contribute in data driven regressions were compared to their theoretical counterparts to see if the data gathered here support the Transactional Model. Second, the overall variability in emotion explained was compared between theoretical and data driven models in order to explore whether the theoretical models, or indeed, the data driven approach explained more variance, therefore, most accurately representing variable relationships.

As much of the data were found to be non-Normally distributed, alternative methods of regression were considered (e.g. binomial logistic, non-parametric). However, hierarchical linear regression was piloted on a small number of models as it is considered to be a robust statistical test. The Normality assumption for this test is assessed against the residual data rather than raw data. Analysis of standardised residuals for each of these linear regressions demonstrated Normal distributions. Therefore, the use of this methodology was justified and adopted for all models of theory testing.



(Those variables highlighted in **bold** indicate variables which made significant independent contribution to the model at each step)

Figure 3.4. A comparison of theoretically and data driven regressions used in testing of the Transactional Model for anger emotional outcome.

It should be noted that for this specific objective, a cross-sectional design using only baseline data was used. Despite a clear emphasis on longitudinal designs being expressed throughout the remainder of this thesis, a cross-sectional design was used here for two reasons. First, the purpose was not to statistically test clinical outcomes; it was to test a purely theoretical hypothesis. The longitudinal design recommendation expressed earlier in the thesis was largely made with reference to clinical outcome studies, not for theory testing analyses. Furthermore, although some longitudinal association would be expected between components of this model, the current literature (e.g. Lazarus, 1999) implies that changes in these variables would occur rapidly; therefore the three month time-lag between longitudinal data collection in this study was considered inappropriate for theory testing, and would likely introduce further difficulties in detecting relevant effects.

### CHAPTER 4

## **EMPIRICAL INVESTIGATION: RESULTS**

### 4.1 CHAPTER OVERVIEW

This chapter presents all data analyses. Internal consistency data has been reported in the methods chapter (section 3.6.3.2) and so will not be repeated. The first two sections (4.2 and 4.3) present exploratory analyses of the sample; clinical and descriptive data are summarised and comparative analysis is carried out between those who completed all three questionnaires and those who died or failed to respond. Prevalence of each of the main outcomes within this sample then follows (4.4) before analysis of longitudinal changes and inter-correlation between the predictor variables (4.5).

Section 4.6 presents data relevant to thesis question three: this contains both bivariate and multivariate analyses to establish which psychological predictor variables contribute most to each of the main outcomes beyond that predicted by clinical, demographic and control variables. This section concludes with a tentative analysis of when these variables might most effectively be assessed in the clinical setting.

The following two sections (4.7 and 4.8) present data relevant to the theory testing aims of the study. Two approaches are taken. In the first, the longitudinal data set was used to explore correlations between change scores on supposedly associated cognitive and emotional variables. In the second, cross sectional baseline data were used for multivariate analyses testing the uniqueness of the theoretical relationships propounded by Lazarus (1999). For the latter tests, comparisons are drawn between theory driven and data driven models.

The chapter concludes with a thematic analysis of some of the additional comments written by participants at the end of the questionnaire. Data were not sufficient to analyse all emergent themes and so a more focussed approach is taken in exploring comments made related to participants' reflections on their participation in this study.

# 4.2 DEMOGRAPHIC AND CLINICAL DESCRIPTIONS OF THE SAMPLE

Sixty three males and 97 females were recruited, the majority of whom (n=134; 83.8%) were from the North East Wales NHS Trust. The mean sample age

was 64.24 years, however, male patients were generally older than females (Male: M=68.35, SD=8.30, R=49-89; Female: M=61.57, SD=10.09, R=35-80; t(158)=4.45 p<.01). No age differences were found with respect to clinical variables except for cancer type (F(3,156)=8.89, p<.01) where pairwise comparisons demonstrated most difference between prostate and both breast and lung cancer sub-samples (with prostate patients tending to be significantly older).

The majority of participants (*n*=118; 73.8%) identified having a significant other and 17.5% (*n*=28) identified themselves as having dependents. Ethnicity of the sample was 100% white-British. Although this is largely representative of the ethnic distribution in North Wales—the most recent census (2001) revealed that less than 1.2% of the region come from an ethnic minority grouping (National Public Health Service for Wales, 2006)—this does represent some limitation when attempting to extrapolate the findings to other populations. A wide range of qualification status and current employment status were reported.

Recruitment of equal sub-samples of cancer type was not achieved although a comparatively higher proportion of lung patients was recruited (colorectal n=44, 27.5%; breast n=69, 43.1%; lung n=28, 17.5%; prostate n=19, 11.9%; see Chapter 2, Table 2.4, for comparisons). Although all patients were approached within six weeks of diagnosis, there was considerable variability in time between histological diagnosis and recruitment (M=46.12 days, SD=24.81, R=1-116 days). Recruitment delay from diagnosis is further explored by cancer type in table 4.1; although means are relatively equivalent, higher ranges are demonstrated for colorectal and breast sub-samples.

Table 4.1. Differences by cancer group in time (days) between histological diagnosis and consent to participate.

	Mean	SD	Range
Colorectal	46.67	22.90	1-110
Breast	42.88	23.38	9-111
Lung	49.31	34.87	17-110
Prostate	55.41	23.73	27-116

n.b. All participants were approached within six weeks of diagnosis; the remainder of this delay is patient-delay in returning questionnaires.

Referral information was available for 144 of the patients recruited. Whilst 48 (33.3%) were referred as non-urgent suspected cancers, 87 (60.4%) were referred urgently. Three were referred privately (2.1%) and four (2.8%) were of an unknown referral type. Twenty four of the 69 breast referrals were made through the Breast Test Wales screening service. Urgent referrals were more commonly used for the breast and prostate cancer patient sub-samples. This latter finding can be explained primarily by the explicit clinical presentation of symptoms associated with these cancers.

As would be expected, waiting time to treatment was shorter for urgent referrals (1-67 days) compared to non-urgent referrals (3-195 days). As demonstrated in table 4.2 these waiting times were typically longer for colorectal and prostate cancer patients.

Table 4.2. Breakdown of differences in time to treatment by cancer sub-sample.

Waiting		Cancer Sub-Sample								
Time*	Colorectal	Breast	Lung	Prostate	<del></del>					
Very Short	21%	11.9%	38.5%	26.3%	18.9%					
Short	17.9%	28.4%		10.5%	20.5%					
Medium	21.4%	26.9%	7.7%		19.7%					
Long	11.1%	25.4%	46.2%	5.3%	21.3%					
Very Long	28.6%	7.5%	7.7%	44.0%	19.7%					

<sup>\*</sup> See section 3.5.1.2 for definitions of these categories

Just two patients were referred to specialist cancer psychotherapy services, although it is likely that others may have received less formal psychological support or non-cancer specific psychological referral.

Although site-specific clinical data were not available for all patients, the main findings are summarised in table 4.3.

Table 4.3. Clinical description of participants by cancer sub-type.

Colorectal (total n=44)

		Clinic	cal Staging	,		Specific histology	,			Treatment			
	T		N		М		Neoar	djuvant	Surgery	Adji	uvant		
TO	2.8%	NO	66.7%	MO	100%	Moderately differentiated	51.0%	Radio.	35.7%	Laparascopic resection	26.2%	Chem.	52.3%
T1	2.8%	N1	25.0%		'	In situ	26.8%	Chem.	21.4%	Hemicolectomy	21.4%	Radio.	13.6%
T2	33.3%	N2	8.3%		,	Well differentiated	12.2%			Abdominal perineal resection	19.0%		
<i>T3</i>	58.3%	N3	0.0%			Differentiated	7.3%	1		Total colectomy	14.9%		
T4	2.8%	N4	0.0%		'	Poorly differentiated	2.4%	1		Sigmoid colectomy	4.8%		
		· 			······································		· · · · · · · · · · · · · · · · · · ·	<u> </u>		Panprotocolectomy	4.8%		

Chem. = Chemotherapy; Radio. = Radiotherapy

Breast (total n=69)

	Clinica	l Staging		Specific histology	Treatment							
Grade I	Grade II	Grade III	Metastatic		Neoadjuvant Surgery						vant	
19.6%	51.0%	28.0%	1.4%	Invasive ductal	55.0%	Chem.	4.3%	Local excision	54.2%	Chem.	8.7%	
!				Ductal in Situ	21.7%	i		Mastectomy	33.3%	Radio.	55.2%	
				Mixed	11.6%			Local excision & mastectomy	10.6%	Horm.	34.8%	
			i	Invasive lobular	7.2%			Microductectomy	1.4%	Hercep.	1.4%	
İ				Invasive metaplastic	1.4%			-				
				Invasive mucinous	1.4%			Auxillary node clearance	68.1%			
				Paget's disease	1.4%			•				

Chem. = Chemotherapy; Radio. = Radiotherapy; Horm = Homone therapy (Taxmoxifen / Arimidex / Letrazole); Hercep. = Herceptin

Lung (total n=28)

		Clinic	al Staging		Specific histology	•			Treatment			
	T		N	M			Neoad	juvant	Primary Treatmen	nt	Adju	ıvant
TO	10.0%	N0	66.0%	<i>M0</i> 90.0	6   Squamous cell	50.0%	Chem.	7.1%	Chem.	46.4%		
T1	20.0%	N1	0.0%	M1 10.0	6 Adenocarcinoma	14.3%			Lobectomy	17.9%	(Chem.	7.1%)
T2	60.0%	N2	10.0%		Non-small cell carcinoma	14.3%			Radiotherapy	17.9%		
Т3	0.0%	N3	30.0%		Small cell mesothelioma	7.1%			-			
T4	10.0%	N4	0.0%		Carcinoma	7.1%						
					Bronchioalveolar carcin.	3.6%						
					Bronchial adenocarcinoma	3.6%						

Chem. = Chemotherapy; Radio. = Radiotherapy

Table 4.3. Clinical description of participants by cancer sub-type (continued).

Prostate (total n=19)

		Cl	inical Stagin	ıg		Specific histology	Specific histology					
	T		Gleason		PSA	-						
TO	0.0%	1	0.0%	<10	66.6%	Adenocarcinoma	59.0%	Radiotherapy	38.9%			
T1	43.8%	2	0.0%	10-19	16.6%	Bilateral adenocarinoma	23.6%	Hormone therapy	38.9%			
<i>T2</i>	37.5%	3	0.0%	20-29	5.6%	Invasive adenocarinoma	12.0%	Radical therapy	33.3%			
<i>T3</i>	18.7%	4	0.0%	30-39	5.6%	Prostatic intraepithelial neoplasia	5.6%	Surgery	11.1%			
T4	0.0%	5	5.6%	40-49	0.0%	·		Active surveillance	11.1%			
		6	50.0%	50-59	0.0%			Biphosphonate (Zometa)	5.6%			
		7	33.3%	60-69	0.0%							
		8	5.6%	70-79	5.6%							
		9	5.6%									

Chem. = Chemotherapy; Radio. = Radiotherapy

### 4.3 SAMPLE ATTRITION

Of the 160 participants, 38 did not contribute to every timepoint of data collection. Exploration of possible differences between these groups is important to further investigate the generalisability of these findings.

## 4.3.1 Drop out and non-responders

For the purposes of this comparative analysis, study drop-out and follow up non-responders were merged into a single group totalling 28 participants (colorectal n=7; breast n=11; lung n=7; prostate n=3). Those participants who died were excluded from this analysis. These participants were compared with the remainder of the sample on all clinical, demographic, predictor variable, and outcome variables but few variables were found to show significant differences: Those who dropped out were more likely at baseline to report higher self-blame appraisals (U=1314.5, p=<.05) and, higher regret (U=1172.0, p=<.05) shame/humiliation (U=1239.5, p=<.05) and anger (U=1082.0, p=<.05) emotions. These findings may indicate significantly more negative cognitive and emotional reactions to illness within this group.

### 4.3.2 **Deaths**

Ten patients (6.3%) died over the course of this study: one colorectal cancer patient; two breast cancer patients; and seven lung cancer patients. This difference in frequency of death between cancer type was found to be significant ( $\chi^2$ =25.98, p<.01). Although the higher death rate for lung cancer is not surprising, the unequal group sizes mean that following analyses should be considered in a cautionary manner. As would be expected, those referred urgently were significantly more likely to have died in the study than non-urgent referrals ( $\chi^2$ =14.31, p<.01).

Emotional well-being (measured by the FACT) was significantly lower in those who died (t=.219, p<.01). Additionally, those who died also scored higher on negative emotion (t=1.94, p=.05) and lower on positive emotion (t=-.196, p=.05). Significant differences were also found based on relational meaning at diagnosis with those who died scoring higher on 'other blame' U=431.00, p=.02) and 'loss/helplessness' (U=376.00, p<.01). Those who died also scored higher on hopeless/helplessness (t=2.41, t=.02) as measured using the MAC, and also

reported less behavioural disengagement (U=519.00, p=.03) and more self-blame (U-=466.00, p=.02) on the BriefCOPE.

Baseline scores of depression and anxiety were also higher in those who died (t=3.266, p<.01 and t=2.38, p=.02 respectively). No other significant differences were found in those that died.

Taken together, these findings may imply a possible relationship between negative adjustment (higher negative emotion, increased HADS scores, decreased quality of life etc.) and survival. This tentative finding, however, should be treated with caution: these effects may be spurious in nature arising as a result of multicomparison tests.

# 4.4 PREVALENCE OF ANXIETY, DEPRESSION AND QUALITY OF LIFE

In order to explore the psychological characteristics of the sample, a number of tests were conducted. This section will describe the prevalence of each of the main outcome variables—quality of life, anxiety and depression—at each stage of data collection. Descriptive statistics for all outcome variables are presented in table 4.4. Significance levels for stability of each variable are also provided.

Total quality of life is slightly lower at three month follow-up than baseline but returns to a higher level by six months. This change was not significant over time. Analysis of physical and functional subscales demonstrate a similar pattern possibly indicating that the cause of the temporary decrease is physiological in nature (three month assessments were typically made during the most intensive treatment phase). Over the full six months, a significant decrease in social quality of life (Z(106)=-.47, p<.01) was observed, however, emotional quality of life improved over the course of the study (t(116)=-4.65, p<.01). Colorectal, breast, and prostate symptom specific subscales improved significantly over time (t(34)=-8.19, p<.01; t(48)=-7.05, p<.01; t(11)=-6.00, p<.01 respectively), with the effect clearly most pronounced for the prostate subsample. Whilst there is a temporary improvement in lung symptom specific quality of life at three month follow up, this then decreases by six months. This is most likely due to the worse prognosis for this cancer type. Graphical presentation of these results are shown in figure 4.1.

Table 4.4. Descriptive statistics (mean, median, standard deviation, standard error and confidence intervals) for anxiety, depression and quality of life at each timepoint of data collection. Significance levels represent tests of difference between scores at T1 and T3.

	Time	1					Time	2					Time	3					p*
					95% CI	s					95% CI	s					95% CI	's	
	n	М	Med.	SD	Lower	Upper	n	М	Med.	SD	Lower	Upper	n	М	Med.	SD	Lower	Upper	
Quality of life																			
Total	149	84.63	87.00	14.76	82.24	87.02	134	82.04	85.50	15.93	79.31	84.76	116	86.71	89.00	13.16	84.29	89.13	.76
Physical	155	22.30	24.00	5.31	21.46	23.14	135	20.96	22.00	5.81	19.97	21.95	120	22.79	24.00	4.47	21.99	23.60	.79
Social	157	24.46	26.00	4.63	23.73	25.20	135	23.18	24.00	5.23	22.29	24.07	118	22.99	24.00	4.51	22.16	23.80	<.01
Emotional	153	17.46	18.00	4.94	16.70	18.28	136	18.52	20.00	4.55	17.75	19.29	118	19.50	20.00	368	18.83	20.17	<.01
Functional	155	20.00	21.00	5.99	19.05	20.95	136	19.20	20.00	6.38	18.11	20.28	120	21.30	22.00	5.14	20.10	21.96	.56
Cancer Site-Spec	ific Oua	lity of Li	fe																
Colorectal	43	13.39	14.00	2.96	12.39	14.21	37	19.35	20.00	4.35	17.78	20.91	35	20.86	22.00	4.74	19.26	22.52	<.01
Breast	66	12.49	12.00	5.39	11.16	13.81	64	23.23	25.00	7.09	21.46	25.00	52	24.12	26.50	7.11	22.14	26.10	<.01
Lung	26	15.96	16.00	4.42	14.17	17.75	15	18.72	19.00	5.28	15.80	21.64	11	17.09	17.00	4.72	13.92	20.26	.72
Prostate	18	18.46	18.00	4.42	16.26	20.66	19	31.29	33.00	7.46	27.69	34.88	12	33.00	34.00	8.25	27.76	38.24	<.01
HADS Scores																			
Anxiety	158	6.62	6.00	4.57	5.90	7.34	136	5.78	5.00	4.45	5.02	6.52	122	5.29	5.00	3.47	4.66	5.90	<.01
Depression	158	3.40	2.00	3.51	2.84	3.95	136	4.08	3.00	3.65	3.49	4.70	122	3.41	3.00	3.04	3.96	3.76	.01

<sup>\*</sup>The p-value presented here is the result of a t-test based (or non-parametric equivalent where relevant) on only the sub-sample who completed all timepoints of data collection and should not be read as a direct test of comparison between means presented for full cross-sectional samples also in the table.

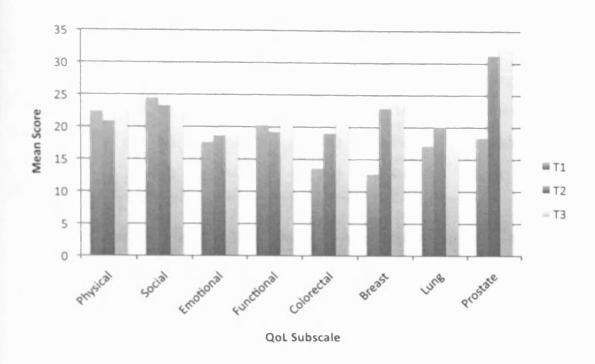


Fig 4.1. Graphical display of trends over time for all QoL subscales (physical, social, emotional and functional are means from the full sample: colorectal, breast, lung and prostate are means for their respective sub-samples).

As would be expected given that quality of life improved over time, anxiety levels significantly decreased over time (Z=-3.49, p=<.01). Depression levels also show an overall decrease through the study (Z=-2.45, p=.01) although there was a slight non-significant increase in mean score at three month follow up.

To further explore longitudinal changes in anxiety and depression, scores were converted categorically according to standardised cut-off scores (Zigmond & Snaith, 1983) for normal caseness, borderline caseness, and probable caseness (see table 4.5).

Table 4.5. Number of participants in each HADS caseness category by time (n=123).

	Tin	ne One	Tir	ne Two	Tim	e Three
	Anxiety	Depression	Anxiety	Depression	Anxiety	Depression
Non-Case	84	111	87	96	84	99
Non-Case	(68.3%)	(90.2%)	(73.7%)	(82.1%)	(75.0%)	(88.4%)
Borderline Case	21	8	17	11	21	9
borderine case	(17.1%)	(6.5%)	(14.4%)	(9.4%)	(18.8%)	(8.0%)
Probable Case	18	4	14	10	7	4
riodable case	(14.6%)	(3.3%)	(11.9%)	(8.5%)	(6.2%)	(3.6%)
Missing	2	2	7	8	13	13

For ease of interpretation, these scores are also presented in figures 4.2 and 4.3 which display trends of change over time for mean scores of anxiety and depression respectively based on baseline caseness categorisation. These figures allow a more in-depth analysis of whether different baseline status predicts different adjustment patterns over the six months of the study.

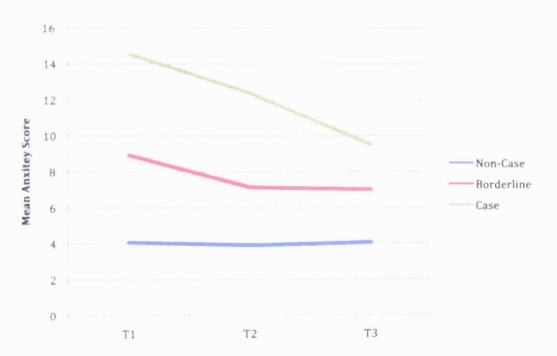


Fig 4.2. Graphical display of trends over time for anxiety (n=110).

Of particular note here are differences between groups. Those originally categorised as non-cases, remained that way. Borderline cases show early improvement with scores decreasing into the non-case score range by three month follow up and stabilising from this point forward, albeit at a higher mean score than the original non-cases. Those scoring within the case range at baseline show

continued improvement throughout the study, although their mean scores do not decrease into the borderline score-range until six month follow up.

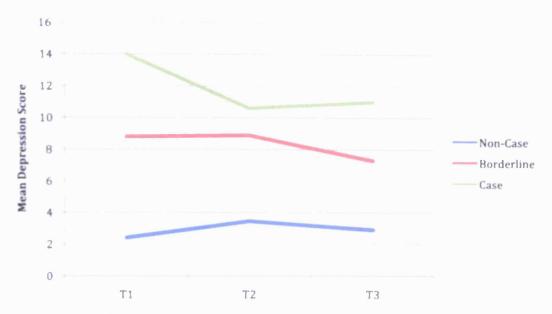


Fig 4.3. Graphical display of trends over time for depression (n=110).

There was just a slight increase in depression scores at three month follow up for the non-cases, but their scores in general remained fairly stable. Unlike anxiety scores, the borderline cases do not show any early improvement; remaining stable between baseline and three month follow up, this group do not improve until six month follow up when their mean scores fall just within the top end of the non-case score range. Those participants initially scoring within the clinical caseness range of scores show marked improvement in the first three months of the study with mean scores decreasing by M=3.4, almost enough to bring them within the borderline range. However, between three and six month follow up a slight increase in scores is observed again indicating worsening levels of depression for this sub-group of participants.

It is important to regard these changes over time with caution due to small sample sizes in the borderline and case categories, however, they seem to indicate different adjustment trajectories depending on initial distress levels.

## 4.5 EXPLORATORY ANALYSIS OF PREDICTOR VARIABLES

Exploratory analysis of the longitudinal changes in, and correlation between, each of the psychosocial predictor variables is important to inform and interpret later multivariate analyses. Descriptive data for the psychological variables are presented in table 4.6.

#### 4.5.1 Longitudinal stability of predictor variables

Standard deviations and ranges for each of the trait personality variables indicated a wide spread of scores on each were evident within the sample. As would be expected, optimism was found not to be stable over time (t=2.72, p<.01) but trait personality variables generally were, the only exception being a comparison between baseline and later levels of conscientiousness. Similarly, a range of scores were reported for health control beliefs. As with personality variables, some significant changes over time are reported. General and other people subscales of locus of control decreased over time although, in reality, the sizes of these differences are minimal.

A much higher level of anxious preoccupation on the MAC was found than for any other MAC subscales at baseline. Where the majority of MAC subscales remained stable over time, scores on anxious preoccupation were found to significantly decrease over time (t=2.78, p<.01).

Surprisingly low scores on appraisals of motivational relevance were reported; the appraised importance of the cancer diagnosis seems to be limited within this sample. Furthermore, changes on scores of motivational (in)congruence indicate that over the course of the study, participants in general perceived less incongruence between their cancer and other aspects of their life (Z=-5.15, p<.01). Other-accountability appraisal scores are higher than self-accountability appraisals. Comparatively higher scores may indicate that participants perceived themselves more able to emotionally cope with cancer than to practically deal with it. Despite the relatively good clinical prognosis for most of this sample, future expectancy scores were low at baseline, and remained this way throughout each stage of data collection; participants were not confident of a positive outcome.

Table 4.5. Descriptive statistics for all psychological predictor variables at each point of data collection.

		1	1			T	2	The Control of the Co	- Annual Contact (Annual Contact of the Contact of	T	3		
Variable	CT*	SD	Min	Max	CT•	SD	Min	Max	CT*	SD	Min	Max	P_
Personality													
Optimism	16.01	5.01	1.00	24.00	16.49	4.71	3.00	24.00	17.34	4.80	3.00	24.00	<.01
Neuroticism	17.27	7.82	1.00	38.00	18.53	10.09	0.00	67.00	15.46	7.66	0.00	36.00	.30
Extroversion	28.92	6.61	13.00	42.00	28.26	7.17	11.00	42.00	28.37	6.48	7.00	42.00	.07
Openness	25.06	5.95	9.00	41.00	25.43	6.27	9.00	40.00	26.24	6.33	8.00	40.00	.25
Agreeableness	34.47	5.14	19.00	45.00	34.27	5.17	22.00	44.00	34.37	5.08	22.00	46.00	.22
Conscientiousness	36.68	5.97	20.00	48.00	36.48	5.67	18.00	48.00	35.94	5.72	21.00	48.00	<.05
Health Locus of Control													
Internal LoC	17.34	5.82	6.00	35.00	16.38	5.25	6.00	28.00	16.64	6.17	6.00	34.00	.14
Chance LoC	21.18	6.35	6.00	34.00	21.08	7.17	6.00	36.00	21.27	6.73	7.00	36.00	.39
General Others LoC	28.54	5.03	14.00	36.00	27.13	5.41	12.00	36.00	27.40	5.22	14.00	36.00	<.01
Doctor LoC	15.50	2.38	6.00	18.00	14.82	15.03	2.59	7.00	15.43	2.30	10.00	18.00	.49
Other People LoC	13.04	3.68	3.00	18.00	11.75	12.10	3.94	3.00	11.99	3.86	3.00	18.00	<.01
Mental Adjustment to Cancer													
Hopelessness/Helplessness	11.75	3.73	8.00	26.00	11.60	4.23	8.00	28.00	11.41	3.80	8.00	26.00	.79
Anxious Preoccupation	19.75	6.09	8.00	32.00	18.70	5.61	8.00	31.00	18.47	5.20	8.00	32.00	<.01
Fighting Spirit	13.35	2.13	4.00	16.00	12.99	2.38	7.00	16.00	13.20	2.58	5.00	13.00	.89
Fatalism	14.54	2.64	8.75	20.00	14.30	2.85	6.00	20.00	14.37	2.45	9.00	20.00	.45
Cognitive Avoidance	10.32	2.71	4.00	16.00	10.10	2.81	4.00	16.00	10.12	2.66	4.00	16.00	.76
Appraisal Components													
Motivational Relevance	1.00	/	3.00	11.00	1.00	1.74	5.00	11.00	1.00	1.43	4.00	11.00	.14
Motivational Incongruence	5.00	/	1.00	11.00	4.50	1.78	1.00	11.00	4.00	4.37	1.00	11.00	<.01
Motivational Congruence	8.00	,	1.00	11.00	8.00	2.42	1.00	11.00	10.00	2.54	1.00	11.00	.53
Self-Responsibility	1.00	/	1.00	11.00	1.00	2.28	1.00	11.00	1.00	2.23	1.00	11.00	.78
Other Responsibility	4.50	,	1.00	11.00	3.00	2.11	1.00	11.00	1.00	2.22	1.00	11.00	.51
Future Expectancy	2.00	,	1.00	11.00	2.00	2.12	2.00	11.00	2.00	2.25	1.00	11.00	.46
Problem Focussed Coping Potential	4.00	,	1.00	11.00	<i>2</i> .95	3.00	1.00	11.00	4.00	3.09	1.00	11.00	.15
Emotion Focussed Coping Potential	8.50	./	1.00	11.00	10.00	1.83	3.00	11.00	9.000	1.92	3.00	11.00	.41

Table 4.5. Descriptive statistics for all psychological predictor variables at each point of data collection (continued).

		and the same and t	- Annual Marie Control of the Contro	A MARIE AND THE CONTROL AND ARREST OF THE CONTROL O									
Core-Relational Themes											4.00		4.7
Self Consciousness	6.5 <i>0</i>	/	1.00	8.00	1.00	1.20	0.00	8.00	1.00	1.36	1.00	9.00	.47
Relevance	1.00	/	1.00	9.00	7.00	2.24	1.00	9.00	7.00	2.25	1.00	9.00	<.01
Unexpectedness	1.00	/	1.00	9.00	7.00	2.70	1.00	9.00	7.00	2.50	1.00	9.00	.93
Irrelevance	<i>5.50</i>	/	0.00	9.00	1.00	1.95	1.00	9.00	1.00	2.08	1.00	9.00	.01
Lack of Concern	1.00	/	1.00	9.00	4.00	2.63	1.00	9.00	5.00	2.82	1.00	9.00	<.01
Removal of Threat	1.00	/	1.00	9.00	<i>5.00</i>	2.89	1.00	9.00	5.00	2.79	1.00	9.00	<.01
Other-Blame	6.5 <b>0</b>	/	1.00	9.00	7.00	1.70	1.00	8.00	1.00	1.26	1.00	7.00	.84
Self-Blame	1.00	/	1.00	9.00	1.00	1.45	1.00	9.00	1.00	1.13	1.00	8.00	.92
Threat	3.00	/	1.00	9.00	2.00	2.45	1.00	9.00	2.00	2.25	1.00	9.00	<.01
Loss/Helplessness	1.00	/	1.00	9.00	1.00	1.91	1.00	9.00	1.00	2.24	1.00	9.00	.68
Effortful Optimism	6.00	/	1.00	9.00	8.00	2.21	1.00	9.00	7.00	2.14	1.00	9.00	.08
Success	1.50	/	1.00	9.00	5.00	2.92	1.00	9.00	6.00	2.59	1.00	9.00	<.01
Emotion Themes													
Surprise	1.00	/	1.00	9.00	5.00	2.90	1.00	9.00	6.00	2.77	1.00	9.00	.71
Guilt	8.00	/	1.00	9.00	1.00	1.34	1.00	7.00	1.00	1.59	1.00	9.00	.80
Resignation	7.00	/	1.00	9.00	1.00	2.02	1.00	9.00	1.00	2.19	1.00	9.00	.83
Tranquillity	1.00	/	1.00	9.00	5.00	2.37	1.00	9.00	5.00	2.28	1.00	9.00	.54
Frustration	4.00	/	1.00	9.00	3.00	2.66	1.00	9.00	2.00	2.56	1.00	9.00	.27
Self-Directed Anger	2.00	/	1.00	9.00	1.00	2.22	1.00	9.00	1.00	1.78	1.00	8.00	.73
Regret	1.00	/	1.00	9.00	1.00	1.82	1.00	9.00	1.00	2.00	1.00	9.00	.86
Sadness	3.00	1	0.00	9.00	3.00	2.63	1.00	9.00	2.00	2.58	1.00	9.00	.94
Shame/Humiliation	1.00	/	1.00	9.00	1.00	1.40	1.00	9.00	1.00	1.30	1.00	7.00	.04
Interest	8.00	/	1.00	9.00	6.00	2.53	1.00	9.00	6.00	2.63	1.00	9.00	.90
Happiness	2.00	/	0.00	9.00	2.00	2.59	1.00	9.00	2.00	2.54	1.00	9.00	.12
Boredom/Detachment	11.00	/	1.00	9.00	1.00	1.24	1.00	7.00	1.00	1.63	1.00	9.00	.34
Anger	1.00	,	0.00	9.00	1.00	2.31	1.00	9.00	1.00	2.23	1.00	9.00	.82
Relief	9.50	/	1.00	9.00	4.00	3.13	1.00	9.00	5.00	3.14	0.00	9.00	.01
Hope/Challenge	8.00		2.00	13.49	15.00	3.74	2.00	18.00	15.00	3.85	2.00	18.00	.90
Fear/Anxiety	9.00	./	2.00	18.00	8.00	5.37	2.00	18.00	8.00	4.94	2.00	18.00	.13
Total Positive	35.81	10.85	7.00	61.00	36.27	10.46	11.00	71.00	37.54	10.18	15.00	63.00	.09
Total Negative	31.09	15.42	11.00	84.00	30.15	15.32	11.00	71.00	25.50	15.57	11.00	79.00	.73

Table 4.5. Descriptive statistics for all psychological predictor variables at each point of data collection (continued).

					NAMES OF TAXABLE PARTY OF TAXABLE PARTY.	and a second control of the second	a company of the company of the company	Appearance of the second second second second			40.00		
Coping											0.00	. 00	n.
Active Coping	4.00	/	0.00	6.00	4.00	2.97	0.00	6.00	4.00	1.77	0.00	6.00	.86
Planning	3.00	/	0.00	6.00	3.00	1.84	0.00	6.00	3.00	1.99	0.00	6.00	.21
Positive Reframing	3.00	/	0.00	6.00	3.00	1.77	0.00	6.00	3.00	1.76	0.00	6.00	.08
Acceptance	6.00	1	1.00	6.00	6.00	1.23	0.00	6.00	5.00	1.33	0.00	6.00	.97
Humour	2.00	/	0.00	6.00	2.00	2.03	0.00	6.00	2.00	1.91	0.00	6.00	.04
Religion	0.00	1	0.00	6.00	0.00	2.07	0.00	6.00	0.00	2.16	0.00	6.00	.44
Emotional Support	5.00	,	0.00	6.00	5.00	1.85	0.00	6.00	4.00	1.72	0.00	6.00	<.01
Instrumental Support	4.00	,	0.00	6.00	3.00	1.81	0.00	6.00	3.00	1.85	0.00	6.00	.05
Self-Distraction	4.00	,	0.00	6.00	3.00	1.80	0.00	6.00	3.00	1.76	0.00	6.00	<.01
Denial	0.00	,	0.00	6.00	0.00	1.73	0.00	6.00	0.00	1.54	0.00	6.00	.43
Venting	0.00	,	0.00	6.00	1.00	1.45	0.00	6.00	0.00	1.33	0.00	6.00	.77
Substance Use	0.00	,	0.00	6.00	0.00	0.09	0.00	6.00	0.00	1.13	0.00	4.00	.06
Behavioural Disengagement	0.00	,	0.00	6.00	0.00	1.16	0.00	5.00	0.00	0.99	0.00	5.00	.93
Self-Blame	0.00	,	0.00	5.00	0.00	1.19	0.00	6.00	0.00	0.94	0.00	5.00	.70
Total Adaptive Coping	26.25	7.97	0.00	45.00	25.22	8.08	4.00	46.00	25.58	8.64	2.14	43.00	.09
Total Maladaptive Coping	7.10	4.54	0.00	24.00	6.74	5.22	0.00	29.00	6.22	4.10	0.00	18.00	.06
Health Status													
Physical	42.53	11.55	15.97	62.06	49.60	10.89	17.00	58.94	42.79	10.28	17.60	59.92	.39
Mental	49.04	9.89	16.98	63.53	49.60	10.81	15.05	65.08	51.96	8.77	26.56	66.10	.03

<sup>\*</sup>CT=Central Tendency. Those shown in standard font refer to a mean as these data were normally distributed. Those in italics are a median as these variables were non-normally distributed. Standard deviations are included only for normally distributed data.

Although a range of scores were reported on the importance of each corerelational theme for each participant, analysis of changes over time demonstrated
significant changes in these cognitions. At baseline, the highest median
frequencies were for self-consciousness, situational irrelevance, other-blame and
effortful optimism. At six-month follow-up, however, relevance, unexpectedness,
lack of concern, threat removal, effortful optimism and success are most frequently
reported. Whilst those frequently reported at baseline did not significantly
change, those which were absent but then later became more frequently reported
represent significant change. Median scores on emotion themes were not found to
significantly change over time. The most frequently reported emotions were guilt,
resignation, detachment, fear/anxiety, relief, and hope/challenge reflecting a
varied emotional response to cancer diagnosis within this sample. Participants
reported far more use of adaptive coping strategies than maladaptive coping
strategies, particularly acceptance and seeking emotional support.

Where perceived physical health status was stable, perceived mental health status significantly improved over time (t=2.19, p<.01).

### 4.5.2 Correlations between predictor variables

A relatively high degree of co-variance would be expected between the predictor variables; they are, after all, variations in psychological responses to the same stressor. For the current purpose, only predictors at baseline and three-month follow-up were used in multivariate analyses. Therefore, correlation analysis was conducted between all predictor variables at these timepoints. Tables 4.7 and 4.8 display the correlation matrices for these variables.

Table 4.7. Concurrent correlation matrix of baseline predictor variables (effect size displayed; \*p<.05; \*\*p<.01)

									Correl	ation Effe	ect Size							
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1	Optimism	1.00	59**	.34**	.21**	.17*	.23**	12	- 15	.10	20*	.00	·.37**	33**	.28**	18 <b>*</b>	.03	.07
2	Neuroticism		1.00	46**	24**	.33*	35**	.16*	.18*	05	17*	.04	.51**	.46**	27**	.16*	.03	.14
3	Extroversion			1.00	.07	23**	.43**	06	03	05	.11	14	24**	07	.34**	.05	.05	.20*
4	Openness				1.00	.10	.05	12	10	01	.06	05	15	21**	.08	26**	.15	06
5	Agreeableness					1.00	.18*	11	21*	07	.03	11	24**	19*	.10	04	.01	12
6	Conscientiousness						1.00	30	.00	.10	.19*	.00	11	.06	.25**	- 06	.09	.23**
7	Internal LoC							1.00	.09	.14	.12	.11	.16*	.17*	.10	.01	.10	03
8	Chance LoC								1.00	.07	00	.09	24**	.15	04	.32**	.12	.21
9	General Others LoC									1.00	.73**	.90**	04	.07	.15	.12	.23**	.18*
10	Doctor LoC										1.00	.34**	21**	07	.25**	.15	.29**	.22*
11	Other People LoC											1.00	.08	.14	.04	.07	.13	.06
12	Hopelessness/Helplessness												1.00	.62**	18*	.14	.18*	02
13	Anxious Preoccupation													1.00	.01	.27**	.09	.12
14	Fighting Spirit														1.00	.07	.19*	.05
15	Cognitive Avoidance															1.00	.24**	07
16	Fatalism																1.00	04
17	Motivational Relevance																	1.00

Table 4.7. Concurrent correlation matrix of baseline predictor variables (effect size displayed; \* p<.05; \*\*p<.01)(continued).

		18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34
1	Optimism	01	05	09	17*	.33**	.23**	.35**	20*	.21*	06	07	07	06	22 <b>**</b>	15	28**	34**
2	Neuroticism	.12	04	.11	.26**	27**	18°	42**	.20*	.08	.08	.03	.04	.08	.29**	.17*	.38**	.43**
3	Extroversion	.15	.01	11	20°	.22**	.26**	.22**	15	03	.12	07	11	07	11	07	11	18*
4	Openness	12	10	.06	.04	08	02	.04	.01	.12	21**	00	02	02	08	.04	06	14
5	Agreeableness	00	01	11	20*	.02	.00	.14	25	05	- 10	- 08	.00	09	33**	17°	.20*	- 20°
6	Conscientiousness	.15	02	10	05	.09	.12	.13	10	01	.14	40*	18*	14	06	14	.00	06
7	Internal LoC	15	.22**	.07	.13	04	.13	05	.17*	.07	02	.06	.10	.14	.09	.19*	.02	.17*
8	Chance LoC	.12	06	.16	.02	09	09	09	.10	.05	.02	.11	.12	.03	.04	04	.06	.13
9	General Others LoC	04	.01	.08	.11	.09	.05	.01	.04	.27**	.02	01	.19*	.18*	08	10	.03	.02
10	Doctor LoC	.21*	14	.13	.60	06	.14	.07	.10	02	.22**	.04	.08	.09	.17*	07	09	05
11	Other People LoC	067	.12	.34**	09	.18*	.04	.00	1	.06	.23**	01	03	.14	04	07	.07	.03
12	Hopelessness/Helplessness	03	05	12	01	.18*	35**	24 <sup>**</sup>	42**	.24**	.10	.00	.08	04	.32**	.16*	.41**	.44**
13	Anxious Preoccupation	.70**	.08	.53**	01	.24**	28**	21 <sup>••</sup>	50**	.11	.28**	.27**	06	28**	.35**	.14	.64**	.56**
14	Fighting Spirit	04	.41**	.14	.07	03	.19*	.28**	.22**	11	.19*	.16*	.00	04	03	00	07	08
15	Fatalism	.11	.05	.37**	12	.06	10	.02	.00	07	.14	.08	.03	.12	.09	02	.02	.05
16	Cognitive Avoidance	.05	.21**	.05	13	.05	08	08	10	.02	13	.28**	.04	04	.12	04	.11	.22**
17	Motivational Relevance	.55**	22**	13	.13	.06	.04	.01	.00	.23*	.13	13	11	07	.17*	03	.23**	.20*
18	Motivational Incongruence	1.00	49**	.17*	.09	.04	06	12	.03	.14	.17°	00	07	- 16	.12	13	.12	.07
19	Motivational Congruence		1.00	.02	12	.07	.12*	.07	10	- 21*	07	01	04	.10	05	.17*	13	11
20	Self-Responsibility			1.00	.25**	28**	11	08	2.6	02	09	.03	01	.10	.12	.39**	.07	.16*
21	Other Responsibility				1.00	15	.02	11	.01	.15	.03	08	.04	.14	.47**	.15	.28**	.24**
22	Future Expectancy					1.00	.51**	.49**	16°	08	.11	.03	.12	.34**	38**	18°	36**	43**
23	PF Coping Potential						1.00	.37**	13	04	02	01	.01	.21**	10	.05	22**	29**
24	EF Coping Potential							1.00	18*	12	.01	02	.15	.17*	29**	09	53**	46**
25	Self Consciousness								1.00	02	1	.45**	.12	.09	.19	.27**	.19*	.34**
26	Relevance									1.00	09	02	01	08	.10	.06	.25**	.10
27	Unexpectedness										1.00	.01	.10	.00	.10	09	.04	.11
28	Irrelevance											1.00	.31**	.31**	.09	.24**	.03	.13
29	Lack of Concern												1.00	.49**	.00	.12	19	05
30	Removal of Threat													1.00	03	.08	22**	0 <del>9</del>
31	Other-Blame														1.00	.27**	.47**	.50**
32	Self-Blame															1.00	.13	.31**
33	Threat																1.00	.69**
_34	Loss/Helplessness																	1.00

Table 4.7. Concurrent correlation matrix of baseline predictor variables (effect size displayed; \* p<.05; \*\*p<.01)(continued).

		35	36	37	38	39	40
1	Optimism	.21**	05	.28**	26**	.08	36**
2	Neuroticism	05**	.00	45**	.50**	03	.40**
3	Extroversion	.18*	.07	.11	09	.30	07
4	Openness	.05	11	01	17*	.19*	11
5	Agreeableness	10	10	05	23**	.06	14
6	Conscientiousness	.14	.02	.15	.02	.14	03
7	Internal LoC	.15	.09	.17*	.22**	.21*	.24**
8	Chance LoC	.13	.18*	.11	.05	.03	.22**
9	General Others LoC	.06	.10	.13	02	.05	08
10	Doctor LoC	.09	.07	.14	05	.13	14
11	Other People LoC	.02	.07	.09	.00	02	02
12	Hopelessness/Helplessness	14	00	26**	.40**	11	.32**
13	Anxious Preoccupation	.00	21°	30**	.66**	.06	.56**
14	Fighting Spirit	.33**	02	.25**	00	.40**	.61
15	Fatalism	08	.07	.00	.98	.00	.46
16	Cognitive Avoidance	04	.03	05	.16	.06	.34**
17	Motivational Relevance	.12	00	03	.21*	.18*	.22**
18	Motivational Incongruence	.08	13	15	.12	04	.21**
19	Motivational Congruence	80	.05	.22**	06	01	14
20	Self-Responsibility	03	.09	.07	.16	.08	.13
21	Other Responsibility	08	.03	01	.28**	10	.18*
22	Future Expectancy	.28**	.32**	.38**	29**	.01	22 <b>**</b>
23	PF Coping Potential	.37**	.21*	.40**	07	.12	09
24	EF Coping Potential	.24**	.23**	07	41**	.04	25**
25	Self Consciousness	.06	.11	.09	.20*	.02	.07
26	Relevance	.17*	20*	.12	.23**	.07	.11
27	Unexpectedness	.20*	.11	.07	.21**	.147*	.16
28	Irrelevance	.12	.13	.31**	.03	.02	16
29	Lack of Concern	.10	.31**	.38**	17*	07	14
30	Removal of Threat	.06	.67**	14	.10	01	21°
31	Other-Blame	04	00	02	.38**	10	.22**
32	Self-Blame	.12	.12	23**	.32**	01	.21*
33	Threat	10	23**	31**	.59**	.06	.41**
34	Loss/Helplessness	08	07	.36**	.57**	00	.37**
35	Effortful Optimism	1.00	.23**	.36**	.09	.17*	06
36	Success		1.00	.38**	07	.09	12
37	Total Positive			1.00	.21*	.10	25**
38	Total Negative				1.00	.08	.55**
39	Total Adaptive Coping					1.00	.29**
_40	Total Maladaptive Coping						1.00

Table 4.8. Concurrent correlation matrix of thee month predictor variables (effect size displayed; \* p<.05; \*\*p<.01)

			**************************************			··········			Correl	ation Effe	ect Size							
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1	Optimism	1.00	57**	.35**	.30**	.21*	.24**	.00	25**	00	.07	05	49**	38**	.33**	04	.20*	06
2	Neuroticism		1.00	41**	31**	22*	<b>27</b> ••	.11	.14	12	12	08	.54**	.47**	17	.22*	09	.03
3	Extroversion			1.00	.12	.21*	.34**	01	09	.04	.13	03	35 <b>**</b>	16	.34**	.10	.16	.09
4	Openness				1.00	.03	12	07	- 15	06	12	00	28**	- 27**	07	21°	.03	19*
5	Agreeableness					1.00	.42**	14	03	02	.11	10	·.23**	.00	.26**	.16	.09	.19*
6	Conscientiousness						1.00	00	.05	.18*	.38**	01	30**	04	.32**	.09	.17	.19*
7	Internal LoC							1.00	.04	.19*	.12	.20*	01	.05	.19*	.15	.11	05
8	Chance LoC								1.00	.21*	.12	.22*	.04	.10	.00	.13	.25**	07
9	General Others LoC									1.00	.77**	.90**	23**	.10	.26**	.07	.34**	.10
10	Doctor LoC										1.00	.41**	30**	.05	.29**	.03	.33**	.19*
11	Other People LoC											1.00	13	.11	.17*	.08	.26**	01
12	Hopelessness/Helplessness												1.00	.55*	33**	.17	- 12	06
13	Anxious Preoccupation													1.00	.15	.39**	.14	.35**
14	Fighting Spirit														1.00	.36**	.40**	.14
15	Cognitive Avoidance															1.00	.37**	05
16	Fatalism																1.00	.09
17	Motivational Relevance																	1.00

Table 4.8. Concurrent correlation matrix of three month predictor variables (effect size displayed; \* p<.05; \*\*p<.01)(continued).

		18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34
1	Optimism	06	.05	01	13	.26**	.26**	.37**	17	04	05	08	.16	.09	23**	14	42**	34 <b>**</b>
2	Neuroticism	04	.09	.23**	.20*	2 <b>7**</b>	20*	46**	.13	03	.03	.21*	19*	21°	.17	.24**	.44**	.48**
3	Extroversion	.10	02	15	12	.18*	.21*	.24**	.04	.08	.15	05	01	.18*	.07	18°	12	21°
4	Openness	07	00	.05	.12	12	04	.09	15	02	15	25**	.01	05	11	02	28**	14
5	Agreeableness	.10	07	20**	13	00	.02	.04	15	.05	05	13	08	06	13	16	- 16	07
6	Conscientiousness	.05	10	15	15	.13	.09	.08	11	.10	02	15	12	05	04	18°	.02	14
7	Internal LoC	20°	.11	.44**	.21°	.03	.29**	08	.27**	.14	05	.06	08	.13	.16	.37**	.15	.14
8	Chance LoC	11	.11	13	02	.01	.02	04	.01	.21*	.15	.11	.16	.12	.05	.05	.17	.17
9	General Others LoC	.08	.02	09	02	.18*	.06	00	04	.22*	.11	21°	.11	.07	08	07	.06	10
10	Doctor LoC	.20•	.01	16	11	.20*	.18*	.09	10	.27**	.16	22°	.08	.16	21°	22°	03	17
11	Other People LoC	03	.07	02	.07	.10	03	04	.02	.16	.07	16	.12	02	.04	.06	.11	.11
12	Hopelessness/Helplessness	03	.01	.14	.17*	37**	32**	40**	.24**	04	.06	.15	20°	34**	.32**	.31**	.51**	.56**
13	Anxious Preoccupation	.17	17	.08	.20*	28**	26**	46**	.21°	.12	.24**	.12	37**	20°	.19*	.25**	.62**	.46**
14	Fighting Spirit	.07	.02	11	11	.23**	.31**	.24**	.03	.25**	.06	.09	09	.13	09	10	.03	14
15	Fatalism	05	.25**	21°	06	00	.02	.04	.07	.20•	.02	02	.09	05	.01	.05	.20•	.08
16	Cognitive Avoidance	.05	.10	04	.01	00	07	15	.11	03	.01	.20*	08	.16	.01	08	.07	.02
17	Motivational Relevance	.49**	24**	11	07	.04	.06	04	.03	.22*	.27**	.04	13	.08	03	02	.24**	.04
18	Motivational Incongruence	1.00	28**	27*	10	01	11	.05	.07	.15	.25**	.08	.03	.03	05	06	.07	.06
19	Motivational Congruence		1.00	.06	.00	.112	.24**	.06	.11	05	04	.09	.14	.08	03	.07	08	01
20	Self-Responsibility			1.00	.38**	22**	.00	27**	.24**	.00	05	.04	07	10	.18*	.47**	.20*	.24**
21	Other Responsibility				1.00	27**	03	29	.12	.05	06	06	.19*	13	.21*	.17	.21*	.29**
22	Future Expectancy					1.00	.43**	.52**	15	06	.06	07	.10	.24**	32**	25**	30**	52**
23	PF Coping Potential						1.00	.45**	.02	.10	.05	.01	.07	.20*	211	04	16	27**
24	EF Coping Potential							1.00	12	.01	.02	08	.17	.16	30**	24**	45**	38**
25	Self Consciousness								1.00	.01	.09	.21*	.02	.17	.47**	.59**	.29**	.26**
26	Relevance									1.00	.19*	.02	.08	.11	06	.01	27**	.19*
27	Unexpectedness										1.00	05	.08	.15	.12	01	.09	.15
28	Irrelevance											1.00	.15	.04	.16	.19*	.24**	.27**
29	Lack of Concern												1.00	.42**	08	.00	25**	10
30	Removal of Threat													1.00	.05	.15	28**	15
31	Other-Blame														1.00	.41**	.39**	.38**
32	Self-Blame															1.00	.25**	.40**
33	Threat																1.00	.55**
34	Loss/Helplessness																	1.00

Table 4.8. Concurrent correlation matrix of three month predictor variables (effect size displayed; \* p<.05; \*\*p<.01)(continued).

		35	36	37	38	39	40
1	Optimism	.29**	.17	.29**	-57**	.16	<b>37</b> °
?	Neuroticism	29**	·.24**	·.29**	.58**	15	.41*
3	Extroversion	.20*	.22*	.32**	23**	.19*	19
4	Openness	.11	.05	.03	.30**	.11	09
5	Agreeableness	04	.04	07	19*	.11	18
5	Conscientiousness	.17	11	.02	17	.24**	05
7	Internal LoC	.08	.17	.29**	.07	.26**	.24*
8	Chance LoC	.09	.10	.10	.13	00	.10
9	General Others LoC	.20*	.11	.18*	11	18*	12
10	Doctor LoC	.20•	.12	.10	15	.18*	12
11	Other People LoC	.17	.07	.19*	04	.14	09
12	Hopelessness/Helplessness	35**	30**	034	.69**	16	.57•
13	Anxious Preoccupation	14	29**	17	.63**	.15	.50•
14	Fighting Spirit	.47**	.10	.48**	20*	.47**	11
15	Fatalism	.04	04	.28*	08	.32**	07
16	Cognitive Avoidance	.18*	.20*	.07	.15	.24**	.27•
17	Motivational Relevance	.03	.00	.05	.17*	.12	.16
18	Motivational Incongruence	.04	.00	03	.03	11	.04
19	Motivational Congruence	01	.20*	.19*	05	.16	05
20	Self-Responsibility	02	.08	.01	.18*	.04	.17
21	Other Responsibility	08	01	15	.25**	.03	.19
22	Future Expectancy	.28**	.25**	.33**	34**	.02	32
23	PF Coping Potential	.31**	.29**	.36**	27**	.16	22
24	EF Coping Potential	.13	.12	.29**	51**	10	38
25	Self Consciousness	.04	.18*	.09	.28**	.04	.15
26	Relevance	.26**	.14	.24**	.10	.32**	.17
27	Unexpectedness	.02	.14	.24**	.24**	06	.02
28	Irrelevance	11	01	.03	.22*	11	.15
29	Lack of Concern	.04	.31**	.24**	27**	18 <b>*</b>	28*
30	Removal of Threat	.19*	.71**	.32**	21*	.18*	10
31	Other-Blame	06	.03	01	.42**	01	.27*
32	Self-Blame	.02	.21*	05	.26**	.06	.28*
33	Threat	.01	25**	07	.60**	.08	.48*
34	Loss/Helplessness	25	19*	21	.52**	07	.39•
35	Effortful Optimism	1.00	.24**	.41**	27**	.39**	04
36	Success		1.00	.33**	20*	.13	15
37	Total Positive			1.00	23**	.17	24*
8	Total Negative				1.00	.02	.55*
39	Total Adaptive Coping					1.00	.27*
40	Total Maladaptive Coping						1.00

As expected, inter-correlations between these variables was high with approximately 40% of tests demonstrating a significant association across both cross-sectional timepoints. Of course, caution is necessary when interpreting these results. Due to the vast number of tests, the standard alpha level of p<.05 is not suitable; however, a Bonferroni correction to this would minimise the alpha to such a great extent that the findings would be meaningless due to the very conservative nature of this particularly type of correction (Field, 2009). As this section of analysis is oriented on a pragmatic approach to clinical testing, it was not considered appropriate to use these results to exclude potentially unnecessary variables from the regression analyses in an arbitrary fashion. Instead, collinearity tests were run as part of the test to explore whether these inter-correlations are potentially problematic. These correlations are, however, referred to when interpreting the final regression models.

#### 4.6 PREDICTING CLINICALLY RELEVANT PSYCHOLOGICAL OUTCOMES

In this section, findings will be presented to establish the extent of variance explained by potentially modifiable psychological predictor variables. Time-lagged analyses will establish whether different predictor variables exert influence over outcome at different time-points of the illness adjustment period.

#### 4.6.1 Bivariate analyses of time-lagged variable relationships

Only those predictor variables that significantly correlated with outcome variables were entered into regressions, a procedure often used in studies of this type and magnitude (Tabachnick & Fidell, 2006). In order to both further minimise the number of variables entered into regressions, and to render the findings comparable with the literature, computed sub-totals of emotion and coping were used rather than the many individual subscales. Highly significantly associated predictor variables were not discounted at this stage (see section 4.5.2). Instead, statistical tests of collinearity were carried out. None of these demonstrated significance, and thus the correlations were not concluded to be problematic. As the focus of these analyses was three and six month outcome prediction, concurrent associations are not presented. Instead, tables 4.9 to 4.11 summarise findings from correlation analyses between time one predictors and time two outcomes; time one predictors and time three outcomes; and time two predictors and time three outcomes, respectively.

Table 4.9. Associations between predictors at time one, and outcomes at time two.

	Qo	L (T2)	Anx	iety (T2)	Depres	sion (T2)
	r	p	r	р	r	p
Personality						
Optimism	.30	<.01	38	<.01	20	.02
Neuroticism	47	<.01	.49	<.01	.39	<.01
Extroversion	.24	<.01	20	.02	24	<.01
Openness	.08	.38	12	.18	07	.46
Agreeableness	.33	<.01	24	<.01	26	<.01
Conscientiousness	.08	.38	07	.45	11	.20
Health Locus of Control					•	.20
Internal LoC	.03	.74	.19	0.3	01	00
Chance LoC	.03 03	.7 <b>4</b> .78		.03	.01	.90
General Others LoC	.01	.78	00	.93	05	.54
Doctor LoC	.09	.31	13	.13	06	.50
Other People LoC	.0 <del>9</del> 04	.31 .70	19 06	.03 .51	10 03	.25 .96
•	04	.70	00	.51	03	.96
Mental Adjustment to Cancer						
lopelessness/Helplessness	40	<.01	.39	<.01	.34	<.01
Anxious Preoccupation	47	<.01	.48	<.01	39	<.01
fighting Spirit	.06	.47	06	.47	06	.50
atalism	01	.98	01	.92	02	.81
Cognitive Avoidance	03	.72	.01	.93	06	.50
Appraisal Components						
Motivational Relevance	10	.23	.07	.43	.13	.13
Motivational Incongruence	16	.06	.09	.30	.16	.07
Motivational Congruence	.18	.04	05	.54	14	.10
Self-Responsibility	13	.12	.19	.02	.16	.07
Other Responsibility	20	.02	.18	.04	.21	.01
future Expectancy						
,	.33	<.01	18	.04	23	<.01
Problem Focussed Coping	.20	.02	11	.22	14	.11
Emotion Focussed Coping	.42	<.01	38	<.01	33	<.01
Core-Relational Themes						
Self Consciousness	25	<.01	.10	.25	.12	.16
Relevance	05	.57	03	.75	.06	.48
Unexpectedness	.03	.77	02	.87	03	.70
rrelevance	.03 02	.83	.02	.81	.03	.78
Lack of Concern	.21	.02	20	.03	.03 11	.22
	.12		.04	.03 .70	06	.51
Removal of Threat		.17				.51 <.01
Other-Blame	40	<.01	.29	<.01	.26	
Self-Blame	14	.11	.22	.01	.13	.15
Threat	50	.11	.46	<.01	.33	<.01
Loss/Helplessness	40	<.01	.38	<.01	.32	<.01
Effortful Optimism	.06	.50	16	.07	02	.79
Success	.14	.11	00	.97	02	.87
Emotion Themes						
Total Positive	.34	<.01	25	<.01	28	<.01
Total Negative	56	<.01	.55	<.01	.53	<.01
Coping						
Coping  Total Adaptive Coping	.07	.41	.06	.50	06	.47
Total Maladaptive Coping  Total Maladaptive Coping	33	<.01	.38	<.01	.25	<.01
	55	3.01	.50	2		
Health Status	2.	. 04	10	27	24	<.01
Physical	.26	<.01	10	.27	24 42	<.01 <.01
Mental	.54	<.01	50	<.01	42	<.01
Outcome (T1)						
Outcome (T1) QoL	.68	<.01	55	<.01	59	<.01
	55	<.01	.73	<.01	.50	<.01
Anxiety Depression	56	<.01	.67	<.01	.61	<.01

Table 4.10. Associations between predictors at time one, and outcomes at time three.

	QoL	(T3)	Anxiet	y (T3)	Depressi	on (T3)
. Dec	<u> </u>	Р	r	р	r	р
Personality	2.4					
ptimism	.26	<.01	37	<.01	14	.14
leuroticism	35	<.01	.54	<.01	.18	.05
extroversion	.19	.05	20	.03	16	.07
<b>)pe</b> nness	.18	.06	15	.12	09	.32
lgreeableness	.12	.20	25	<.01	14	.12
<b>Cons</b> cientiousness	.15	.11	12	.18	02	.85
iealth Locus of Control						
nternal LoC	.01	.91	.15	.12	01	.92
hance LoC	.08	.41	.00	.97	11	.22
General Others LoC	08	.39	02	.84	.01	.91
Ooctor LoC	.20	.04	15	.12	08	.41
Other People LoC	02	.86	.05	.58	.70	.46
lental Adjustment to Cancer						
lopelessness/Helplessness	33	<.01	.31	<.01	.22	.01
Anxious Preoccupation	33 43	<.01	.31 .46	<.01	.30	.01 <.01
Fighting Spirit	.20	.03	.46 13	.15	.30 17	.06
rignting Spirit Fatalism	.20 .15		13 02	.15 .82	1 <i>7</i> 08	.06 .40
	.15	.10 .22				
Cognitive Avoidance	.12	.22	.03	.73	14	.12
Appraisal Components						
Motivational Relevance	04	.70	.18	.05	.13	.16
Motivational Incongruence	12	.20	.20	.03	.16	.08
Motivational Congruence	.21	.02	17	.07	15	.10
Self-Responsibility	22	.02	.18	.05	.18	.05
Other Responsibility	31	<.01	.32	.00	.33	<.01
Future Expectancy	.34	<.01	11	.23	20	.03
					01	.95
Problem Focussed Coping	.12	.22	.08	.39		
Emotion Focussed Coping	.35	<.01	31	<.01	21	.02
Core-Relational Themes						
Self Consciousness	14	.15	.17	.07	.13	.16
Relevance	09	.33	.05	.60	.09	.34
Unexpectedness	07	.44	.06	.51	.08	.35
Irrelevance	10	.92	.07	.44	08	.38
Lack of Concern	.18	.05	01	.31	11	.23
Removal of Threat	.10	.31	.15	.11	05	.57
Other-Blame	38	<.01	.33	<.01	.35	<.01
Self-Blame	15	.11	.14	.13	.09	.33
Threat	37	<.01	.49	<.01	.29	<.01
Loss/Helplessness	32	<.01	.35	<.01	.21	.03
Effortful Optimism	01	.93	12	.20	.04	.67
Success	.03	.78	.09	.36	.05	.60
Emotion Themes	.26	<.01	15	.12	13	.17
Total Positive Total Negative	.20 45	<.01	.55	<.01	.37	<.01
•		- <del>-</del>				
Coping	ar	.02	.00	1.00	21	.02
Total Adaptive Coping	.25		.34	<.01	.09	.37
Total Maladaptive Coping	26	.04	.34	<b>~.01</b>	.07	.57
Health Status						<u>.</u> -
Physical	.33	<.01	25	<.01	28	<.01
Mental	.48	<.01	50	<.01	30	.<.01
Outcome (T1)	.65	<.01	60	<.01	52	<.01
QoL	.65 37	<.01	.68	<.01	.22	.01
Anxiety Depression	37 50	<.01	.48	<.01	.57	<.01

Table 4.11. Associations between predictors at time two, and outcomes at time three.

	QoL	. (T3)	Anxie	ty (T3)	Denress	sion (T3)
_	<u> </u>	Р.	r	p	r	P
Personality						
<b>Optimism</b>	.37	<.01	45	<.01	25	<.01
Neuroticism	41	<.01	56	<.01	.25	<.01
Extroversion	.16	.09	19	.04	13	.16
Openness	.16	.09	19	.04	12	.19
Agreeableness	.14	.14	20	.03	12	.15
Conscientiousness	.23	.01				
Health Lague of Cameral		.01	14	.13	05	.56
Health Locus of Control	•					
Internal LoC	.01	.92	.14	.14	05	.63
Chance LoC	06	.51	.06	.56	06	.50
General Others LoC	06	.55	.06	.51	.03	.74
Doctor LoC	.03	.73	.06	.55	04	.69
Other People LoC	10	.29	.05	.61	.06	.52
Mental Adjustment to Cancer						
Hopelessness/Helplessness	47	<.01	20	- 04		
Anxious Preoccupation	56		.39	<.01	.33	<.01
Fighting Spirit	56 .15	<.01	.57	<.01	.39	<.01
Fatalism		.12	09	.32	15	.10
ratalism Cognitive Avoidance	.08	.40	02	.84	12	.21
CORTIGUE AVOIDANCE	.03	.75	.16	.09	09	.34
Appraisal Components						
Motivational Relevance	12	.22	.21	.02	.02	.86
Motivational Incongruence	05	.61	01	.95	02	.84
Motivational Congruence	.19	.05	.00	1.00	04	.75
Self-Responsibility	15	.10	.14	.13	.13	
Other Responsibility	27	<.01	.20	.03	.13	.26
Future Expectancy	.32	<.01	18	.03 .06	.3 <del>4</del> 25	<.01
Problem Focussed Coping	.16	.08	10 12	.18	25 10	.03
Emotion Focussed Coping	.37	.08 <.01	43	<.01		.40
amotton rocussed coping	.57	<.U1	43	<.01	35	<.01
Core-Relational Themes						
Self Consciousness	13	.17	07	.47	.02	.89
Relevance	.09	.33	02	.83	14	.22
Unexpectedness	21	.03	.09	.36	01	.96
Irrelevance	.01	.93	.05	.57	03	.78
Lack of Concern	.12	.22	26	<.01	01	.94
Removal of Threat	.16	.09	08	.39	16	.17
Other-Blame	28	<.01	.26	<.01	.26	.02
Self-Blame	19	.05	.17	.07	.15	.18
Threat	23	.01	.45	<.01	.24	.04
Loss/Helplessness	29	<.01	.27	<.01	.15	.20
Effortful Optimism	.30	<.01	08	.41	.15 24	.04
Success	.29	<.01	21	.03	30	.01
ouccess	.27	<.U1	21	.03	30	.01
Emotion Themes						
Total Positive	.24	.01	15	.19	18	.06
Total Negative	50	<.01	.47	<.01	.43	<.01
_					.43	<.01
Coping						
Total Adaptive Coping	.18	.06	.16	.09	06	.54
Total Maladaptive Coping	24	<.10	.40	<.01	.16	.09
Health Status						
	.44	<.01	29	<.01	.49	<.01
Physical Manael	.33	<.01 <.01	49 49	<.01	.28	<.01
Mental	.33	<.01	47	<.01	.20	<.01
Dune						
Outcome (T2)		- 04		- 01	50	- 01
<b>S</b> or	.68	<.01	60	<.01	58	<.01
Anxiety	51	<.01	.80	<.01	.38	<.01
Depression	44	<.01	.56	<.01	.66	<.01

In relation to the outcomes measured, personality was prominent, with a number of significant associations between these groups of variables. Although openness and conscientiousness rarely feature as significant correlates, relationships with optimism, neuroticism and extroversion are more consistently associated, particularly for quality of life and anxiety; correlations with depression seem far more time-dependent with the six-month time lagged correlations dropping substantially in effect size. Where baseline agreeableness scores significantly correlated with three month outcomes, this effect was not sustained into the remaining correlation analyses.

Correlations between health locus of control and outcome are far less important. Effect sizes, whilst generally stable across different time-lagged analyses, are very low and some even appear inconsistent in direction. Baseline scores, for example, are all negatively correlated with three month anxiety, however, three month scores are all positively correlated with six month anxiety.

Both hopeless/helplessness and anxious preoccupation subscales of the MAC are strongly and consistently significantly correlated with all outcomes, independent of time-lag. The effects of fighting spirit, fatalism, and cognitive avoidance are less consistent (with regard to statistical significance) and are typically reported with much smaller effect sizes.

A high number of appraisal components were significantly correlated with outcome in all time-lagged analyses, although comparatively fewer reached significance for six month depression from three month predictors. There is a tentative indication that secondary appraisals—especially other responsibility and emotion focussed coping potential appraisals—are more strongly correlated with outcome than are primary appraisals, although some exceptions can be observed, for example in the case of correlations with motivational incongruence. Effect sizes of correlations between core-relational themes and outcomes are typically smaller than for the appraisal components but still around half of these correlations reached significance. Again, there is some indication of an outcome bias in that these cognitions are more frequently significantly correlated with quality of life than anxiety and depression.

Effect sizes of correlations between negative emotion and outcome are far higher and more consistently significant than are correlations between positive

emotion and outcome. Where both subscales are correlated in baseline to three month outcome correlations, effect sizes between positive emotion and anxiety and depression at six month follow up are much reduced. Similarly, with just one exception (baseline predictors and six month depression), maladaptive coping is more strongly correlated with outcome than is adaptive coping.

As expected, by far the most consistent and strongest effect sizes are reported for correlations using earlier levels of outcome as a predictor variable. Both mental and physical subscales of perceived health status are also consistently correlated with outcome, although the effect sizes are much higher for correlations with mental rather than physical subscale scores.

# 4.6.2 Multivariate analyses: predicting anxiety, depression and quality of life

The next set of analyses had two purposes. First, to identify which psychological predictor variables contributed to the variance in outcome scores above and beyond the variance already explained by non-modifiable and/or control) demographic, clinical and personality variables. Second, to establish whether these significant variables are most predictive when measured at baseline or at a later time point. As such, three regression analyses were performed for each outcome variable:

- Baseline predictors and three month outcome
- Baseline predictors and six month outcome
- Three month follow up predictors and six month outcome

A detailed consideration of method of data entry into these models has previously been provided (section 3.6.3.3). In summary, for each model, a two-block design was used. In the first block, all non-modifiable and/or control variable were inputted using the *enter* command. Control variables for this block were selected by various means. Demographic variables were selected based on the results of the systematic review. Just one clinical variable was entered as standard: cancer type. Remaining clinical data could not be entered due to data limitations (see section s3.4.5 and 3.6.3.2) The remaining clinical data were unsuitable for entry into regressions because they either resulted in small subsample groupings (i.e. treatment) or because of too much missing and unavailable data (i.e. waiting time to treatment). Previous levels of all outcomes and perceived

health status variables were selected based on their high level of expected contribution to the models; and trait personality variables were selected if they had previously been highlighted as significantly correlated (section 4.5.2). Only inclusion of personality variables, therefore, distinguished between this block of each regression model. The residual level of the outcome not explained by this block of variables was then used as the dependent variable for a subsequent block of potentially modifiable psychological variables inputted using a *stepwise* (p in =.05, p out = .10) method. Therefore, the  $R^2$  output from this block of the regression is representative of variance explained in the remaining proportion of emotion only; a proportional addition to the true percentage variance explained is then calculated. Only those participants with data for all variables (included or excluded) in both blocks of the model were included to ensure accurate comparison between blocks.

For each model, collinearity diagnostics and plots of residuals were explored.

No evidence was found that the assumptions of linear regression had been violated.

### 4.6.2.1 Quality of Life

For the three month outcome regression (from time one predictors; table 4.12) block one—the control variables—accounted for 60.0% of the variance in quality of life. Within this block, gender, presence of a significant other, cancer type, previous level of quality of life, and anxiety contributed most, however only the coefficients for quality of life and anxiety were significant.

Table 4.12. Regression analysis for quality of life at three months, from baseline predictors!

	Unstand coeffic			Model Su	mmary
	В	SE	df	R <sup>2</sup>	F
Block 1 (Enter)					
Constant	27.24	21.16	12, 90	.60	11.34**
Gender	1.73	2.93			
Age	08	.13			
Significant other	65	2.81			
Cancer type	1.26	1.27			
Physical health status	00	.13			
Mental health status	12	.20			
Quality of life	.66**	.15			
Depression	.32	.63			
Anxiety	-1.05*	.45			
Neuroticism	09	.19			
Extroversion	.07	.19			
<b>Agreea</b> bleness	.27	.23			
Block 2 (Stepwise•)					
Constant	3.96	2.21	1, 101	.04	3.96*
Negative Emotion	14	.07*			

<sup>\*</sup>p<.05 \*\*p<.01

A high number of variables were initially entered into block two, spanning a range of appraisals, core-relational themes, emotions, coping, and MAC components. However, only negative emotion was included as a significant predictor of quality of life; the more negative the emotional reaction to diagnosis, the lower the quality of life rating. This block explained 4.0% of the residual level of quality of life which equates to an additional 1.6% of the overall variance.

Table 4.13 summarises the findings for the regression analysis predicting six month quality of life from baseline predictors. Block one of this model accounted for 66.0% of the variance in quality of life. Only baseline level of quality of life was a significant contributors to the model (p<.01).

<sup>\*</sup>Excluded variables (see appendix 4.1): Optimism; Hope/helplessness; Anxious Preoccupation; Motivational congruence; Motivational incongruence; Other responsibility; Future expectancy; Problem focussed coping potential; Emotion focussed coping potential; Self-consciousness; Lack of concern; Other-blame; Loss/helplessness; Positive emotion;; Maladaptive coping.

In all tables that follow in the results section, a total  $R^2$  (or percentage equivalent) is not provided as to do so required further computation of the  $R^2$  for the stepwise block. The adjusted percentage variance explained is, therefore, referred to both in text and in the summary table (table 4.21) on page 224.

Table 4.13. Regression analysis for quality of life at six months, from baseline predictors.

	Unstand coeffic			Model Sur	mmary
	В	SE	df	R <sup>2</sup>	F
llock 1 (Enter)					
Constant	28.26	17.24	12,81	.66	13.00**
Gender	3.13	2.35			
Age	.11	.11			
Significant other	3.26	2.37			
Cancer type	37	1.09			
Physical health status	.05	.10			
Mental health status	11	.17			
Quality of life	.56**	.13			
Depression	76	.53			
Anxiety	16	.37			
Neuroticism	13	.15			
Extroversion	10	.17			
Openness	.27	.17			
Block 2 (Stepwise*)					
Constant	-2.32	1.38	1, 92	.04	4.24*
Lack of concern	.63*	.31			

<sup>•</sup>p<.05 ••p<.01

Again, a range of variables was initially entered into block two. Only the core relational theme of lack of concern emerged as significant (p<.05). As would be expected a higher score (indicative of less concern) and predictive of higher quality of life scores. This block explained 4.4% of the residual level of quality of life, which equates to an additional contribution of 1.5% of the overall variance.

Finally, table 4.14 summarises the findings for the regression analysis predicting six month quality of life from predictor variables measured at three month follow up. Block one of this model accounted for 64.0% of the variance in quality of life. Once again, both the earlier level of quality of life (p<.01), and also age (p<.05) and neuroticism (p<.05), were significant contributors to this model.

<sup>\*</sup>Excluded variables (see appendix 4.2): Optimism; Anxious Preoccupation; Fighting spirit; Fatalism; Motivational congruence; Future Expectancy; Hope/Helplessness; Other responsibility; Emotion focussed coping potential; Other-blame; Threat; Loss/helplessness; Positive emotion; Negative emotion; Adaptive coping; Maladaptive coping.

Table 4.14. Regression analysis for quality of life at six months, from three month predictors.

·	•	•			•
	Unstand coeffic			Model Su	mmary
	В	SE	df	R <sup>2</sup>	F
Block 1 (Enter)					
Constant	41.05	16.17	13, 75	.64	10.06**
Gender	2.22	2.24			
Age	.21*	.11			
Significant other	4.21	2.50			
Cancer type	-2.08	1.09			
Physical health status	.23	.13			
Mental health status	.02	.15			
Quality of life	.34**	.11			
Depression	48	.50			
Anxiety	04	.37			
Neuroticism	28*	.12			
Extroversion	19	.17			
Openness	08	.16			
Conscientiousness	.14	.19			
Block 2 (Stepwise*)					
Constant	84	3.35	4, 84	.26	7.45**
Adaptive coping	.24*	.09			
Unexpectedness	85**	.28			
Other responsibility	13**	.44			
Threat	.68*	.32			

<sup>•</sup> p<.05 •• p<.01

Four variables emerged as significant predictors of the residual level of quality of life: adaptive coping, other responsibility appraisals, and the core relational themes of unexpectedness and threat. This final block explained 26.0% of the residual level of quality of life, an additional 9.4% of the overall variance in addition to the 64.0% explained in the first block.

<sup>\*</sup>Excluded variables (see appendix 4.3): Optimism; Hope/helplessness; Anxious Preoccupation; Motivational congruence; Self-responsibility; Future expectancy; Problem focussed coping potential; Emotion focussed coping potential; Effortful Optimism; Threat removal; Other-blame; Self-blame; Loss/helplessness; Success; Positive emotion; Negative emotion; Maladaptive coping.

#### 4.6.2.2 Anxiety

The three statistical models for anxiety follow. The first (table 4.15) shows that the control and non-modifiable variables at baseline account for a total 68.0% of the variance in anxiety at three month follow-up. Only previous levels of quality of life and anxiety emerged as significant contributors to this model (p=.04 and <.01 respectively).

**Table 4.15**. Regression analysis for three month anxiety from baseline predictors.

		Unstandardised Model Sum coefficients		mmary	
	В	SE	df	R <sup>2</sup>	F
Block 1 (Enter)					
Constant	1.59	5.06	12, 91	.68	15.84**
Gender	1.24	7.2			
Age	.04	.03			
Significant other	81	.67			
Cancer type	.20	.31			
Physical health status	.03	.03			
Mental health status	.06	.05			
Quality of life	08*	.04			
Depression	09	.15			
Anxiety	.66**	.11			
Neuroticism	.06	.05			
Extroversion	03	.05			
Agreeableness	05	.06			
Block 2 (Stepwise*)					
Constant	211	.37	2, 101	.10	5.56**
Self-responsibility	.28**	.10			
Other-blame	26*	.13			

<sup>\*</sup>p<.05 \*\*p<.01

In block two, higher self-responsibility appraisals and lower core-relational theme other-blame scores were predictive of 10.0% of the residual level of anxiety. This contributes an additional 3.2% to the overall variance.

Of the control variables for the six month time-lagged analysis (table 4.16), only age and baseline anxiety were significant contributors to this model.

Nonetheless, this first block of variables together explain 67.1% of the variance in six month follow up anxiety levels.

**Excluded** variables (see appendix 4.4): Optimism; Hope/helplessness; Anxious Preoccupation; Other responsibility; Future expectancy; Emotion focussed coping potential; Doctor locus of control; Lack of concern; Self-blame; Threat; Loss/helplessness; Effortful optimism; Positive emotion; Negative emotion; Maladaptive coping.

Table 4.16. Regression analysis for six month anxiety from baseline predictors.

	Unstandardised coefficients			Model Su	mmary
	В	SE	df	R <sup>2</sup>	F
ock 1 (Enter)					
Constant	8.08	4.29	12, 83	.67	14.08**
Gender	.09	.59			
Age	02	.03			
Significant other	08	.58			
Cancer type	.11	.26			
Physical health status	04	.03			
Mental health status	.01	.04			
Quality of life	05	.03			
Depression	.06	.13			
Anxiety	.46**	.09			
Neuroticism	.07	.04			
Extroversion	.01	.04			
Agreeableness	03	.05			

<sup>\*</sup>p<.05 \*\*p<.01

None of the additional psychological predictors were found significantly to improve upon this model; exploration of alternative stepwise criteria found that the p in (for F change) criterion would need increasing to p<.15 for any additional variables to enter the model. Conventionally, a p in of p<.05 is preferred in order to maintain a low error probability. However, had the criterion been set at this higher level, negative emotion, the core-relational theme of loss/helplessness, and maladaptive coping would all have entered as significant predictors. In this case though, the probability of making a Type I error (wrongly rejecting the null hypothesis) would have substantially increased.

<sup>\*</sup>Excluded variables (see appendix 4.5): Optimism; Hope/helplessness; Anxious Preoccupation; Motivational relevance; Motivational incongruence; Motivational congruence; Self responsibility; Other responsibility; Emotion focussed coping potential; Self-consciousness; Other-blame; Threat; Loss/Helplessness; Negative emotion; Maladaptive coping.

A high 72.4% of variance in six-month anxiety was predicted by the non-modifiable and/or control variables (block 1) at three-month follow-up (table 4.17). Of these variables, anxiety and neuroticism were all significant predictors (p<.01) with physical health status approaching significance.

Table 4.17. Regression analysis for six month anxiety from three month predictors.

	Unstand coeffic			Model Summary	
	В	SE	df	R <sup>2</sup>	F
Block 1 (Enter)					
Constant	7.49	3.46	13, 82	.72	16.51**
Gender	19	.50			
Age	04	.02			
Significant other	.22	.54			
Cancer type	.10	.23			
Physical health status	05	.03			
Mental health status	05	.03			
Quality of life	.01	.02			
Depression	10	.11			
Anxiety	.50**	.08			
Neuroticism	.10**	.03			
Extroversion	.02	.03			
Agreeableness	00	.05			
Openness	02	.03			
Block 2 (Stepwise•)					
Constant	40	.25	1, 94	.05	4.94*
Other-blame	.29	.13			

<sup>•</sup>p<.05 ••p<.01

Only the core-relational theme of other-blame contributed additional variance explanation where higher other-blame was predictive of higher anxiety. This second regression block explain 5.0% of the residual level of anxiety, thus contributing an additional 1.4% to the overall variance.

<sup>\*</sup>Excluded variables (see appendix 4.6): Optimism; Hope/helplessness; Anxious Preoccupation; Cognitive avoidance; Motivational relevance; Other responsibility; Future expectancy; Emotion focussed coping potential; Lack of concern; Self-blame; Threat; Loss/helplessness; Success; Positive emotion; Negative emotion; Adaptive coping; Maladaptive coping.

#### 4.6.2.3 Depression

This first block of the baseline—three month time-lagged regression (table 4.18) explained 57.0% of the total variance in depression (at three month followup). Significant contributors to the model included age (p<.01), mental health status (p<.05), baseline quality of life (p<.05), baseline depression (p<.01) and neuroticism (p<.05).

Table 4.18. Regression analysis for three month depression from baseline predictors.

	Unstandardised coefficients		Model Su		mmary	
	В	SE	df	R <sup>2</sup>	F	
Nock 1 (Enter)						
Constant	-2.61	4.82	12, 92	.57	10.24**	
Gender	18	.68				
Age	.06*	.03				
Significant other	.24	.65				
Cancer type	56	.29				
Physical health status	.03	.03				
Mental health status	.11*	.05				
Quality of life	09*	.04				
Depression	.51**	.15				
Anxiety	.20	.10				
Neuroticism	.09*	.05				
Extroversion	01	.05				
Agreeableness	.03	.05				

DIUCK & (Stepwise\*)

No further variance could be explained by the potentially modifiable psychological predictor variables; none of the variables could be entered until the input criterion was increased to p=.10, at which point other-blame, negative emotion, threat, emotion focussed coping potential and future expectancy would all enter the model as significant predictors. Again, whilst including more variables, the statistical accuracy of the model would be questionable given the higher probability of making a type I error.

<sup>\*</sup>p<.05 \*\*p<.01

<sup>•</sup>Excluded variables (see appendix 4.7): Optimism; Hope/helplessness; Anxious Preoccupation; Motivational incongruence; Motivational congruence; Self responsibility; Other responsibility; Future expectancy; Emotion focussed coping potential; Other-blame; Threat; Loss/Helplessness; Positive emotion; Negative emotion; Maladaptive coping.

Baseline control variables explained a total of 57.0% variance in six-month follow up depression levels (table 4.19). Only baseline quality of life and depression emerged as significant variables (p<.05 and <.01 respectively). Once again, no additional variables were entered into this model; exploratory analysis revealed that a higher input criterion of p=.15 would be necessary for any of the excluded variables to otherwise contribute. Had this non-conventional alpha level been used, emotion focussed coping potential, negative emotion, and fighting spirit would have been first to enter the model.

Table 4.19. Regression analysis for six month depression from baseline predictors.

	Unstandardised coefficients			Model Summary	
	В	SE	df	R <sup>2</sup>	F
Block 1 (Enter)					
Constant	6.70	4.30	11, 84	.57	10.13**
Gender	82	.59			
Age	.01	.03			
Significant other	.12	.60			
Cancer type	21	.27			
Physical health status	.01	.03			
Mental health status	.05	.04			
Quality of life	08*	.03			
Depression	.56**	.13			
Anxiety	.04	.09			
Neuroticism	00	.04			
Extroversion	.02	.04			

<sup>\*</sup>p<.05 \*\*p<.01

Control variables measured at three month follow-up explained 49.0% of variance in depression at six month follow-up (table 4.20). Here, only depression level (p<.01) and perceived physical health status at three months were significant (p<.05). Once again, no additional variables were entered into this model; a much higher input criterion of p=.30 would have been necessary for this .

<sup>\*</sup>Excluded variables (see appendix 4.8): Hope/helplessness; Anxious Preoccupation; Fighting Spirit; Motivational incongruence; Motivational congruence; Self responsibility; Other responsibility; Future expectancy; Emotion focussed coping potential; Other-blame; Threat; Loss/Helplessness; Negative emotion; Maladaptive coping.

**Table 4.20**. Regression analysis for six month depression from three month follow-up predictors.

	Unstandardised coefficients			Model Su	Model Summary	
	В	SE	df	R <sup>2</sup>	F	
lock 1 (Enter)						
Constant	4.31	3.49	10, 88	.49	8.48**	
Gender	.07	.52				
Age	01	.03				
Significant other	18	.55				
Cancer type	.36	.25				
Physical health status	07*	.03				
Mental health status	.01	.04				
Quality of life	01	.03				
Anxiety	.38	.12				
Depression	00**	.09				
Neuroticism	.04	.03				

<sup>°</sup>p<.05 °°p<.01

# 4.6.2.4 Summary and comparison of regression models.

In order to be able to explore similarities and differences between each of the regression models, a summary table follows in table 4.21.

Overall model performance for quality of life and anxiety was far better than for depression. The lower level explained for depression, however, should not be dismissed as their range of 47.0 to 57.0% remains a substantial proportion of variance.

<sup>•</sup>Excluded variables (see appendix 4.9): Hope/helplessness; Anxious Preoccupation; Fighting Spirit; Motivational incongruence; Motivational congruence; Self responsibility; Other responsibility; Future expectancy; Emotion focussed coping potential; Other-blame; Threat; Loss/Helplessness; Negative emotion; Maladaptive coping.

Table 4.21. Summary of regression models for each set of analysis (variables in bold indicate significant individual predictors).

	<u>T1-T2</u>	T1-T3	T2-T3
Quality of life			
Block 1	Gender	Gender	Gender
	Age	Age	Age
	Significant other	Significant other	Significant other
	Cancer type	Cancer type	Cancer type
	Physical health status	Physical health status	Physical health status
	Mental health status	Mental health status	Mental health status
	Quality of life	Quality of life	Quality of life
	Anxiety	Anxiety	Anxiety
	Depression	Depression	Depression
	Neuroticism	Neuroticism	Neuroticism
	Extroversion	Extroversion	Extroversion
	Agreeableness	Openness	Openness
	· ·	•	Conscientiousness
Block 2	Negative emotion	Lack of concern	Adaptive coping Unexpectedness Other responsibility Threat
Total Variance	61.6%	67.5%	73.4%
Inxiety			
Block 1	Gender	Gender	Gender
	Age	Age	Age
	Significant other	Significant other	Significant other
	Cancer type	Cancer type	Cancer type
	Physical health status	Physical health status	Physical health status
	Mental health status	Mental health status	Mental health status
	Quality of life	Quality of life	Quality of life
	Anxiety	Anxiety	Anxiety
	Depression	Depression	Depression
	Neuroticism	Neuroticism	Neuroticism
	Extroversion	Extroversion	Extroversion
	Agreeableness	Agreeableness	Agreeableness
	Agreeablelless	Agreeablelless	Openness
Block 2	Self-responsibility		Other-blame
DIOCK 2	Other-blame		omor braine
Total variance	71.2%	67.0%	73.5%
Pepression			
Block 1	Gender	Gender	Gender
	Age	Age	Age
	Significant other	Significant other	Significant other
	Cancer type	Cancer type	Cancer type
	Physical health status	Physical health status	Physical health status
	Mental health status	Mental health status	Mental health status
	Quality of life	Quality of life	Quality of life
	Anxiety	Anxiety	Anxiety
	Depression	Depression	Depression
	Neuroticism	Neuroticism	Neuroticism
	Extroversion	Extroversion	11Cui OttoiSiii
	Agreeableness	TYTI OAGI 21011	
	9	variables entered in block 2	
		variables entered in block 2	,= aa.
Total variance	57.0%	57.0%	47.0%

Depression was most successfully predicted using baseline predictor variables. Quality of life models improved with the prediction of later levels of the outcome variable (six month rather than three month) and even more so when three month predictor variables are used over baseline predictors. Anxiety was most poorly predicted when the time-lag between measurement of predictor variables and outcome was largest; similar levels of prediction were found for models predicting outcome three months later regardless of whether prediction is made at baseline or three month follow up.

the most predictive variables; however, some differences emerge. Where quality of life featured as a significant variable in the prediction of later anxiety and depression the opposite effect is not so consistent. Although anxiety at baseline was predictive of quality of life at three months, depression does not contribute to prediction of this outcome at all. Age was the only demographic variable to feature at all, and even so, only for the three to six month quality of life regression model. Concurrent health status featured only in prediction of depression; for three month prediction mental health status is important, however, for six month prediction, physical health status takes prominence. Neuroticism featured significantly in later quality of life prediction (three to six month), but early depression (baseline to three month).

Of the many additional variables initially entered in block two of the analyses, few remained in the final models. No additional variance was explained by these potentially modifiable variables for depression, however, for both quality of life and anxiety, additional variance was explained by variety of components of the Transactional Model. Cognitions feature most frequently. Appraisal components of other responsibility and self responsibility feature in the prediction of quality of life and anxiety (three to six month model and baseline to three month models respectively) and the core relational themes of other blame (anxiety baseline to three month and tree to six month); lack of concern (quality of life baseline to six month); and, unexpectedness and threat (quality of life three to six month). The implications and applications of these findings will be discussed in the next chapter.

#### **47 THEORY TESTING**

In contrast to the previous section which presented more clinically oriented data, this section presents results related to theoretical tests of the Transactional Model. Essentially, the purpose was to test whether or not the defined macro and micro cognition combinations which, according to Lazarus (1999), form emotional reaction to stressors (see section 1.5) are evident in this patient group. Two approaches are taken: exploration of correlation between changes scores across the full longitudinal database and regressions using cross sectional baseline data.

# **4.7.1** Correlating change in associated components of the Transaction Model

## 4.7.1.1 Introduction to the statistical approach taken

The first set of analysis (4.7.1) considers longitudinal patterns in the data. Due to the high level of theoretical association between specific appraisal, corerelational themes and emotions, it would be expected that a change over time in
one component, would be highly correlated with a change in its theoretically
associated components. Furthermore, because these theoretical associations are
supposedly unique, it is expected that change would not be correlated with
theoretically un-associated components. For example, anger is theoretically
proposed to be associated with three appraisals (motivational relevance,
motivational incongruence, and other responsibility) and the core relational theme
of other blame. Therefore, it would be expected that changes on any of these
specific components would be highly correlated with each other, but less
correlated with change scores on the numerous other appraisal and core-relational
themes. This was tested by calculating change scores for each component between
baseline and six-month follow-up and conducting a series of Spearman's Rho
correlation tests (selected due to non-Normality of the change scores).

Table 4.22 presents the results of correlations between each emotion and the two levels of cognition (appraisal and core-relational theme). Correlations are presented for components that theory would lead one to expected to be correlated, but also any unexpected correlations that emerged. Note that under the expected correlations column, not all emotions have an expected cognition correlate – this is because different emotions are at different levels of theoretical development (see section 1.4 and 3.4.1.3) and some emotions are developed such that appraisals and

core-relational themes are clearly defined, for others just a core-relational theme, or even nothing at all, is hypothesised. For these latter cases, the only correlations presented are those listed under the additional correlates column.

Due to the high number of correlations being tested for each emotion, Bonferroni adjustment to the significance level was required; this equated to an adjusted alpha level of p-.003. Results of expected component correlations are listed whether significant or not; inclusion of exact significance levels for each correlation can be used to assess whether or not this low level of significance was met. Results of additional components are only included if the correlation is significant at p<.01 in order to also highlight those components which didn't meet the adjusted significance level, but approached.

#### 4.7.1.2 Results

Few significant correlations were found between the emotions and their expected cognitive correlates. Effect sizes were typically low and few correlations even approached significance. Just three core-relational themes reached the Bonferroni corrected significance level: Self-consciousness for shame-humiliation; threat removal for relief; and, self-blame for guilt. Three further core-relational themes approached this significance level: success for happiness; unexpectedness for surprise; and, loss/helplessness for sadness. It is important to note that none of the appraisal change scores were significantly correlated with changes in emotion.

Table 4.22. Correlations between change on components of cognition and emotion.

Emotion	Expected correlates	5		Additional co	rrelates	
		r	P		r	р
Anger	Appraisal components:			Core-relational theme:		
_	Motivational Relevance	.04	.741	Self-blame	.27	.004
	Motivational Incongruence	01	.936	Loss/helplessness	.24	.011
	Other Responsibility	01	.924	Success	25	.010
	Core-relational theme:					
	Other-blame	.12	.208			
Guilt	Appraisal components:			Core-relational theme:		
	Motivational Relevance	.17	.134	Self-consciousness	.25	.008
	Motivational Incongruence	.03	.793	Threat	.34	<.001
	Self Responsibility	.21	.023			
	Core-relational theme:					
	Self-blame	.29	.002			
Fear/Anxiety	Appraisal components:		***************************************	Appraisal components:		
	Motivational Relevance	.11	.344	Self Responsibility	.25	.007
	Motivational Incongruence	.01	.946	Core-relational theme:		
	Emotion Focussed Coping Potential	16	.097	Self-blame	.24	.010
	Core-relational theme:			Success	.25	.007
	Threat	.13	.167			
Sadness	Appraisal components:			Core-relational theme:		
	Motivational Relevance	.10	.356	Self-consciousness	.25	.006
	Motivational Incongruence	04	.687	Other-blame	.26	.005
	Future Expectancy	.09	.363	Threat	.26	.005
	Problem Focussed Coping Potential	.00	.968			
	Core-relational theme:					
	Loss/helplessness	.28	.008			
Hope/Challenge	Appraisal components:			Core-relational theme:		
., .	Motivational Relevance	04	.759	Loss/Helplessness	30	.001
	Motivational Congruence	.16	.089	, .		
	Problem Focussed Coping Potential	.11	.242			
	Core-relational theme:					
	Effortful optimism	22	.019			

Table 4.22. Correlations between change on components of cognition and emotion (continued).

Emotion	Expected corre	Expected correlates				
		r	P		r	P
Happiness	Appraisal components:					
	Motivational Relevance	.13	.260			
	Core-relational theme:					
	Success	.25	.010			
Shame/Humiliation	Core-relational theme:			Appraisal components:		
·	Self-consciousness	.33	<.001	<b>Emotion Focussed Coping Potential</b>	29	.002
				Core-relational theme:		
				Irrelevance	.30	.001
Relief	Core-relational theme:		*******	Core-relational theme:		
	Removal of threat	.43	<.001	Success	.38	<.001
Surprise	Appraisal components:					
	Motivational Relevance	.07	.526			
	Motivational Incongruence	.14	.111			
	Core-relational theme:					
	Unexpectedness	24	.008			
Tranquility	Core-relational theme:	***************************************				
	Lack of concern	03	.736			
Resignation	Core-relational theme:					
	Loss/helplessness	07	.432			
Boredom	Core-relational theme:					
	Irrelevance	.09	.328			
Self-directed anger				Appraisal components:		
				Self Responsibility	.30	.007
				Core-relational theme:		
				Self-consciousness	.38	.001
				Self-blame	.42	<.001
				Loss/helplessness	.35	.003

Table 4.22. Correlations between change on components of cognition and emotion (continued).

<u>r</u>	p
.34	<.001
25	.009
.31	.001
.25	.003
.38	<.001
	.25

There were four emotions for which no additional components were significantly correlated due to the adjusted significance level. Had a standard alpha of p<.05 been used, additional components would also have been added for surprise, tranquillity, resignation and boredom, the effect sizes for which ranged between r=.19 to 26.

In most cases, additional components found to be significant were comparable, if not bigger, in effect size that any significant expected correlates. Contrary to theory, for a number of emotions multiple core-relational themes were found to highly correlate. There were just three occasions where changes in appraisal correlated highly with changes in emotion: emotion focussed coping potential for shame/humiliation and self-responsibility for both self-directed anger and fear/anxiety. Finally, some unusual patterns in correlations also emerge in terms of direction of effect. There are instances where the implications of the direction of a correlation are surprising. For example, the negative correlation between motivational incongruence and both anger and sadness is opposite to that which would be expected; if the situation became more incongruent, anger and sadness would be expected to increase, not decrease. Similarly, the negative correlation between increased unexpectedness related cognitions and decreased surprise seems somewhat contradictory.

# 4.7.2. Comparing theory versus data driven statistical tests of the Transactional model.

#### 4.7.2.1 Introduction to the statistical approach taken

In this approach to theory testing, a number of regression analyses were conducted. For each emotion, a theory driven regression was compared with an entirely data driven regression. Where the data driven model used a stepwise approach, the theory driven analyses were more structured. In the first block, theoretically derived appraisals were entered. The residual of the emotion variable was then saved and used as the dependent variable for the second block, where theoretically derived core-relational themes were entered. Again, the residual outcome was saved and used as the dependent variable for a third block in which all other variables were entered. Once again, therefore, the  $R^2$  stated in the subsequent blocks needed to be proportionally adjusted in order to calculate the total variance explained (see also p.214 and footnote on p.215); a summary of

total percentage variance explained for this section is presented in table 4.40 (p.253-254).

Theory driven regressions indicate how well theoretically associated appraisals and core-relational themes contribute to variance in emotion and whether the additional contribution of non-theoretically derived components contributed additional variance. A comparison with a data driven regression established whether these theoretically associated components were indeed the best initial predictors of emotion and whether the unique packages of cognitive and emotional variables of Lazarus's theory were valid.

Regression models demonstrated a range of overall effect sizes. The lowest effect was for boredom where both theory driven and data driven models explained just 7% of variance. Relief was best explained with the theory driven model explaining 49.9% variance and the data driven model explaining 54%.

## 4.7.2.2 Results for the 'hot' cognitions

Six cognition-emotion groupings fall into this category: anger, guilt, fear/anxiety; sadness; hope/challenge; and happiness (Lazarus, 1999). It is only for these six emotions that a clear literature is available to suggest which appraisals and core-relational themes are most highly associated. For that reason they have been the focus of the majority of theory testing to date.

Analysis of these data revealed high similarity in total variance explained by theory and data-driven models, but in two cases (anger and sadness) this similarity did not emerge until additional variables were added in block three of the theory driven regression. There was just one case where the theory driven analysis resulted in a higher effect size than did its comparable data driven model (anger: 29.4% versus 23.9%). Fear/anxiety and sadness both resulted in models where slightly more variance was explained by the data driven approach. Each of these regression models will be presented and discussed in turn.

For anger (see table 4.23), 10.2% variance was explained in block one (theoretically derived appraisals) but of the three appraisals hypothesised, just one emerged significant. A further 3.6% was explained by higher other-blame core relational theme scores ( $R^2$ =.04 of the residual emotion). Further variance (15.5%) was explained by additional components including higher concern, lower emotion focussed coping potential and, perhaps more strangely, increased effortful optimism. The data driven model predicted 5.1% less variance than the theory driven model (theory, 29.4%: data, 23.0%).

Although there is some overlap with block three of the theory driven model, none of the included predictors for anger are the same as those proposed by the theory. This model, which included one appraisal component and four corerelational themes, demonstrates that whilst not equivalent, similar levels of variance can be explained by an entirely different set of cognitive components. Most notable differences are in orientation of blame—the theory driven model includes other blame but the data driven includes self-blame, both as positive coefficients of anger—and the importance of coping related appraisals rather than goal related appraisals in both models.

Table 4.23. Theory and data driven tests of the cognitive precursors of anger.

	Theory	y Driven				
	Unstand	ardised	Mo	del Sumi	nary	
	Coeffic	cients				
	В	SE	df	R≥	F	
Block 1 (Enter)						
(Constant)	22	1.31	3, 134	.10	5.09**	
Motivational Relevance	.08	.12				
Motivational Incongruence	.16	.09				
Other Responsibility	.21*	.07				
Block 2 (Enter)						
(Constant)	<b>4</b> 0	.25	1, 136	.04	5.59*	
Other Blame	.24*	.10				
Block 3 (Stepwise*)						
(Constant)	1.68	.93	3, 134	.18	9.99**	
Lack of Concern	23**	.07				
EF Coping Potential	27**	.09				
Effortful Optimism	.22**	.08				

	Unstand Coeffic		Мо	del Sumi	narv
	• -	cients			
	В	SE	df	R2	F
vise•					
onstant)	2.61*	1.24	5, 132	.24	11.93*
reat	.20**	.08			
expectedness	.21**	.07			
f-Blame	.38**	.12			
ck of Concern	21**	.07			
Coping Potential	21*	.10			

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.10): Motivational Congruence; Self-Responsibility; Future Expectancy' Problem Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Threat Removal; Self-Blame; Threat; Loss/Helplessness; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.11): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Self-Consciousness; Relevance; Irrelevance; Threat Removal; Other-Blame; Loss/Helplessness; Effortful Optimism; Success.

Table 4.24. Theory and data driven tests of the cognitive precursors of guilt.

	Theory	Driven				
	Unstand	ardised	Mo	del Sumi	nary	
	Coeffic	cients			-	
	В	SE	df	R2	F	
Block 1 (Enter)						
(Constant)	2.33**	.87	3, 136	.12	6.32**	
Motivational Relevance	.05	.08				
Motivational Incongruence	16**	.06				
Self Responsibility	.13**	.05				
Block 2 (Enter)						
(Constant)	67*	.16	1, 138	.07	10.53**	
Self Blame	.26**	.08				
Block 3 (Stepwise*)						
No variables a	dded					

	Data	Driven			
	Unstand	ardised	Mo	odel Sumi	nary
	Coeffic	cients			
	В	SE	df	R2	F
Stepwise•					
(Constant)	2.55**	.55	3, 136	.19	10.43*
Self-Blame	.28**	.08			
Motivational Incongruence	16 <b>**</b>	.05			
Self Responsibility	.09*	.05			

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.12): Motivational Congruence; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Other blame; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Threat; Loss/Helplessness; Effortful Optimism; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.113): Motivational Relevance;; Motivational Congruence; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Irrelevance; Unexpectedness; Lack of Concern; Threat Removal; Other-Blame; Threat; Loss/Helplessness; Effortful Optimism; Success.

Regressions of the cognitive precursors of guilt (table 4.24) largely confirmed theory. No additional variance was explained in block three of the theory driven approach and a comparative data driven approach revealed no different predictors than those proposed by theory. Total variance explained for the theory driven model was 18.4% and for the data driven model was 18.7%. The absence of motivational relevance in the data driven approach, and indeed, the lack of significance for inclusion of this in the theory driven approach, suggests that the contribution of this component is redundant. There is, once again, a clear focus on blame and responsibility cognitions with higher guilt resulting from higher self-blame and responsibility and lower perceived other-blame. However, compared with anger, goal related appraisals emerge as more important than coping related appraisals.

For fear/anxiety (table 4.25), the majority of variance in the theory driven analysis was explained by two of the three hypothesised cognitive appraisals: higher motivational relevance and lower emotion focussed coping potential (33% of the 40.8% total variance). Two additional core relational themes, self-blame and unexpectedness, added a further 3.8% to the overall variance explained (residual  $R^2$ =.06). Although the theory hypothesised core-relational theme, threat, added just a small 4% to the over all variance, in the data driven model, this cognition was by far the largest contributor. The data driven model (which explained a total of 43.3% variance) also included self-blame and unexpectedness core relational themes confirming the importance of these additional variables. Whilst proposed by theory as an important predictor of fear/anxiety, motivational incongruence did not emerge as significant in either the theory driven, or data driven models.

Table 4.25. Theory and data driven tests of the cognitive precursors of fear/anxiety.

	Theory	y Driven					Data	Driven			
		Unstandardised Coefficients		Model Summary			Unstandardised Coefficients		Model Summary		
	В	SE	df	R2	F		В	SE	df	R²	F
Block 1 (Enter)						Stepwise*					
(Constant)	10.87**	3.29	3, 135	.33	22.14**	(Constant)	5.93	3.5	5, 133	.43	20.29**
Motivational Relevance	.75**	.25				Threat	.61**	.17			
Motivational Incongruence	.24	.17				EF Coping Potential	80**	.21			
EF Coping Potential	-1.26**	.19				Motivational Relevance	.54*	.23			
Block 2 (Enter)						Self-Blame	.63*	.25			
(Constant)	-1.58*	.62	1, 137	.07	9.72**	Unexpectedness	.633*	.14			
Threat	.42**	.13				-					
Block 3 (Stepwise*)											
(Constant)	-2.65*	1.04	2, 136	.06	4.66*						
Self-blame	.63*	.25									
Unexpectedness	.27**	.14									

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variablse (see appendix 4.14): Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Self-Consciousness; Relevance; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Loss/Helplessness; Effortful Optimism; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.15): Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Self-Consciousness; Relevance; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Loss/Helplessness; Effortful Optimism; Success.

Table 4.26. Theory and data driven tests of the cognitive precursors of sadness.

	Theory	Driven				
	Unstand	ardised	Mo	del Sumi	mary	
	Coeffic	cients		Ť		
	В	SE	df	R?	F	
Block 1 (Enter)						
(Constant)	1.38	1.66	4, 134	.10	3.59**	
Motivational Relevance	.21	.14				
Motivational Incongruence	.19	.10				
Future Expectancy	<b>26</b> •	.10				
PF Coping Potential	.04	.10				
Block 2 (Enter)						
(Constant)	-1.09**	.28	1, 137	.18	30.08**	
Loss/Helplessness	.43**	.08				
Block 3 (Stepwise*)						
No variables a	dded					

	Data	Driven			
	Unstand	lardised	Mo	odel Sumi	mary
	Coeffi	cients			
	В	SE	df	R²	F
Stepwise <sup>*</sup>					
(Constant)	29	.83	3, 135	.37	25.83*
Threat	.30**	.09			
Loss/Helplessness	.35**	.10			
Motivational Incongruence	.18*	.08			

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.16): Motivational Congruence; Self-Responsibility; Other-Responsibility; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat; Threat Removal; Other-Blame; Self-Blame; Effortful Optimism; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.17): Motivational Relevance; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Effortful Optimism; Success.

The majority of statistical variance in sadness (table 4.26) was explained by core-relational themes; higher loss/helplessness in the theory driven model, and both higher threat and higher loss/helplessness in the data driven approach. Of the four theorised appraisal components, only future expectancy emerged as significant in the theory driven model. Inclusion of this variable was not confirmed by the data driven model as here, motivational incongruence was included. The inclusion of threat in the data driven model seems to have improved overall variance explained slightly, though, it's absence from the theory driven model (and subsequently equivalent effect size) may indicate, once again, that the predictors of emotion are not unique and that varying combinations may be permissible.

Differences in the appraisal components included may account for the 12% difference in overall variance between the theory (total variance explained 25.9%) and data (36.5%) driven model. In the data driven model, there is a clear focus on concurrent goal related appraisals, however, the theory driven model seems otherwise focussed around future oriented appraisals.

Of the theorised appraisal predictors of hope/challenge (table 4.27), only problem focussed coping potential emerged as significant in the theory driven analysis. Just 3.6% variance was added by the theorised core-relational theme, effortful optimism, but the model was strengthened by inclusion of higher emotion focussed coping potential and higher relevance scores (total variance explained being 22.3%). The data driven model confirms the necessary inclusion of additional cognitive predictors and explained 21.6% of the total variance. Just one of the four variables included in the model matches theory; two are equivalent to those added in block three of the theory driven model; and one additional core-relational theme, lower levels of loss/helplessness, was included. As with anger, the emphasis here is on coping oriented appraisals rather than goal, responsibility or future oriented appraisal.

Table 4.27. Theory and data driven tests of the cognitive precursors of hope/challenge.

	Theor	y Driven					Data	Driven			
	Unstand	lardised	Mo	odel Sumi	mary		Unstand	lardised	M	odel Sumi	mary
	Coeffi	cients				Coefficients		cients			
	В	SE	df	R²	F		В	SE	df	R2	F
Block 1 (Enter)						Stepwise <sup>*</sup>					
(Constant)	9.22**	2.28	3, 133	.11	5.43**	(Constant)	5.22*	2.25	4, 132	.22	9.09**
Motivational Relevance	.06	.21				EF Coping Potential	.47*	.19			
Motivational Congruence	.18	.12				PF Coping Potential	.32*	.13			
PF Coping Potential	.45**	.13				Relevance	.36•	.15			
Block 2 (Enter)						Loss/Helplessness	31°	.15			
(Constant)	-2.2 <b>7</b> *	1.06	1, 135	.04	5.03*						
Effortful Optimism	.33*	.15									
Block 3 (Stepwise*)											
(Constant)	-6.95**	1.92	2, 134	.09	6.78**						
EF Coping Potential	.53**	.16									
Relevance	.32*	.15									

<sup>\*</sup>p<.05, \*\*p<.001

\*Excluded Variables(see appendix 4.19): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Self-Consciousness; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Threat; Effortful Optimism; Success.

<sup>\*</sup>Excluded Variables (see appendix 4.18): Motivational Incongruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Self-Consciousness; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness; Success.

<sup>\*</sup>p<.05, \*\*p<.001

Table 4.28. Theory and data driven tests of the cognitive precursors of happiness.

	Theory	y Driven					Data	Driven			
	Unstand	ardised	Ma	del Sumi	mary		Unstand	ardised	M	odel Sum	mary
	Coeffic	cients			•		Coeffic	cients			·
	В	SE	df	R²	F		В	SE	df	R:	F
Block 1 (Enter)						Stepwise*					
(Constant)	3.20*	1.39	2, 136	.01	.39	(Constant)	.02	.64	2, 136	.22	18.90**
Motivational Relevance	06	.13				Success	.32**	.06			
Motivational Congruence	.06	.08				Effortful Optimism	.19*	.09			
Block 2 (Enter)						•					
(Constant)	-1.45**	.32	1, 137	.19	31.77**						
Success	.34**	.06									
Block 3 (Stepwise*)											
(Constant)	-1.38*	.61	1, 137	.04	5.58*						
Effortful Optimism	.20*	.08									

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.20): Motivational Incongruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.21): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness.

The analyses for happiness, the final 'hot' cognition, are surprising (table 4.29). Whilst the theoretically derived appraisals explained virtually none of the variance in happiness, more variance was explained by the addition of the specified core-relational theme than in any other case (an equivalent addition of 18.8%). One further core-relational theme, effortful optimism, was added in block three. The predictive strength of these two core-relational themes above all other cognitions is further evidenced in the data-driven model which produces equivalent results and only slightly lower overall predictive ability (data driven explained 21.7% of the variance compared to 22.6% in the theory driven model). No appraisal components at all added to this model.

### 4.7.2.3 Results for the less theoretically developed emotions

Literature relating to the remaining ten emotions is less explicit about which cognitive components are most strongly related to each specific emotion (Smith & Ellsworth, 1985; Smith & Lazarus, 1993; Lazarus, 1999). Unlike for the 'hot' cognitions, no explicit appraisal patterns are specified in the literature, in part probably explaining the previous lack of empirical theory testing. For seven of these emotions, unique core-relational themes and emotion pairings are still proposed and results pertaining to these follow.

For these analyses, the theory driven regressions are presented slightly differently. As no appraisals are defined in the literature, the first block of the regression was unnecessary. Therefore, for the following models, block one consisted of a regression based on the uniquely paired core relational theme (enter) method (the equivalent of block two in the previous tests). Block two used a stepwise method to explore all appraisals, and all remaining core-relational themes for the residual emotion dependent variable. The analytic strategy for data driven models remains unchanged.

Unlike for the 'hot' cognitions, there was far more similarity between the theory driven and data driven models, not only in which predictors contributed to the model, but subsequent equivalence in how much overall variance in emotion was explained. This is not surprising given the proportion of testing now using the same, stepwise, approach as in data driven models.

**Table 4.29. Theory and data driven tests** of the cognitive predictors of boredom.

	Theory	Driven					Data	Driven			
	Unstand	ardised	Mo	del Sumi	mary		Unstand	ardised	Мо	del Sum	mary
	Coeffic	cients			·		Coeffic	cients			·
	В	SE	df	R2	F		В	SE	df	$R^2$	F
Block 1 (Enter)						Stepwise*					
(Constant)	1.65**	1.9	1, 137	.00	.00	(Constant)	3.45**	.59	1, 137	.07	10.09**
Irrelevance	00	.01				Motivational Incongruence	18**	.06			
Block 2 (Stepwise*)											
(Constant)	1.83**	.59	1, 137	.07	10.09**						
Motivational Incongruence	18 <b>**</b>	.06									

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.22): Motivational Relevance; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness; Effortful Optimism; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.23): Motivational Relevance; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness; Effortful Optimism; Success.

The theoretically hypothesised core-relational theme emerged significant in six out of seven of the theory driven models (not boredom) but to varying extents ranging from  $R^2$ = .02 to .41. These core-relational themes also significantly emerged in five of the seven data driven models (not boredom nor shame/humiliation). Consistent with theory, six theory driven models benefitted from the addition of one or more appraisal components; only shame/humiliation didn't, one of the poorest performing of all models included. However, as with the results from analysis reported in the previous section, additional core-relational themes were included in five out of seven cases.

Only low variance was explained for boredom (7.0%; table 4.29) and these results are incongruent with theory; the hypothesised core-relational theme was not an important component. Motivational incongruence appraisals instead significantly predicted this emotional outcome.

For five of the remaining emotions within this group (surprise, table 4.30; resignation, table 4.32; tranquillity, table 4.33; interest, table 4.34; and, relief, table 4.35), whilst the theoretically derived core-relational theme was significant in both theory driven and data driven analyses, many more variables were necessary for optimal prediction. In all cases, cognitive components do not differ between data driven and full theory driven regressions (although these do include the final stepwise additions). These additions included additional core-relational themes and a number of appraisals components (see table 4.30). For a summary of total proportioned variance explained, see table 4.40 (p.253).

Table 4.30. Summary of additional cognitive precursors for surprise, resignation, tranquillity, relief and interest.

-	Additional o	omponents	Variance		
Emotion	Appraisals	Core relational themes	added		
Surprise	Motivational Relevance	Lack of Concern Self-consciousness	9.5%		
Resignation	Other Responsibility	Threat Removal	7.8%		
Tranquility	EF Coping Potential	•	14.0%		
Interest	EF Coping Potential Motivational Incongruence Self-Responsibility Future Expectancy	Effortful Optimism Self-blame	33.3%		
Relief	Self-Responsibility Motivational Congruence	Loss/helplessness	8.9%		

Here, a clear role for responsibility-oriented appraisals emerges, especially so for the emotions of resignation and relief. Resignation was further explained by higher loss/helplessness cognitions and the core-relational theme of other responsibility. These results are in no way counterintuitive and make logical sense. Similarly, the three core-relational themes included as significant predictors of relief (threat removal, success, and lower loss/helplessness), and the one for tranquillity (lack of concern) also seem fitting to the nature of these emotional reactions. These associations are not unexpected.

Surprise was associated with goal-related appraisals and unexpectedness. The correlation between high surprise and low self-consciousness and lack of concern are perhaps not so obvious.

Interest was one of few emotions that required a much higher number of cognitive precursors to be included for optimal explanation of variance. Unlike for other emotions which seem to have specific subsets of appraisal attached to them, the full range of goal oriented, responsibility oriented, coping focused and future related appraisals feature.

The final emotion within this section, shame/humiliation (table 4.36), was unique in that no appraisal components were included. Furthermore, the theory hypothesised core-relational theme of self-consciousness failed to emerge as a significant predictor. Instead, one additional core-relational theme (other blame) was included in the theory driven model, and two additional core-relational themes in the slightly better performing data driven model (other blame and self blame). That self-blame didn't emerge in the theory driven model possibly indicates covariance with self-consciousness.

	Theor	y Driven			
	Unstand	lardised	Mo	del Sumi	mary
	Coeffic	cients			
	В	SE	df	R²	F
Block 1 (Enter)					
(Constant)	2.27**	.59	1, 138	.21	35.67**
Unexpectedness	.50**	.08			
Block 2 (Stepwise*)					
(Constant)	-3.78*	1.44	3, 136	.12	6.2**
Motivational Relevance	.35**	.13			
Lack of Concern	.212**	.08			
Self-Consciousness	<b>43</b> *	.18			

	Data	Driven			
	Unstandardised		Mo	nary	
	Coeffi	cients			
	В	SE	df	R²	F
Stepwise <sup>*</sup>					
(Constant)	-1.23	1.49	4, 135	.31	14.79**
Unexpectedness	.44**	.08			
Motivational Relevance	.36**	.13			
Lack of Concern	.23**	.08			
Self-Consciousness	44*	.18			

\*p<.05, \*\*p<.001

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.24): Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Relevance; Irrelevance; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness; Effortful Optimism; Success.

<sup>\*</sup>Excluded Variables (see appendix 4.25): Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Relevance; Irrelevance; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness; Effortful Optimism; Success.

	Theory	Driven			
	Unstandardised Coefficients		Mo	odel Sumi	mary
	В	SE	df	R2	F
Block 1 (Enter)		· · · · · · · · · · · · · · · · · · ·			
(Constant)	1.24**	.25	1, 138	.22	39.17**
Loss/Helplessness	.43**	.07			
Block 2 (Stepwise*)					
(Constant)	91**	.29	2, 137	.10	7.19**
Threat Removal	.16*	.06			
Other Responsibility	.14*	.06			

•n<	05	**n<	.001
<i>u</i> ~	·vJ,	יע	.001

<sup>\*</sup>Excluded Variables (see appendix 4.26): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Other-Blame; Self-Blame; Threat; Effortful Optimism; Success.

		Driven			
	Unstand	ardised	Ma	idel Sumi	nary
	Coefficients				
	В	SE	df	R2	F
Stepwise <sup>*</sup>					
(Constant)	.40	.34	3, 136	.30	19.07**
Loss/Helplessness	.40**	.07			
Threat Removal	.16**	.06			
Other Responsibility	.15*	.07			

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.27): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Other-Blame; Self-Blame; Threat; Effortful Optimism; Success.

Table 4.33. Theory and data driven tests of the cognitive precursors of tranquility.

	Theory	Driven			
	Unstand	ardised	Mo	del Sumi	nary
	Coefficients				-
	В	SE	df	R2	F
Block 1 (Enter)					
(Constant)	3.75**	.34	1, 137	.07	10.32**
Lack of Concern	.25**	.08			
Block 2 (Stepwise*)					
(Constant)	-4.10**	.85	1, 137	.15	24.55**
EF Coping Potential	.46**	.09			

	Data	Driven			
	Unstand	lardised	Mo	odel Sum	mary
	Coefficients				
	В	SE	df	R²	F
Stepwise•					
(Constant)	25	.86	2, 136	.21	18.55**
EF Coping Potential	.47**	.09			
Lack of Concern	.20**	.07			

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.28): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness; Effortful Optimism; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.29): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Threat Removal; Other-Blame; Self-Blame; Threat; Loss/Helplessness; Effortful Optimism; Success.

Table 4.34. Theory and data driven tests of the cognitive precursors of interest.

	Theory	Driven			
	Unstand		Model Summary		
	Coeffic	cients			
	B	SE	df	R²	F
Block 1 (Enter)					
(Constant)	3.78**	.74	1, 137	.02	4.05*
Relevance	.21*	.10			
Block 2 (Stepwise*)					
(Constant)	-4. <b>48**</b>	1.39	6, 132	.34	11.12*
EF Coping Potential	.29**	.11			
Effortful Optimism	.36**	.09			
Motivational Incongruence	- 22°	.08			
Self-Blame	38•	.14			
Self Responsibility	.19*	.08			
Future Expectancy	.19*	.09			

	Data	Driven							
	Unstandardised Coefficients						Мо	odel Sumi	mary
	В	SE	df	R2	F				
Stepwise <sup>*</sup>									
(Constant)	88	1.50	7, 131	.36	10.32**				
Effortful Optimism	.36**	.09							
EF Coping Potential	.29**	.11							
Motivational Incongruence	22**	.09							
Self-Blame	38**	.14							
Relevance	.24**	.09							
Self-Responsibility	.19**	.08							
Future Expectancy	.19*	.09							

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.30): Motivational Relevance; Motivational Congruence; Other-Responsibility; Problem Focussed Coping Potential; Self-Consciousness; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Threat; Loss/Helplessness; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.31): Motivational Relevance; Motivational Congruence; Other-Responsibility; Problem Focussed Coping Potential; Self-Consciousness; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Threat; Loss/Helplessness; Success.

Table 4.35. Theory and data driven tests of the cognitive precursors of relief.

	Theory	Driven			
	Unstandardised Coefficients		Мо	odel Sumi	mary
	<i>B</i> "	SE	df	R²	F
Block 1 (Enter)					
(Constant)	1.35**	.32	1, 137	.41	94.03**
Threat removal	.67**	.07			
Block 2 (Stepwise*)					
(Constant)	30	.34	3, 135	.15	8.05**
Self Responsibility	.23**	.07			
Loss/Helplessness	22 <b>**</b>	.08			
Motivational Congruence	.17*	.07			

	Data	Driven			
	Unstand	ardised	Model Summary		
	Coefficients				
	В	SE	df	R <sup>2</sup>	F
Stepwise <sup>,</sup>					
(Constant)	.84*	.43	5, 133	.54	30.55
Threat Removal	.44**	.08			
Success	.24**	.08			
Self-Responsibility	.24**	.07			
Loss/Helplessness	22**	.07			
Motivational Congruence	.15*	.06			

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.32): Motivational Relevance; Motivational Incongruence; Other-Responsibility; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Threat; Effortful Optimism; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.33): Motivational Relevance; Motivational Incongruence; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Other-Blame; Self-Blame; Threat; Effortful Optimism.

Table 4.36. Theory and data driven tests of the cognitive precursors of shame/humiliation.

	Theory	Driven			
	Unstandardised Coefficients		Mo	del Sumn	nary
	В	SE	df	R²	F
Block 1 (Enter)					
(Constant)	1.07**	.16	1, 137	.04	5.61*
Self Consciousness	.21	.09			
Block 2 (Stepwise*)					
(Constant)	22	.14	1, 137	.04	5.33°
Other Blame	.13*	.06			

to to the entropy of the control of	Data Driven Unstandardised Coefficients		Мо	del Sumn	nary
	со <b>е</b> јун В	ci <b>ents</b> SE	.16	R²	c
	B	<u> </u>	<u>uj</u>		r
Stepwise•					
(Constant)	.89**	.16	2, 136	.10	7.76*
Other Blame	.14*	.06			
Self Blame	.17*	.07			

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.34): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Self-Blame; Threat; Loss/Helplessness; Effortful Optimism; Success.

<sup>\*</sup>p<.05, \*\*p<.001

<sup>\*</sup>Excluded Variables (see appendix 4.35): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Threat; Loss/Helplessness; Effortful Optimism; Success.

# 4.7.2.4 Exploratory results for regret, frustration and self-directed anger.

For these remaining three emotions, no literature exists to suggest which appraisals nor which core-relational themes act as cognitive precursors to these specific emotional outcomes. Thus, an entirely data driven approach was used.

Only the model for self-directed anger included both appraisals and corerelational themes: higher self-directed anger was predicted by higher self responsibility appraisals, and higher scores on the core-relational themes of selfblame, loss/helplessness, and unexpectedness. The final model explained 36% of variance in the emotion (table 4.37).

Table 4.37. Data driven tests of the cognitive precursors of self-directed anger.

	Theory	: Driven			
	Unstandardised Coefficients B SE		Model Summary		
			df	R <sup>2</sup>	F
Stepwise					
(Constant)	- 46	.49	4, 134	.36	18.40**
Self-Blame	49**	.12			
Loss/Helplessness	.26**	07			
Self-Responsibility	.21**	.06			
Unexpectedness	.13*	.06			

<sup>\*</sup>p< 05, \*\*p<.001

\*Excluded Variables (see appendix 4.36): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness, Relevance; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Threat: Effortful Optimism; Success.

The analyses for both frustration and regret resulted in models containing core-relational themes only. Higher self-blame and threat were predictive of higher frustration ( $R^2$ =.13; see table 4.38); and higher threat and loss/helplessness were predictive of higher regret ( $R^2$ =.23; see table 4.39).

**Table 4.38**. Data driven tests of the cognitive precursors of frustration.

	Theory	Driven	_		
		Unstandardised Coefficients			nary
	В	SE	df	R2	F
Stepwise					
(Constant)	1.81**	.38	2, 136	.13	9.92**
Threat	.27**	.08			
Self-Blame	.30*	.14			

<sup>\*</sup>p<.05, \*\*p<.001

Table 4.39. Data driven tests of the cognitive precursors of regret.

	Theory	Driven			
	Unstand Coeffic		Model Summary		
	В	SE	df	R <sup>2</sup>	F
Stepwise					
(Constant)	1.16**	.30	2, 136	.23	19.93**
Threat	.23**	.08			
Loss/Helplessness	.23**	.09_			

<sup>\*</sup>p<.05, \*\*p<.001

### 4.7.3 Summary of results of theory testing

Longitudinal theory testing of change scores (section 4.7.1) did not support the unique cognition-emotion associations of Lazarus's theory (1999). Correlation effect sizes were generally small and a number of supposedly non-associated components were found significantly to correlate. A summary table of the results of the cross-sectional regression theory tests from section 4.7.2 (including effect sizes and significant predictors) is presented in table 4.39.

<sup>\*</sup>Excluded Variables (see appendix 4.37): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Loss/Helplessness; Effortful Optimism; Success.

<sup>\*</sup>Excluded Variables (see appendix 4.38): Motivational Relevance; Motivational Incongruence; Motivational Congruence; Self-Responsibility; Other-Responsibility; Future Expectancy; Problem Focussed Coping Potential; Emotion Focussed Coping Potential; Self-Consciousness; Relevance; Unexpectedness; Irrelevance; Lack of Concern; Threat Removal; Other-Blame; Self-Blame; Effortful Optimism; Success.

Table 4.40. Summary findings from theory testing regressions (negative coefficient indicated in parentheses).

		Summary statistical results		sults	Summary models			
Emotion	Theoretical hypothesis	Theory Driven			Data	Theory Driven	Data Driven	
		Appraisa	I CRT	Extra	Driven			
Anger	A: Motivational Relevance	$R^2 = .10$	$R^2 = .04$	$R^2 = .18$		A: Other Responsibility	C: Threat	
	A: Motivational Incongruence	(10.2%)	(3.6%)	(15.6%)	$R^2 = .24$	C: Other Blame	C: Unexpectedness	
	A: Other Responsibility	Total: 29.4%			C: Lack of Concern (-ve)	C: Self-blame		
	C: Other Blame				(23.9%)	A: EF Coping Potential (-ve)	C: Lack of Concern (-ve)	
						C: Effortful Optimism (-ve)	A: EF Coping Potential (-ve)	
Guilt	A: Motivational Relevance	$R^2 = .12$	$R^2 = .07$	$R^2 = .00$		A: Motivational Incongruence (-ve)	C: Self-blame	
	A: Motivational Congruence	(12.2%)	(6.2%)		$R^2 = .19$	A: Self Responsibility	A: Motivational Incongruence (-ve)	
	A: Self Responsibility		Total: 18.4%		(18.7%)	C: Self-blame	A: Self Responsibility	
	C: Self-blame						•	
Fear /	A: Motivational Relevance	$R^2 = .33$	R²=.07	$R^2 = .06$		A: Motivational Relevance	C: Threat	
Anxiety	A: Motivational Incongruence	(33.0%)	(4.0%)	(3.8%)	3.8%) $R^2 = .43$ (43.3%)	A: EF Coping Potential (-ve)	A: EF Coping Potential (-ve)	
·	A: EF Coping Potential (-ve)		Total: 40.8%	,		C: Threat	A: Motivational Relevance	
	C: Threat					C: Self-blame	C: Self-blame	
						C: Unexpectedness	C: Unexpectedness	
Sadness	A: Motivational Relevance	$R^2 = .10$	$R^2 = .18$	$R^2 = .00$		A: Future Expectancy (-ve)	C: Threat	
	A: Motivational Incongruence	(9.7%)	(16.2%)	$R^2 = .37$	C: Loss/Helplessness	C: Loss/Helplessness		
	A: Future Expectancy (-ve)		Total: 25.9%				A: Motivational Incongruence	
	A: PF Coping Potential (-ve)				(36.5%)		· ·	
	C: Loss/Helplessness							
Hope /	A: Motivational Relevance	$R^2 = .11$	$R^2 = .04$	$R^2 = .09$		A: PF Coping Potential	A: PF Coping Potential	
Challenge	A: Motivational Incongruence	(10.9%)	(3.6%)	(7.8%)	$R^2 = .22$	C: Effortful Optimism	A: EF Coping Potential	
_	A: PF Coping Potential		Total: 22.3%		(21.6%)	A: EF Coping Potential	C: Relevance	
	C: Effortful Optimism				•	C: Relevance	C: Loss/Helplessness (-ve)	
Happiness	A: Motivational Relevance	$R^2 = .01$	$R^2 = .19$	$R^2 = .04$	)4 23 22	C: Success	C: Success	
• •	A: Motivational Congruence	(0.6%)	(18.8%)	$(3.2\%)$ $R^2 = .22$	C: Effortful Optimism	C: Effortful Optimism		
	C: Success		Total: 22.6%		(21.7%)		-	
Boredom	C: Irrelevance		$R^2 = .00$	$R^2 = .07$	D2_ 07	A: Motivational Incongruence (-ve)	A: Motivational Incongruence (-ve)	
			Total: 6.9%	$ \begin{array}{ccc} R^2 = .07 \\ (6.9\%) & R^2 = .07 \\ (6.9\%) \end{array} $				

A: Appraisal components; C: Core-relational theme

Table 4.40. Summary findings from theory testing regressions (continued).

		Summary statistical results				Summary models		
Emotion	Theoretical hypothesis	Theory Driven			Data	Theory Driven	Data Driven	
		Appraisal	CRT	Extra	Driven			
Surprise	C: Unexpectedness		$R^2 = .21$	$R^2 = .12$		C: Unexpectedness	C: Unexpectedness	
		(	(20.5%)	(9.5%)	$R^2 = .31$	A: Motivational Relevance	A: Motivational Relevance	
		To	tal: 30.0%		(30.5%)	C: Lack of Concern	C: Lack of Concern	
						C: Self-consciousness (-ve)	C: Self-consciousness (-ve)	
Resignation	C: Loss/helplessness		$R^2 = .22$	R2=	$R^2 = .30$	C: Loss/helplessness	C: Loss/helplessness	
_		(	(22.2%)	(7.8%)	(29.6%)	C: Threat Removal	C: Threat Removal	
		To	tal: 30.0%		(29.070)	A: Other Responsibility	A: Other Responsibility	
Tranquility	C: Lack of Concern		$R^2 = .07$	$R^2 = .15$	$R^2 = .21$	C: Lack of Concern	A: EF Coping Potential	
. ,			(7.0%)	(14.0%)		A: EF Coping Potential	C: Lack of Concern	
		To	tal: 21.0%		(21.4%)			
Interest	C: Relevance		$R^2 = .02$	$R^2 = .34$		C: Relevance	C: Effortful Optimism	
			(2.9%)	(33.3%)		A: EF Coping Potential	A: EF Coping Potential	
		To	tal: 36.2%	,	D2 26	C: Effortful Optimism	A: Motivational Incongruence (-ve)	
					$R^2 = .36$	A: Motivational Incongruence (-ve)	C: Self-blame (-ve)	
					(36.0%)	C: Self-blame (-ve)	C: Relevance	
						A: Self Responsibility	A: Self Responsibility	
						A: Future Expectancy	A: Future Expectancy	
Relief			$R^2 = .41$	$R^2 = .15$	_,	C: Threat Removal	C: Threat Removal	
		(	(40.7%)	(8.9%)	D2 54	A: Self Responsibility	C: Success	
		•	tal: 49.6%		$R^2 = .54$	C: Loss/Helplessness (-ve)	A: Self Responsibility	
					(53.5%)	A: Motivational Congruence	C: Loss/Helplessness (-ve)	
						Ü	A: Motivational Congruence	
Shame /	C: Self Consciousness		$R^2 = .04$	$R^2 = .04$	D2 40	C: Other-blame	C: Other-blame	
Humiliation			(3.9%)	(3.8%)	$R^2 = .10$		C: Self-blame	
			tal: 7.7%	` ,	(10.5%)			
Self-directed	***************************************					<del></del>	C: Self-blame	
Anger					$R^2 = .36$		C: Loss / Helplessness	
~					(35.5%)		A: Self Responsibility	
					· •		C: Unexpectedness	
Frustration					$R^2 = .13$		C: Threat	
					(12.7%)		C: Self-blame	
Regret			***************		$R^2 = .23$		C: Threat	
0					(22.7%)		C: Loss / Helplessness	

For the six 'hot' cognitions, relatively equal results were found in the theory driven and data driven approach. However, theory in and of itself was insufficient to explain all variance in the emotion for four out of these six emotions and the additional block using stepwise methods added substantially. In all six cases, some of the theoretically hypothesised cognitive components were not significant. Additional variables were required. Content of three of the six data driven models replicated that found in theory driven models, although the comparative coefficient sizes were different. Prominently, for some emotions, equal variance could be explained with a largely different set of predictors to that predicted by theory. For all emotions (including the less empirically developed emotions), the results largely support the notion that both appraisals and core-relational themes are necessary for best variance to be explained (with just three exceptions). However, findings do not support unique emotion and core-relational theme pairings. There were no occasions where the directional relationship of **coefficients** opposed theory or was not as expected and few occasions where the specific cognitive precursors seemed illogical or unanticipated. Whilst a wide range of overall effect sizes resulted from the models, there were no occasions where cognitions were able to entirely predict variance in emotion.

# 4.8 ANALYSIS OF QUALITATIVE COMMENTS

At the end of each questionnaire, participants were given the opportunity to write freely about their experiences, and/or their participation in the study. Analysis of this data allows a rich interpretation of the quantitative results and helps to generate further research hypotheses. Furthermore, due to the sensitive nature of some of the questions, it seemed reasonable that some participants might want an opportunity to express some of their responses to participation. Therefore, the qualitative element of the research was anticipated to act similarly to a debrief.

As participants were not directly asked to comment, it was not expected that enough data would emerge for a sophisticated qualitative analysis, therefore a basic content analysis was planned.

Overall, 92 participants (57.5%) made some level of comment in this section of the questionnaires; many commented at more than one time point. Length of comments varied greatly from just a few words, up to (in 10 cases) one to two sides of handwritten notes. Upon transcription of these comments it became clear that whilst a simple content analysis may be adequate, a basic level thematic analysis may also be possible. This thematic analysis led to the construction of 28 separate themes (subordinate themes) which were grouped into five independent categories or superordinate themes. A hierarchy of these themes is presented in table 4.41. Transcription and primary analysis of this data were carried out by the candidate and validated by the supervision team.

Table 4.41. Thematic summary of qualitative data.

	Superordinate Theme		Subordinate Theme
1	Causation & Control	1.1	Life event prior to diagnosis
		1.2	Life events post diagnosis
		1.3	Religious control
		1.4	Other causes
		1.5	Hereditory concerns
2	Cancer & Treatment	2.1	Treatment
		2.2	Cancer symptoms
		2.3	Comorbidity
		2.4	Preparedness
		2.5	Health care interactions
		2.6	Diagnosis and treatment delay
		2.7	Perceived current health status
3	Psychological Psychological	3.1	Adjustment to diagnosis
	Adjustment	3.2	Expected nature of diagnosis
		3.3	Desirability of diagnosis
		3.4	Emotional reaction to illness
		3.5	Coping with cancer
		3.6	Religious coping
		3.7	Social support
		3.8	Body image
4	Transition & Return to	4.1	Personal growth
	Normality	4.2	Future expectations of return to normality
	•	4.3	Thoughts of recurrence and survival
5	Participation Issues	5.1	Presentation of questionnaire
	-	5.2	Relevance of study
		5.3	Religious enquiry
		5.4	Benefits and harms of participation

Because the thematic analysis was so varied, and given that fewer than 60% of participants made any comment at all, it is not surprising that some themes

theoretical insight. Thus, not all thematic descriptions will be presented here. Theme five, however, seemed particularly relevant to understand both why participants did (and didn't) answer certain sections of the questionnaire, and also to understand their personal experiences and reflections of participation. This information is useful in both evaluating the current study, and planning future protocols with this patient group and so analysis follows. The chart of transcribed comments relevant to this theme is presented in appendix 4.39 and a written summary of this theme follows. Very few participants commented on this theme at more than one time-point, but where they have, any changes in opinion will be highlighted. Accordingly, the remaining comments have not been separated by time-point. The appended transcriptions contain this information for reference (appendix 4.39).

## 4.8.1 Subordinate theme 5.1: Presentation of the questionnaire

Quite a complex questionnaire. Have done my best.

Participant 005, T1.

The over-arching message of these comments is that participants found the questionnaire very difficult, both in content and how they were asked to provide answers. Across the three time points, 19 participants made comments in line with this theme. Two participants commented on specific measures within the questionnaire pack. Participant 30, for example, did not understand one of the measures, and participant 108 found those questions relating to causation particularly difficult:

I had difficulty answering the questions relating to 'blame'. As I understand my condition it is age related and as a consequence it would have happened anyway.

Participant 108, T2.

Seven participants (1, 30, 52, 106, 112, 158) also commented on the way that they were asked to answer particular questions. Participant 158 also commented on the seeming "...duplicat[ion]..." through the questionnaire.

Participant 106 suggested that a "...neutral response..." would have been helpful and another participant said the following:

Respectfully note that I find some of your questions to be rather nebulous and not easy to respond to specifically.

Participant 001, T2

Two participants related their difficulty to complete the questionnaire to fluctuations in their feelings and emotions over time (11, 132). Seven participants (18, 62, 93, 101, 113, 122, 141) commented that it was difficult to isolate their answers to the cancer from other health problems and specific features of their treatment. For example, participant 113 related most his problems to his "...ileostomy and kidney failure". One participant (018) felt that his age (more than the cancer) would have influenced his answers throughout and participant 122 commented that more than his health affecting the answers given, it was daily appointments at the hospitals for treatment which impact life to a greater extent. Similarly, another participant found that it was not direct health problems which restricted activity and affected life, but the indirect effects of health advice:

I also found difficulty answering with regard to restricted activities. I was told not do any lifting for three months. I have carefully avoided this.

Participant 093, T2

One participant commented that answering the questionnaires got increasingly more difficult as she progressed through the study due to the uncertainty as here illness progressed:

This questionnaire has been more difficult to answer as I am coming to the end of the chemo treatment, so do not know what will be the next stage.

Participant 131. T3

Given the length of the questionnaire, it is perhaps surprising that only two participants (027, 152) commented on this:

It is far too long and too repetitive and requires an "act of will" to answer it at all.

Participant 027, T2

### 4.8.2 Subordinate theme 5.2: Relevance of the study

Two participants raised questions of the general relevance the study to cancer patients. For one patient, this ambiguity was resolved after both speaking the her GP and being given time:

I feel tons better about participating, as he explained it's [sic] relevance in the light of recent thought relating to a positive attitude...having got my head around things now, I found completion of the questionnaire considerably easier.

Participant 106, T2

The other participant did not feel that this issue was resolved but related this to her previous experience of cancer. She commented that her personal experience seemed in contrast to the aims of the study:

I really find it difficult to know how these answers really help in the ongoing fight against cancer. My partner was an <u>extremely</u> positive person...he died aged 58 from pancreatic cancer. So I am fatalistic about these things.

Participant 084, T3

Similarly, one participant felt that some specific questions were inappropriate, especially given the timing:

Spirituality and sexuality are deeply personal issues, and I am not prepared to offer an opinion...also felt rather annoyed at being confronted with this at such a deeply emotional time

Participant 106, T1

A number of participants commented on the irrelevance of some questions in respect to their treatment. Two (101, 141) had received only minimal treatment due to their diagnosis being made at an early stage:

As I had a non-aggressive malignant tumour some of the questions have been irrelevant...therefore I have tried to answer the questions adequately, sometimes with difficulyt.

Participant 101, T2

A further seven participants (012, 025, 045, 052, 081, 122, 135) felt that some of the questions were irrelevant because they had not yet started treatment:

I have been unable to answer some of the questionnaire, because I think I need to have started treatment before I can do so

Participant 012, T1

However, these participants also acknowledge that this is likely to change over the course of treatment leading them to feel "...more involved..." (Participant 135, T1).

# 4.8.3 Subordinate theme 5.3: Religious enquiry

One participant felt that the questions in this study were not of relevance to medicine:

The questionnaire has many facets in common with the Church of Jesus Christ Scientists (Scientology). It has nothing in common with a serious medical scientific study.

Participant 027, T2

This opinion was similar to that of seven other participants who commented on the necessity to include questions about religion and spirituality. Participant 152 suggested that such questions should be left out as "...not all people believe..." and that "there is too much [sic] question on God". Participant 75 wrote simply that she has "...found the issue of God difficult", but with no further expansion it is difficult to know whether this is because having cancer has made her question her spirituality, or if she is simply referring to difficulty in knowing how to answer these questions. One participant claimed to be confused at the inclusion of spirituality in this study with a further suggestion that to fully understand this, research should ask about the "...relevance of a person's faith in the usual circumstances... and whether it has helped in the present circumstances." (Participant 093, T3).

Three participants (001, 93, 151) reflected on the wording of these particular **questions** commenting that they provide a biased impression of God:

Your question gives me a feeling of being critical or negative toward God.

Participant 001, T2

The questions imply a draconian God who 'deals out' cancer on a random basis. I do not believe that God decides that I get a disease...[I] believe in a God who cares and supports me.

Participant 151, T2

This latter extract also further highlights the importance of establishing a participant's personal faith in addition to appraisals of religious control; this participant felt that questions of spiritual blame were irrelevant because of their personal definition of God. This is further expanded by participant 72 who claims that "blaming God is stupid...we don't ask to be ill, it just happens."

# 4.8.4 Subordinate theme 5.4: Benefits and harms from participation

Only three participants reported harms, or negative effects from the study: **Participant** 106 felt that it:

..focused the mind so strongly on things that are difficult to cope with, when [I] would rather 'go with the flow'.

Participant 106, T3

**A similar** but stronger reaction was written by participant 027, who felt that such "...dwelling...is not constructive." This participant further expanded on this claiming "I do not approve of this study." (T2). A less critical, but equally negative reaction, was reported by another participant:

Filling in this has reduced me to tears, don't understand why.

Participant 28, T2

**Despite** this emotional reaction, this same participant wrote about the benefits of "...hav[ing] written it all down" and in a later follow-up seems to have found understanding of why her reaction is so emotional:

This questionnaire has made me confront my condition. I have not accepted that I've had cancer...I have had to face reality and my emotions and end up in tears...I do not think I am handling my condition in the way that I should.

Participant 23, T3

**Participant** 117 also commented that participation helped in the process of **realisation** that the "...cancer, although small, was real".

One participant directly commented that participation had helped, but went on to claim that:

It would be good to talk to people, including doctors, and be given help in adopting a positive attitude.

Participant 057, T1

A further two participants wrote of their gratitude of having had the opportunity to take part. The first seems thankful for the opportunity to help others:

Many thanks for allowing me the opportunity to take part...I do hope that it will benefit others.

Participant 103, T3

**For** participant 103, it is not benefit to others that is the cause of her gratitude, but benefit on a much more personal level. She comments, "Thankyou for listening."

# CHAPTER 5 EMPIRICAL STUDY: DISCUSSION

### **5.1** CHAPTER OVERVIEW

The summary of the results will be organised around the four principle **objectives** for this study:

- To identify the most important psychological predictors of anxiety, depression and quality of life at three and six month timepoints after cancer diagnosis.
- 2) To identify at what time-period (baseline, three or six month follow up) predictor variables best predict each of the outcomes at three and six month follow-up.
- 3) To examine whether theoretically associated components of the Transactional model (cognitive appraisal, core-relational themes, emotion themes, and coping) vary equivalently over time.
- 4) To test the hypothesised associations between specific cognitive appraisals, core-relational themes, and emotion themes (i.e. the 'exclusively' linked components) in relation to cancer diagnosis.

These will be grouped by their primary aim: prediction of clinically-relevant psychosocial outcomes (objectives 1 and 2; section 5.2) and theory testing (objectives 3 and 4; section 5.3). Findings are discussed in the context of the psychosocial oncology literature, in particular those studies included in the systematic review (Chapter 2). A general study evaluation (section 5.4), and future recommendations follow (section 5.5).

## **5.2** PREDICTING ANXIETY, DEPRESSION AND QUALITY OF LIFE

### 5.2.1 Overview of score distributions and outcome prevalence

In relation to sample distributions, a full range of scores on optimism were obtained, but the mean was relatively high compared to similar research (e.g. Scheier et al., 1994). Mean scores of neuroticism were low, although again, a wide spread of scores were demonstrated. When compared to normative data (Furnham & Bramwell, 2006), mean neuroticism scores were lower than would be expected (17.27 as opposed to the normative mean of 24.56). The same is true for both extroversion and openness (although to a lesser extent). Conversely, means

scores on both agreeableness and conscientiousness were higher than normative data.

A full range of scores on the Smith and Lazarus (1993) measures was observed. Median scores from these indicate, not surprisingly, that motivational relevance was high. That is, diagnosis was important in relation to individuals' current goals. Furthermore, the data seemed to show that the situation was largely incongruent with perceived achievement of those goals. Few patients held themselves responsible, but perceptions of other-responsibility were at a higher level. Confidence in future expectancy was low but perceived coping expectancies high. Most highly reported relational meanings included self-consciousness, irrelevance, other blame, and effortful optimism. Loss and helplessness were rated very low as was, perhaps surprisingly, perceived threat. The most highly reported emotions were guilt, resignation, interest, boredom/detachment and anxiety and relief. Low median scores on challenge, hope, anger and fear (all scoring a median of 1 out of a possible 9) were surprising given previous literature reporting high levels of negative emotions in similar samples (e.g. Longman et al., 1999).

In accordance with findings reported by Lowery et al. (1993), in a comparison of each subscale of locus of control, internal control scored lowest, other-people oriented control highest, and chance control in the middle. On the MiniMac, hopelessness was low but scores on fighting spirit, fatalism and avoidance both tended towards the higher ends of the scale. There were no significant changes in these variables over the course of the study. In terms of coping; acceptance, distraction and seeking social support were most common at diagnosis. Grouped adaptive strategies were reported more commonly than maladaptive strategies. Concurrent health status was rated fairly highly, and although only minor changes were observed over time, these seem to indicate worsening physical, but improving mental health over the six months of study.

Quality of life was high, possibly in large part due to the less physically demanding nature of early stage illness. This finding confirms that of Kessler (2002). Whilst further improvements were observed for all site-specific subscales, for lung cancer patients this was less noticeable and non-significant. Although there was a slight depreciation in total mean quality of life at three month follow-up (which had returned to earlier levels by six months), emotional

quality of life subscales consistently improved at each time point. This pattern of results is congruent with those previously reported in the associated literature (e.g. Hee et al., 2005; Schou et al., 2004).

Mean anxiety and depression scores were consistently below clinical cut-off scores at each time point and are representative of a comparatively psychologically 'healthy' sample when viewed alongside other literature (e.g. Maguire, 2000). Crawford, Henry, Crombie and Taylor (2001) provide normative data for a non-clinical adult populations on the HADS and these compare favourably with the data from this study. Their anxiety normative mean score is reported at 6.14. In this study, mean anxiety scores at each timepoint were 6.62, 5.78, and 5.29; although slightly higher than the general population at baseline, anxiety decreases below general population levels in later stages of illness adjustment. Similarly, Crawford et al.'s depression data suggest a normative mean score of 3.68. In this study, mean scores of 3.40, 4.08 and 3.41 were found at each timepoint; patients are at most risk from increases in depression at a midpoint of adjustment. There were cases above clinical cut off at all timepoints, though proportionally more for anxiety, again reflective of trends in the previous literature (see systematic review). As with quality of life, depression scores increased at three month follow-up, but had returned to baseline levels by six month follow up (two cases met clinical cut off at baseline, nine at three months, and none at six months). Anxiety scores improved consistently throughout the study, with most decrease in the latter three months. Even though only small numbers reached clinical cut-offs at diagnosis, by three month follow-up none of the participants reached such cut-offs for either psychological disorder.

It is clear that adjustment to diagnosis is not straightforward. Whilst consistent improvements in anxiety support the notion of an immediate post-diagnosis adjustment process (Trask et al., 2003; Yan & Sellick, 2004; Deshields et al., 2005), quality of life and depression incidence seem to indicate a more delayed process, perhaps, as suggested by other researchers (Bleiker et al., 1995; Nordin & Glimelius, 1998; Butow et al., 1999), not commencing until treatment is underway. Low clinical caseness figures do not allow for direct comparison of this data with other longitudinal studies such as Bleiker et al. (1995) and Nordin & Glimelius (1998).

# 5.2.2 Objective one: Identifying the most important predictors of outcome

### **5.2.2.1** Demographic variables

Age, gender, and the presence of a significant other were entered into regression analyses for all outcomes. Of these, only age emerged as a significant predictor, and only on one occasion (three-to-six month prediction of quality of life). The absence of a gender effect on these outcomes is surprising given previous results reported by Hassanein *et al.* (2001), Lehto *et al.* (2005), and Ranchor *et al.* (2002).

Considerable evidence indicates that elderly patients adjust better to diagnosis than their younger peers (see section 3.7.4), but once again, this variable failed to reach significance in multivariate tests. Previous literature also emphasises the importance of social support both as a buffer to psychological distress and as a primary mechanism in psychological intervention studies (Llewelyn et al., 1999; Schou et al., 2004; Bloom, 2007). In the current study, no confirmatory data for this relationship were found.

One possible explanation for the lack of effect for demographic variables in these analyses may be due to the longitudinal nature of the study. In all cases, regressions included previous levels of outcome. It is possible that the effects of these demographic variables may act more on initial reaction than later adjustment (i.e. anxiety, depression, and quality of life as measured at baseline). Therefore, their effect could be encapsulated within the large effect sizes of previous outcome included in each model. Alternatively, Osoweicki and Compass (1998) suggest that demographic variables influence coping processes far more than outcome and this might well explain the absence of effect here.

#### 5.2.2.2 Clinical variables

Previous literature (e.g. Alhama et al. 1996; Gallagher et al. 2002; Kessler et al. 2002) reports on the effects of cancer type, cancer stage, treatment differences and time since diagnosis as outcome moderators and mediators. Just one of these variables (cancer type) was suitable for inclusion in the analysis; other data were not usable primarily due to quantities of missing data, and small and unequal subsamples sizes for clinical categories of treatment and specific histological diagnosis. Although entered into regression analyses, no significant effects of cancer site (colorectal, breast, lung or prostate) were found. Again, this could be

an effect of unequal group sizes. Alternatively, it could be that the individual's perception of illness (i.e. perceived health status) is more predictive than the dinical variables themselves.

## **5.2.2.3** Personality

High intercorrelation was found between personality variables but differences emerged regarding their association with outcome. Where optimism and neuroticism were both consistently and highly correlated with all outcomes, regardless of time-lag, extroversion and agreeableness were correlated less frequently. Both were found to be highly significant for all outcomes in baseline-to-three month correlation, but only for anxiety in three-to-six month correlation. Only extroversion remained correlated in baseline-to-six month correlations, and only with quality of life and anxiety. No significant correlations were found for openness or conscientiousness, with the one exception of openness in three-to-six month anxiety.

Although associations between extroversion and outcome have previously been studied (with inconsistent conclusions), few studies have investigated the effects of openness, agreeableness and conscientiousness. The current data suggest an equally important role of agreeableness as for extroversion, but a lack of evidence for the importance of openness and conscientiousness.

of all personality variables, only neuroticism emerged significantly predictive in the regression analyses, although this was affected by time point. For quality of life and anxiety, neuroticism emerged significant only for later outcome (three-to-six month) whereas for depression, it featured only for early outcome (baseline-to-three month). Correlation data provide no explanation for this: effect sizes are relatively consistent within each outcome across different timepoint. There are suggestions in the general psychology literature that some factors of supposed trait personality actually demonstrate moderate instability over the life-course (Roberts, Walton & Viechtbauer, 2006). Should this be a valid hypothesis, this may explain differences observed in the trait structure here, and why some factors, particularly neuroticism and extroversion appear to effect outcome more similarly to optimism than their trait counterparts.

The failure of optimism to emerge as a significant predictor in regression models is surprising given previous literature (e.g. Carver, 2003) however, this

may be due to the specificity of the outcome. Effects reported in the literature (see particularly table 2.7 in the systematic review) tended to be for generic outcomes such as distress or well-being, rather than specific disorders such as anxiety and depression.

#### **5.2.2.4** Health locus of control.

The systematic review (Chapter 2) highlighted the inconsistency of findings relating to associations between locus of control and outcome, hence the hypothesis that these would not be found in the current data set. In this study, just three significant correlations emerged between the five sub-scales and the three outcomes and given the sheer number of correlation tests conducted in this section, it is possible that these appeared simply by chance. None of these effects emerged as significant in multivariate analysis, confirming the results of Naus et al. 2005) and DeValck & Vink (1996). This hypothesis (hypothesis two) was, therefore, supported.

#### **5.2.2.5** Cognitions and emotions

Correlations between appraisal components and outcome were frequent. Where a range of appraisals correlated with quality of life and anxiety, only components of secondary appraisal (coping and responsibility oriented) correlated significantly with depression. Whilst the generic influence of cognitive appraisal on outcome is consistent with findings reported by Krietler et al. (1996) and Burgess and Haaga (1998), the absence of focus on goal-related appraisals is somewhat at odds with more recent research (e.g. Lampic et al., 2002; Schroevers et al., 2008).

There were also far more correlations between core-relational themes and quality of life than for anxiety and depression. Four of the twelve core-relational themes (other-blame, threat, threat removal, and loss/helplessness) seem more pervasive in effect than the remainder. Threat and loss/helplessness in particular were associated throughout all correlation tests. However, where other-blame is most highly correlated with early levels (three month follow-up) of the three outcomes, threat removal is more highly correlated with later levels (six month follow-up). This particular focus is not surprising given the nature of the stressor in question and confirms findings reported by Padilla, (1992, Glinder and Compas (1999) and Green (2003).

In multivariate analysis just two appraisal components emerged: other responsibility for three-to-six month quality of life, and self responsibility for baseline-to-three month anxiety. Core-relational themes of lack of concern emerged for baseline-to-six month quality of life; unexpectedness and threat for three-to-six month quality of life; and, other blame for both baseline to three month and three to six month anxiety.

Emotions were highly correlated with all outcomes, a finding also is supported by previous research (e.g. Watson *et al.* 1999; Longman *et al.* 1999; Kessler *et al.*, 2002). Whereas negative emotion was consistently correlated with all outcomes, across all time-lagged correlations, an alternative pattern of results emerges for positive emotion. For quality of life, correlation with positive emotion was found consistently across all regression timepoint, but anxiety and depression only significantly correlate for analyses of early adjustment (baseline to three month correlations) with effect sizes significantly decreasing where six month outcomes are used. Emotions feature in just one regression model, showing the importance of negative emotion for baseline-to-three month quality of life.

#### 5.2.2.6 Coping

There were just two occasions where adaptive coping was significantly associated with outcome: baseline coping to six month quality of life and depression. Maladaptive coping was correlated with poorer adjustment on all outcomes at baseline, but only associations with quality of life and anxiety remain significantly correlated at three month follow-up. In multivariate analysis, only three-month adaptive coping emerged as a significant predictor of six month quality of life, a surprising finding given that this was one of the lowest correlation effect sizes found.

There is a wide literature reporting the direct and mediating effects of coping on anxiety, depression and quality of life (see table 2.11 for a summary). That coping was not included in more regression models is unexpected. In this study, most cognitive appraisals and core-relational themes correlated with outcome measures with equal, if not higher effect sizes, than the small to medium effect sizes previously reported for coping to outcome relationships (de Ridder & Schreurs, 1996). It is possible, therefore, that coping was rendered unnecessary in

the regression models because of the larger amount of variance already explained by its cognitive precursors.

The choice of coping measure may also be partly responsible for these findings. Rather than using individual sub-scales, or more traditional composite score dichotomies (see also section 1.5), the BriefCOPE employs an adaptive-maladaptive dichotomy (see also section 1.5). Although the use of these composite scores is validated (Carver, 1997) there is some question, more broadly, over the validity of the nature of grouping coping responses in this way. Some literature instead recommends the use of individual strategies in data analysis (Jensen, Turner & Romano, 1992). Due to data limitations (power and normality) such analysis was not here possible but with larger sample sizes, exploration of each individual coping type may yield different results.

#### 5.2.2.7 Mental Adjustment to Cancer Variables

Hopelessness/helplessness and anxious preoccupation were consistently correlated with all three outcomes, regardless of time-lag. Whilst fighting spirit also emerged significantly correlated with quality of life and depression in baseline-to-three month outcome only, correlations between both fatalism and cognitive avoidance with outcome were small to negligible. These associations are only in part supportive of those in the published literature (e.g. Watson *et al.*, 1991; Hassannein *et al.*, 2005). The larger effects of anxious preoccupation and hopelessness/helplessness on these three outcome measures are particularly reflective of the results of the meta-analysis earlier in this thesis (see table 2.7).

That components of the MiniMAC were not included in the regression models was unexpected given the previous literature on their effects. This may be due to the underlying constructs which are measured by the scale. As previously reported (in sections 2.6.3 and 3.4.1.7) there is some debate regarding the specific construct measured. Despite this, there is consensus that it is likely to be a cognition or coping construct rather than personality or emotion. Correlation data from this study between the MAC, BriefCOPE and Smith and Lazarus (1993) appraisal and emotion measures confirms strongest relationships between the MAC and core-relational themes which may go some way to clarifying this conceptual issue in favour of the cognition argument (see also Nelson *et al.*, 1994). Collinearity between the MAC and core-relational themes was tested as part of the

regression procedure and no problematic effects were found. However, it is likely that there is some degree of shared variance. Given that the core-relational themes were prominent in the regression models, this may explain why MAC components did not add further variance.

# 5.2.2.8 Concurrent health status and earlier measures of the outcome variables

Concurrent physical and mental health status were significantly correlated with all three outcomes and remained so over the larger time-lagged baseline-to-six month correlation tests. By far the most significant and largest correlations are those between earlier and concurrent anxiety, depression and quality of life. These high effect sizes remained significant contributors in the multivariate regression analyses.

In regression analyses, concurrent health status emerged significant only for depression. For this outcome, a noticeable distinction was observed between mental health status which is predictive in baseline-to-three month regressions, and physical health status which is predictive in three-to-six month regression.

In all statistical models, earlier levels of the outcome variables were highly significant of later levels of these same variables. There was also some cross-over effects of baseline levels of outcome with anxiety emerging a significant predictor of baseline-to-three month quality of life; and baseline quality of life predictive of three month anxiety, and both three and six month depression. The high correlation and predictive power between these constructs was expected and is congruent with the published literature (e.g. Malcarne *et al.*, 1995; D'Antonio *et al.*, 1998; Green, 2002; Badger *et al.* 2004).

#### **5.2.2.9 Summary**

Hypothesis one stated that potentially modifiable psychological variables would contribute to prediction of psychosocial outcomes. This was confirmed in the current study, but the limited number of individual predictors significantly entering the regression models was unexpected. Hypothesis two stated that locus of control would not be predictive of outcome. This was also supported. The implications and application of these findings will be further discussed later in this chapter.

# 5.2.3 Objective two: Optimal assessment times for best outcome prediction

Three regression models were tested for each of the outcomes variables (anxiety, depression and quality of life): baseline predictors and three month outcome; baseline predictors and six month outcome; and, three month predictors and six month outcome. Across all multivariate analyses, final models produced higher effect sizes than expected ranging from  $R^2$  = .47 to .74. It is unusual to find such high levels in the psychosocial oncology literature and this may reflect the importance of including multi-component measures.

For quality of life, prediction from baseline measures proved least effective, although still explaining 61.6% variance in outcome. Models became more efficient when both six month outcomes and three month predictor data were used (total variance increasing to 67.5% and 73.4% respectively). A interesting pattern of inclusion of modifiable psychological predictors was also evident. In the early adjustment model (baseline-to-three months), only negative emotion was included. Oriented toward six month outcome, emotion was replaced by lack of concern, a core-relational theme. The three-to-six month model included the highest number of additional variables within this set of analyses; predictors included an appraisal component, two core-relational themes and adaptive coping.

Total variance explained for baseline-to-three month and three-to-six month anxiety were relatively equal. Both models included the core-relational theme of other blame. Although the early adjustment model also included the appraisal component of self-responsibility, the overall variance explained is lower. It is likely that, as with quality of life, the addition of neuroticism in block one of the three-to-six month regressions improved the predictive ability of the model.

More variance for depression was explained using baseline measures than those measured at three month follow-up; whether predicting over a three or six month time-lag, overall variance explained was 57.0%.

These differing trajectories of outcome over time do not provide clear answers to hypotheses three which had predicted longer time-lagged analyses (i.e. baseline-to-six months) to perform worst. Hypothesis four further predicted that later models of adjustment would outperform early models of adjustment. Again, this was not confirmed by the current data as each outcome demonstrated different patterns over time. Quality of life was worst predicted in the early

adjustment model (baseline-to-three month) and depression was worst predicted in the late adjustment model (three-to-six months). Only findings for anxiety supported this hypothesis by producing a model for baseline-to-six month prediction that was worse performing that other variable and time combinations. Although a complex picture of adjustment, these findings are not unique. Bleiker et al. (1995), for example, proposed that for quality of life, adjustment processes and improvements do not begin until after treatment has finished because the situation is simply far too complex and unstable. This may go some way to explaining the increased variance predicted in the later models regardless of time lag; at this later stage, physical aspects of illness are beginning to settle. Cognitions and coping are more likely to stabilise, thus increasing their predictive ability for psychological outcome.

## 5.2.4 Applications to clinical practice and policy

There are two important applications from these data: the identification of significantly predictive control, demographic and clinical variables; and, the additionally significant modifiable psychological variables.

The primary purpose for including clinical, demographic and control variables into the analyses was such that the potential clinical impact of the psychological variables (in block two) could be assessed against those variables that cannot easily be modified. More will be said on this in due course. A secondary outcome, however, was the identification of a group of core predictors of anxiety, depression and quality of life. Measurement of these in routine clinical assessment may provide an efficient method of clinical screening for the prediction of the psychological outcomes and the monitoring of those who may later encounter adjustment difficulties.

The majority of variables entered in block one of these regression analyses did not reach significance. Nonetheless, their presence did add some level of variance and together they provide a comprehensive outline of those patients who may be most at risk. Consistent with the previous literature, these included younger, female patients, lacking in the support of a significant other. Clinically, lung cancer patients were most likely to report poorer quality of life and higher anxiety and depression scores than the other cancer groups. Personality risk factors were not so easy to identify. So far as the results demonstrated,

agreeableness consistently correlated with better outcome, as did openness and conscientiousness, in the few models into which they were included. Neuroticism was clearly associated with poorer outcome and being the most highly and significantly associated of all personality traits, this is the primary sub-scale on which risk might be best assessed. A direction of risk for extroversion is more difficult to establish as at different time points of analysis, even within the same outcome, the direction of effect for this variable regularly changed. Extroversion is unlikely, therefore, to enable reliable screening assessment.

That early levels of psychosocial outcome are the best predictor of later levels was expected. Given trends observed in the current data, it appears that where adjustment difficulties are identifiable early on in illness, that these are likely to persist throughout the illness experience. Ongoing adjustment difficulties can pose a threat to not only psychological health, but also to physical aspects of illness including treatment adherence, symptom management and further worsening of quality of life (Jacobsen, Donovan, Trask, Fleishman, Zabora, Baker & Holland, 2004). Regular and routine assessment of quality of life and psychological disorders at early states of illness is suggested to be important to both identify at risk patients, and to provide additional psychological support and treatment to those in need. Such psychosocial support strategies are likely to reduce longerterm adjustment-related complications. The recent development of short screening tools, such as the Distress Thermometer (Roth, Kornblith, Batel-Copel, Peabody, Scher & Holland, 1998) have enabled early screening to be applied to dinical care far more routinely (Mitchell, 2007) and the findings from the current study would encourage the continuation of such practices.

Variables entered into block two of the regression models were specifically separated from block one variables as they represented psychological constructs with most potential for modification through psychological intervention. Once again, these results indicate which variables which may be potentially effective screening tools, but also to inform interventions targeted at the main study outcomes of anxiety, depression and quality of life. The current data demonstrate that of all components in the Transactional Model, illness cognitions (whether at an appraisal component or core-relational theme level) are more strongly correlated with, and predictive of, future outcome. Thoughts and emotions are

often difficult topics to discuss in clinical practice (Brennan & Moynihan, 2004), however, inclusion into clinical consultation may reduce their negative impact. Research with clinical staff on communication skills has demonstrated that training workshops on the discussion of difficult issues with cancer patients and their families can be effective (e.g. Fallowfield & Jenkins, 2004; Baile & Aaronson, 2005). From the findings of this study, it is suggested that such training might benefit, at least in part, from training clinicians in how to discuss and respond to patients' cognitive and emotional reactions to illness, in addition to training on more conventional issues such as breaking bad news.

The individual cognitive predictors that emerged as most significant were perceived threat, issues of blame and responsibility, and unexpectedness. These hold most promise for effective intervention components. There is some limitation here in that different variables are predictive of outcome at different time-points though; it is unlikely that a general intervention could be developed to target all outcomes, for all patients, at any time-point. This concurs with the guidance of the Cancer Reform Strategy (Department of Health, 2007) that psychosocial support needs to be tailored to both the individual and to specific illness points.

Analyses demonstrated that prediction of six month quality of life was better than prediction of three month quality of life. There are two plausible mechanisms by which this might occur which would both have implications for clinical intervention. First, it may be that there was simply too much intraparticipant variability in the predictor variables at this earlier timepoint. This variability is likely caused by the wide-ranging psychological and physical impact of cancer diagnosis and this may affect how amenable these measures might be as adjustment screening tools if used at this early timepoint. Second, it could be that these predictor variables do not have an immediate impact on quality of life. In this case, delay between intervention and impact on quality of life should be expected. For anxiety, short time-lagged (three month as opposed to six month delay) analyses consistently produced better results. Whilst this is likely reflective of the inherent instability of anxiety measurement, those aiming to implement psychological interventions into clinical practice for this outcome may wish to consider whether more regular interventions are better able to manage

this instability. The current data do not provide clear evidence of when depression-oriented interventions might be most, or less, effective.

As a final point on the topic of clinical intervention, it was surprising that components of the MAC, in particular, fighting spirit, were neither highly correlated with outcome, nor featured as significant predictors in the regression models. The MAC framework has long been recommended as a basis for intervention in psychosocial oncology, with therapists claiming that increased fighting spirit provides a sensible target outcome for cognitive behavioural therapy (Greer, 2008). What the current study demonstrated was the predictive power of more personally reflective appraisal processes over the effects of fighting sprit. O'Baugh, Wilkes, Luke and George (2003) also highlight this distinction and proposed that whilst high levels of fighting spirit were identified by clinicians as an indicator of positive adjustment, for patients themselves, it is the continuation of normal life that is key. These authors, and others (e.g. Wilkinson & Kitzinger, 2000; Hulbert-Williams, Storey & Wilson, in prep), propose that the focus of therapeutic intervention might benefit from a shift from encouragement of fighting spirit, to management and acceptance (but not necessarily change) of cognitions and towards continuation of normality despite cancer. Whilst not providing a therapeutic framework, this study clearly supports these theoretical propositions. Further work is now required to explore how this information might best be used to inform effective interventions for cancer patients and what the longer-term clinically-related benefits of such interventions might be.

# 5.2.5 The contribution of the Transactional Model to understanding the cancer adjustment process

Data from this study demonstrated that each component of the Transactional Model was associated with one or more of the psychosocial outcomes measured. It can be concluded, therefore, that the Transactional Model provided a useful framework for a more holistic approach to assessment of the potential psychological predictors of adjustment and outcome. Cognitive elements of the theory in particular, enabled higher variance to be predicted for anxiety and quality of life than is reported in much of the previous literature (see Chapter 2: Systematic Review). The application of the model for depression was limited as

significant association was found in bivariate anlaysis only, failing to reach significance in the regression models.

From a theoretical perspective, it is intriguing that different components are important predictors at different time-points through the first six months of illness. The theory assumes that components are in constant dynamic flux and implies that changes in each component occurs regularly and affects associated components soon thereafter (Lazarus, 1999). In reflection of this dynamic processes, it was expected that each outcome model would include a variety of components from the Transactional Model. Though the analyses did not fully test the process nature of the model (they were simply not sufficiently powered for a path analysis) some interesting findings emerge nonetheless, particularly for quality of life.

Bivariate and multivariate statistical tests showed that where baseline predictor data were used, both cognitions and emotions emerge as highly correlated and predictive variables of quality of life at three and six month follow-up. Where three month follow-up predictor data are used, cognitions, emotions and coping significantly correlate, but only cognitions and coping emerge in stepwise regression models. The absence of baseline coping and of three month emotions as predictors is noteworthy. One possible explanation for this changing importance of different predictor variables might be that variables early in the process (e.g. appraisals and emotions) are in too much flux to enable general patterns of later processes (e.g. coping) to reliably emerge.

This suggests there is a delay between stressor onset and when coping becomes predictive of outcome based upon the extent of disruption to appraisals and emotions. Whilst not explicitly described by Lazarus (1999), this seems a particularly logical conclusion for this study. At baseline, participants would have been dealing with many uncertainties; few had begun treatment, and many had only very recently received their confirmed diagnosis. Their prognosis and the implications of having the illness would have been largely unknown. Whilst cognitions and emotions may be prominent predictors here, the amount of flux and change within these variables may prevent the adoption of stable and reliably predictive coping strategies. At three month follow-up, however, most would have had opportunities to adjusted to a new conception of normality (Taylor,

2006). Those with early-stage illness would have completed active treatment and would by this time be regularly receiving follow-up care. Those with more advanced illness would likely still be engaged in active treatment but would still have gained the experience to know what to expect and potentially how to cope with its associated demands. It may not be until this stage of illness, when enough uncertainty has passed, that cognitions and emotions begin to stabilise enough such that patients can begin to actively monitor and engage in more stable psychological coping strategies to manage the stress of cancer. These then may become more predictive of outcome than some of the ealier components. This supports the conclusions of related studies, for example Bleiker *et al.* (1995), Nordin and Glimelius (1998) and Butow *et al.* (1999) which also provide evidence that coping with, and adjusting to, being diagnosed with cancer does not begin until after treatment has finished and patients begin to re-adapt back to normality.

Previous empirical tests of the Transactional Model have been limited to the effects of acute and vicarious stressors, rather than chronic and major life event stressors such as receiving a cancer diagnosis. This may also account for some of the process differences suggested by the quality of life results. The psychological effects of acute and chronic stressors are not thought to be qualitatively different, but it is plausible that they may result in different statistically predictive frameworks over varying time-frames (Lazarus, 1999). The data from this study are not, therefore, opposed to Lazarus's model, nor do they contradict the already established evidence base for it which works sufficiently well for acute stressors and in laboratory based simulations (Smith & Lazarus, 1993). Instead, these data indicate that with higher-impact stressors, coping may not be predictive of outcome until some of the initial reactive flux in cognitions and emotions subsides. The suggestion of a time delay in the predictability of coping is clearly deserving of further research but potentially provides useful extension in understanding of the process nature of the Transactional Model.

Caution is required in the interpretation of this conclusion. The purpose of these analyses was not to develop, nor even to test this model, but to simply use it as a research framework for applied research in a clinical setting. The analyses conducted, therefore, may not be entirely appropriate for theory development.

Nonetheless, the emerging observations are both theoretically and clinically

relevant and some attempt to interpret them collectively is imperative. The conclusion is drawn entirely from the trends in quality of life as data for anxiety and depression findings were less consistent. Once again, this may be indicative of very different underlying adjustment processes for different types of psychosocial outcomes.

### 5.3 TESTING THE TRANSACTIONAL MODEL

Two specific objectives were tested in this part of the thesis, each involving a separate analytical strategy. Investigation of bivariate associations between change scores on theoretically linked Transactional Model over time, and multivariate testing of the significant cognitive precursors of each emotional response to stress.

# **5.3.1** Objective three: Correlations of change between Transactional Model components.

Two hypotheses were made: First, that all components of the Transactional model would fluctuate over time (hypothesis five), and second, that the extent of change between them would be equivalent for each theoretically associated component (hypothesis six). The data from the current study showed surprisingly little change over the six months of data collection on any components of the Transactional Model. Only one third of the mean scores demonstrated changes but even fewer of these reached significance. Just one appraisal component (out of eight), two emotions (out of twelve) and seven core-relational themes (also out of twelve) reached a significant level of change.

Where previous theory testing research (e.g. Bennett et al, 2003; Bennett et al, 2008) has used correlation approaches, this has been restricted to cross-sectional correlations of concurrent ratings of each component. These studies have reported largely supportive evidence for the theory. Lazarus (1999) claims that the model could be used to predict changes in coping and stress outcomes over time, but to test this empirically cross-sectional analyses are limited. There has remained a need to test this using a robust longitudinal approach. This study aimed to fill this research gap. Cross-sectional data collected at baseline and six month follow-up were used to calculate change scores for each appraisal component, core-relational theme, and emotion over time. Correlation tests were then conducted between change scores. The anticipated advantage for this

modified approach was to allow for interpretation of whether these components do indeed act as part of a dynamic process rather than demonstrating fixed concurrent correlations only.

Effect sizes from these tests were typically low; far less correlation was found between change scores than has been reported previously for cross-sectional correlations. Due to the high number of tests conducted, Bonferroni corrections were applied to significance levels to safeguard against Type I error but this correction substantially minimised the impact of the findings. No appraisal components and just three core-relational themes reached the adjusted significance level. Even less anticipated were the results of correlations between theoretically unassociated components. For these, higher effect sizes, and more significant correlations, were found when compared to the associations hypothesis by Lazarus (1999). The current data demonstrated that some emotion change scores correlated with no appraisal components whatsoever, and that others were significantly correlated with more than one core relational theme. This finding is in contradiction to the Transactional Model.

Little has been published to suggest over what time-period these stress adjustment processes may operate. For example, there is scarce mention in the literature to date which might suggest what length of time delay might be expected between a change on the specific appraisal and a subsequent change in emotion scores. Early theory (e.g. Lazarus & Folkman, 1984; Lazarus, 1991) implied that the process is rapid, dynamic, and continuous involving constant reappraisal and feedback. Due to this implication of speed in associated component change, and given that concurrent correlations were previously demonstrated to reach significance, so too were hypothesised correlations between change scores on associated components. It was also assumed from the associated literature that change on components which are theoretically associated would be more strongly correlated then correlations with their non-associated counterparts. This was clearly not the case in the current study. Changes over time for some variables were apparent, thus partially supporting hypothesis five. Hypothesis six was rejected though as correlations between theoretically aligned components were both inconsistent and typically failed to reach significance.

This study represented a novel attempt to theory test the Transactional Model and as such, the findings should be interpreted with caution. The lack of expected associations may not necessarily mean that the theory is inaccurate. The Transactional Model is an undoubtedly complex theory with clearly predicted specific patters of association between components. Within the six months of this study it is likely that many other stressful situations and changes in personal circumstances will have been encountered by the participants, each potentially being accountable to different causes from both within and external to the cancer diagnosis. Whilst this does not negate the expectation that association components would be correlated, this is mentioned to draw attention to the fact that each component would have been under constant flux in both directions of effect, and to varying extents. It is possible that the methodological and statistical approaches taken were simply not complex enough to test this constantly changing model.

A further complication is that whilst core-relational themes and emotions theoretically share unique one-to-one associations (unsupported by the current data), theory proposes that changes in numerous appraisal components in conjunction will lead to changes in emotion components. It may, therefore, be the case that changes in each appraisal were too small to significantly correlate with change in emotion and that calculation of composite scores of all relevant appraisal for each emotion may prove to be more highly correlated.

Bennett *et al.* (2003) claim that when testing the Transactional model, participants should be explicitly asked to report on a specific recent stressful encounters. In future testing of longitudinal cognition and emotion associations, it might be beneficial to take this guidance into account and to ask participants directly to report on their own perceptions of how they think their appraisals and emotions have change over time with regard to a specific stressor. Compared to a statistically computed changes score, these data might be more appropriate for the subjective and dynamic nature of this process model. An alternative might be to use shorter measures which are more regularly administered, but assessment burden must here be considered.

Whilst these data do not provide a clear answer to this specific thesis objective, they do represent a sound first approach to testing the longitudinal

relationships of the Transactional Model in a novel way. Further research is clearly needed to verify the findings of this study but some challenges will need attention in the design of such studies. Consideration needs to be given to what is the most appropriate method of measuring these data: calculation of change scores from cross-sectional data or self report of perceived changes on each individual component. The issue of how often to collect data needs also be considered. It may be that the six month time-lag in the current study was simply too long for effects to be separately identified from the effects of other concurrent stressors. More frequent data collection might valuable. Brevity will, however, be important to ensure good participant retention rates given the more demanding nature of this type of research.

# 5.3.2 Objective four: Regression analyses of the emotions and their cognitive precursors

Previous attempts to test and validate the Transactional Model have used regression analyses to explore the extent to which variance in emotion is explained by theoretically derived cognitive appraisals and core-relational themes. Such testing, has, however been limited by two primary factors. First, they have explored only a small sub-set of six emotions included in the Smith and Lazarus (1993) measures: the so-called 'hot' cognitions. The remaining emotions barely feature in empirical research and receive only cursory mention in the theoretical literature. This study, therefore, aimed to test a much larger range of emotions from the measures excluding just two that were considered inappropriate for this particular sample and stressor type—affection and sympathy. Second, the statistical approach to testing has been limited. With just one exception, these published studies conduct regression analyses in which theoretically hypothesised components are entered first, and then theoretically non-associated components tested on the residual amount of the emotion outcome variable. Whilst this is not a statistically inappropriate method of analysis, the extent to which this constitutes wholly unbiased theory testing is debateable as early steps of the analysis are limited based upon a theoretical assumption. It is possible that non-theoretically aligned cognitive precursors may actually explain far more variance in the emotion than those drawn from the literature. But structured in this way, these components will have little chance to enter the model until much of their share of

the variance has already been accounted for. In the current study, in addition to conducting regressions to replicate this already established method, separate regressions using an entirely data-driven, stepwise approach were conducted in parallel. The findings were anticipated to demonstrate whether variance is best explained by theory-derived components, and which individual component combinations are the best predictors of each emotion.

Overall the data did not fit neatly with the specifically prescribed cognition-emotion associations of the most developed version the Transactional Model (Lazarus, 1999). For the six, fully developed 'hot' cognitions in particular, the fit between data and theory was incomplete. For some emotions, very large proportions of the variance remained unexplained. In others, theoretically derived models were statistically inappropriate for the best modelling of outcome variance. Four out of the six hot cognitions benefitted from the inclusion of additional, theoretically non-hypothesised variables, which in one case improving  $R^2$  by .018. Hypothesis seven—that the theoretically unique relationships for the hot cognitions would be replicated—was, therefore, not supported.

For the remaining emotions, the data failed to confirm the theoretically derived pairings between specific core-relational themes and the emotions. Hypothesis eight was, therefore, also rejected.

There were some elements of the results, however, that do support the theory. First, variance in each emotion was best explained using a combination of both appraisal components and core-relational themes. Second, there were no occasions whereby the direction of association between predictor and outcome variables was not as expected, and few occasions where individual cognitive precursors seemed illogically matched. Third, there were no occasions where different emotions were explained by the same set of cognitive predictors; consistent with theory, each had a unique combination of cognitive precursors.

In addition to specifying unique pairings between core-relational themes and emotions, Lazarus (1999) states that each emotion will also be associated with a specific set of appraisal components. He added that this unique combination should include both components of primary and secondary appraisal. This proposition was not supported by the current data. Data driven models indicated that although most emotions required combinations of up to four appraisals for

optimal variance modelling, four emotions did not benefit from inclusion of appraisals at all. All eight appraisal components featured at least once in these analyses, however, there were only four occasions where a combination of both primary and secondary appraisals were included in the same model. Goal-related appraisals featured in seven models; responsibility-related appraisals in five; coping-related appraisals in three; and future-expectancy in just one model. These findings better replicate a more recent theory testing paper from Bennett and Lowe (2008) which also reports a failure of the primary appraisal to emerge as consistent predictors of the emotions.

With regard to the unique pairings between core relational themes and emotion, the findings of the current study were equally inconsistent. One of the emotion models did not include a significant core-relational theme at all and thirteen others included more than one core relational theme (up to four in the case of anger). Although not theory consistent, this is not necessarily a surprising finding given the similarity between overlapping core-relational themes. The relief model, for example, included the significant contributions of three core-relational themes: threat removal; success; and, reduced loss/helplessness. All of these are entirely plausible correlates of relief. This example is not unique in the current data but represents a finding not previously reported in the literature. The implication being, once again, that the Transactional Model may simply be too specific in its hypotheses.

Of the twelve core-relational themes, some were incorporated more frequently than others. Some did not feature at all. The most commonly included were self-blame which appeared in seven models; loss/helplessness which emerged in six; threat which was included in five models; and, unexpectedness in four. Lack of concern and threat removal emerged significant in just three models; effortful optimism and success in two; and, self-consciousness and other blame emerged significant in just one model. No models included the core-relational themes of relevance or irrelevance. These findings are difficult to compare with the literature as no published research to date has fully investigated associations between the full range of variables that were included in this study. More research on this wider range of core-relation themes and emotions is clearly required.

The comparisons between theory and data driven models in this study demonstrated that for some emotions, equally high variance can be explained by entirely different combinations of cognitive precursors than those hypothesised in the literature. None of the six 'hot' cognition data driven models included all of the theoretically proposed components: sadness included just two out of five proposed cognitions; guilt and fear/anxiety included two our four proposed; hope/challenge and happiness, included just one of four; and, anger didn't include any. Once again, comparison of these findings with other theory testing literature is difficult as no other studies have used a similar comparative design between theory and data driven analytic approaches.

The Bennett and Lowe (2008) study also breaks from the traditional method of testing these relationships in a theory biased manner. Instead, all potential appraisals are entered together, followed by all potential core-relational themes also being entered together using forced entry regression. This is less biased because all components have an equal opportunity to be included in the models. However, this approach still assumes that variance explained by appraisals and core-relational themes must be dealt with in separate regression blocks rather than using concurrent analysis (as was the case in the current study). Three approaches to theory testing now exist. A replication study which compares the results of all three of these would be an interesting and useful question for further research in this field.

In summary, the findings of this study failed to replicate all of those found in previous theory testing literature (Smith and Lazarus, 1993; Bennett *et al.*, 2003; and Bennett *et al.*, 2008), although some concordant conclusions were reached at the general, rather than specific, level of the model. This was probably due to two methodological features: the differing extent of stressor under question (as outlined in section 5.2.5), and the alternative method of data analysis. Whilst the findings did not confirm all aspects of Lazarus's (1999) theory, there are sufficient similarities such that they did not seem to deviate from the generic process structure of the Model, even if the specifics of it are called into question. The complexity of relationships between reactions to stress, cognitions and emotions were demonstrated. The findings suggest that that the theory as outlined in

Lazarus (1999) is perhaps too prematurely specific given the complex and dynamic nature of the stress experience.

#### 5.4 STUDY EVALUATION

Having used a validated quality assessment tool in the systematic review (Kmet *et al.*, 2004) to evaluate the quality of the previous literature, it seemed appropriate to evaluate the current study on similar criteria. This allowed for objective evaluation of the comparative strengths and weakness of the current study.

# 5.4.1 Study design, timing of recruitment and timing of follow-up

Clinically-oriented objectives. As suggested in the conclusions of the systematic review, this study employed a longitudinal design. Patients were all recruited post diagnosis and in many cases, pre-treatment. Although not ideal in that there was variance in treatment experiences, this does represent an improvement on some of the published literature which recruited many weeks into, and after completion of treatment. Timing of recruitment into this study was a mean of 116 days post-diagnosis, which although longer than hoped for, compares favourably. In a further improvement on previous methodology, the range of time between diagnosis and recruitment was substantially decreased: the sample recruited formed a more homogenous group.

Follow-up data were collected at three and six month follow-up timepoints in effort to ensure that data was comparable with other published literature. Due to delays between diagnosis and recruitment into the study, this actually represented follow-up data collection at approximately five and eight months post diagnosis.

Theory-testing objectives. The design of this part of the study represented a marked improvement on much previous theory testing research. Primarily, the design allowed the theory to be tested according to a homogenous chronic stressor common to all participants. Additionally, it allowed for statistical testing of the longitudinal stress process rather than focussing entirely on cross sectional data.

#### 5.4.2 Sample and recruitment

Clinically-oriented objectives. The recruitment target of 160 patients was achieved. This is lower than some, but higher than other comparable studies included in the systematic review (Chapter 2). The systematically reviewed

papers ranged in response rates but just five recording a response rate of less than 30%. The 34.6% response rate in this study was toward the lower end of the range.

Participant eligibility rates were a source of concern as far fewer patients were deemed suitable by their clinical nurse specialist than expected. Within cancer type, eligibility between data collection site were also variable. These findings raise some concerns about the nature of the sample, however, the cause is not clear. It could be a consequence of very different populations attending clinic in each trust, unclear study inclusion criteria, or covert protectionism of patients, on the part of the nurses. This is clearly an issue that will need to be clarified and, where possible improved upon, in future research.

Three features of the study design may be accountable for the low response and eligibility rates: the early timing of recruitment; the length of the questionnaire; and, the inclusion of multi-site cancer patients. In recruiting both male and female patients, a less gender-biased sample was achieved than in comparative studies, but males remained outnumbered at a ratio of approximately 2:3. This resulted primarily from recruitment of a higher number of breast cancer patients into the study. Compared with the literature reviewed in Chapter Two, especially that also recruiting mixed cancer samples, the current study sample comprised a more equal distribution between the four cancer sites, notably by including more lung cancer patients. This study was unique in that it included both male and female breast cancer patients, however, only two male patients were diagnosed during the recruitment timeframe. To these ends, the current study comprised a sample more representative of cancer patients in general. The wide variability in treatments and specific histological diagnoses, particularly within the breast cancer sub-sample, continue to represent challenges to data analysis which this study was unable to reconcile.

It is pertinent to review the justification for recruiting across multiple cancer site recruitment. Although prompted by pragmatic necessity to speed up recruitment into the study, the rationale was supported by evidence provided in the systematic review (see section 2.7.2.5): inclusion of multiple sites typically maximises the generalisability of the data. In this study, no between cancer-site differences were found for any outcome variable. This should not, however, be

taken as indication that future studies should focus recruitment on a single cancer site only. It is instead recommended that where possible, expansion of recruitment to other cancer sites is preferable but efforts to better control for a wider range of clinical variables would be welcomed.

Clinically, the sample was relatively healthy, both physically and psychologically. This was no doubt a result of focusing recruitment on early stage diagnoses only. Nonetheless some patients did progressively worsen at a quicker rate. Ten patients died during the six months of this study; deaths were mainly from the lung cancer patient subgroup who by the very nature of their illness had much poorer prognosis at the time of diagnosis.

Just two participants had been referred to secondary care based specialist psychosocial oncology services. There are two plausible explanations for this. First, it might indicate that the sample recruited were biased in that they were coping well and did not have need for this level of care. Second, it may be indicative of either limited service provision or unclear clinical referral pathways which prevented patients accessing these specialist psychological services.

From a methodological perspective, future research would benefit from also recruiting those at more advanced stages of illness and those who have not psychologically adjusted to their diagnosis. Expanding recruitment in this way would aid the understanding of how varying disease extent can lead to differences in the psychological adjustment process. From an ethical perspective, however, recruitment of these samples may prove difficult. Not only might they be less physically capable to take part, but also at higher risk of distress of other negative responses as a consequence of participation. These issues should not render attempts impossible, but it is essential that adequate safeguards be put into place to protect participants both physiologically and psychologically.

A mix of demographic cases was achieved in terms of age, gender and education level, but the sample was entirely Caucasian in ethnic origin. This was largely a byproduct of where participants were recruited from and are actually representative of the population in North Wales. Some effects of age on psychosocial outcome were reported although these were limited by a bias toward older, retired participants. This should be borne in mind when applying the findings of this study: at different stages of life, activities, values and priorities are

likely to change thus affecting the impact that diagnosis may have. Whilst representative of the population from which the sample was drawn, these sample restrictions limit the extent to which the findings may be generalisable to other cancer populations. This also prevented testing of ethnic and cultural differences in adjustment, a subject of growing research attention.

The follow-up sample used in longitudinal analysis was smaller than ideal. Participant retention was a very high 76.8%, again a comparative improvement on other similarly designed research (see table 2.4). But the loss of participants through death, and especially through drop out and non-response, limited the data available for analysis. One hundred and twenty-three patients provided longitudinal data, but due to missing data, particularly on the Smith and Lazarus (1993) measures, the regressions were based on samples of approximately 100 participants. Reflecting back to the original sample size calculation (see section 3.5.1), to ensure that analyses were sufficiently powered (to  $\beta$ =.80;  $\alpha$ =.05) to detect medium effect sizes, the recruited sample would only have allowed for six or seven variables to be entered into the analysis. Whilst block one of the clinical outcome regressions contained more variables than this (between 10 and 13 variables were entered), the combined effect size for this block was higher than expected, approaching what would be considered a large effect size. Green (1992) suggests that a sample size such as this would sufficiently power analyses to detect large effect sizes with up to 30 predictor variables entered and medium effect sizes with around nine variables entered. The current study did not fall substantially away from this. Whilst effect sizes added in the second block were certainly no bigger than medium effect sizes, far fewer variables (between one and four) were included in the statistical models. This suggests that the analyses were sufficiently powered for the research question. It is always possible that other psychological predictor variables didn't enter the model because they influence the outcomes with only small effect sizes for which analyses were not able to detect. This is usually a risk of conducting multiple linear regression in the human sciences. Whilst a larger sample size might have produce models which also included these variables, the clinical relevance of such findings is limited. It is unlikely that findings based on the identification of small effect sizes would provide a sufficient evidence base to justify changes to standard clinical practice, especially given the

much larger effect sizes exhibited by other demographic, clinical, control and psychological variables.

Theory testing objectives. From a theory testing perspective, the demographic and clinical variety obtained in recruitment was advantageous and ensured for a well-representative sample. That the sample was not recruited from student populations representing comparative improvement of Transactional Model relevant research and continues the trend previously set by Bennett and colleagues for designs with increased external validity. Correlation analysis used a sample of n=100 participants and regression analysis used a sample of n=145 participants. This compares favourably with other published literature in which sample sizes range between n=104 and n=196. Given the effect sizes reported in previous research and those that were resultant from the current analyses, the analyses were on the whole sufficiently powered.

#### 5.4.3 Measurement

All data collected for this study were obtained using pre-validated measures. The majority of these performed well, although some (such as the God Locus of Control Scale and site-specific sub-scales of the FACT) had low Cronbach alphas in internal consistency (see section 3.4.5). Such scales were not used in the regression analyses and may benefit from further psychometric development.

Where possible, constructs measured were comparable to published literature through selection of similar measurement instruments, such as the NEO-FFI for personality, the Brief COPE for coping, and the HADS for psychological comorbidity. Only those constructs pertaining to the Transactional Model were single-item measures; these were avoided elsewhere in order to address the criticism of such practices highlighted in the review. Whilst these single-item measures have been used and validated in previous research, Smith and Lazarus (1993) have also developed an alternative measure whereby each component is scored from between two and four items. These were not used in the current study to reduce participant burden, but the use of this measure is recommended for future research as it is likely to be a more robust and reliable tool increasing the likelihood of enabling parametric statistical analysis.

In exploratory analysis, some of the variables measured were found to be non-Normally distributed. In most cases, this was not problematic for the

statistical approaches taken: either adjustments could be made to the data or the tests chosen were robust enough to deal with this. However, one subscale of the MHLC (God Locus of Control) had to be removed from the analysis due both to its abnormal distribution and high number of missing data.

## 5.4.4 Control of confounding variables.

Potentially confounding demographic and clinical variables were measured, and included, where possible, in correlation analyses. Those that were significantly associated with outcome were then included in multivariate analyses. However, due to variability in the recording and coding of the data, some could not be analysed. Primary examples include treatment received and the exact histological nature of diagnosis where in both cases sample subgroups were so numerous that sub-sample sizes were very small. Treatment waiting time was also excluded from the analysis as these data were was only available for patients recruited from one hospital; to have included this variable in the analysis would have reduced the sample size such that statistical power would have been jeopardised.

The inability to control for all confounding variables in the current study was largely a result of recruiting using multi-site strategies. In future studies, it may be beneficial to recruit more equal numbers of patients in each category of these variables. Of course, such a design would either require a very large sample or a much more focussed sub-set of clinical cases. As an alternative, future research could consider developing methods by which these variables can be grouped for equivalence between cancer site. Such improvements would allow for analysis using more complex path analysis and multi-level modelling techniques.

### 5.4.5 Appropriateness of statistical analysis

Clinically oriented objectives. The current study conformed with all statistical recommendations made in the systematic review: descriptive, bivariate and multivariate analyses were all conducted, each of which being adequately powered for confidence in the findings to be maintained. Where possible, effect sizes were reported and discussed in addition to statements of statistical significance. No composite outcome scores were used in this study. Where composite predictor

variables were used, these were calculated in accordance with published methods for doing so.

Theory testing objectives. Statistical analysis used in the theory testing component of the thesis represented an improved, less theoretically biased approach to analysis. Although resulting in some rather disappointing findings, this more robust and objective method was more statistically rigorous and produced some interesting possibilities for further research.

### 5.4.6 Evaluative insights gained from the qualitative comments

This study had the advantage of collecting qualitative comments regarding study participation which can be used in evaluation of the design. Comments were only received from 56% of participants and in future, it is recommended that this aspect of data collection be a requirement of participation rather than an optional extra as was the case in the current study. Few comments made were of a negative nature.

The most frequent comment was that the questionnaire and response options were complex, and in particular, it was difficult for participants to isolate their answers related to the cancer from both other co-morbidities and enforced rehabilitation restrictions. The length of the questionnaire was considered an issue both by the clinical teams involved in recruitment and the ethics committee, and this may have acted as a disincentive to participation. However, with only two comments made on the length it seems that for those participants who do commit to participation, the length of the questionnaire is of less relevance.

Also to be considered in the planning of future studies are comments made by a number of participants that the timing of approach to participate was inappropriate. It is important to relate this to comments made about the overall relevance of the study. Comments seemed to indicate that the information provided did not make the purpose and relevance of the study explicitly clear—perhaps had this been clearer, participants may not have felt the timing so intrusive and indeed, some non-participators may have more inclined to take part.

Comments made on the inclusion of questions relevant to religion and beliefs about God are also important to note; the overarching message here is that sensitivity is required and care must be taken to ensure that both the questions are worded in an unbiased way, perhaps using more culturally sensitive terms by

referring to spiritual beliefs for example, rather than beliefs specifically about God.

Furthermore, it is important to make the relevance of such questions clear.

Comments made on this theme were useful in understanding the high rate of missing data on this variable.

Although some negative emotional impacts from participation were reported, these were few and judging by the nature of the comments no issues of risk or increased distress were aroused.

Just as important for evaluative purposes are the positive comments received which demonstrated that participation in this study enabled some participants to both confront the reality of their situation and express feelings and emotions that they would not otherwise have had opportunity to do so. Indeed, a number of participants explicitly expressed gratitude for being given the opportunity to help other patients with cancer and to benefit scientific progress through their own participation. A number of others were explicitly grateful for an opportunity to talk about these psychological issues. There is clearly a need for more opportunity for emotional expression within this patient group. It is likely that in this region, these needs are not being met by current clinical services. Access to clinical debriefing may have been a useful and perhaps more ethical addition to this study and is recommended for future research.

# 5.5 RECOMMENDATIONS AND IMPLICATIONS FOR RESEARCH, POLICY AND CLINICAL PRACTICE

To an extent, recommendations from, and implications of, this study have already been partially covered elsewhere in this chapter when discussing the findings related to each research objective. A summary follows.

Regarding prediction of psychosocial outcome, this study demonstrated the multi-faceted nature of adjustment and it is clear that cognitive appraisals are an important component of this adjustment process. More research is needed on the exact nature of interactions between clinical variables, emotions, coping and these cognitive appraisals. The ability of these variables to predict psychosocial outcome would also benefit from further research attention in order that clinical intervention can be based a sound empirical evidence base. This study seemed to indicate that not only would interventions benefit from being tailored to outcome, but also to time point through diagnosis and treatment. The study concluded that

interventions might benefit from increased focus on cognitive aspects of adjustment more than other aspects (e.g. coping), but again, confirmatory studies would be useful to provide an adequate basis for such intervention programmes to be developed. Future research also needs to consider how best to test the adjustment process. This study has been useful in highlighting the large number of contributing psychological variables. Future studies need to evaluate how best to assess these in a succinct and reliable manner to develop accurate clinical screening tools. Application of this questionnaire into clinical practice as it currently stands would be infeasible. Shorter and easier response assessment is essential.

One clear extension of the clinically-oriented research objective is to explore survival data. Published literature to date is inconclusive about the ability of psychological variables to predict survival (see section 1.4). However, such studies also focussed measurement on the ability of personality variables and coping responses to predict survival, not cognitive appraisal variables. In the current study, there were too few deaths to test this statistically. Indications are that those who did die scored lower in emotional quality of life, reported higher levels of negative emotion, more other-blame cognitions, higher levels of loss/helplessness, and more likelihood of using maladaptive coping strategies. The results are likely a consequence of worse functional status within this subsample due to a poorer underlying clinical presentation of the more advanced and aggressive nature of the illness. Although not definitive, the preliminary findings established in the current sample are worthy or further investigation. Given current drop out rates, it is unlikely that sufficient sample will still be alive and responsive at five year follow-up (the standard time-point for survival studies) for further data to be collected and tested and so future research should plan in advance for this when estimating sample size calculations.

The qualitative component of this study highlighted the importance of giving participants the opportunity to express themselves for both personal reasons and as a methodological evaluation tool. It is recommended that inclusion of some open-ended response questions would be beneficial as a research development tool and as a form of additional data collection, particularly for emotionally vulnerable participant groups who may wish to express more subjective and

individual responses beyond the restrictive format of many psychometric assessment tools.

Although it has a long theoretical history, the Transactional Model has relatively recently been re-developed (Lazarus, 1999). This latest version had not previously been sufficiently empirically tested using a wide range of samples and stressor types. This study aimed to expand upon this literature by investigating the process in a chronically stress samples. The findings from this study do not fully support the theory. It is not clear whether these different conclusions are a consequence of testing the model with a different stressor type, due to differences in statistical approach, or even whether they simply occurred spuriously. Future development of the model needs to continue the trend to explore this stress adjustment process for a number of other chronic stressor situations including, for example, other illness diagnoses, bereavement, divorce and so forth. When using the model for research purposes, whether that be to investigate chronic stress, acute stress, or even daily hassles, it is recommended that both theory driven and data driven approaches be used until a reliable and generalisible theoretical framework of cognition-emotion relationships is developed. In a move away from research exploring the impact of stressors retrospectively, this study has demonstrated that it is possible, and advantageous, to recruit participants who were much closer to the time of stress in order to prospectively explore the process of adjustment over time.

Further work is clearly required, to build upon this study and to replicate the findings. In general, the results indicate that it may be possible to assess which patients may need more psychosocial care and support to prevent poor adjustment by means of assessing stress-process variables. It is recommended that such assessment could usefully be implemented as part of routine clinical practice at early time-points in the illness experience to screen those most at risk of late psychosocial adjustment problems. The development of methodologically sound interventions focussing on these cognitive variables may be beneficial, but these would likely require high-level resources for application into clinical practice. For those researching adjustment to cancer, the Transactional Model provides a thorough research framework, although further empirical development of both measurement and conceptual processes are necessary.

#### **CHAPTER 6**

### **THESIS EVALUATION & FUTURE RESEARCH DIRECTIONS**

#### **6.1 CHAPTER OVERVIEW**

The thesis rationale (section 1.11) concluded with the suggestion that the Transactional Model of stress, whilst not fully understood within clinical samples, had potential to enable better understanding of the patient adjustment process following cancer diagnosis. Strengths of this model over competing theories of adjustment included its multi-dimensional nature and a particular emphasis on cognitive and emotional processes. Empirically, however, the model was not well supported, especially within the context of a major life stressors such that cancer represents.

Methodological critiques of the psychosocial oncology literature led to a plethora of identified weaknesses, but the absence of a systematic review in the field meant that a comprehensive understanding of which particular methodological improvements are necessary was unknown. Additionally, meta-analysis and systematic review of the many disparate studies of cognitions, emotions and personality was required to inform the direction of future research

Set against this backdrop, the thesis was designed to answer four principal research questions. The first two of these were explored through a systematic review of the literature:

- 1) What evidence is there currently in the literature demonstrating predictive associations between personality, cognitive appraisal, emotions, and psychosocial outcome?
- 2) Since early reviews, has research methodology in the field improved? If not, what further steps need to be taken?

In response to the findings, an empirical study was then designed in to address the third research question. Using a framework defined by the Transactional Model of stress, the aim was to assess:

3) What are the most important predictors of psychosocial outcome in newly diagnosed cancer patients, and leading from this, at what time point (baseline or three month follow-up) are these most predictive of longitudinal (three or six month) outcome. The final question aimed to develop the Transactional Model through extensive testing of the micro-level cognitive processes within this illness-related stressful situation:

4) Are the hypothesised associations between cognitive appraisals, core-relational themes, and emotions in Lazarus's Transactional Model supported in a sample of newly diagnosed cancer patients?

This final chapter will consider the success of the thesis in addressing these four research questions. Two primary evaluations will be made. First, whether or not the aims and objectives of each individual study have been achieved (section 6.2); in doing so, a summary of the pertinent points of study critique will be highlighted. Second, the overall impact made upon research and clinical practice will be evaluated (section 6.3). This will be followed by a short description of further research protocols being developed in follow up to the work contained in this thesis.

# 6.2 HAVE THE AIMS AND OBJECTIVES FOR THE THESIS BEEN ACHIEVED?

#### 6.2.1 Systematic review

This study aimed to review published evidence on associations between either personality, cognitive appraisal, or emotions and psychosocial outcome (either quality of life, anxiety or depression) in cancer patients. The specific objectives were to provide a précis of the current literature and a methodological critique of this field of research. The purpose was to inform the direction of hypothesis setting and methodological approaches used in future research. Despite a much larger body of literature being included than expected, the studies were predictably heterogenous and varied both in quality and content.

A number of demographic and clinical factors were highlighted as potentially important variables in cancer adjustment. Primarily, these included age, gender, stage of illness, time since diagnosis and treatment received. Personality was found to be a consistent predictor of psychosocial outcome, sometimes through independent predictive pathways, and other times through mediating effects of other psychological variables (such as coping). Incongruence was found for the reported associations between cognitive appraisal or emotion and psychosocial outcome. In relation to thesis question one, the review highlighted, above all else,

the lack of evidence to draw confident conclusions about the role of these predictor variables in influencing psychosocial outcome.

Methodological quality ranged in excess of 60% with the majority of studies scoring within the range of 81-85%. Despite this, a number of methodological weaknesses were highlighted. Methodologically poor studies were not just restricted to older published literature, indicating that the recent publication of a number of critical reviews has not yet led to the adoption of improved research designs. In response to thesis question two, the following measures are recommended for those planning research into psychosocial adjustment:

- Longitudinal rather than cross-sectional research is preferable.
- Participants should be recruited as close to diagnosis as possible, if not at a
  pre-diagnosis stage. Additionally, for this particular research area, efforts
  should be made to recruit patients within a much smaller range of time
  since diagnosis in order to minimise the effects of potentially confounding
  variables.
- Timing of follow-up in longitudinal research requires some level of standardisation to enable effective comparison between the literature.
   Those most commonly used are three, six, nine, twelve, eighteen and twenty-four months and it would seem sensible for these to be retained.
- Research needs to expand beyond predominantly breast cancer focussed
  research to reduce both clinical characteristic and demographic biases.
  Lung, colorectal and prostate cancer studies are all highlighted as pertinent
  areas of expansion due to their high clinical incidence, although the use of
  mixed-site recruitment may often be more advantageous.
- Researchers need to be aware of incoherence in definitions and use of psychosocial constructs and measures and ensure that only those most appropriate are used.
- Improved clarity and transparency in recruitment and the reporting of response statistics is desirable in order to better assess the generalisability of findings.
- In analysis, researchers are encouraged to use robust parametric and multivariate statistical approaches where possibility to ensure that the full

- complexity of intra-variable interactions and relationships can be fully explored.
- Finally, the use of composite outcome scores must be discouraged except where valid and reliable methods have been developed for the calculation of such scores.

Although the aims and objectives for the systematic review were achieved, there are some shortcomings of the work which should be considered when interpreting the findings. A formal review evaluation based on the Russell *et al.* (1998) quality checklist provided an overall score of 11 out of 14 and highlighted two main areas of weakness: first, single reviewer data extraction, and second, inadequate search methodology. With regard to data extraction, quality would have been improved had sources other than electronic databases been used.

Additionally, the highly sensitive search strings, which although useful in exploratory reviews, may have inadvertently caused some research to be omitted from inclusion; smaller scope, specific reviews focussed on numerate aspects of the current work may prove more reliable. Furthermore, in such cases it would be far more feasible to also include non-published literature which was not possible in this case.

A lack of concordance in quality assessment between reviewers was also of concern; differences in scores may be a consequence of reviewer subjectivity or could be indicative of a weakness in Kmet *et al.'s* (2002) assessment tool. This latter possibility should be borne in mind when planning to use the tool in future reviews. Finally, as a result of heterogeneity between included studies, the meta-analyses were based on very small numbers of studies and, therefore, the findings must be regarded as indicative only, and used as evidence with caution.

#### 6.2.2 Empirical study

The aim of this study was to investigate relationships between personality, cognitive appraisals, emotional reaction to diagnosis and psychosocial adjustment in a cohort of newly diagnosed cancer patients. There were four specific objectives pertaining both to theory development and clinical application. First, to identify important psychological predictors of three primary psychosocial outcomes for

newly diagnosed cancer patients. Second to identify at what time-period these are most predictive. The third objective was to examine whether associated components of the Transactional Model varied equivalently over time. And finally, the fourth objective was to test the hypothesised associations between specific cognitive appraisals, core-relational themes and emotion in relation to cancer diagnosis. All four of these objectives were achieved to an extent.

A longitudinal questionnaire based study was planned in order to accrue data. A three centre, multi-centre recruitment strategy was developed and whilst both time-consuming and at times challenging, the target sample size of 160 patients was recruited. Participant retention was high and a follow-up sample of between 100 and 140 patients (dependent on analysis and quantity of missing data) was available. Although representing a more methodologically rigorous design, the study did have a number of weaknesses. Although timing of recruitment and follow-up represented a methodological improvement (particularly from a clinical perspective), for theory-driven analyses, three monthly follow-ups were not ideal as Transactional Model constructs are so frequently changing. The difficulty of testing both clinical questions and developing this theory in the same study are apparent.

The sample, whilst of sufficient size to adequately power the analyses and less biased than that of some other published research, was focussed on early-stage cancer patients only. This impacts upon both the representativeness of the sample and generalisability of the findings. A future challenge will be to include patients at all stages of disease but to control for such clinical differences in analysis. This will be a challenge from practical (ethical and recruitment) issues perhaps moreso than statistically.

Time-lagged correlation and regression analysis demonstrated that a range of personality, appraisal, core-relational themes, emotions and coping added to variance already explained by control clinical and demographic variables for anxiety, depression and quality of life. Locus of control and the mental adjustment to cancer were the only measures found not to contribute to outcome prediction. Hypotheses one and two were therefore accepted. Across all combinations of time-lag, regression effect sizes were larger than expected compared to the

previous literature. This in itself may be indicative of the importance of an all-inclusive framework such as the Transactional Model.

Comparison of anxiety, depression and quality of life regression models highlighted the importance of different predictor variables. Additionally, different time-lagged analyses were most predictive for different outcomes. These differing trajectories of adjustment do not provide clear answers to either hypothesis three or four. Outcomes from these analyses can potentially be applied to the clinical setting to inform screening assessments and psychological interventions for cancer patients.

The theory testing component of this thesis represented both replication and development of statistical testing methods of similar studies. Whilst fluctuation on Transactional Model components was observed over time, change score correlations were not as expected and did not provide full support for Lazarus's theoretical model. Hypothesis five was therefore supported, but hypothesis six rejected. Similarly, the results of theory testing regressions only partially supported both previous theory and empirical findings. Hypotheses seven and eight were, therefore, both rejected. Methodological and statistical issues were discussed as primary explanations for the failure of this study to confirm theory.

In conclusion, whilst further research and development of the Transactional Model is clearly necessary, even in its current state, the model is able to provide a useful framework through which to study adjustment to major life event stressors and upon which to develop psychosocial interventions for newly diagnosed cancer patients.

#### 6.3 IMPACT, AND FUTURE DIRECTIONS, OF THE RESEARCH

The individual impact of each study in terms of how it might influence further work has already been presented. Instead, the direct impact that the research has had will be discussed.

Final outcomes of the study are yet to be disseminated to local clinical collaborators. A short report outlining the main findings has been produced for the study funder (appendix 6.1) and copies of this will shortly be distributed to all clinical teams involved with the study. Short presentations and discussions of the

research will also be offered to cancer management teams and each clinical multidisciplinary team involved.

Perhaps of most importance within the clinical setting is the impact upon nurses resulting from their role within the study. Although data were not collected on this issue, nurses involved with the study reported that they were more enthusiastic about research and more understanding of the processes. It is hoped that this may contribute to a more research-active ethos within their clinical practice. Indeed, in the process of recruiting into this study a recruitment method has been developed which is acceptable from research, clinical and ethical perspectives and we hope to access more patients using such systems in the future. Since the cessation of patient recruitment, mutually beneficial relationships have been maintained between the research and clinical teams and it is hoped that more collaborative research will be planned in the future. The author has already been approached on a number of occasions to provide ad-hoc consultancy-style advice to the clinical teams, particularly with respect to routine data collection used for monitoring psychosocial adjustment and patient satisfaction with clinical services. The study has been disseminated at a number of national and international conferences (see appendix 6.2 for a summary list and appendices 6.3-6.9 for abstracts). The numerous studies included are also being written up for submission to relevant journals. The systematic review and meta-analysis will be submitted to Health Psychology within a few weeks of submitting this thesis. The clinically oriented outcomes will be written and submitted to Psycho-Oncology and the theory testing to Cognition and Emotion, both scheduled for submission later this summer. Some secondary analysis to psychometrically develop some of the measures used is also underway and will also be submitted for publication.

A number of new protocols are also in development as extensions of this programme of research. Given the number of qualitative responses received in the questionnaires, it was clear that many participants had far more to say on this research question and felt the quantitative format of data collection too restrictive. Funding was received from the North Wales Research Committee to conduct a qualitative follow-up to this study using Interpretative Phenomenological Analysis (IPA). A sub-sample of three breast, three colorectal, and three prostate cancer patients have all been interviewed and primary analysis has been completed.

Secondary validation of the thematic analysis is currently underway and is expected to be completed later this year. It is hoped that the results from this can be triangulated with some of the thesis data to give a more rounded impression of psychosocial adjustment processes to cancer diagnosis.

It is also important to remember that the adjustment process does not resolve for many months (or ever in some cases). The end of treatment stage—that from being a patient to resuming a normal life once again—is yet another period prone to adjustment difficulties. It is possible that the same process may be at work here too and that similar psychological predictors may be influential. Focussing primarily on future expectancy appraisals and later realisation (or not) of such appraisals, work is underway with a number of colleagues to develop research into the end of treatment transition period.

Also in the late stage of development is a qualitative study in collaboration with NHS collaborators to investigate willingness and confidence of cancer nurse specialists to provide psychological support for patients. It is hoped that this study, if funded, will additionally highlight any important training and support needs for the nurse community.

Last, but by no means least, it is important to reflect on the rationale for this thesis; that prior to the implementation of new psychological interventions for cancer patients, theory based empirical testing of the adjustment process and important predictor variables is necessary. It was recommended in section 5.4 that in light of these findings, such interventions should focus efforts on cognitive appraisals. This also conforms with the findings of psychosocial oncology research conducted using a Self-Regulation framework, see for example, Schroevers et al. (2008). The emphasis on goal and value based appraisals is congruent with newly developed interventions based on Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999), one of the third-wave cognitive-behavioural therapies. Interventions based on ACT have had great success in the field of mental illness, but research emphasis has also expanded to the trialling of the therapy for the effects of physical illness. As such, the candidate has led authorship (in collaboration with both UK and USA based academics) of a position paper proposing the future potential use of ACT within oncology settings. Applications for funding for pilot studies using both ACT based psychometric

constructs in survey research, and intervention development studies, are currently in the early stages of preparation.

### **6.4 CONCLUDING STATEMENT**

A number of key objectives and hypotheses were defined for this thesis, each of which has been addressed, at least to an extent. In meeting these aims, evidence has been produced which provides some clarity into the nature of adjustment to cancer diagnosis, but which also which questions the stress-related theoretical framework used. Further empirical testing of the three outcomes (anxiety, depression and quality of life) is necessary. Despite the criticism lodged against psychological interventions for cancer patients, the findings from the thesis clearly show that psychological mechanisms are responsible, at least in part, for both psychological and quality of life outcomes. With improved methodological approaches and consideration of psychological models focussing especially on cognitive and affective processes, it seems possible that new interventions can be developed which may have greater impact upon clinical oncology (see also Schofield et al., 2006). In response to the seemingly important contribution of cognitive appraisals in predicting psychological outcome, the use of acceptancebased therapies may show particular theoretical promise for an intervention framework.

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# **APPENDIX 2.1:** PUBLICATION DETAILS AND CAUSE FOR LATER EXCLUSION **OF THOSE STUDIES FOR WHICH SUFFICIENT INFORMATION WAS NOT AVAILABLE <u>TO ASSESS INCLUSION FOR THE REVIEW.</u>**

Authors & Date	Title	Reason for exclusion
Aarstad, Aarstad, Birkhaug, Bru & Olofsson (2003)	The personality and quality of life in HNSCC patients following treatment.	Unavailable mailbox
Arathuzik. (1991)	The appraisal of pain and coping in cancer patients.	No response to email request.
Beadle, Yates, Najman, Clavarino, Thomson, Williams, et al. (2004)	Illusions in advanced cancer: The effect of belief systems and attitudes on quality of life.	Data not available.
Beckham, Burker, Lytle, Feldman & Costakis. (1997)	Self-efficacy and adjustment in cancer patients: a preliminary report.	No response to email request.
Berckman & Austin. (1993)	Causal attribution, perceived control, and adjustment in patients with lung cancer.	Corresponding author untraceable.
Fehring, Miller & Shaw. (1997)	Spiritual well-being, religiosity, hope, depression, and other mood states in elderly people coping with cancer.	No response to email request.
Fife, Huster, Cornetta, Kennedy, Akard & Broun. (2000)	Longitudinal study of adaptation to the stress of bone marrow transplantation.	No response to email request.
Friedman, Baer, Lewy, Lane & Smith. (1988)	Predictors of psychosocial adjustment to breast cancer.	Data not available.
Grassi, Rosti, Albertazzi & Marangolo. (1996)	Depressive symptoms in autologous bone marrow transplant (ABMT) patients with cancer: an exploratory study.	No response to email request.
Jenkins & Paragament. (1988)	Cognitive appraisals in cancer patients.	Unavailable mailbox.
Lev, Paul & Owen. (1999)	Age, self efficacy, and change in patients' adjustment to cancer.	Data not available.
Montgomery, Pocock, Titley & Lloyd. (2003)	Predicting psychological distress in patients with leukaemia and lymphoma.	Data not available.

Authors	Title	Reason for exclusion
Mytko, Knight, Chastain, Mumby, Siston & Williams. (1996)	Coping strategies and psychological distress in cancer patients before autologous bone marrow transplant.	Corresponding author untraceable.
Nair. (2000)	Quality of life in cancer of the cervix patients.	No response to email request.
Secchi & Strepparava. (2001)	The quality of life in cancer patients: a cognitive approach.	Unavailable mailbox
Schnoll, Mackinnon, Stolbach & Lorman. (1995)	The relationship between emotional adjustment and two factor structures of the mental adjustment to cancer (MAC) scale.	Data not available.
Tamburini, Filiberti, Ventafridda & De Palo. (1986)	Quality of life and psychological state after radical vulvectomy.	Data not available.
Wagner & Armstrong. (1995)	Cognitive determinants of quality of life after onset of cancer.	Corresponding author untraceable.

# APPENDIX 2.2: LIST OF MEASURES USED BY INDIVIDUAL STUDIES AND THEIR ASSIGNED ABBREVIATIONS USED IN TABLE 2.3.

Abbreviation	Full Title
ABS	Affect Balance Scale
AEI	Anger Expression Inventory
AEI	Anger Expression Inventory
AS	Appraisal Scale
BAI	Beck Anxiety Inventory
BDI	Beck Depression Inventory
BIS/BAS	Behavioural Inhibition System/Behavioural Activation System Inventory
CARES	Cancer Rehabilitation Evaluation System
CBS	Coping Behaviours Scale
CECS	Courtauld Emotional Control Scale
CES-D	Centre for Epidemiologic Studies Depression Scale
CLoCS	Cancer Locus of Control Scale
CLQoL	Cantrill Ladder of Quality of Life
COPE	COPE Coping Inventory
CRI	Coping Responses Inventory
CSC	Cancer Specific Control Scale
CSI	Coping Strategies Inventory
DASS	Depression Anxiety Stress Scales
DCL	Dutch Complaints List for Cancer Patients
DS	Depression Scale
EES	Epstein Emotion Scales
<b>EORTC-QLQ</b>	European Organisation for Research and Treatment of Cancer-
	Quality of Life Questionnaire
EPI	Eysenck Personality Questionnaire
FQCI	Frieburg Questions of Coping with Illness
GBI	General Behaviour Inventory
GHQ	General Health Questionnaire
GRQLI	Global Rating of Quality of Life Inventory
GSES	General Self-Efficacy Scale
HADS	Hospital Anxiety and Depression Scale
HLCS	Health Locus of Control Scale
HRQoL	Health Related Quality of Life Scale
HS	Hope Scale
IBQ	Illness Behaviour Questionnaire
I-E	Internal-External Control Scale
IES	Impact of Events Scale
IWB	Index of Well Being
JGLI	Japanese Quality of Life Inventory Linear Analogue Self Assessment Questionnaire
LASA	Montal Adjustment to Cancer Scale
MAC	Mental Adjustment to Cancer Scale
MAS	Manifest Anxiety Scale Moos Coping Scale
MCS	Millon Health Inventory
MHI	Million Health inventory

MHLC Multidimensional Health Locus of Control Scale MQOLS-CA Multidimensional Quality of Life Scale-Cancer

MUIS Mischel Uncertainty in Illness Scale

NAS **Negative Affect Scale** 

Perceived Adjustment to Cancer PAC

Perceived Adjustment to Chronic Illness Scale **PACIS** 

Perceived Adjustment to Illness Scale PAIS **PANAS** Positive And Negative Affect Scale **PCBC** Profile of Concerns about Breast Cancer

PCI **Prostate Cancer Index** 

PHQ Perceived Health Questionnaire

Purpose in Life Test PLT Purpose in Life Test **PLT Profile Of Mood States POMS PRF** Personality Research Form **Perceived Stress Scale PSS** QLS **Ouality of Life Scale** 

Dutch MOS Health Survey (36 Item) RAND Rotterdam Symptom CheckList **RSCL** Rosenberg Self-Esteem Inventory RSE

Self-Assessment Questionnaire-Nijmegen SAQ-N

Self-Blame Interview SBI **Symptom Check List** SCL **Symptom Distress Scale SDS** Side Effects Checklist SEC

Short Form MOS Health Survey (36 Item) **SF36** 

Standard Psychiatric Interview SPI State-Trait Anxiety Questionnaire STAI-S/T Svebak Humour Questionnaire SVQ Spiritual Well Being Scale

**SWBS** 

University of Washington Quality of Life Scales UWQOL

Visual Analogue Scales for Appraisal VASA

Ways of Coping Scale WoC **Zung Anxiety Scale** ZAS Zung Depression Scale ZDS

### APPENDIX 2.3: QUALITY ASSESSMENT TOOL AND SCORING GUIDELINES.

	CRITERIA	YES/GOOD (2)	PARTIAL (1)	NO/POOR (0)	N/A (X)	SCORE
STUI	DY AIMS					
1.	Is the hypothesis/objective sufficiently described in paper introduction?	Specifies: (1)purpose; (2) population; (3) associations under investigation	Vague / incomplete / not clear.	Incomprehen-sible or not reported		
DESI	GN					
2.	Is the study design well described and appropriate?	Clear, well described and appropriate	Not clearly described or design only partially addresses question	Poorly described or inappropriate design for question		
3.	Are predictor and outcome measures clearly described in the intro/methods and appropriate	Defined and measured according to criteria	Definition open to subjectivity or description missing / not reported	Not mentioned until results or not/inconsistently defined		
4.	Is follow up data collected and timing between study components appropriate?	Data collected and timing appropriate	Data collected but timing not specified / appropriate	No follow up data collected	Not required for study design	
SAM	PLE					
5.	Is selection/recruitme nt well described and appropriate so as to not introduced bias?	Clear and appropriate with defined inclusion criteria	Not fully described, but appropriate or bias not likely to influence results	Not described <i>or</i> inappropriate <i>or</i> bias likely to influence results		
6.	Are participant characteristics / subgroup categorisation clearly described?	Sufficient demographic info and categorisation criteria defined.	Incomplete demographics or poorly defined criteria	No demographics or criteria supplied		
7.	Have patients been lost of follow-up been described?	Losses reported and not likely to affect results	Losses not well reported but not likely to affect results	No information <i>or</i> large losses likely to affect results	Not collected or no losses	
3.	Is the sample size adequate?	Sample size is adequate	Sample size inadequate but justified / explained	Sample size too small		
METI	HODOLOGY (RCT & INTE	RVENTION STUDIES	S MAINLY)			
10.	Were participants randomised to intervention / trial groups?	Randomisation method clearly described	Randomisation mentioned but method not described	Randomisation not mentioned although feasible and appropriate	Not approp- riate	

11.	Are trial / intervention components clearly described and appropriately justified?	All components clearly described and appropriate	Appropriate but not well described or some components inappropriate	Inappropriately justified components	Not approp- riate	
12.	Was randomisation / allocation concealed from participants?	Evidence of method of concealment	Concealment reported, but not described	No randomisation reported although feasible and appropriate	Conceal- ment not app- ropriate	
14.	Were data analysed according to 'intention to treat' principles?	All data analysed regardless of adherence to protocol	Inappropriate attempts made or some participants not included	No attempt made	ITT not appropr- iate for design	
ANAI	YSIS & RESULTS				l	
15.	Are methods of analysis clearly described and appropriate?	All described and appropriate	Not reported, but probably most analysed appropriately	Methods not described		
16.	Are estimates of variance reported for the main results?	Appropriate estimates provided (SD/SE/Confiden ce intervals)	Undefined <i>or</i> not provided for all results	Not provided		
17.	Are confounding variables adequately controlled for?	Appropriate control or participants comparable at baseline	Incomplete control or considered but unlikely to affect results	Not controlled and likely to affect results		
13.	Was randomisation / allocation concealed from investigators?	Investigators blind to participant allocation	Inadequate: investigator maybe aware of participant randomisation	Not attempt made to blind	Blinding not approp- riate.	
	Do analyses adjust for different lengths of follow up or time between intervention and outcome	Different lengths of time adjusted for and described	Differences probably adjusted for but not described	Differences ignored	Same time or not collected	
18.	Are the main findings clearly described?	Clear reporting of descriptive data for all major findings	Incomplete or inappropriate descriptive statistics	No / inadequate descriptive statistics		
CONC	CLUSIONS					
19.	Are the conclusions supported by the results?	All conclusion supported by results	Some supported; others not or speculative interpretations no indicated as such	None/few conclusions supported by data		

### **APPENDIX 2.4: META-ANALYSIS CALCULATIONS**

This example of the meta-analysis calculations is based on relationships between Self-efficacy and distress. Two studies were entered into the analysis: Ranchor et. al., 2002, (n = 167, r = -.33) and Green et. al., 2002 (n = 65, r = -.01). Meta-analyses were conducted using Hunter and Schimdt's method, following the procedural guidance of Field (2001).

1) Mean Effect Size [MES]

$$\bar{r} = \frac{\sum_{i=1}^{k} n_i r_i}{\sum_{i=1}^{k} n_i} = \frac{(167 \times -.33) + (65 \times -.01)}{(167 + 65)} = -.240$$

2) Standard Deviation of the MES

$$SD_{\bar{r}} = \sqrt{\frac{\sum_{i=1}^{k} n_{i} (r_{i} - \bar{r})^{2}}{\sum_{i=1}^{k} n_{i}}} = \sqrt{\frac{\left(167(-.33 - -.24)^{2}\right) + \left(65(-.01 - -.24)^{2}\right)}{\left(167 + 65\right)}} = \sqrt{\frac{\left(167 \times .0081\right) + \left(65 \times .0527\right)}{232}} = .144$$

3) Standard Error of the MES

$$SE_{\bar{r}} = \frac{SD_r}{\sqrt{k}} = \frac{.144}{\sqrt{2}} = .102$$

4) Calculation of the z-score

$$z = \frac{\overline{r}}{SE_{\overline{z}}} = \frac{-.240}{.102} = -2.365$$

### 5) Significance

Minitab was used to generate the observed significance level. The cumulative distribution function gives a value of p(Z<z)=.009 under the standard Normal curve. This value was subtracted from 1 and multiplied by 2 to yield a two-tailed p value of p=.018.

Therefore,  $\bar{r} = -.240$ , p < .05.

### APPENDIX 3.1: FUNDING AWARD LETTER



National Public Health Service for Wales

Gwasanaeth lechyd Cyhoeddus Cenedlaethol Cymru

Our ref / Ein cyf: Your ref / Eich cyf:

Dr J H P Evans Gwenfro Unit 5 Wrexham Technology Park Wrexham LL13 7YP 01978 316238/5 JeffEvans@iha.demon.co.uk LindaHull@iha.demon.co.uk

22nd April 2005

Mr Nick Hulbert Postgraduate Research Student Cardiff University, Wales College of Medicine Dept. of General Practice Gwenfro Unit 5, Wrexham Technology Park Wrexham, LL13 7YP

Dear Mr. Hülbert

Re - Your Application for Funding from the North Wales Research Committee - The importance of personality in appraisal and psycho-social outcome prediction for colorectal cancer patients'

I am very pleased to be able to inform you that your application for funding of the above research project has been successful. The amount approved was £5,000. The committee, I should add, is not in a position to approve grants in excess of £5,000 as a consequence the additional £283.84 which you requested was not approved.

A condition of the approval was that members' comments should be sent to the lead applicant. These, in summary, therefore follow.

With regard to the methodology, members were uncertain whether the proposed sample size would be large enough given that this patient group was very heterogeneous. Associated with that situation was the subsequent generalisability of the material. The suggestion was therefore made that sub-divisions of the sample might be necessary, in addition there was the comment that as the sample was self-selecting then the results could well be affected by this. Concern was expressed too at the length and complexity of the questionnaire which could be too much for patients already in discomfort and under considerable stress.

Would you please also note the following requirements which relate to your grant:-

- 1. <u>Invoices</u> Would you please send all invoices to me for certification. I will then pass them on to the Treasurer's Department for payment.
- 2. <u>Progress Reports</u> Progress reports will be expected for each North Wales Research Committee meeting. These occur bi-annually and usually in March and October. I will inform you of the need for a report one month in advance of a meeting so that a progress report can be prepared for inclusion in the Committee's agenda papers.
- 3. Extension of completion date If the project is not completed by 31st November 2007

Partner Organisations: National Public Health Service for Wales; North East Wales institute of Higher Education; University of Wales College of Medicine; Wreitham County Borough Countd

National Public Health Service for Wales Preswylfa, Hendy Road, Mold, Flintshire CH7 1PZ Tel: 01352 700227 Fax: 01352 700043 erham County thorough Council Gwasanaeth lechyd Cyhoeddus Cenedlaethol Cymru Preswylfa, Ffordd Hendy, Yr Myddgrug, Sir Y Pflint CH7 1PZ Ffôn: 01352 700227 Ffacs: 01352 70043





Cont. overleaf

an extension must be sought on a timely basis. Extensions to completion dates will usually not exceed three months unless sufficient reason is given.

- 4. Final Report A final report needs to be provided on completion of the research.
- 5. <u>Acknowledgement of Support</u> Acknowledgement of the support given by the North Wales Research Committee is expected in any publication of your research findings and a copy of the publication(s) should be provided when this is available.

Should you require any further help or should problems arise then please contact me. Otherwise may I wish you all the best with your project.

Yours sincerely

Dr J H P Evans Executive Secretary

North Wales Research Committee

encs

## APPENDIX 3.2: CONFIRMATION OF SPONSORSHIP FROM CARDIFF UNIVERSITY

Research and Commercial Division Director Geraint W Jones

Adran Ymchwil a Masnach Cyfarwyddwr Geraint W Jones

21 March 2005

Dr Richard Neal
MEDIC
Department of General Practice
Cardiff University
Maelfa
Llanedeyrn
Cardiff

Dear Dr Neal



Cardiff University
7° Floor
30-36 Newport Road
Cardiff CF24 ODE
Wales, UK
Tel Ff0n +44(0)29 2087 5834
Fax Ffacs +44(0)29 2087 4189
Prifysgol Caerdydd
Lilawr 7
30-36 Heol Casnewydd
Caerdydd CF24 ODE
Cymru, Y Deyrnas Gyfunol

## The importance of personality in appraisal and psycho-social outcome prediction for colorectal cancer patients

I confirm that Cardiff University agrees in principle to act as Sponsor for the above project, as required by the Research Governance Framework for Health and Social Care.

Final confirmation of acceptance of Sponsorship responsibilities will be provided in due course by the Joint Cardiff and Vale NHS Trust / University Peer and Risk Review Committee (JTUPERR).

You will have received the Guidance Note and Appendices covering the Research Governance Framework and The Medicines for Human Use (Clinical Trials) Regulations 2004 (MHUR) (formerly the EU Clinical Trials Directive) which sets out the responsibilities of the Sponsor and any individual undertaking. You should ensure that your responsibilities as Chief/Principal Investigator are fully understood.

You should quote the following unique reference number as evidence of Cardiff University accepting, in principle, sponsorship for the above project:

#### **SPON CU 121**

This reference number should be quoted on all documentation associated with this project.

Yours sincerely

Dr K J Pittard Davies

Head of Research Policy & Management

KONHaviere.

Direct line: +44 (0) 29208 79274 Email: DaviesKP2@cf.ac.uk

c Dr Jane Jones

Trust R & D Manager

### APPENDIX 3.3: DETAILS OF RESEARCH LIABILITY INSURANCE

Woburn House 20 Tavistock Square London WC1H 9HW Tel: 0207 388 9222 Fax: 0207 388 9229



#### TO WHOM IT MAY CONCERN

1st August 2004

Dear Sir/Madam

## CARDIFF UNIVERSITY AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:-

#### **EMPLOYERS' LIABILITY**

Certificate No.

42UKA09609/027

Period of Cover

1 August 2004 to 31 July 2005

Limit of Indemnity

£10,000,000 any one event unlimited in the aggregate.

Includes

Indemnity to Principals

Cover provided by

ACE Insurance S.A.-N.V. and Excess Insurers.

### PUBLIC AND PRODUCTS LIABILITY

Certificate of Entry No.

UM027/95

Period of Cover

1 August 2004 to 31 July 2005

includes

Indemnity to Principals

Limit Of Indemnity

£50,000,000 any one event and in the aggregate in respect of Products Liability and Unlimited in the aggregate in respect of

Public Liability.

Cover provided by

U.M. Association Limited and Excess Cover Providers led by ACE

Insurance S.A. - N.V.

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Peter Watkins

For U.M. Association Limited

Woburn House 20 Tavistock Square London WC1H 9HW Tel: 0207 388 9222 Fax: 0207 388 9229



TO WHOM IT MAY CONCERN

1st August 2004

Dear Sir/Madam

## CARDIFF UNIVERSITY AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:-

#### PROFESSIONAL INDEMNITY

Certificate of Entry No.

UM027/95

Period of Cover

1 August 2004 - 31 July 2005

Limit of Indemnity

 $\pounds 5,000,000$  any one claim and in the aggregate except for Pollution where cover is limited to £1,000,000 in the aggregate.

Cover provided by

U.M. Association Limited and Excess Cover Providers led by ACE

insurance S.A. - N.V. ٠.

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Peter Watkins

For U.M. Association Limited

### APPENDIX 3.4: LETTER OF ETHICAL APPROVAL

### Pwyllgor Moeseg Ymchwil Dwyrain Gogleddd Cymru North East Wales Local Research Ethics Committee

Cydlynydd Moeseg Ethics Co-ordinator Ysbyty Maelor Wrecsam/Wrexham Maelor Hospital Croesnewydd Road Wrecsam/Wrexham LL13 7TD

Ffon/Tel: (01978) 725368 (llinell uniongyrchol/direct line)

Ffacs/Fax: (01978) 725368

Livth-el/E-mail: Eleanor. Thomas a new-tr. wales. nhs. uk

28th April 2005

Mr N Hulbert
PhD Student
Cardiff University, Wales College of Medicine
Gwenfro Unit 5
Wrexham Technology Park
Wrexham
LL13 7YP

#### Dear Mr Hulbert

Full title of study:

The Importance of Personality In Appraisal And Psycho-Social

Outcome Prediction For Colorectal Cancer Patients?

REC reference number: 05/WNo03/10

Thank you for your letter of 13<sup>th</sup> April 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 27<sup>th</sup> April 2005. A list of the members who were present at the meeting is attached.

#### 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.

#### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document Type:	Version:	Dated:	Date Received:
Application		08/03/2005	09/03/2005
Investigator CV		08/03/2005	09/03/2005
Protocol	1	07/03/2005	09/03/2005
Covering Letter		08/03/2005	09/03/2005
Covering Letter			09/03/2005

Cont. overleaf

Compensation		01/08/2004	09/03/2005
Arrangements			
Copy of Questionnaire			09/03/2005
Participant Information Sheet	1	08/03/2005	09/03/2005
Participant Consent Form	1	08/03/2005	09/03/2005
Response to Request for Further Information		13/04/2005	14/04/2005
Summary C.V for Cheif Investigator			09/03/2005

### Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

#### Notification of other bodies

The Committee Administrator will notify the research sponsor that the study has a favourable ethical opinion.

#### 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.

05/WNo03/10 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project,

Yours sincerely,

Mr P Richards

Associate Specialist - Surgery, Secretary

North East Wales LREC

Enclosures

List of names and professions of members who were present at the

meeting and those who submitted written comments

Standard approval conditions Site approval form (SF1)

Cont. overleaf

### Pwyllgor Moeseg Ymchwil Dwyrain Gogleddd Cymru North East Wales Local Research Ethics Committee

Cydlynydd Moeseg Ethics Co-ordinator Ysbyty Maelor Wrecsam/Wrexham Maelor Hospital Crossnewydd Road Wrecsam/Wrexham LL13 7TD Ffon/Tel: (01978) 725368 (llinell uniongyrchol/direct line)

Ffacs/Fax: (01978) 725368

Livth-el/E-mail: Eleanor. Thomas a new-tr. wales.nhs.uk

28th April 2005

Mr N Hulbert
PhD Student
Cardiff University, Wales College of Medicine
Gwenfro Unit 5
Wrexham Technology Park
Wrexham
LL13 TYP

Dear Mr Hulbert

Full title of study:

The Importance of Personality In Appraisal And Psycho-Social

**Outcome Prediction For Colorectal Cancer Patients?** 

REC reference number:

05/WNo03/10

The Research Ethics Committee reviewed the above application at the meeting held on 27th April 2005.

We have written to you separately with the outcome of the review. This letter relates specifically to your declaration that this is a study with no local investigators.

The Committee agreed that this is a "no local investigator" study and site-specific assessment is not required for sites involved in the research. No information about the study needs to be submitted to Local Research Ethics Committees. However, you should arrange for all relevant host organisations to be notified that the research will be taking place before the research commences.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

REC reference number:

05/WNo03/10 Please quote this number on all correspondence

Yours sincerely,

Miss E Thomas

Research Ethics Co-ordinator North East Wales LREC

E Thomas

### APPENDIX 3.5: LETTER OF PERMISSION TO CONDUCT RESEARCH FROM TRUST A



North East Wales NHS Trust Internal Review Panel Clinical Audit / Research Effectiveness Department Wrexham Medical Institute Croesnewydd Road Wrexham LL13 7YP Tel: 01978 291100 ext 7453

Our Ref JJ/jh/RP05/06/01

21st July 2005.

Private & Confidential
Nick Hulbert
North Wales Clinical School
Cardiff University Department of General Practice
Gwenfro Unit 5, Wrexham Technology Park
Croesnewydd Road, Wrexham, LL13 7YP

Dear Nick

RE: The Importance of personality in appraisal and psycho-social outcome prediction for colorectal cancer patients

Thank you for responding regarding the amendments requested to the above project by the North East Wales NHS Trust Internal Review Panel, following review on 9th June 2005. Following the Internal Panel Review meeting on 14th July I would like to inform you on behalf of the Review Panel that your project has now received full approval. Attached for your information is a list of the Panel members who reviewed your project.

As part of the approval process, 6-monthly progress reports and a final report will be required by the panel. These should be sent to the above address.

Any amendments to the research protocol should be notified to the panel.

As you know you are also required to have approval from a Research Ethics Committee before you can proceed with your project.

Yours sincerely

Mrs Julie Jones

Research & Audit Manager

Clinical Audit / Research Effectiveness

Pencadlys Ymddiriedolaeth: Ffordd Croesnewydd, Wreciam LL13 7TD. Ffôn 01978 291100

Trust Headquarten: Croesnewydd Road, Wrecham LL13 7TD. Tel: 01978 291100

Cadelrydd/Chairman: Lloyd Fizzhugh, OBE, DL. Prif Weithredwr/Chief Executive:Hillary Pepler



Pencadlys Ymddirledoleeth: Ffordd Croesnewydd, Weciaem LL13 7TD. Ffôn 01978 291100 Trust Headquarters: Croesnewydd Road, Wresham LL13 7TD. Tel: 01978 291100 Cadeirydd/Chairman: Lloyd Rizzhugh, OBE, DL. Prif Weithredwr/Chief Executive:Hillary Pepler



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Panel Members who reviewed your project are as follows:-

Sally Ann Baker, Lecturer Researcher, NEWI, Centre for Health & Community Research, Directorate of Medical Education, Health, Sports & Science.

Dr Emma Bedson, Research Officer, All Wales Alliance for Research and Development (AWARD) Institute of Medical & Social Care (IMSCar) University of Wales, Bangor

Mr Tony daSilva, Consultant Surgeon, North East Wales Trust

Mr John Day, Consultant Audiological Scientist, """

Mrs Julie Jones, Clinical Audit/R & D Manager

Dr David Parker, Associate Medical Director, Lead Clinician: Clinical Audit/Research & Development

Ron Iphofen, Senior Lecturer in Sociology of Health.

Mrs Louise Howard Baker, Senior Pharmacist

Dr Jim Turner, Senior Research Fellow, Dept Clinical Audit/Research Effectiveness

Clive Williams, Consultant Biochemical Pathologist

### APPENDIX 3.6: LETTER OF PERMISSION TO CONDUCT RESEARCH IN CENTRE B



### Ymddiriedolaeth GIG Siroedd Conwy a Dinbych Conwy & Denbighshire NHS Trust

TO: Mr Nicholas J Hulbert North Wales Clinical School Cardiff University Wales College of Medicine, Gwenfro Unit 5 Wrexham Technology Park Wrexham LL13 7YP

Ein cyt/Our ref: LTJ/June/2005
Eich cyt/Your ref:
Dyddiad/Date: 27 June 2005
Wrth flonio gofynnwch am/lif telephoning ask for
Lona Tudor Jones
Llinell Uniongyrchol/Direct Line:
01745 - 589624
E-Mail Address
Lona: Tudor Jones(20cd-tr. wales, n.h.s. u.k.)

Dear Mr Hulbert

Re: Trust Approval to Proceed

Project Title: The importance of personality in appraisal and psychosocial outcome prediction for colorectal cancer patients.

Trust Ref:2005/Onc/240

I am pleased to inform you that, following the R&D Internal Review panel meeting held on 7 June 2005, the above project has obtained approval to proceed at the Conwy and Denbighshire NHS Trust subject to ethical approval.

As part of regular monitoring undertaken by the Trust R&D Committee, you will be required to complete a short progress report. This will be requested on a six monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Trust is keen to reduce the burden of paperwork for Researchers failure to produce a progress report may result in withdrawal of approval and any allocated funding.

To confirm the details and amount of funding, if any, allocated to your project, please contact Shelagh Evans, Management Accounts in the Finance Department, H M Stanley Hospital. Ext. 3771.

All research conducted at Conwy and Denbighshire NHS Trust must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D webpages. Alternatively you may obtain a paper copy of this document via the Trust R&D Office.

Please note the following as Principal investigator ie. the person designated as taking overall responsibility within the team of researchers for the design, conduct and reporting of the study.

- Controlled trials are registered.
- The research proposal has ethical approval.
- The study complies with ethical and legal requirements.
- The research follows the protocol approved by the relevant ethics committee and the research sponsor.





Ysbyty H. M. Stanley, Llanelwy, Sir Ddinbych LL17 0RS. Ffön: 01745 583910 Ffacs: 01745 589600 H. M. Stanley Hospital, St. Asaph, Denbighshire LL17 0RS. Phone: 01745 583910 Fax: 01745 589600 Website: www.conwy-denbighshire-nhs.org.uk

Cont. overleaf

- Any proposed changes or amendment to or deviations from the protocol and submitted for approval to the ethics committee, the research sponsor and any other appropriate body.
- The research proposal is worthwhile, of high scientific quality and value for money
- The arrangements, resources proposed and procedures are in place to ensure the collection of high quality, accurate data and the integrity and confidentiality of data during processing and storage.
- The research team are suitably qualified and have the necessary skills and experience. Students and new researchers have adequate supervision, support and training.
- Care staff are suitably informed about their patients raking part in research.
- Assistance will be provided to any potential enquiry audit or investigation related to the funded work. All data associated with the study are available for audit.
- The principal investigator plays a key role in detecting and preventing scientific misconduct by adopting the role of guarantor on published outputs.
- Unless participants or the relevant ethics committee request otherwise, participants' care professionals are given information specifically relevant to their care which arises in the research.
- The findings from the work are open to critical review.

I trust this is in order. If you would like further information on any of the points covered by this letter, please do not hesitate to contact me. On behalf of the R&D Committee, may I wish you every success with your research.

Yours sincerely

Lona Tudor Jones R&D Manager

Cc Julie Whitmore, Ethics Glan Clwyd Hospital Shelagh Evans, Finance, H M Stanley Hospital

Lana Turbor Jones



## Trust Research Governance Committee Internal Review Panel

3 June 2005

Mr. N. Hulbert Cardiff University, Wales College of Medicine Gwenfro Unit 5, Wrexham Technology Park Wrexham LL13 7YP

Dear Mr. Hulbert,

Re: 05/WNo03/10 ' The importance of personality in appraisal and psychosocial outcome prediction for colorectal cancer patients'

The above research project was reviewed at the meeting of the Internal Review Panel held on 2 June 2005

I have pleasure in confirming that the Trust Research Governance Committee / Internal Review Panel is pleased to grant Trust approval for the conduct of this research at the North West Wales NHS Trust sites.

As part of the regular monitoring undertaken by the Trust's Research Governance Committee you will be required to complete a short progress report. This will be requested on an annual basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Trust is keen to reduce the burden of paperwork for researchers failure to produce a report may result in withdrawal of approval.

All research conducted at the North West Wales NHS Trust sites must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely,

Rossila Startesa

P Dr. K.D. Griffiths

Consultant Biochemist - Assistant to the Medical Director Chairman, Trust Research Governance Committee Acting Chairman, Internal Review Panel

WKG 0184

## **APPENDIX 3.8: DEMOGRAPHIC QUESTIONNAIRE**

## **Demographic Questionnaire**

Ple	ase complete the following questions o	about yours	elf by ticking the appropriate box:	
1.	Are you	Male	Female	
2.	What is your date of birth?			
3.	Which best describes you (please	se tick one	box only):	
! !	Employed full-time Self-employed Retired Not employed (seeking work) Not employed (not seeking work for c	other reason	Employed part-time In full-time education Other (please specify below) Not employed (ill health) n)	
4.	Would you describe yourself as etc.)?	s having a 's Yes No	significant other' (e.g. wife, husband	i, partner,
5.	Do you live with your 'significal	nt other'?		
		Yes No N/A		
6.	Do you care for any dependants	s (tick and i	ndicate number as appropriate)?	
7.	Are you-	Under 18 18-65 Over 65	B	
	White Black-Caribbean Asian-Pakistani Chinese		Black-African Asian-Indian Asian-Bangladeshi Other (please specify)	
8.	What is your highest level of qu	ualification?		
	None 'A' Level Degree (or equivalent)		GCSE 'O' Level Diploma (or equivalent) Other (please specify)	

9.	What is your GP's name and address?
10.	What hospital are you being treated at?
11.	What is your consultant's name?
12.	Who is your assigned nurse specialist?
13.	What treatment have you had so far/are you having for your illness?

## **APPENDIX 3.9: LIFE ORIENTATION TEST**

### LOT-R

This next set questions asks about your feelings. Answer according to your own feelings, rather than how you think "most people" would answer. Please use the following key and answer by circling the most appropriate number.

1 3 5	I disagree a lot I neither agree nor disagree I strongly agree	2 4	I disagree a little I agree a little					
1.	In uncertain times, I usually expect the b	est.		1	2	3	4	5
2.	It's easy for me to relax.			1	2	3	4	5
3.	If something can go wrong for me, it will	•		1	2	3	4	5
4.	I'm always optimistic about my future.			1	2	3	4	5
5.	I enjoy my friends a lot.			1	2	3	4	5
6.	It's important for me to keep busy.			1	2	3	4	5
7.	I hardly ever expect things to go my way	<b>'.</b>		1	2	3	4	5
8.	I don't get upset easily.			1	2	3	4	5
9.	I rarely count on good things happening	to me.		1	2	3	4	5
10.	Overall, I expect more good things to ha	ppen t	o me than bad.	1	2	3	4	5

## **APPENDIX 3.10: NEO-FFI INVENTORY**

This section contains 60 statements. Read each one carefully. For each statement, circle the response that best represents your opinion. Please use the following key and answer by circling the most appropriate number.

- 1 Strongly Disagree
- 2 Disagree
- 3 Neither Agree nor Disagree
- 4 Agree
- 5 Strongly Agree

1.	I am not a worrier.	1	2	3	4	5
2.	I like to have a lot of people around me.	1	2	3	4	5
3.	I don't like to waste my time daydreaming.	1	2	3	4	5
4.	I try to be courteous to everyone I meet.	1	2	3	4	5
<b>5</b> .	I keep my belongings neat and clean.	1	2	3	4	5
6.	I often feel inferior to others.	1	2	3	4	5
7.	I laugh easily.	1	2	3	4	5
8.	Once I find the right way to do something, I stick to it.	1	2	3	4	5
9.	I often get into arguments with my family and co-workers.	1	2	3	4	5
10.	I'm pretty good about pacing myself so as to get things done on time.	1	2	3	4	5
11.	When I'm under a great deal of stress, sometimes I feel like I'm going to pieces.	1	2	3	4	5
12.	I don't consider myself especially "light-hearted".	1	2	3	4	5
13.	I am intrigued by the patterns I find in art and nature.	1	2	3	4	5
14.	Some people think I'm selfish and egotistical.	1	2	3	4	5
15.	I am not a very methodical person.	1	2	3	4	5
16.	I rarely feel lonely or blue.	1	2	3	4	5
17.	I really enjoy talking to people.	1	2	3	4	5
18.	I believe letting students hear controversial speakers can only confuse and mislead them.	1	2	3	4	5
19.	I would rather cooperate with others than compete with them.	1	2	3	4	5
20.	I try to perform all the tasks assigned to me conscientiously.	1	2	3	4	5
21.	I often feel tense and jittery.	1	2	3	4	5
22.	I like to be where the action is.	1	2	3	4	5
23.	Poetry has little or no effect on me.	1	2	3	4	5
24.	I tend to be cynical and sceptical or others' intentions.	1	2	3	4	5
25.	I have a clear set of goals and work toward them in an orderly fashion.	1	2	3	4	5
26.	Sometimes I feel completely worthless.	1	2	3	4	5
27.	I usually prefer to do things alone.	1	2	3	4	5

28.	I often try new and foreign foods.	1	2	3	4	5
29.	I believe most people will take advantage of you if you let them.	1	2	3	4	5
30.	I waste a lot of time before settling down to work.	1	2	3	4	5
31.	I rarely feel fearful or anxious.	1	2	3	4	5
32.	I often feel as if I'm bursting with energy.	1	2	3	4	5
33.	I seldom notice the moods or feelings that different environments produce.	1	2	3	4	5
34.	Most people I know like me.	1	2	3	4	5
35.	I work hard to accomplish my goals.	1	2	3	4	5
36.	I often get angry at the way people treat me.	1	2	3	4	5
37.	I am a cheerful, high-spirited person.	1	2	3	4	5
38.	I believe we should look to our religious authorities for decisions on moral issues.	1	2	3	4	5
<b>39</b> .	Some people think of me as cold and calculating.	1	2	3	4	5
<b>40</b> .	When I make a commitment, I can always be counted on to follow through.	1	2	3	4	5
41.	Too often, when things go wrong, I get discouraged and feel like giving up.	1	2	3	4	5
<b>42</b> .	I am not a cheerful optimist.	1	2	3	4	5
43.	Sometimes when I am reading poetry or looking at a work of art, I feel a chill or wave of excitement.	1	2	3	4	5
<b>44</b> .	I'm hard-headed and tough-minded in my attitudes	1	2	3	4	5
<b>45</b> .	Sometimes I'm not as dependable or reliable as I should be.	1	2	3	4	5
46.	I am seldom sad or depressed.	1	2	3	4	5
47.	My life is fast-paced.	1	2	3	4	5
48.	I have little interest in speculating on the nature of the universe or the human condition.	1	2	3	4	5
49.	I generally try to be thoughtful and considerate.	1	2	3	4	5
<b>50</b> .	I am a productive person who always gets the job done.	1	2	3	4	5
<b>51</b> .	I often feel helpless and want someone else to solve my problems	1	2	3	4	5
<b>52</b> .	I am a very active person.	1	2	3	4	5
<b>53</b> .	I have a lot of intellectual curiosity.	1	2	3	4	5
<b>54</b> .	If I don't like people, I let them know it.	1	2	3	4	5
<b>55</b> .	I never seem to be able to get organized.	1	2	3	4	5
56.	At times I have been so ashamed I just wanted to hide.	1	2	3	4	5
57.	I would rather go my own way than be a leader of others.	1	2	3	4	5
<b>58</b> .	I often enjoy playing with theories or abstract ideas.	1	2	3	4	5
59.	If necessary, I am willing to manipulate people to get what I want.	1	2	3	4	5
60.	I strive for excellence in everything I do.	1	2	3	4	5

## **APPENDIX 3.11: APPRAISAL COMPONENTS QUESTIONNAIRE**

Below are a number of questions concerning your thoughts about your diagnosis. For each question please circle the relevant number (from 1 to 11) to indicate what you now think about the time of your diagnosis. For each question, specific endpoints are provided to help you define the scale for that question.

1.	How important or si	gnifi	cant t	o you	was y	our i	llness	diagr	osis?				
	Not at all	1	2	3	4	5	6	7	8	9	10	11	Extremely
2.	To what extent was	this a	ın unc	lesira	ble ev	vent?							
	Not at all	1	2	3	4	5	6	7	8	9	10	11	Extremely
3.	To what extent was	this a	desi:	rable	event	?							
	Not at all	1	2	3	4	5	6	7	8	9	10	11	Extremely
4.	Did you consider yo	ursel	f resp	onsib	le for	your	illnes	s?					
	Not at all	1	2	3	4	5	6	7	8	9	10	11	Extremely
<b>5</b> .	Did you consider so	meor	ie or s	omet	hing	else re	espon	sible	for yo	ur illı	ness?		
	Not at all	1	2	3	4	5	6	7	8	9	10	11	Extremely
6.	When you think abo	ut ho	w yo	u war	it this	situa	tion t	o turr	out,	are yo	ou con	fiden	t that this will happen?
	Not at all	1	2	3	4	5	6	7	8	9	10	11	Extremely
7.	How much do you th out of your illness?	nink y	you ca	an infl	luence	e thin	gs to 1	make	sure y	ou ge	et wha	t you	want (and don't want)
	Certain would not be able to	1	2	3	4	5	6	7	8	9	10	11	Certain would be able to
8.	How well do you thi	nk y	ou wil	ll be a	ble to	deal	emoti	onall	y with	this	illness	?	
	Certain would not be able to	1	2	3	4	5	6	7	8	9	10	11	Certain would be able to

### **APPENDIX 3.12: CORE RELATIONAL THEMES OUESTIONNAIRE**

Below are a number of clusters of statements that describe thoughts that people often have about various situations. Please indicate the extent to which each characterises your current thoughts about your illness diagnosis.

Please use the nine-point scale depicted below. Indicate your ratings by writing the appropriate number (1 to 9) in the box provided next to each cluster of statements.

uie	oox provided next to each cluster of s 1		8	9
	Does not characterise my feelings at all	Characterises my feelings somewhat		Characterises my feelings extremely well
1.	I have made a fool of myself in th	his situation.		
	People disapprove of what I've d People think I'm stupid in this si			
2.	Something important to me is ha	appening in this situation.		
	This situation touches upon my part of the things to the	-		
3.	I didn't expect this at all. I never thought this would happe	en.		
	What happened here was totally			
4.	This situation is totally irrelevan	nt to my concerns.		
	I don't care at all about what is h What's happening here is a total	••		
5.	There's nothing I need to be doin	ng right now.		
	Everything is fine for now. For the moment there's nothing	I need to be concerned about.		
6.	A burden has been lifted from m	ny mind.		
	Things have worked out after all	il.		
	A threat or harm has been remo	oved from the situation.		
7.	Someone is interfering with my	goals.		
	I've been cheated or wronged.			
	Someone else is to blame for the I've been dealt with shabbily	e situation I'm in.		
8.	I have done something bad.			
	Things are bad because of me.	<b>.</b>		
	I am to blame for this bad situat	non.		

### **APPENDIX 3.13: EMOTION THEMES OUESTIONNAIRE**

Below are a number of clusters of adjectives that describe emotions and feelings. Each group of adjectives is meant to get at a single basic feeling or emotion. Please indicate the extent to which each cluster of adjectives characterises your current feelings and emotions about your illness diagnosis.

Please use the nine-point scale depicted below. Indicate your ratings by writing the appropriate number (1 to 9) in the box provided next to each cluster of statements.

	Does not characterise my feelings at all	Characterises my feelings somewhat	,	Characterises my f well	eelings extremely
1.	Surprised		10.	Embarrassed	
	Amazed			Humiliated	<del></del>
	Astonished			Disgraced	
2.	Guilty		11.	Interested	
	Remorseful			Involved	
	Ashamed			Intrigued	
3.	Defeated		12.	Joyful	
	Resigned			Нарру	[
	Beaten			Light-hearted	
4.	Tranquil		13.	Bored	
	Calm	<del></del>		Indifferent	
	Serene			Apathetic	
5.	Frustrated		14.	Nervous	
	Thwarted	<del></del>		Anxious	
	Exasperated			Tense	
6.	Annoyed with myself	<del></del>	15.	Hopeful	
	Mad at myself			Optimistic	
7.	Challenged		16.	Angry	
	Determined			Annoyed	
	Eager			Resentful	
8.	Regretful		17.	Afraid	
	Dissatisfied			Frightened	
	Disappointed in myself			Scared	
9.	Sad		18.	Relieved	
	Downhearted	<b></b>			
	Sorrowful				

## APPENDIX 3.14: MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL SCALE

Each item below is a belief statement about your medical condition with which you may agree or disagree. Please use the following key in answering the following questions, by circling the most appropriate answer.

1 3 5	Strongly Disagree 2 Moderately Disagree Slightly Disagree 4 Slightly Agree Moderately Agree 6 Strongly Agree						
1.	If my condition worsens, it is my own behaviour which determines how soon I will feel better again.	1	2	3	4	5	6
2.	As to my condition, what will be, will be.	1	2	3	4	5	6
3.	If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6
4.	If my condition worsens, it is up to God to determine whether I will feel better again.	1	2	3	4	5	6
5.	Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
6.	Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6
7.	I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
8.	Most things that affect my condition happen because of God.	1	2	3	4	5	6
9.	Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	2	3	4	5	6
10	. Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6
11	Luck plays a bit part in determining how my condition improves.	1	2	3	4	5	6
12	God is directly responsible for my condition getting better or worse.	1	2	3	4	5	6
13	In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
14	Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
15	5. The main thing which affects my condition is what I myself do.	1	2	3	4	5	6
16	6. Whatever happens to my condition is God's will.	1	2	3	4	5	6
17	<ol> <li>I deserve the credit when my condition improves and the blame when it gets worse.</li> </ol>	1	2	3	4	5	6
18	<ol><li>Following doctor's orders to the letter is the best way to keep my condition from getting any worse.</li></ol>	1	2	3	4	5	6
19	9. If my condition worsens, it's a matter of fate.	1	2	3	4	5	6
20	). Whether or not my condition improves is up to God.	1	2	3	4	5	6
21	l. If I am lucky, my condition will get better.	1	2	3	4	5	6
22	<ol> <li>If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.</li> </ol>	1	2	3	4	5	6
23	<ol> <li>The type of help I receive from other people determines how soon my condition improves.</li> </ol>	1	2	3	4	5	6
24	4. God is in control of my condition.	1	2	3	4	5	6

### **APPENDIX 3.15: BRIEFCOPE INVENTORY**

These items deal with way's you've been coping with the stress in your life since you found out about your diagnosis. Use the following key to indicate what extent you've been doing what the item says—not if they are working or not, just whether or not you're doing it.8

- I haven't been doing this at all
- 2 I've been doing this a little bit
- 3 I've been doing this a medium amount
- 4 I've been doing this a lot

1.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2.	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3.	I've been saying to myself "this isn't real".	1	2	3	4
4.	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
<b>5</b> .	I've been getting emotional support from others.	1	2	3	4
6.	I've been giving up trying to deal with it.	1	2	3	4
<b>7</b> .	I've been taking action to try to make the situation better.	1	2	3	4
8.	I've been refusing to believe that it has happened.	1	2	3	4
9.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10.	I've been getting help and advice from other people.	1	2	3	4
11.	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13.	I've been criticizing myself.	1	2	3	4
14.	I've been trying to come up with a strategy about what to do.	1	2	3	4
15.	I've been getting comfort and understanding from someone.	1	2	3	4
16.	I've been giving up the attempt to cope.	1	2	3	4
17.	I've been looking for something good in what is happening.	1	2	3	4
18.	I've been making jokes about it.	1	2	3	4
19.	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20.	I've been accepting the reality of the fact that it has happened.	1	2	3	4
21.	I've been expressing my negative feelings.	1	2	3	4
22.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23.	I've been trying to get advice or help from other people about what to do.	1	2	3	4
24.	I've been learning to live with it	1	2	3	4
25.	I've been thinking hard about what steps to take.	1	2	3	4
26.	I've been blaming myself for things that happened.	1	2	3	4
27.	I've been praying or meditating.	1	2	3	4
28.	I've been making fun of the situation.	1	2	3	4

## **APPENDIX 3.16: SF-12 INVENTORY**

These	questions ask	about your views ab . Please answer each	out your he	alth, how	you feel and	how well	vou are able	to do
1.	In general,	would <u>you</u> say your	า <i>by murkin</i> ยู่ health is:	g tne box	wnich most	nts now yo	и јееі.	
E	xcellent	Uery Good	Goo	] d	 Fair		Poor	
The fo	ollowing items	are about activities	you might	do during	a typical da	ay. Does <u>y</u>	our health i	now
رعسسر	<u>w</u> in these at	ctivities: If so, flow	mucm		Yes, Limit A Lot		s, Limited A Little	No, Not Limited
2.		<b>ctivities,</b> such as m ng a vacuum cleaner		r				
3.	Climbing se	veral flights of stair	S.					
		eeks, have you had ies as a result of you			problems wi	•		r
<b>4</b> . <b>5</b> .		<b>ned less</b> than you w d in the <b>kind</b> of wor		ctivities.		Ye	s	No
	ar daily activit	reeks, have you had ties as a result of any				eling depr	essed or	
6. 7.		ned less than you w ork or other activition		lly as		Ye		No
8. No	_	past 4 weeks, how a outside the home as A little bit	•	rk)?	re with you Quite a		vork (includ	
For ea	ach question,	e about how you fee please give the one a me during the <u>past </u>	answer that <u>4 weeks</u> :	comes clo	e been for your sest to the A Good	ou <u>during</u> way you h Some of	the past 4 v ave been fe A Little	<u>veeks</u> . eling. None
9.	Have you fel	t calm and	All of the Time	Most of the Time	Bit of the Time	the Time	of the Time	of the Time
10. 11.		e a lot of energy? t downhearted						
12. probl	During the	past 4 weeks, how d with your social a	mudthe				or el ona	
All	of the Time	Most of the Time	Some of the	」 he Time	A little o		None of the	Time

### **APPENDIX 3.17: MINI MENTAL ADJUSTMENT TO CANCER SCALE**

A number of statements are given below which describe people's reactions to having cancer. Please use the following key and circle the response that indicates how far it applies to you at present.

- 1. Definitely does not apply to me
- 2. Does not apply to me
- 3. Applies to me4. Definitely applies to me

	4. Definitely applies to me				
1.	At the moment I take one day at a time.	1	2	3	4
2.	I see my illness as a challenge.	1	2	3	4
<b>3</b> .	I've put myself in the hands of God.	1	2	3	4
4.	I feel like giving up.	1	2	3	4
<b>5</b> .	I feel very angry about what has happened to me.	1	2	3	4
6.	I feel completely at a loss about what to do.	1	2	3	4
7.	It is a devastating feeling.	1	2	3	4
8.	I count my blessings.	1	2	3	4
9.	I worry about the cancer returning or getting worse.	1	2	3	4
10.	I try to fight the illness.	1	2	3	4
11.	I distract myself when thoughts about my illness come into my	1	2	3	4
	head.	1		_	-
12.	I can't handle it.	1	2	3	4
13.	I am apprehensive.	1	2	3	4
14.	I am not very hopeful about the future.	1	2	3	4
<b>15</b> .	I feel there is nothing I can do to help myself.	1	2	3	4
16.	I think it is the end of the world.	1	2	3	4
17.	Not thinking about it helps me cope.	1	2	3	4
18.	I am very optimistic.	1	2	3	4
19.	I've had a good life what's left is a bonus.	1	2	3	4
20.	I feel that life is hopeless.	1	2	3	4
21.	I can't cope.	1	2	3	4
22.	I am upset about having cancer.	1	2	3	4
23.	I am determined to beat this disease.	1	2	3	4
24.	Since my diagnosis of cancer I now realise how precious life is	1	2	3	4
	and I'm making the most of it.	-	_		
25.	I have difficulty in believing that this happened to me.	1	2	3	4
26.	I make a positive effort not to think about my illness.	1	2	3	4
27.	I deliberately push all thoughts of cancer out of my mind.	1	2	3	4
28.	I suffer great anxiety about it.	1	2	3	4
<b>29</b> .	I am a little frightened.	1	2	3	4

### **APPENDIX 3.18: FACT-G INVENTORY**

Below is a list of statements that other people with your illness have said are important. By circling one number for each, please indicate how true each statement has been for you during the past 7 days. Please use the following scale when selecting your answer:

0	Not at all					
1	A little bit					
2	Somewhat					
3	Quite A Bit					
4	Very Much					
Phy	sical Well Being					
1.	I have a lack of energy	0	1	2	3	4
2.	I have nausea.	0	1	2	3	4
3.	Because of my physical condition, I have trouble meeting the needs of my family.	0	1	2	3	4
4.	I have pain.	0	1	2	3	4
5.	I am bothered by side effects of treatment.	0	1		3	4
6.	I feel ill.			2		4
7.	I am forced to spend time in bed.	0	1	2	3	4
Soc	rial/Family Well Being					
8.	I feel close to my friends.	0	1	2	3	4
9.	I get emotional support from my family.		1			4
10.	• • • • •			2		4
11.				2		4
12.			1		3	4
13.		0	1	2	3	4
14.	following question. If you prefer not to answer it, please tick this		]			
	box and go to the next section.					
15.	I am satisfied with my sex life.	0	1	2	3	4
Em	otional Well Being					
16.	<del>-</del>	0	1	2	3	4
17.	I am satisfied with how I am coping with my illness.	0	1	2	3	4
18.				2		4
19.	I feel nervous.	0			3	4
20.	I worry about dying.	0	1		3	4
21.	I worry that my condition will get worse.	0	1	2	3	4
Fui	nctional Well Being					
22.		0	1	2	3	4
23.		0	1	2	3	4
24.		0	1	2	3	4
25.		0	1	2	3	4
26.	· · · · · · · · · · · · · · · · · · ·	0	1	2	3	4
27.	· · · · · · · · · · · · · · · · · · ·	0	1	2	3	4
28		0	1	2	3	4

## **APPENDIX 3.19: FACT-C INVENTORY**

29.	I have swelling or cramps in my stomach area.	0	1	2	3	4
30.	I am losing weight.	0	1	2	3	4
31.	I have control of my bowels.	0	1	2	3	4
<b>32</b> .	I can digest my food well.	0	1	2	3	4
33.	I have diarrhoea	0	1	2	3	4
34.	I have a good appetite.	0	1	2	3	4
<b>35</b> .	I like the appearance of my body.	0	1	2	3	4
36.	Do you have an ostomy appliance? (Tick one box)  If yes, please answer the next two items:	No 🗌		•	Yes	
37.	I am embarrassed by my ostomy appliance.	0	1	2	3	4
38.	Caring for my ostomy appliance is difficult.	0	1	2	3	4

## **APPENDIX 3.20: FACT-P INVENTORY**

29.	I am losing weight.	0	1	2	3	4
30.	I have a good appetite.	0	1	2	3	4
31.	I have aches and pains that bother me.	0	1	2	3	4
32.	I have certain parts of my body where I experience significant pain.	0	1	2	3	4
33.	My pain keeps me from doing things I want to do.	0	1	2	3	4
34.	I am satisfied with my present comfort level.	0	1	2	3	4
35.	I am able to feel like a man.	0	1	2	3	4
37.	I have trouble moving my bowels.	0	1	2	3	4
38.	I have difficulty urinating.	0	1	2	3	4
39.	I urinate more frequently than usual.	0	1	2	3	4
40.	My problems with urinating limit my activities.	0	1	2	3	4
41.	I am able to have and maintain an erection.	0	1	2	3	4

## **APPENDIX 3.21: FACT-B INVENTORY**

29.	I have been short of breath.	0	1	2	3	4
30.	I am self-conscious about the way I dress.	0	1	2	3	4
31.	One or both of my arms are swollen or tender.	0	1	2	3	4
<b>32</b> .	I feel sexually attractive.	0	1	2	3	4
33.	I am bothered by hair loss.	0	1	2	3	4
34.	I worry that other members of my family might someday get the same illness I have.	0	1	2	3	4
35.	I worry about the effect of stress on my illness.	0	1	2	3	4
36.	I am bothered by a change in weight.	0	1	2	3	4
37.	I am able to feel like a woman.	0	1	2	3	4
38.	I have certain parts of my body where I experience significant pain.	0	1	2	3	4

## **APPENDIX 3.22: FACT-L INVENTORY**

29.	I have been short of breath.		0	1	2	3	4
30.	I am losing weight.		0	1	2	3	4
31.	My thinking is clear.		0	1	2	3	4
32.	I have been coughing.		0	1	2	3	4
<b>3</b> 3.	I am bothered by hair loss.		0	1	2	3	4
34.	I have a good appetite.		0	1	2	3	4
35.	I feel tightness in my chest.		0	1	2	3	4
36.	Breathing is easy for me.						
37.	Have you ever smoked?						
		No			•	Yes	Ш
	If yes:						
38.	I regret my smoking.		0	1	2	3	4

### APPENDIX 3.23: HOSPITAL ANXIETY & DEPRESSION SCALE (HADS)

This section will tell us more about how you feel and your illness-related emotions. Read each item and tick the box nest to the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies; you immediate reaction will probably be more accurate than a long thought out response.

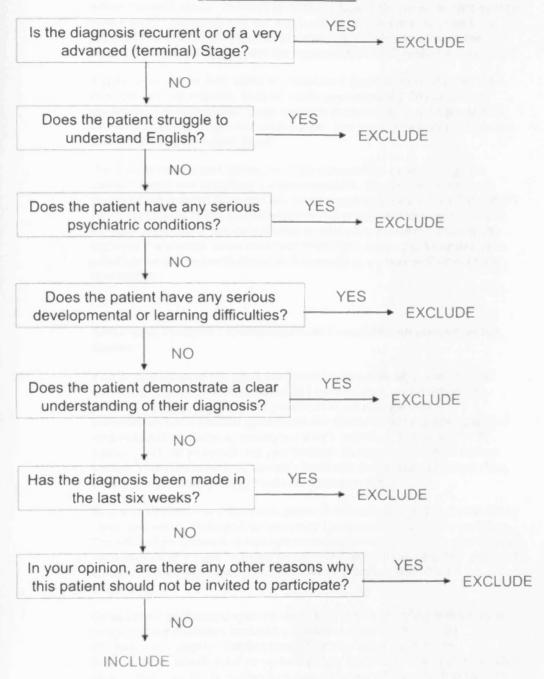
1. I feel tense or wound up:

8. I feel as if I am slowed down:

1. I reel tense or wound up:	8. I feel as if I am slowed down:
Most of the time	Nearly all the time
A lot of the time	Very often
From time to time, occasionally	Sometimes
Not at all	Not at all
2. I still enjoy the things I used to enjoy:	9. I get a sort of frightened feeling like 'butterflies' in the stomach:
Definitely as much	Not at all
Not quite as much	Occasionally
Only a little	Quite often
Hardly at all	Very often
3. I get a sort of frightened feeling as if somethin awful is about to happen:	g 10. I have lost interest in my appearance:
Very definitely and quite badly	Definitely
Yes, but not too badly	I don't take so much care as I should
A little, but it doesn't worry me	I may not take quite as much care
Not at all	I take just as much care as ever
4. I can laugh and see the funny side of things:	11. I feel restless as if I have to be on the move:
As much as I always could	Very much indeed
Not quite as much now	Quite a lot
Definitely not so much now	Not very much
Not at all	Not at all
5. Worrying thoughts go through my head:	12. I look forward with enjoyment to things:
A great deal of the time	As much as I ever did
A lot of the time	Rather less than I used to
From time to time, but not too often	Definitely less than I used to
Only occasionally	Hardly at all
Only occasionally	Hardiy at all
6. I feel cheerful:	13. I get sudden feelings of panic:
Not at all	Very often indeed
Not often	Quite often
Sometimes	Not very often
Most of the time	Not at all
7. I can sit at ease and feel relaxed:	14. I can enjoy a good book or radio/TV programme:
Definitely	Often
Usually	Sometimes
Not often	Not often
Not at all	Very seldom

### APPENDIX 3.24: INCLUSION CRITERIA MATRIX

# Personality Differences in Cancer Patients Inclusion Criteria Matrix



#### **APPENDIX 3.25: PATIENT INVITATION LETTERS**

### Research Study - Personality Differences in Cancer Patients.

I am writing to you on behalf of a team of researchers at the Cardiff University School of Medicine. They would like to invite you to take part in a new research study. This will investigate how different personalities cope with a cancer diagnosis and the implications that this may have on their physical and emotional adjustment throughout illness, treatment, the future. If you agree to take part the research team will contact you directly.

To take part, you will be asked to complete a questionnaire at three times over the next six months. Each will take approximately 30 minutes to complete. The researchers hope that this study will help to improve care delivery to people diagnosed with cancer. For more information please see the enclosed 'Information Sheet'.

If you wish to take part, please read the information carefully, sign the consent forms and complete the questionnaire. Please then return two copies of the consent form and the questionnaire in the enclosed FREEPOST envelope (please retain the information sheet and the third consent form for your records). If you do not wish to take part, please return all of the enclosed documents in the enclosed FREEPOST envelope. Your decision whether or not to participate in this study in no way will affect your treatment.

#### Astudiaeth Ymchwil - Gwahaniaethau Personoliaeth mewn Cleifion Canser

Ysgrifennaf atoch ar ran tîm o ymchwilwyr, Ysgol Meddygaeth Prifysgol Caerdydd. Hoffen nhw eich gwahodd i gymryd rhan mewn astudiaeth ymchwil newydd. Bydd hyn yn ymchwilio i sut mae gwahanol bersonoliaethau'n ymdopi gyda diagnosis canser a'r goblygiadau posibl ar eu haddasiad corfforol ac emosiynol trwy'r salwch, y driniaeth ac ar ôl hynny. Ni fydd yr astudiaeth yn effeithio'r ffordd y byddwch yn derbyn triniaeth am eich salwch ac unwaith byddwch wedi cytuno i gymryd rhan, bydd y tîm ymchwil yn cysylltu â chi'n uniongyrchol.

Er mwyn cymryd rhan, byddwch angen cwblhau holiadur tair gwaith dros y chwe mis nesaf. Bydd pob un yn cymryd oddeutu 30 munud i'w gwblhau. Tra ein bod yn sylweddoli bod hyn yn gofyn llawer, gobeithiwn y byddwch yn manteisio ar y cyfle i'n helpu yn ein hymdrechion i wella gofal i gleifion â chanser. I gael gwybodaeth bellach, gweler y 'Daflen Wybodaeth' amgaeedig.

Os byddwch yn dymuno cymryd rhan, darllenwch yr wybodaeth yn ofalus, arwyddwch y ffurflenni caniatâd a chwblhewch yr holiadur. Yna, dychwelwch 2 gopi o'r ffurflen ganiatâd a'r holiadur yn yr amlen RHADBOST (cadwch y daflen wybodaeth a'r 3ydd ffurflen ganiatâd ar gyfer eich cofnodion). Os na fyddwch yn dymuno cymryd rhan, dychwelwch yr holl ddogfennau amgaeedig yn yr amlen RHADBOST amgaeedig. Ni fydd eich penderfyniad i gymryd rhan yn yr astudiaeth ai peidio yn effeithio ar eich triniaeth o gwbl.

### **APPENDIX 3.26: PATIENT INFORMATION SHEET**

#### Personality Differences In Cancer Patients

#### Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done. Please take time to read the following information carefully and discuss it with friends, relatives or those in your medical care team. Ask us if there is anything that is not clear or if you would like more information.

#### Background and study purpose

This study is investigating how individual differences can affect how newly diagnosed cancer patients adjust to being diagnosed, and whether this can be used to predict their longer-term psycho-social outcomes, such as their quality of life, mental adjustment, and vulnerability to psychological illnesses such as depression.

We are approaching all patients with a new cancer diagnosis within three North Wales NHS hospitals. We will be asking about 150 people to take part. The study will take approximately two years and will be written up for Mr Hulbert's PhD thesis.

#### Why have I been chosen?

You have been approached for this study because you have recently received a cancer diagnosis. You have been contacted by your appointed Clinical Nurse Specialist on behalf of Mr Hulbert.

#### Do I have to take part? What happens if I don't take part?

No – you do not have to take part at all and you need not give a reason for this decision. You are also free to withdraw at any time during the study period. This will not affect the standard of care you receive for your illness.

If you decide not to take part, we would appreciate the return of the blank questionnaire and consent form in the FREEPOST envelope. You may take as long as you need in making this decision.

#### What will happen to me if I take part? What do I have to do?

If you agree to take part, you are required to sign the enclosed consent form. You will also need to complete the questionnaire (this should take you no longer than 30 minutes) and return both the questionnaire and consent form in the enclosed FREEPOST envelope. The questionnaire consists of three sections (About you; About your illness and how you are dealing with it; and, About your reaction to diagnosis) which must all be completed if you wish to participate. You will receive acknowledgement that we have received your response and then, in three month's time, you will receive a second questionnaire. This should be completed in the same way. The final questionnaire will be posted to you a further three months later. This type of questionnaire repetition is important to allow us to study how you have changed over time as a result of your illness. Please do not allow anyone to complete the questionnaire on your behalf; it is your personal thoughts and feelings that we are interested in learning about. Additionally, you will be asked to consent for our research team to record some details from your medical notes so that we can accurately understand your illness. Your GP and Consultant will be informed that you are taking part in this research, however this will not affect your care in any way.

Is there any potential harm from taking part in the study?

There are no harmful effects from taking part. At what may be a difficult time for you, we realise that some of the questions may be upsetting for you, but we hope this is balanced out by the potential gains from studies of this type.

### How will I benefit from the study?

There are no direct benefits to you as a patient. The results will be used to inform the development of new, holistic treatment programmes to help and support patients through their illnesses. You may, however, indirectly benefit from the opportunity to express some of your feelings, thoughts, and emotions at this very difficult time.

#### What if something goes wrong?

If you wish to make a complaint about any aspect of this research, or how you have been treated as a participant, please make to the Head of Department, Department of General Practice, Cardiff University, Wales College of Medicine. If at any time you have a question or concern regarding your medical condition, please refer these to your own care team (GP, Nurse etc.)

#### Confidentiality

The data provided by you, or obtained from your medical notes, will be used only for the purposes of this research. Information will be kept confidentially and securely, and you will remain entirely anonymous in any written reports, scientific papers, or study summaries. Data will be stored in accordance with the Data Protection Act and Cardiff University Research Policies and destroyed after three years from submission of Mr Hulbert's PhD thesis.

#### What will happen to the results of the study?

The main documentation of the study is for Mr. Hulbert's PhD thesis. From this, academic papers will be written and submitted to health psychology- and cancer-related scientific journals. Some results may also be presented at scientific meetings and conferences. In all results, all participants will remain anonymous. If you would like a summary of the results, please contact Mr Hulbert to arrange this.

#### Who is organizing and funding this research study?

The study is being organized, sponsored, and funded by Cardiff University, Wales College of Medicine. Mr Hulbert is being supervised by Dr Richard Neal (Wrexham GP), Prof. Clare Wilkinson (Director of Research, North Wales Clinical School, Wrexham), and Dr Val Morrison (Health Psychologist, University of Wales, Bangor).

#### Where can I get further information?

Please feel free to contact Mr N Hulbert, Department of General Practice, North Wales Clinical School, Cardiff University, Gwenfro Unit 5, Wrexham Technology Park, Wrexham, LL13 7YP. Tel: 01978 727859; email: <a href="https://hulbertnj.org/nc.uk">hulbertnj.org/nc.uk</a>. Please note that Mr Hulbert is not qualified to comment on any aspect of your condition or treatment.

Please keep this Information Sheet for your future reference, and, if you decide to take part, also keep one copy of the Patient Consent Sheet. Thankyou for taking part in this research.

#### **GWYBODAETH I GLEIFION**

Canser a Gwahaniaeth mewn Personoliaethau

#### Gwahoddiad

Gwahoddir chi i gymryd rhan mewn astudiaeth ymchwil. Cyn penderfynu, mae'n bwysig eich bod yn deall pam y cynhelir yr ymchwil. Cymerwch amser i ddarllen yr wybodaeth ganlynol yn ofalus a thrafodwch gyda ffrindiau, perthnasau neu rhai yn y tîm gofal meddygol. Gofynnwch os bydd rhywbeth yn aneglur neu os hoffech dderbyn mwy o wybodaeth.

#### Cefndir a phwrpas yr astudiaeth

Mae'r astudiaeth hon yn ymchwilio sut y gall gwahaniaeth rhwng unigolion effeithio ar sut mae cleifion sydd wedi derbyn diagnosis o ganser yn addasu i dderbyn diagnosis a pha un a ellir defnyddio hyn i ragweld eu deilliannau seico-gymdeithasol tymor hir, fel ansawdd eu bywyd, addasiad meddwl a bregusrwydd i salwch seicolegol fel iselder.

Rydym yn cysylltu â phob claf gyda diagnosis o ganser newydd mewn pum ysbyty GIG gwahanol yng Nghymru. Byddwn yn gofyn i oddeutu 150 o bobl i gymryd rhan. Bydd yr astudiaeth yn cymryd oddeutu dwy flynedd a pharatoir ar gyfer traethawd PhD Mr Hulbert.

#### Pam cefais fy newis?

Cysylltwyd â chi ar gyfer yr astudiaeth hon gan eich bod wedi derbyn diagnosis o ganser colorectaidd yn ddiweddar. Darparwyd eich manylion gan yr Arbenigydd Nyrsio a fydd wedi derbyn caniatâd gennych ar lafar i wneud hynny.

## A oes yn rhaid i mi gymryd rhan? Beth fydd yn digwydd os na fyddaf yn cymryd rhan?

Na – nid oes yn rhaid i chi gymryd rhan o gwbl ac ni fydd yn rhaid i chi roi rheswm dros y penderfyniad hwn. Hefyd, gallwch dynnu allan ar unrhyw adeg yn ystod cyfnod yr astudiaeth. Ni fydd hyn yn effeithio ar safon y gofal y byddwch yn ei dderbyn ar gyfer y salwch.

Os byddwch yn penderfynu peidio â chymryd rhan, byddem yn gwerthfawrogi petaech yn dychwelyd yr holiadur a'r ffurflen ganiatâd yn wag yn yr amlen RHADBOST. Gallwch gymryd gymaint o amser ag y dymunwch i wneud y penderfyniad hwn. Ar ôl mis, os na fyddwn wedi derbyn ymateb gennych, efallai y byddwch yn derbyn galwad ffôn i gadarnhau eich bod wedi derbyn pecyn yr holiadur.

## Beth fydd yn digwydd i mi os byddaf yn cymryd rhan? Beth sy'n rhaid i mi ei wneud?

Os byddwch yn cytuno i gymryd rhan, byddwch angen arwyddo'r ffurflen ganiatâd amgaeedig. Hefyd, byddwch angen cwblhau'r holiadur (ni ddylai hyn gymryd mwy na 45 munud) a dychwelyd yr holiadur a'r ffurflen ganiatâd yn yr amlen RHADBOST amgaeedig. Mae'r holiadur yn cynnwys tair adran (Amdanoch chi; Am eich salwch a sut rydych yn delio ag ef; ac am eich ymateb i'r diagnosis) y dylid eu cwblhau i gyd os byddwch yn dymuno cymryd rhan. Byddwch yn derbyn cydnabyddiaeth ein bod wedi derbyn eich ymateb, ac yna ymhen tri mis, byddwch yn derbyn ail holiadur. Dylid cwblhau hwn yn yr un modd. Anfonir yr holiadur terfynol atoch 3 mis yn ddiweddarach. Mae'r math yma o ailadrodd holiadur yn bwysig i'n galluogi i astudio sut rydych wedi newid dros amser o ganlyniad i'ch salwch. Peidiwch â gadael i unrhyw un gwblhau'r holiadur ar eich rhan; mae gennym ddiddordeb mewn dysgu am eich meddwl a'ch teimladau personol chi. Yn ogystal, gofynnir i chi roi caniatâd i'r tîm ymchwil i gofnodi manylion o'ch cofnodion meddygol fel y gallwn ddeall eich salwch yn iawn. Hysbysir eich meddyg teulu a'r ymgynghorydd eich bod yn cymryd rhan yn yr ymchwil hwn, fodd bynnag, ni fydd hyn yn effeithio ar eich gofal mewn unrhyw ffordd.

### A oes unrhyw niwed posibl mewn cymryd rhan yn yr astudiaeth?

Nid oes unrhyw effeithiau niweidiol mewn cymryd rhan. Ar adeg anodd i chi, sylweddolwn y gall rhai o'r cwestiynau fod yn anodd ond gobeithio y bydd manteision posibl o astudiaethau o'r fath yn cydbwyso hyn.

#### Sut byddaf yn manteisio o'r astudiaeth?

Nid oes unrhyw fudd uniongyrchol i chi fel claf. Defnyddir y canlyniadau i ddatblygu rhaglenni triniaeth gyfannol newydd i helpu a chefnogi cleifion trwy eu salwch. Fodd bynnag, efallai y byddwch yn manteisio'n anuniongyrchol ar y cyfle i fynegi rhai o'ch teimladau, meddyliau ac emosiynau ar yr adeg hynod anodd hwn.

#### Beth os bydd rhywbeth yn mynd o'i le?

Os dymunwch gwyno am unrhyw agwedd o'r ymchwil hwn, neu sut rydych wedi cael eich trin fel cyfranogydd, cyflwynwch y gwyn i'r Pennaeth Adran, Adran Meddygaeth Gyffredinol, Prifysgol Caerdydd, Coleg Meddygaeth Cymru. Os bydd gennych gwestiwn neu bryder ynglyn â'ch cyflwr meddygol ar unrhyw adeg, cyfeiriwch y rhain i'ch tîm gofal eich hun (meddyg teulu, nyrs ayyb).

#### Cyfrinachedd

Defnyddir y data a ddarperir gennych chi neu trwy eich cofnodion meddygol ar gyfer yr ymchwil hwn yn unig. Cedwir gwybodaeth yn gyfrinachol ac yn ddiogel a byddwch yn parhau'n gwbl ddienw mewn unrhyw adroddiadau ysgrifenedig, papurau gwyddonol neu grynodeb o astudiaethau. Bydd data yn cael ei storio yn unol â'r Ddeddf Amddiffyn Data a Pholisïau Ymchwil Prifysgol Caerdydd ac yn cael ei dymchwel tair blynedd ar ôl ei chyflwyno ar gyfer traethawd PhD Mr Hulbert.

#### Beth fydd yn digwydd i ganlyniadau'r astudiaeth?

Mae prif ddogfennau'r astudiaeth ar gyfer traethawd PhD Mr. Hulbert. O hyn, paratoir papurau academaidd a chyflwynir i'r seicolegydd iechyd a chylchgronau gwyddonol sy'n gysylltiedig â chanser. Bydd rhai canlyniadau'n cael eu cyflwyno mewn cyfarfodydd a chynadleddau gwyddonol hefyd. Bydd yr holl ganlyniadau a'r holl gyfranogwyr yn parhau'n ddienw. Os hoffech grynodeb o'r canlyniadau, cysylltwch â Mr Hulbert i drefnu hyn.

#### Pwy sy'n trefnu ac yn ariannu'r astudiaeth ymchwil?

Mae'r astudiaeth hon yn cael ei threfnu, ei noddi a'i hariannu gan Goleg Meddygaeth Cymru, Prifysgol Caerdydd. Mae Mr Hulbert yn cael ei oruchwylio gan Dr Richard Neal (MT Wrecsam), Yr Athro. Clare Wilkinson (Cyfarwyddwr Ymchwil, Ysgol Glinigol Gogledd Cymru, Wrecsam) a Dr Val Morrison (Seicolegydd Iechyd, Prifysgol Cymru, Bangor).

#### Ble gallaf gael gwybodaeth bellach?

Gallwch gysylltu â Mr N Hulbert, Adran Meddygaeth Gyffredinol, Ysgol Glinigol Gogledd Cymru, Prifysgol Caerdydd, Uned 5 Gwenfro, Parc Technoleg Wrecsam, Wrecsam, LL13 7YP. Ffôn: 01978 727859; e-bost: <a href="mailto:hulbertnj@cf.ac.uk">hulbertnj@cf.ac.uk</a>. Sylwer nad yw Mr Hulbert yn gymwys i wneud sylw ar unrhyw agwedd o'ch cyflwr na'ch triniaeth.

Cadwch y Daflen Wybodaeth hon i gyfeirio ati yn y dyfodol ac os byddwch yn penderfynu cymryd rhan, cadwch un copi o'r Daflen Caniatâd y Claf hefyd. Diolch i chi am gymryd rhan yn yr ymchwil hwn.

### **APPENDIX 3.27: PATIENT CONSENT SHEETS**

Centre Nur Study Nur Patient Ide					
		CONSE	NT FORM		
Title of Pr	oject: Personality D	ifferences in Ca	ncer Patients		
Name of R	esearcher: Mr Nick Hi	ılbert			
	ial box, sign you namo questionnaires:	e, and complete	your address so that we can contact y	ou with you	
1)			erstood the information sheet for opportunity to ask questions.	_	
2)		ne without givin	is voluntary and that I am free to g any reason, without my medical		
3)	I understand that sections of any of my medical notes may be looked at by responsible individuals from the North Wales Clinical School, Cardiff University, or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.				
4)	I agree to take part	in the above stud	ly.		
5)	Hulbert so that he r	nay contact me v s (please not tha	being held on record by Mr Nick with an invitation to participate in t you can agree to this even if you nt study).		
Name of P	atient	Date	Signature		
Patient ad	dress				
Name of R	e complete all three c	Date opies of this for	Signature m and keep one copy for yourself. On other kept with your medical record	ne will be Is	

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Rhif y Ganolfan:
Rhif Astudio:
Rhif Adnabod y Claf:

#### FFURFLEN GANIATÂD

### Teitl y Project: Gwahaniaeth Personoliaethau mewn Cleifion Canser

Enw'r Ymchwilydd: Mr Nick Hulbert

Llofnodwch y blwch os gwelwch yn dda, llofnodwch eich enw, a chwblhewch eich cyfeiriad f	fel y
gallwn gysylltu â chi gyda'r holiaduron dilynol:	

1)	Cadarnhaf fy mod wed astudiaeth uchod ac w			aeth ar gyfer yr		
2)	Deallaf y byddaf yn cymryd rhan yn wirfoddol ac y gallaf dynnu allan ar unrhyw adeg heb roi rheswm, heb effeithio ar fy ngofal meddygol na hawliau cyfreithiol.					
3)	Cymru, Prifysgol Caer adrannau o fy nghofn	af efallai y bydd unigolion cyfrifol o Ysgol Glinigol Gogledd ru, Prifysgol Caerdydd neu awdurdodau rheoleiddio yn edrych ar nnau o fy nghofnodion meddygol ble bydd hynny'n berthnasol i ymryd rhan yn yr ymchwil. Rhoddaf ganiatâd i'r unigolion hyn fy nghofnodion.				
4)	Cytunaf i gymryd rhar	n yn yr astudiaeth	uchod.			
5)	fel y gall gysylltu â astudiaethau eraill y gallwch gytuno i hyn	yyn cytuno i Mr Nick Hulbert gadw cofnod o fy enw a nghyfeiriad y gall gysylltu â mi gyda gwahoddiad i gymryd rhan mewn tudiaethau eraill yn y dyfodol (nodwch os gwelwch yn dda y llwch gytuno i hyn hyd yn oed os nad ydych yn dymuno cymryd an yn yr astudiaeth gyfredol).				
Enw'r claf		Dyddiad	Llofnod			
Cyfeiriad y	claf _					
	-					
	-					
Enw'r Ymcl	nwilydd	Dyddiad	Llofnod			

Cwblhewch dri chopi o'r ffurflen hon a chadwch un copi i chi. Bydd yr ymchwilydd yn cadw un a'r llall gyda'ch cofnodion meddygol

#### **APPENDIX 3.28: PATIENT THANK-YOU LETTER**

February 2006

Dear.

#### Research Study - Personality Differences in Cancer Patients.

Many thanks for completing the questionnaire for the above named study. The information that you have provided will be a great help in this research study. In approximately 3 months time you will receive a further questionnaire (the same will also happen in 6 months time). The questionnaires are all similar, however, it is very important that you fill them all in carefully so that we can assess how you have changed throughout your illness. These follow-up questionnaires will be posted to you nearer the time.

If you have any further questions about your participation in this study, please do not he sitate to contact me.

On behalf of all involved in the research, I would like to wish you the very best for your treatment.

Chwefror 2006

Annwyl,

#### Astudiaeth Ymchwil - Gwahaniaethau Personoliaeth mewn Cleifion Canser

Llawer o ddiolch am gwblhau'r holiadur ar gyfer yr astudiaeth uchod. Bydd yr wybodaeth a ddarparwyd gennych o gymorth mawr i'r astudiaeth ymchwil hwn. Ymhen oddeutu 3 mis byddwch yn derbyn holiadur arall (bydd yr un peth yn digwydd ymhen 6 mis). Mae'r holiaduron i gyd yn debyg, fodd bynnag, mae'n bwysig eich bod yn eu cwblhau'n ofalus fel y gallwn asesu sut rydych wedi newid yn ystod eich salwch. Anfonir yr holiadur dilynol hwn atoch nes at yr amser.

Os bydd gennych unrhyw gwestiynau pellach ynglyn â chyfrannu at yr astudiaeth hon, gallwch gysylltu â mi.

Ar ran pawb sy'n rhan o'r ymchwil, hoffwn ddymuno'n dda i chi gyda'r driniaeth.

### **APPENDIX 3.29: GP INFORMATION LETTER**

February 2006
Dear Dr,
The importance of personality in appraisal and psycho-social outcome prediction for cancer patients.
As Principal Investigator in the above named study, I am required to inform you that your patient, , has consented to participate in this research. As a participant, they will complete three questionnaires (on initial recruitment, and at a three- and six- month follow up). You do not need to do anything about this and it will not affect the way that they are cared for or treated.
If you have any questions regarding your patient's participation, please do not hesitate to contact me on 01978 727859, or by email at <a href="mailto:hulbertnj@cf.ac.uk">hulbertnj@cf.ac.uk</a> .
Yours sincerely,
Nick Hulbert.

### APPENDIX 3.30: GP FOLLOW-UP LETTER

DATE
Dear Dr ·····
The importance of personality in appraisal and psycho-social outcome prediction for cancer patients.
As Principle Investigator in the above named study, I wrote to you approximately 2 months ago informing you that your patient, (DOB) has consented to participate in this research. The patient is shortly due their three-month follow up questionnaire. Before sending this questionnaire out, we are contacting all of our participants' GPs to ensure that the patient hasn't died, or is close to death, because sending out a follow-up questionnaire in these cases would be both unnecessary and quite distressing for the patient and their families.
If this patient has died or is close to death, we would very much appreciate you letting us know as soon as possible by ticking the appropriate box below and returning this letter to us (at the above address) or by fax on 01978 727431. Alternatively, you can contact me by telephone on 01978 727859, or email at <a href="mailto:hulbertnj@cf.ac.uk">hulbertnj@cf.ac.uk</a> . If the patient is still alive, you do not need to do anything.
Many thanks,
Nick Hulbert.
Please complete in the event that sending a follow-up questionnaire is not suitable:
Patient ID:
This patient died on
This patient is close to death

#### **APPENDIX 3.31: PATIENT DEBRIEF SHEET**

#### Research study - Personality differences in cancer patients.

On behalf of the research team, I would like to thank you for taking the time to participate in our research study.

We won't send you any more questionnaires for this study. All data that you've provided will be used for our final report. If you agreed on your consent form, you may hear from us in the future with invitations to take part in further related research, but there is no obligation to do so.

We are unable to provide individual feedback about your questionnaires, however, if you wuld like a written summary of our results, please do let us know. Please feel free to contact us if you have any further questions about this study. If you have any queries about your medical condition or the illness, we suggest that you refer these back to your GP or cancer team at the hospital where you are being treated.

Once again, many thanks for participating in this research. We all wish you the very best for any treatment that you may still be receiving.

Nick Hulbert-Williams, Chief Investigator

#### Astudiaeth ymchwil - Gwahaniaethau ym mhersonoliaeth cleifion canser

Ar ran y tîm ymchwil, hoffwn ddiolch i chi am gymryd amser i gyfrannu at yr astudiaeth ymchwil.

Ni fyddwn yn anfon mwy holiaduron atoch ar gyfer yr astudiaeth hon. Os bydd hyn yn eich synnu gan nad ydych wedi cwblhau'r holl holiaduron dilynol. Defnyddir yr holl ddata a ddararwyd gennych ar gyfer yr adroddiad terfynol. Os byddwch wedi cytuno ar eich ffurflen ganiatâd, efallai y byddwch yn clywed gennym yn y dyfodol gyda gwahoddiad i gymryd rhan mewn ymchwil cysylltiol arall, ond nid oes rhaid i chi wneud hynny.

Ni allwn ddarparu adborth unigol am eich holiaduron, fodd bynnag, os hoffe dderbyn crynodeb ysgrifenedig o'n canlyniadau, gadeqch I ni wybod. Croeso i chi gysylltu â ni os bydd gennych unrhyw gwestiynau eraill am yr astudiaeth hon. Os bydd gennych unrhyw ymholidadau am eich cyflwr meddygol neu'r salwch, awgrymwn eich bod yn cyferirio'r rhain at eich meddyg teulu neu'r tîm canser yn yr ysbyty ble rydych yn derbyn triniaeth.

Unweaith eto, diolch yn fawr iawn i chi am gyfrannu at yr ymchwil hwn. Rydym i gud un dymuno'n dda i chi gydag unrhyw driniaeth rydych yn parhaw I'w derbyn.

Nick Hulbert-Williams, Prif Ymchwilydd.

# APPENDIX 4.1: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF THREE MONTH QUALITY OF LIFE FROM BASELINE PREDICTORS.

Variable	Unstandardised Residuals			
variable	Beta In	t	Significance	
Optimism	.000	006	.995	
Hopeless/helplessness	.209	1.901	.060	
Anxious preoccupation	.109	.789	.432	
Motivational congruence	002	020	.984	
Motivational incongruence	.182	1.887	.062	
Other Responsibility	.060	.580	.563	
Future Expectancy	.097	.911	.364	
PF Coping Potential	.092	.932	.354	
EF Coping Potential	119	-1.024	.308	
Self-consciousness	023	227	.821	
Lack of concern	.117	1.164	.247	
Other-blame	.011	.103	.918	
Loss/Helplessness	.117	.959	.340	
Positive emotion	003	026	.980	
Maladaptive coping	.182	1.548	.125	

APPENDIX 4.2: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF SIX MONTH QUALITY OF LIFE FROM BASELINE PREDICTORS.

Variable	Unstandardised Residuals			
vai lable	Beta In	t	Significance	
Optimism	018	179	.858	
Hopeless/helplessness	.145	1.430	.156	
Anxious Preoccupation	.012	.107	.915	
Fighting Spirit	.194	1.901	.060	
Fatalism	.046	.440	.661	
Doctor Locus of Control	.093	.909	.366	
Motivational Congruence	.102	1.002	.319	
Self Responsibility	038	365	.716	
Other Responsibility	068	664	.508	
Future Expectancy	.121	1.189	.238	
EF Coping Potential	135	-1.290	.200	
Other-blame	.035	.341	.734	
Self-blame	.031	.287	.775	
Loss/Helplessness	018	172	.864	
Positive Emotion	036	333	.740	
Negative Emotion	084	793	.430	
Adaptive Coping	.168	1.657	.101	
Maladaptive Coping	.130	1.256	.212	

# APPENDIX 4.3: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF SIX MONTH QUALITY OF LIFE FROM THREE MONTH PREDICTORS.

Variable	Unstandardised Residuals			
——————————————————————————————————————	Beta In	t	Significance	
Optimism	111	-1.038	.302	
Hopeless/helplessness	042	384	.702	
Anxious preoccupation	054	428	.670	
Motivational congruence	.008	.081	.935	
Self Responsibility	100	980	.330	
Future Expectancy	023	209	.835	
PF Coping Potential	058	061	.549	
EF Coping Potential	.027	.247	.806	
Removal of threat	.106	1.039	.302	
Other blame	134	-1.366	.176	
Self-blame	048	483	.631	
Loss/helplessness	037	274	.784	
Effortful optimism	.094	.942	.349	
Success	.005	.052	.959	
Positive emotion	040	379	.706	
Negative emotion	124	979	.330	
Maladaptive coping	.148	1.253	.214	

# APPENDIX 4.4: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF THREE MONTH DEPRESSION FROM BASELINE PREDICTORS.

Variable	Unstandardised Residuals			
variable	Beta In	t	Significance	
Optimism	.017	.167	.868	
<b>Doctor Locus of Control</b>	132	-1.376	.172	
Hopeless/helplessness	.059	.523	.602	
Anxious preoccupation	046	433	.666	
Other Responsibility	021	196	.845	
Future Expectancy	027	237	.813	
PF Coping Potential	.067	.670	.504	
Lack of concern	057	596	.552	
Self-blame-blame	.080	.771	.443	
Threat	002	016	.987	
Loss/Helplessness	029	199	.843	
Effortful optimism	130	-1.358	.177	
Positive emotion	.013	.131	.868	
Negative emotion	.105	.941	.349	
Maladaptive coping	046	441	.660	

# APPENDIX 4.5: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF SIX MONTH DEPRESSION FROM BASELINE PREDICTORS.

Variable	Unstandardised Residuals			
variable	Beta In	t	Significance	
Optimism	.106	.945	.347	
Hopeless/helplessness	082	647	.519	
Anxious preoccupation	147	-1.000	.320	
Motivational Relevance	.123	1.214	.228	
Motivational Incongruence	.069	.696	.488	
Motivational Congruence	067	662	.509	
Self Responsibility	024	231	.818	
Other Responsibility	.020	.186	.853	
EF Coping Potential	.167	1.359	.178	
Self- consiousness	.106	.072	.943	
Other-blame	.008	965	.337	
Threat	149	.091	.928	

# APPENDIX 4.6: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF SIX MONTH DEPRESSION FORM THREE MONTH PREDICTORS.

Variable	<b>Unstandardised Residuals</b>			
variable	Beta In	t	Significance	
Optimism	.057	.556	.580	
Hopeless/helplessness	106	-1.037	.302	
Anxious preoccupation	.021	.206	.837	
Cognitive avoidance	.047	.466	.643	
Motivational Relevance	.112	1.114	.268	
Other Responsibility	174	-1.741	.085	
Future Expectancy	.084	.794	.429	
EF Coping Potential	.131	1.299	.197	
Lack of concern	.088	.871	.386	
Self-blame	048	428	.670	
Threat	103	982	.329	
Loss/Helplessness	191	-1.685	.095	
Success	064	638	.525	
Negative emotion	113	-1.055	.294	
Adaptive coping	.045	.449	.654	
Maladaptive coping	098	955	.342	

# APPENDIX 4.7: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF THREE MONTH ANXIETY FROM BASELINE PREDICTORS.

Variable	Unstai	ndardised I	Residuals
	Beta In	t	Significance
Optimism	.009	086	.932
Hopeless/helplessness	.038	.333	.740
Anxious preoccupation	018	169	.866
Motivational incongruence	.028	.283	.778
Motivational congruence	080	823	.413
Self Responsibility	.121	1.236	.219
Other Responsibility	.076	.694	.489
Future Expectancy	248	.111	257
EF Coping Potential	.302	.133	.264
Other-blame	397	.159	304
Threat	222	.116	265
Loss/Helplessness	087	583	.561
Positive emotion	.005	.049	.961
Negative emotion	.075	.023	.436
Maladaptive coping	.006	.062	.951

# APPENDIX 4.8: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF SIX MONTH ANXIETY FROM BASELINE PREDICTORS.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Hopeless/helplessness	.108	.956	.341
Anxious preoccupation	.228	1.791	.077
Fighting spirit	192	-1.882	.063
Motivational congruence	.125	1.229	.222
Motivational incongruence	052	507	.613
Self Responsibility	.035	.345	.731
Other Responsibility	.180	1.782	.078
Future Expectancy	154	-1.373	.173
EF Coping Potential	.190	1.845	.068
Other-blame	.086	.810	.420
Threat	.231	1.900	.061
Loss/Helplessness	.134	1.135	.259
Negative emotion	.381	3.296	.001
Adaptive coping	133	-1.315	.192

APPENDIX 4.9: SUMMARY TABLE OF EXCLUDED VARIABLES FOR REGRESSION OF SIX MONTH ANXIETY FROM THREE MONTH PREDICTORS.

Variable	<b>Unstandardised Residuals</b>		
	Beta In	t	Significance
Optimism	.156	1.423	.158
Hopeless/helplessness	085	691	.491
Anxious preoccupation	.042	1.081	.282
Fighting Spirit	.083	.817	.416
Other Responsibility	.008	.080	.936
Future Expectancy	.094	.897	.372
EF Coping Potential	.182	1.584	.117
Other-blame	.094	.926	.357
Threat	235	-1.957	.053
Loss/helplessness	099	912	.364
Effortful optimism	076	741	.461
Success	020	188	.851
Positive emotion	.066	.647	.519
Negative emotion	109	817	.416
Maladaptive coping	125	-1.133	.260

APPENDIX 4.10: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF ANGER.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
<b>Motivational Congruence</b>	.042	.527	.599
Self Responsibility	015	192	.848
Future Expectancy	.084	.949	.344
PF Coping Potential	.088	1.035	.302
Self-consciousness	029	345	.731
Unexpectedness	.144	1.812	.072
Relevance	.073	.909	.365
Threat removal	084	953	.342
Irrelevance	044	531	.597
Self-blame	.116	1.462	.146
Threat	.088	.932	.353
Loss/helplessness	.087	1.012	.313
Success	.044	.522	.602

APPENDIX 4.11: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF ANGER.

Variable	Unstai	ndardised I	Residuals
	Beta In	t	Significance
Motivational Relevance	.018	.234	.815
Motivational Incongruence	.132	1.829	.070
Motivational Congruence	039	531	.596
Self Responsibility	029	381	.7104
Other Responsibility	.134	1.744	.084
Future Expectancy	.089	1.103	.272
PF Coping Potential	.117	1.535	.127
Self-consciousness	046	567	.571
Relevance	.112	1.445	.151
Irrelevance	064	834	.406
Threat removal	038	457	.649
Other-blame	.126	1.416	.159
Loss/helplessness	.071	.696	.487
Effortful optimism	.112	1.506	.134
Success	.057	.721	.472

APPENDIX 4.12: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF GUILT.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Congruence	067	799	.425
Self Responsibility	075	894	.373
Other Responsibility	052	616	.539
Future Expectancy	.078	.867	.387
PF Coping Potential	.027	.309	.758
EF Coping Potential	111	-1.294	.198
Self-consciousness	080	945	.346
Relevance	.037	.430	.668
Irrelevance	.031	.359	.720
Lack of concern	070	791	.431
Threat removal	.071	.629	.530
Other-blame	124	-1.481	.141
Threat	.078	.892	.374
Loss/helplessness	.017	.199	.842
Effortful optimism	017	202	.840
Success	.063	1.737	.085

APPENDIX 4.13: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF GUILT.

Variable	<b>Unstandardised Residuals</b>		
	Beta In	t	Significance
Motivational Relevance	.045	.557	.578
Motivational Congruence	063	740	.460
Other Responsibility	031	390	.697
Future Expectancy	.105	1.327	.187
PF Coping Potential	059	.761	.448
EF Coping Potential	074	947	.345
Self-consciousness	072	862	.39
Relevance	.008	.101	.920
Unexpectedness	.146	1.884	.062
Irrelevance	.032	.406	.685
Lack of concern	024	309	.758
Threat removal	.130	1.679	.095
Other-blame	120	-1.481	.141
Threat	.047	.603	.547
Loss/helplessness	.016	.199	.843
Effortful optimism	.002	.024	.981
Success	.137	1.768	.079

APPENDIX 4.14: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF FEAR/ANXIETY.

Variable	Unstandardised Residuals		
variable	Beta In	t	Significance
Motivational Congruence	.098	1.181	.240
Self Responsibility	013	152	.879
Other Responsibility	084	985	.327
Future Expectancy	.005	.054	.957
PF Coping Potential	.137	1.655	.100
Self-consciousness	005	058	.954
Relevance	.078	.929	.355
Irrelevance	067	792	.430
Lack of concern	087	-1.026	.306
Other-blame	046	524	.601
Loss/helplessness	001	015	.988
Effortful optimism	084	984	.327
Success	003	034	.973

APPENDIX 4.15: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF FEAR/ANXIETY.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Incongruence	.118	1.733	.085
<b>Motivational Congruence</b>	.030	.459	.647
Self Responsibility	028	404	.687
Other Responsibility	066	936	.351
Future Expectancy	014	188	.852
PF Coping Potential	.078	1.088	.278
Self-consciousness	.035	.479	.633
Relevance	.066	.958	.340
Irrelevance	054	791	.431
Lack of concern	073	-1.058	.292
Threat removal	073	-1.076	.284
Other-blame	019	242	.809
Loss/helplessness	.051	.543	.588
Effortful optimism	079	-1.173	.243
Success	029	423	.673

# APPENDIX 4.16: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF SADNESS.

Variable	<b>Unstandardised Residuals</b>		
	Beta In	t	Significance
Motivational Congruence	111	-1.290	.199
Self Responsibility	.022	.263	.793
Other Responsibility	.014	.164	.870
EF Coping Potential	120	-1.422	.157
Self-consciousness	.000	011	.991
Relevance	.171	1.972	.051
Unexpectedness	.122	1.452	.149
Irrelevance	.024	.281	.779
Lack of concern	055	643	.521
Threat removal	.110	1.314	.191
Other-blame	.011	.132	.898
Self-blame	.046	.542	.589
Loss/helplessness	.128	1.469	.144
Effortful optimism	012	146	.884
Success	022	251	.802

APPENDIX 4.17: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF SADNESS.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	022	294	.769
Motivational Congruence	104	-1.364	.175
Self Responsibility	.048	.680	.497
Other Responsibility	.055	.747	.456
Future Expectancy	.071	.905	.367
PF Coping Potential	.117	1.621	.107
EF Coping Potential	116	-1.384	.169
Self-consciousness	.006	.083	.934
Relevance	.102	1.438	.153
Unexpectedness	.112	1.622	.107
Irrelevance	.014	.199	.843
Lack of concern	.000	010	.992
Threat removal	.095	1.331	.185
Other-blame	.103	1.119	.265
Self-blame	.081	1.113	.268
Threat	037	534	.594
Success	048	666	.507

APPENDIX 4.18: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF HOPE/CHALLENGE.

Variable	<b>Unstandardised Residuals</b>		
	Beta In	t	Significance
Motivational Incongruence	.095	1.149	.253
Self Responsibility	.065	.788	.432
Other Responsibility	073	892	.390
Future Expectancy	.057	.629	.530
Self-consciousness	.001	.010	.992
Unexpectedness	.067	.923	.358
Lack of concern	.038	.450	.653
Threat removal	.010	.123	.902
Other-blame	073	824	.412
Irrelevance	095	-1.148	.253
Self-blame	047	559	.577
Threat	018	171	.864
Effortful optimism	164	-1.805	.073
Success	.081	.938	.350

APPENDIX 4.19: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF HOPE/CHALLENGE.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	.059	.737	.462
Motivational Incongruence	.033	.415	.679
Motivational Congruence	.131	1.663	.099
Self Responsibility	.091	1.174	.243
Other Responsibility	040	477	.634
Future Expectancy	.096	.999	.320
Self-consciousness	.082	.955	.342
Unexpectedness	.113	1.456	.148
Irrelevance	043	546	.586
Lack of concern	.046	.586	.559
Threat removal	.030	.369	.713
Other-blame	.025	.235	.815
Self-blame	.047	.557	.578
Threat	.105	.934	.352
Effortful optimism	.135	1.678	.096
Success	.127	1.559	.121

APPENDIX 4.20: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF HAPPINESS.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Incongruence	068	812	.418
Self Responsibility	.014	.161	.872
Other Responsibility	082	970	.334
Future Expectancy	019	217	.829
PF Coping Potential	048	555	.580
EF Coping Potential	.049	.581	.562
Self-consciousness	.042	.500	.618
Unexpectedness	.064	.753	.453
Irrelevance	.088	1.041	.299
Lack of concern	.142	1.689	.094
Threat removal	.039	.459	.647
Other-blame	.047	.550	.583
Self-blame	144	-1.714	.089
Threat	042	500	.618
Loss/Helplessness	007	086	.932
Relevance	.140	1.666	.098

APPENDIX 4.21: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF HAPPINESS.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	033	431	.667
Motivational Congruence	104	-1.370	.173
Motivational Incongruence	.088	1.142	.255
Self Responsibility	.021	.272	.786
Other Responsibility	083	-1.083	.281
Future Expectancy	012	141	.888
PF Coping Potential	031	390	.697
EF Coping Potential	.063	.798	.426
Self-consciousness	.033	.433	.666
Relevance	.108	1.375	.172
Unexpectedness	.053	.684	.495
Irrelevance	.092	1.196	.234
Lack of concern	.147	1.862	.065
Threat removal	.103	1.021	.309
Other-blame	.029	.381	.704
Self-blame	130	-1.707	.090
Threat	069	869	.387
Loss/Helplessness	025	328	.744

APPENDIX 4.22: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF BOREDOM.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	.112	1.304	.194
Motivational Incongruence	.064	.699	.486
Self Responsibility	.021	.248	.805
Other Responsibility	.068	.821	.413
Future Expectancy	.066	.795	.428
PF Coping Potential	.107	1.294	.198
EF Coping Potential	067	808	.420
Self-consciousness	030	359	.720
Unexpectedness	.088	1.067	.288
Relevance	002	021	.984
Lack of concern	094	-1.136	.258
Threat removal	.005	.055	.956
Other-blame	.076	.916	.361
Self-blame	.016	.190	.850
Threat	.089	1.072	.286
Loss/Helplessness	.119	1.452	.149
Effortful optimism	.004	.051	.959
Success	.014	.168	.867

APPENDIX 4.23: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF BOREDOM.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	.112	1.300	.196
Motivational Incongruence	.064	.700	.485
Self Responsibility	.021	.249	.804
Other Responsibility	.068	.820	.414
Future Expectancy	.066	.795	.428
PF Coping Potential	.107	1.294	.198
EF Coping Potential	067	810	.420
Self-consciousness	029	351	.726
Unexpectedness	002	018	.986
Relevance	.088	1.068	.287
Lack of concern	093	.130	.897
Threat removal	.005	-1.129	.261
Other-blame	.076	.063	.950
Self-blame	.016	.919	.360
Threat	.089	.194	.846
Loss/Helplessness	.120	1.073	.285
Effortful optimism	.005	1.455	.148
Success	.014	.055	.956

APPENDIX 4.24: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF SURPRISE.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Incongruence	.061	.716	.475
Motivational Congruence	.085	1.044	.298
Self Responsibility	.122	1.491	.138
Other Responsibility	.116	1.424	.157
Future Expectancy	.026	.310	.757
PF Coping Potential	.036	.440	.660
EF Coping Potential	.031	.365	.715
Relevance	032	397	.692
Irrelevance	075	835	.405
Threat removal	.037	.400	.690
Other-blame	.044	.500	.618
Self-blame	.016	.179	.858
Threat	.022	.251	.802
Loss/Helplessness	042	473	.637
Effortful optimism	147	-1.819	.071
Success	.006	.069	.945

APPENDIX 4.25: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF SURPRISE.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Incongruence	.056	.744	.458
Motivational Congruence	.072	.986	.326
Self Responsibility	.106	1.453	.149
Other Responsibility	.105	1.442	.152
Future Expectancy	020	.265	.792
PF Coping Potential	.028	.377	.707
EF Coping Potential	.019	.250	.803
Relevance	037	510	.611
Irrelevance	065	806	.422
Threat removal	.029	.359	.720
Other-blame	.048	.612	.542
Self-blame	.004	.050	.960
Threat	.024	.307	.760
Loss/Helplessness	026	325	.746
Effortful optimism	125	-1.718	.088
Success	.009	.115	.908

APPENDIX 4.26: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF RESIGNATION.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	.000	011	.991
Motivational Incongruence	031	383	.702
Motivational Congruence	.068	.836	.405
Self Responsibility	038	457	.648
Future Expectancy	.114	1.237	.218
PF Coping Potential	.015	.182	.856
EF Coping Potential	.068	.818	.415
Self-consciousness	137	-1.697	.092
Relevance	020	245	.807
Unexpectedness	007	089	.929
Irrelevance	159	-1.880	.062
Lack of concern	095	-1.036	.302
Other-blame	100	-1.037	.302
Self-blame	088	-1.050	.295
Threat	010	115	.908
Effortful optimism	008	.103	.918
Success	012	114	.910

APPENDIX 4.27: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF RESIGNATION.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	.004	.052	.959
Motivational Incongruence	029	396	.693
Motivational Congruence	.058	.791	.430
Self Responsibility	031	427	.670
Future Expectancy	.100	1.18	.253
PF Coping Potential	.003	.040	.968
EF Coping Potential	.057	.686	.494
Self-consciousness	132	-1.660	.099
Relevance	018	245	.807
Unexpectedness	002	021	.983
Irrelevance	139	-1.822	.071
Lack of concern	082	-1.007	.316
Other-blame	099	948	.345
Self-blame	074	960	.339
Threat	.019	.196	.845
Effortful optimism	.006	.079	.937
Success	011	114	.909

APPENDIX 4.28: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF TRANQUILITY.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	113	-1.438	.153
Motivational Incongruence	069	865	.389
Motivational Congruence	009	113	.911
Self Responsibility	.085	1.074	.285
Other Responsibility	038	483	.630
Future Expectancy	082	930	.354
PF Coping Potential	139	-1.670	.097
EF Coping Potential	013	156	.876
Self-consciousness	.080	1.018	.310
Relevance	151	-1.935	.055
Unexpectedness	.060	.765	.445
Irrelevance	.034	.429	.669
Threat removal	031	367	.714
Other-blame	052	657	.513
Self-blame	.017	.174	.862
Threat	.005	.060	.952
Effortful optimism	016	197	.844
Success	035	423	.673

APPENDIX 4.29: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF TRANQUILITY.

Variable	<b>Unstandardised Residuals</b>		
	Beta In	t	Significance
Motivational Relevance	114	-1.493	.138
Motivational Incongruence	065	841	.402
Motivational Congruence	013	169	.866
Self Responsibility	.081	1.067	.288
Other Responsibility	033	429	.668
Future Expectancy	076	900	.370
PF Coping Potential	135	-1.676	.096
EF Coping Potential	005	062	.951
Self-consciousness	.085	1.109	.269
Relevance	141	-1.839	.068
Unexpectedness	.060	1.007	.316
Irrelevance	.070	.818	.415
Threat removal	022	268	.789
Other-blame	043	556	.579
Self-blame	.005	.059	.953
Threat	.007	.081	.936
Effortful optimism	009	118	.906
Success	020	236	.813

APPENDIX 4.30: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF INTEREST.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	067	895	.372
Motivational Congruence	.054	.672	.503
Other Responsibility	.035	.462	.645
PF Coping Potential	.069	.799	.426
Self-consciousness	023	286	.775
Unexpectedness	.036	.489	.626
Irrelevance	.081	1.103	.272
Lack of concern	.038	.521	.603
Threat removal	053	680	.498
Other-blame	.137	1.606	.111
Threat	.137	1.561	.121
Loss/helplessness	014	160	.873
Success	096	-1.228	.222

APPENDIX 4.31: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF INTEREST.

Variable	<b>Unstandardised Residuals</b>		
	Beta In	t	Significance
Motivational Relevance	070	937	.351
Motivational Congruence	.059	.741	.460
Other Responsibility	.031	.407	.685
PF Coping Potential	.070	.822	.412
Self-consciousness	022	283	.778
Unexpectedness	.039	.530	.597
Irrelevance	.078	1.082	.281
Lack of concern	.036	.491	.625
Threat removal	054	691	.491
Other-blame	.134	1.576	.117
Threat	.137	1.519	.131
Loss/helplessness	016	183	.855
Success	093	-1.178	.241

APPENDIX 4.32: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF RELIEF.

Variable	Unsta	ndardised F	Residuals
	Beta In	t	Significance
Motivational Relevance	.041	499	.618
Motivational Incongruence	.025	.280	.780
Other Responsibility	.049	.571	.569
Future Expectancy	041	454	.651
PF Coping Potential	014	165	.869
EF Coping Potential	.026	.297	.767
Self-consciousness	.108	1.234	.219
Relevance	.072	.886	.377
Unexpectedness	088	-1.097	.274
Irrelevance	118	-1.489	.139
Lack of concern	.021	.269	.789
Other-blame	.065	.609	.544
Self-blame	042	486	.628
Threat	.106	1.026	.307
Effortful optimism	.067	.827	.410
Success	.142	1.782	.077

APPENDIX 4.33: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF RELIEF.

Variable	Unstai	ndardised F	Residuals
	Beta In	t	Significance
Motivational Relevance	028	456	.649
Motivational Incongruence	.042	.625	.533
Other Responsibility	.066	1.021	.309
Future Expectancy	047	631	.529
PF Coping Potential	009	143	.886
EF Coping Potential	017	245	.807
Self-consciousness	.087	1.309	.193
Relevance	.116	1.863	.065
Unexpectedness	087	-1.442	.152
Irrelevance	061	968	.335
Lack of concern	.050	.748	.456
Other-blame	.060	.752	.453
Self-blame	038	593	.554
Threat	.116	1.451	.149
Effortful optimism	.015	.250	.803

APPENDIX 4.34: SUMMARY TABLE OF EXCLUDED VARIABLES FROM THEORY DRIVEN TESTS OF SHAME/HUMILIATION.

Variable	<b>Unstandardised Residuals</b>		
	Beta In	t	Significance
Motivational Relevance	.046	.543	.588
Motivational Congruence	074	876	.383
Motivational Incongruence	.105	1.257	.211
Self Responsibility	.156	1.854	.066
Other Responsibility	.116	1.177	.241
Future Expectancy	.090	.933	.352
PF Coping Potential	.053	.618	.537
EF Coping Potential	.005	.053	.958
Relevance	.069	.817	.416
Unexpectedness	.081	.955	.341
Irrelevance	087	-1.031	.304
Lack of concern	.064	.755	.452
.Threat removal	.114	1.366	.174
Self-blame	.145	1.666	.098
Threat	031	323	.747
Loss/helplessness	.004	.036	.971
Effortful optimism	053	631	.529
Success	.144	1.724	.087

APPENDIX 4.35: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF SHAME/HUMILIATION.

Variable	Unstandardised Residuals		
	Beta In	t	Significance
Motivational Relevance	.029	.355	.723
Motivational Congruence	060	739	.461
Motivational Incongruence	.084	1.037	.302
Self Responsibility	.144	1.729	.086
Other Responsibility	.037	.389	.698
Future Expectancy	.086	.921	.359
PF Coping Potential	.025	.305	.761
EF Coping Potential	039	458	.648
Self-consciousness	.073	.802	.424
Relevance	.054	.653	.515
Unexpectedness	.097	1.165	.246
Irrelevance	053	639	.524
Lack of concern	.052	.634	.527
Threat removal	.113	1.384	.169
Threat	023	245	.807
Loss/helplessness	.016	.142	.887
Effortful optimism	053	634	.527
Success	.139	1.706	.090

APPENDIX 4.36: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF SELF-DIRECTED ANGER.

Variable	<b>Unstandardised Residuals</b>		
	Beta In	t	Significance
Motivational Relevance	.035	.496	.621
Motivational Congruence	053	750	.454
Motivational Incongruence	.010	.141	.888
Other Responsibility	.081	1.078	.283
Future Expectancy	.021	.258	.797
PF Coping Potential	.126	1.715	.089
EF Coping Potential	.094	1.196	.234
Self-consciousness	113	-1.439	.153
Relevance	.039	.543	.588
Irrelevance	111	-1.573	.118
Lack of concern	097	-1.359	.177
Other-blame	.018	.252	.801
Threat removal	084	896	.372
Threat	011	116	.908
Effortful optimism	090	-1.250	.214
Success	017	243	.808

APPENDIX 4.37: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF FRUSTRATION.

Variable	Unsta	ndardised F	Residuals
	Beta In	t	Significance
Motivational Relevance	.102	1.226	.222
Motivational Incongruence	009	113	.910
Motivational Congruence	.072	.889	.376
Self Responsibility	054	651	.516
Other Responsibility	.132	1.560	.121
Future Expectancy	105	-1.204	.231
PF Coping Potential	.148	1.802	.074
EF Coping Potential	.122	1.258	.211
Self-consciousness	097	-1.124	.263
Relevance	.015	.177	.859
Unexpectedness	.111	1.370	.173
Irrelevance	045	551	.583
Lack of concern	007	081	.936
Threat removal	016	192	.848
Other-blame	.114	1.197	.233
Loss/Helplessness	.079	.715	.476
Effortful optimism	080	989	.325
Success	.000	011	.992

## APPENDIX 4.38: SUMMARY TABLE OF EXCLUDED VARIABLES FROM DATA DRIVEN TESTS OF REGRET.

Variable	Unstai	andardised Residuals	
variable	Beta In	t	Significance
Motivational Relevance	.066	.838	.404
Motivational Incongruence	131	-1.738	.085
Motivational Congruence	.107	1.413	.160
Self responsibility	.093	1.221	.224
Other Responsibility	.072	.894	.373
Future Expectancy	110	-1.277	.204
PF Coping Potential	.076	.957	.340
EF Coping Potential	.176	1.929	.056
Self-consciousness	116	-1.408	.161
Relevance	.028	.359	.720
Unexpectedness	.058	.758	.449
Irrelevance	078	-1.023	.308
Lack of concern	025	323	.748
Threat removal	021	268	.789
Other-blame	.113	1.120	.265
Self-blame	.100	1.253	.212
Effortful optimism	.000	001	.999
Success	.079	1.004	.317

## APPENDIX 4.39: TRANSCRIPTS OF ALL COMMENTS RELEVANT TO THEME 5 OF THE OUALITATIVE ANALYSIS

## **Superordinate Theme 5: Participation Issues**

- 5.1 Presentation of questionnaire
- 5.2 Relevance given timing
- 5.3 Relevance of study in general/specific items
- 5.4 Benefit and harms from participation

#### **SUPERORDINATE THEME 5: PARTICIPATION ISSUES**

## EMERGENT THEME 5.1: PRESENTATION OF THE QUESTIONNAIRE

TIME 1

005: Quite a complex questionnaire. Have done my best.

018: I feel that the combination of prostate cancer with my age (90 in Oct 2006) is considerably less devastating than many other cancer diagnoses may be. For this reason I think it unlikely that my experience would be particularly relevant to the experience of others.

030: Cannot understand this page.

**062:** The last 4 weeks have been post-operative so energy levels have obviously been lower than normal. Ordinarily answers would have been very different.

106: Some questions have no neutral response option where I needed one...

112: "I am sorry I can't answer the questions I will put them my way."

113: Most of my problems to date have been because of complications with my ileostomy and kidney failure, not my bowel cancer. Your questionnaire seems specific to the cancer.

132: If I was to fill this form in about another couple of hours the answers would probably be different as my mood is up and down all of the time.

152: I have filled in your questionnaire and I have to say it is a bit too long

**158:** Some of the questions are duplicated and are similar apart from the actual wording.

## TIME 2

**001:** Respectfully not that I find some of your questions to be rather nebulous and not easy to respond to specifically.

**027:** It is far too long and too repetitive and requires an "act of will" to answer it at all.

030: "Difficult to understand. Do not know if I have filled in right"

052: I found the questions I have not relied to difficult to decide an answer.

**083:** I'm sorry I can't finish this because I can't see where you are going with some of the questions.

**088:** I have tried to answer these questions as honestly as possible but did find some of them very difficult to answer.

093: I also found difficulty answering with regard to restricted activities. I was told not to do any lifting for three months. I have carefully avoided this, since I normally do a lto of garden maintenance involving muscular exertion. I continue to restrict this activity, but otherwise I am quite active leading services of Christian worship regularly, which involves careful preparation and some amount of exertion.

101: As I had a non-aggressive malignant tumour some of the question have been irrelevant the conclusion which I experienced therefore I have tried to answer the questions adequately, sometimes with difficulty.

106: Having told my GP about this project, I feel tons better about participating, as he explained it's relevance in the light of recent thought relating to a positive attitude (so I'm much less grumpy this time)... Having got my head around things now, I found completion of the questionnaire considerably easier

**108:** When completing this questionnaire I had difficulty answering the questions relating to "blame". As I understand my condition it is age related and as a consequence it would have happened anyway.

**122:** Some of the questions are ambiguous. My health is not affecting my normal activities, but having to attend hospital daily for radiotherapy obviously does.

152: I think to ask someone how they felt when told they had cancer what would you think you feel you don't go out and a party so that is a soft question to ask any one.

#### TIME 3

**011:** The questionnaire is difficult to complete because one can feel different as the days go by

**018:** I feel that my age (90 on 12/10/06) may be of necessisty affect my answers - particularly with respect to energy and pain which may be more justifiably described to old age than to cancer diagnosis. I have tried to ignore the old-age effects, but have probably not always been successful.

**084:** I suppose I felt this questionnaire a little intrusive as I do try not to dwell on all that has happened and I really find it difficult to know how these answers really help in the ongoing fight against cancer. My partner was an <u>extremely</u> positive person, a high flyer and a great achiever in all aspects of life and he died - aged 58 from pancreatic cancer. So I am fatalistic about these things. What will be will be. However, leading a balanced healthy life definitely helps us all to keep well and happy

**106:** Initially, receiving the questinnaire felt like the last straw, but after talking to my GP about it, I could see the relevance and didn't mind so much.

124: Some of the questions were hard to answer.

#### EMERGENT THEME 5.2: RELEVANCE OF THE STUDY

#### TIME 1

012: I have been unable to answer some of the questionnaire, because I think I need to have started treatment before I can do so.

**025:** I have answered the questions to the best of my ability but please note I have not as yet started radiotherapy

**052:** I find it difficult to answer these questions as they rather refer to after my operation

**045:** I haven't yet had the results from the operation—as to whether there has been any spread to the lymph nodes. That, inevitably will make me feel differently (but I guess, that is something you want to find out!).

**081:** I have only known for about 8 weeks that I have cancer so there are some questions that I have not answered as I feel they are irrelevant.

**101:** As I am in the very fortunate position to have been diagnosed very early through routine mamogramme, I feel some of these questions don't really relate to me.

106: Spirituality and sexuality are deeply personal issues, and I am not prepared to offer an opinion on these options, so have skipped a few. Also felt rather annoyed at being confronted with this at such a deeply emotional time... I also have a few doubts about the relevance of the study, as everyone is an individual and should be treated as such.

122: As I have only recently been diagnosed and only commenced treatment it is likely that some of my answers could change as treatment progresses.

**141:** I found some of the questions a little difficult to answer because having had a mastectomy and having very good results I feel able to continue with my life as before

135: As I have not experienced any pain since my diagnosis, indeed, feel just as healthy as I have been for some time, I found it difficult to answer some of the question - they seemed to be aimed at those who were/are already undergoing treatment. No doubt I will feel 'more involved' after my operation when I answer the second questionnaire.

#### TIME 2

#### TIME 3

## **EMERGENT THEME 5.3: RELIGIOUS ENQUIRY**

#### TIME 1

**093:** My personal faith is important to me and relevant at all times, particularly so in the present situation. I did not feel the questionnaire allowed expression of this importance. References to the place of God seemed to suggest hopeless resignation rather than expression of active faith.

075: I have found the issue of God difficult.

151: I had difficulty answering questions about God's part in the development of my cancer. The questions imply a draconian God who 'deals out' cancer on a random basis. I do not believe that God decides that I get a disease any more than that ford's decides that my mondeo gets a damaged suspension 6 years from the factory! I do, however, believe in a God who cares and supports me, through my curch friends and the medical teams who have been looking after me, in the same way that a parent will look after their child when it becomes ill.

**152:** all the questions about God I think you should leave them out not all people believe and you ask the same question a few times and some of the questions about how you feel about when you found out that you had cancer I don't think that a lot of people would feel responsible for getting cancer.

#### TIME 2

**001:** <u>Questions related to god.</u> Your question gives me a feeling of being critical or negative towards God.

**027:** The questionnaire has many facets in common with the Church of Jesus Christ Scientists (Scientology). It has nothing in common with a serious medical scientific study.

**093:** The place of faith and its essential contribution to life is of great importance to me (and I believe to be relevant to everyone). I consequently found questions referring to God's place in my present situation to be a little confusing. Since all that happens is within His will, I believe this event to be in that will, but I'm no way \*\*\*\*\*. I think the study might gain from asking the relevance of a person's faith in usual circumstances and whether it has helped in the present circumstances. Consequently I found references to fat, luck, and fortune to be irrelevant.

152: There is too much question on god.

#### TIME 3

**072:** A few questions I have crossed out (blaming God is stupid). As I've said on another page, we don't ask to be ill, it just happens.

## EMERGENT THEME 5.4: BENEFIT & HARMS FROM PARTICIPATION

TIME 1

028: I feel better now that I have written it all down.

**057:** It has helped to fill in this questionnaire (a bit) but it would be good to talk to people, including doctors, and be given help in adopting a positive attitude.

103: Taking part in this research has given me the opportunity to make the comment that through a great deal of internal analyzing of <u>all</u> the facets of life, has enable me to come to a balanced conclusion. Obviously there are still questions, but a positive attitude and a belief that anything can be achieved through believing it can - will be. I do hope this will help others.

117: Answering this questionnaire has made me realise that my cancer, although small, was real.

#### TIME 2

**027:** I do not approve of this study, it has necessitated dwelling on my medical condition in a way that is not constructive.

028: Filling in this has reduced me to tears, don't understand why

103: Thankyou for listening.

#### TIME 3

**028:** Answering this questionnaire has made me confront my condition. I have not accepted that I've had cancer, I push all thoughts away and pretend nothing has happened... I have filled the questionnaire in, I have had to face reality and my emotions and end up in tears...I do not think I am handling my condition in the way that I should.

103: Many thanks for allowing me the opportunity to take part in this research project. I do hope that it will benefit others.

106: I have found it a little difficult to fill these in, as it focuses the mind so strongly on things that are difficult to cope with, when I would rather 'go with the flow'.

## **APPENDIX 6.1: END OF PROIECT REPORT**

# The importance of personality, appraisal, and emotion in the prediction of psychosocial outcomes for cancer patients.

# End of Project Report Summer 2009

Hulbert-Williams, N.J.<sup>1,2</sup>, Neal, R.D.<sup>2</sup>, Wilkinson, C.<sup>2</sup>, Morrison, V.<sup>3</sup> & Roberts, A.<sup>4</sup>

- <sup>1</sup> Department of Psychology, University of Wolverhampton
- <sup>2</sup> North Wales Clinical School, Cardiff University
- <sup>3</sup> School of Psychology, Bangor University
- <sup>4</sup> North Wales NHS Trust

## **Background**

Cancer is one of the leading causes of death in the UK accounting for 26% of all deaths (Department of Health, 2007). There were 152,491 cancer-related deaths in the UK in 2005, of which, 47% resulted from a diagnosis of lung, colorectal, breast or prostate cancer (Cancer Research UK, 2008). These remain the most common cancer diagnoses made. The Cancer Reform Strategy (2007) highlights the need for improved integration of psychological services into routine cancer care. Previous research into psychosocial aspects of adjustment is, however, inconsistent.

Distress levels following diagnoses are reported in excess of 30% (Zabora, Brintzenhofezoc, Curbow, Hooker & Piantadosi, 2001; Mitchell, Kaar, Coggan & Herdman, 2008); in some cases being as high as 75% (Galway, Black, Cantwell, Cardwell, Mills & Connelly, 2008). Maguire (2000) reports that, furthermore, around one third of all patients will develop one or more psychological comorbidities at clinical level. Anxiety incidence rates at diagnosis range from 10% (Ratcliffe, Dawson & Walker, 1995) to 41% (Glinder & Compas, 1999) and depression from 2% (Ratcliff et al., 1995) to 34% (Epping-Jordan, Compas, Oxoweicki, Oppedisano, Gerardt, Primo et al., 1999).

Numerous psychological factors have been empirically investigated as possible predictors of these psychological outcomes. These include personality, cognitions, health control beliefs, emotions, and coping. Our earlier systematic review (Hulbert-Williams, Dudley, Neal, Morrison & Wilkinson, *in prep*) highlighted vast inconsistency of these findings both in clinical and statistical size and significance of these effects. Furthermore, the review highlighted a lack of good quality longitudinal studies exploring multiple of these potential predictors together.

Lazarus's Transactional Model of Stress (1984, 1987, 1993, 1999) provides a sound theoretical basis in which to do so. The model states that on encountering a stressful situation, and individual will make a cognitive appraisal of the expected impact and their perceived coping ability to deal with it. In addition to the standard factors which influence these appraisals (personality, demographics, environment), clinical variables are also likely to be an influential factors following diagnosis. The theory proposes that these appraisals then influence emotional

reaction which in turn shapes the coping response, consequently mediating the stress outcome (in this case anxiety, depression and quality of life). The model, whilst theoretically developed, lacks empirical support, particularly with regards the nature of relationships between specific appraisals and emotional reactions. The primary aim of this study was to apply the Transactional Model in an investigation of psychosocial adjustment to cancer. Longitudinal data was tested such that the predictive value of appraisals, emotions, and coping, on later levels of anxiety, depression and quality of life could be assessed. A secondary aim of the study was to empirically test the complex relationships between appraisals and emotions in the Transactional Model.

#### Method

## Design

A longitudinal cohort study was designed in which patients would complete self-report questionnaires at baseline (diagnosis) and three and six month follow up. Predictor variables included personality, appraisals, health control beliefs, emotions, and coping. Outcome variables were anxiety, depression and quality of life. Demographic and clinical data were also collected at baseline in order to control for their potentially confounding effects.

#### Measures

A number of previously validated and reliable psychological measures were used in this study:

- The Life-Orientation Test (Scheier, Carver & Bridges, 1994) for optimism
- The NEO-FFI (Costa & McCrae, 1992) for trait personality
- The Appraisal Components, Core-Relational Theme, and Emotion Themes questionnaires (Smith & Lazarus, 1993) for Transactional Model components
- The Multidimensional Health Locus of Control (MHLC) Scale (Wallston,
   Wallston & DeVellis, 1978) for health control beliefs
- The BriefCOPE (Carver, 1997) for coping
- The Mini Mental Adjustment to Cancer (MAC) Scale (Watson, Greer & Bliss,
   1989) for cancer adjustment
- The SF-12 (Ware, Kosinski & Keller, 1996) for perceived helath status
- The FACT (Cella, Tulsky, Gray, Sarafian, Linn, Bonomi et al, 1993) for quality of life
- And The HADS (Zigmond & Snaith, 1983) for anxiety and depression.

Data was also collected on participants, age, gender, ethnicity, marital status and a number of other demographic variables. Clinical data collected from hospital records included: specific cancer cell type, tumour stage at diagnosis, treatment planned, type of referral, date of diagnosis, and waiting time to treatment.

## Sample

160 patients were recruited into this study representing a low, but not unexpected, response rate of 34.6% from the 462 patients initially approached. A further 440 patients were diagnosed during this time who were assessed to be unsuitable for inclusion by their cancer nurse specialist. The most common reasons for exclusion included: advanced illness at diagnosis; recurrent disease; other physical or mental co-morbidity; or too distressed.

Sixty-three male and 97 female participants were recruited into the study, 84% of which were from the North East Wales NHS Trust. Their mean age was 64 years and although a range of other demographics were found (marital status, employment status etc.), the sample was 100% Caucasian in ethnicity. Four different cancer types were recruited: Colorectal (27.5%), breast (43.1%), lung (17.5%), and prostate (11.9%). All were contacted within six weeks of diagnosis but response delays meant that time between diagnosis and consent ranged from 1 to 116 days. Sixty percent of the sample had entered secondary care through an urgent referral pathway and consistent with the inclusion criteria, most were at an early stage of illness. A wide range of specific cell type and treatments were reported for the sample.

#### **Procedure**

Ethical and research governance approval was sought from all three North Wales NHS Trusts. On a fortnightly basis, NHW met with each nurse specialist to discuss new diagnoses from the previous multi-disciplinary team meeting. Inclusion criteria were assessed by the nurse specialist. Study information and invitation, consent sheet, and questionnaires were posted to all suitable patients with a freepost reply envelope. Reminders were sent one month later in the case of non-response.

For patients wishing to participate, questionnaires took approximately 45 minutes to complete. These were self-report questionnaires. On completion, patients were instructed to return the questionnaire to NHW in the freepost envelope. On receipt, patients were allocated a unique participant identification number. Confirmation of receipt was sent to the participant, and a letter of information sent to their GP. Prior to follow-up (at three and six months), NHW

contacted each participant's GP to ensure that the patient hadn't died or become too ill to participate. The same questionnaire pack was sent for completion at each follow-up stage. Once all three had been returned, the participant was sent a study debrief sheet.

Each patient was asked to give consent for the research team to consult their secondary care medical records. This was collated by NHW, local cancer services, and nurse specialists.

#### Results

## Non-responders and patient deaths

Thirty-eight patients failed to return questionnaires at all three timepoints. Analysis of differences between those retained in the study and the 28 drop-outs revealed few significant difference except a tendency towards more negative appraisal and emotional reactions at diagnosis. The ten patients who died during the study were found to have been lower on psychological subscales of quality of life (p<.05) and again to report more negative appraisals, emotions and maladaptive coping strategies at baseline. Anxiety and depression were also higher at baseline in those who died (t=3.27, p<.01; t=2.38, p=.02 respectively).

#### Prevalence of outcome

Whilst overall levels of quality of life did not significantly change through the study, social quality of life was found to significantly decrease (Z(106)=.47, p<.01) and emotional quality of life to significantly improve (Z(116)=-4.65, p<.01). Cancer specific subscales all demonstrated improvement over time except for the lung cancer patients' scores which improved slightly at three months, but then decreased back to original levels by six month follow-up (see fig. 1)

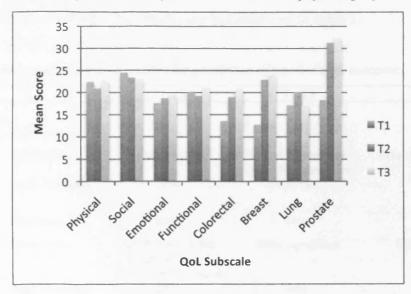


Fig 1. Graphical display of trends over time for all QoL subscales.

As would be expected given the trend towards improvement for quality of life, anxiety and depression were both found to significantly decrease over time (Z=-3.49), p<.012; Z=-2.45, p=.01). Few patients scored above cut-off scores for

clinical levels of anxiety (n=18, 14, and 7 respectively for the three time points) and depression (n=4, 10 and 4).

## Prediction of clinically relevant outcomes

High co-variance was expected between the multiple predictor variables; they are, after all, variations of psychological responses to the same stressor.

Pearson's and Spearman's Rho correlation analyses confirmed this.

Regression analyses were used to test the predictability of psychological variables for anxiety, depression and quality of life at later time-points. Preliminary time-lagged correlation analyses identified those variables which significantly correlated (at p<.10) with outcome. A wide range of significant correlations were found with personality, appraisal, emotion and coping variables emerging over both three month and six-month time lag.

In the first block of the regression analysis, control and potentially confounding variables were entered (age, gender, marital status, cancer type, treatment delay, health status, previous outcomes, trait personality). The residual level of outcome was then saved for use as the dependent variable for block two. In this second block, all significantly correlated predictor variables were entered using a stepwise method. The results are summarised in table 1.

Table 1. Summary of regression models for prediction of psychosocial outcome.

		T1-T2	T1-T3	T2-T3
Quality of Li	fe			
Block 1	Variance	61%	67%	71%
Block 2	Predictors	Congruence	Future Expectancy Hope/Hopelessness	Effortful Optimism
Add. Variance	Add. Variance	5%	14%	9%
Anxiety Block 1	Variance	69%	66%	72%
Block 2	Predictors	Self Responsibility Other-Blame Dr Locus of Control	None significant	Other-blame
Ad	Add. Variance	21%	0%	9%
Depression				
Block 1	Variance	61%	59%	51%
Block 2	Predictors Add. Variance	0%	None significant <b>0%</b>	0%

Far higher levels of variance were explained for quality of life and anxiety than for depression; these lower scores should not, however, be dismissed as their range of 51-61% remains a substantial proportion of variance. Depression was most successfully predicted using baseline psychological predictors than three-month follow up predictors. Quality of life was at six-month was better predicted than three-month levels, irrespective of which time-point of predictor variables were used. Anxiety was best predicted when time-lag between predictor and outcome measure was smallest.

From block one, earlier level of outcome was the most predictive variable. Age, marital status, cancer type, and health status all featured, but not consistently in all models. Few psychological variables significantly contributed to block two of the regressions. None emerged as significantly additive for any depression model. For quality of life and anxiety, only illness cognitions contributed further variance: appraisal of motivational congruence, self-responsibility, and future expectancy; core-relational themes of effortful optimism and other blame; doctor oriented locus of control; and hopelessness/helplessness subscale from the MAC. The absence of emotion and coping here is noteworthy given previous literature.

#### Theory Testing

Extensive theory tests were conducted; a summary only will be provided. First, change scores were calculated for each appraisal and emotion variable between baseline and six-month follow-up scores. Correlations between components were then explored and compared with theory-driven hypotheses. Few of these tests revealed significant results between the emotions and their expected cognitive correlates; none of the effect sizes for appraisals were significant, and just a small amount of core-relational themes fitted patterns proposed in Lazarus' theory. A number of non-expected components demonstrated significant correlations. Contrary to theory, multiple core-relational themes emerged as correlates of single emotions. These effect sizes were far higher than between appraisals and emotions.

Using baseline data only, regression models were constructed to test whether *non-expected* cognition variables contributed additional variance in emotion, above and beyond that already explained by *theoretically expected* 

variables. The results demonstrated that just one out of twelve models failed to benefit from the addition of *non-expected* variables. Not only did the remainder include additional variables, but some of the *expected* variables failed to reach significance for inclusion.

#### Conclusions

The results from the clinically-oriented regression analyses demonstrated far higher effect sizes than the comparable literature (for a review see Hulbert-Williams et al, *in prep*). As hypothesised, cognitive appraisals emerged as far more predictive of psychosocial outcome than did emotional reaction or coping. This strengthens the current trend within the empirical literature to be focussing upon the effects of cognitions rather than coping (e.g. Folkman & Greer, 2000; Schneider, 2008).

The failure of the cognitions to add to models of depression was surprising and is worthy of further research attention. Those appraisals emerging as significant for both quality of life and anxiety may provide an important focus for future psychological interventions for this patient group. Results indicate that for anxiety, appraisals have a time-limited effect on outcome, therefore intervention may need tailoring to different illness time-points. For quality of life, results indicated that intervention may be most effective at a later-time point (e.g three months). The identification of a small set of control variables which reliably predict high levels of psychosocial outcome may have potential application within the clinical setting to allow prediction and monitoring of those who may encounter future adjustment difficulties. Results from this data set indicated that those at most risk may be those patients who are younger, unmarried and perceive themselves to have a poorer physical health status.

Results from theory tests demonstrated little consistency with Lazarus's proposed theory. Not only were different cognitive predictors of emotion identified than would be expected, but the specific nature of the unique pairings between core-relational themes and emotions was not supported. This was one of just a few large scale empirical tests of this model using a homogenously stressed sample. The results indicate that further empirical work is necessary to develop the model further.

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## **APPENDIX 6.2: LIST OF THESIS DISSEMINATION PRESENTATIONS**

Systematic Review

8th World Congress of Psycho-Oncology, Venice, 2006 (appendix 6.2)

British Psychosocial Oncology Society newsletter, 2006 (appendix 6.3)

School of Psychology, Bangor University, 2007 (Invited seminar)

Empirical Study: Clinical Findings

9th World Congress of Psycho-Oncology, London, 2007 (appendix 6.4)

European Health Psychology Society Annual Conference, Maastricht, 2007 (appendix 6.5)

Department of Primary Care & Public Health, Cardiff University, 2008 (invited seminar)

Empirical Study: Qualitative Results

10th World Congress of Psycho-Oncology, Madrid, 2008 (appendix 6.6)

Empirical Study: Theory Testing

Stress & Anxiety Research Society Annual Conference, London, 2008 (appendix 6.7)

British Psychological Society Division of Health Psychology Society Annual Conference, Bath, 2008 (appendix 6.8)

#### **APPENDIX 6.3: IPOS 2006 CONFERENCE ABSTRACT**

#### 644

The Importance of Personality in Appraisal and Prediction of Psychosocial Outcome in Cancer Patients: A Systematic Review

Hulbert NJ<sup>a</sup>, Dudley HC<sup>a</sup>, Nel RD<sup>a</sup>, Wilkinson CE<sup>a</sup>, Morrison VL<sup>b</sup>

<sup>a</sup>Department of General Practice, Cardiff University, Centre for Health Sciences/North Wales Clinical School Wrexham, Wales, UK; <sup>b</sup>School of Psychology, University of Wales Bangor, Bangor, Wales, UK

PURPOSE: Few studies have rigorously addressed the role of personality in appraisal of cancer diagnosis and it's relation to psychosocial outcome. Findings are often inconsistent, contradictory, and criticised for quality and methodology. A comprehensive systematic review of the literature is, therefore, required. METHOD: Search strategies were designed for ten key psychological-and medically based electronic databases. Three questions were explored: the importance of personality in cognitive appraisal of diagnosis (13731 hits); the importance of personality on psychosocial outcome (21 679 hits); and, the relationship between appraisal and psychosocial outcome in cancer patients (23 985 hits). References are being independently assessed by two reviewers against pre-defined inclusion criteria; approximately 1.8% of retrieved hits have been highlighted for possible inclusion. All research (experimental or observational) relevant to any of the three research questions in a sample of adult cancer patients will be included. Commentary articles and opinion-based sources will be excluded. Data extraction and quality assessment will be carried out on included papers in accordance with recommendations from the Centre for Reviews and Dissemination Guidance (2001), the Cochrane Handbook for Systematic Review of Interventions (2005) and other key sources of review methodology literature. RESULTS/CON-CLUSION: The review will critically assess published literature in order to synthesise key findings and highlight core methodological issues where research quality is questionable.

Implications shall be drawn for the development and improvement of personality-based psychosocial oncology research and intervention. The review will be completed by early autumn and the results presented.

> Psycho-Oncology 15: S1-S478 (2006) DOI: 10.1002/pon

#### **APPENDIX 6.4: BPOS NEWSLETTER ARTICLE (2006)**

THE IMPORTANCE OF PERSONALITY AND APPRAISAL IN PREDICTION OF PSYCHOSOCIAL OUTCOME FOR CANCER PATIENTS: A SYSTEMATIC REVIEW. PRELIMINARY FINDINGS FOR ANXIETY AND DEPRESSION.

The work that I presented at the IPOS conference was based on a systematic review being conducted with my colleagues, Helen Dudley, Richard Neal, Clare Wilkinson and, Val Morrison. The work will form the first part of my PhD. The review focuses on published studies which measure either a personality, cognition or emotion predictor variable; and, anxiety, depression or quality of life as an outcome variable. The poster presentation given in Venice gave preliminary results for anxiety and depression.

Cancer diagnosis often represents personal threat, challenge, and loss to patients; further, the illness course is unpredictable, usually interfering with personal goals (see Lazarus et. al. 1987, 1999). This can result in anxiety, stress and distress for many years after diagnosis. Research findings pertaining to the influence of psychological variables are inconsistent, particularly relating to individual variation in appraisal (Watson et. al. 1991; Millar et. al. 2005), and personality which Eysenck (1993) claims to carry equal weight to the stressor itself in determining outcome.

Three search strings were developed for key psychological and medical electronic databases. Inclusion criteria stipulated that only published empirical evidence written using the English language could be included. Any study of adult cancer patients was included provided that samples were recruited within five years of diagnosis. Studies were required to measure either a personality, cognition or emotion variable, in addition to a measure of either psychological co-morbidity or quality of life.

Literature searching revealed over 50,000 published reports. After de-duplication and relevance screening (based on titles and abstracts) by two independent reviewers, the searches were combined. 255 articles were ordered for full-article inclusion assessment. Of these, 174 were excluded. Main reasons for exclusion included foreign language papers (47), inadequate selection of measures for this review (53), or that original study aims were not relevant to this review (31). 19 did not provide adequate information to assess inclusion; lead authors were contacted by email but all were later excluded due to lack of response, or not available information. Three papers were combined with others within the inclusion list as they used the same sample, but reported on different analyses. Therefore, 74 studies were included: 18 measuring quality of life as the outcome variable, 32 measuring anxiety or depression as the outcome variable, and 24 measuring both types of outcome.

Study quality was assessed using a tool based on that of Kmet, Lee and Cook (2004). Overall quality scores take account of clarity of hypotheses, appropriateness of design and sampling, appropriateness and clarity of statistical analysis, and validity of conclusions based on data provided. No studies scored a quality assessment of less than 50%: 60 studies scored 75% or higher.

Thirty-two of the included studies used a cross-sectional design, three were baseline surveys conducted as part of RCTs or intervention studies, and 39 were longitudinal studies with follow-up data collection points ranging between two days and five years. In most cases, sample size was appropriate for individual study designs with a mean n of 127 (ranging from 16-480). Percentage response rates from the originally approached study population were variable, ranging from 28% to 99% (M=77%); this variability is most

likely explained by differences in timing of recruitment and clinical characteristics of the study population.

Psychological co-morbidity was grouped into two categories: anxiety and depression. Based on measures included, 59 of the included studies were potentially relevant to the current analysis. Of these 22 failed to conduct tests beyond simple inferential statistical procedures, leaving 37 reporting findings of association or prediction.

Preliminary results showed that personality, cognition and emotion-related variables are significantly associated to anxiety and depression in cancer patients, however associations based on control beliefs were non-significant. Although not a main focus of this review, there was evidence for a mediating role of coping between some of the predictor and outcome variables. However, optimum coping styles (for better adjustment) are variable both over time and between study.

It was hoped that meta-analysis could be conducted on these 37 studies, however this was not possible in most cases. Over 20 different predictor variables were used, and adequate statistical information was not provided to enable these statistical procedures to be used. In a number of studies, authors chose not to report findings for validated sub-scales of depression or anxiety, but rather merged them into one single outcome variable. This is not always helpful when trying to understand the complexity of results at a more detailed level. Some researchers used factor analysis as the justification for combining results in this way, though the failure of a factor structure to emerge in their data is unsurprising given the small sample sizes used in these particular studies.

Despite the large number of predictor variables highlighted by this preliminary analysis, most of these are illness appraisal or emotion related; only a small number of personality variables have been investigated in relation to psychosocial outcome. Future research should expand on this.

Additionally, several of the measures used in studies in this review have been purported to measure different underlying psychosocial constructs by different researchers. Our preliminary findings raise concerns about the coherence and definition of psychosocial constructs and measurement, and the theoretical basis underlying study rationales.

Theoretical models of adjustment to cancer describe a complex interaction between many psychosocial and clinical factors. The implications (both theoretical and clinically applied) of studies that fail to measure, or report statistical findings of, potentially important tertiary variables is unclear. It is possible that studies have been intentionally limited to avoid over-burdening patients, however in doing so, researchers in this field are inadvertently limiting the applicability of their findings to a subject so heavily based in theory and the application of that theory to clinical practice.

The full review is now in the final stages of data synthesis (including findings related to quality of life) and will be written up for publication shortly. For further details on the project, please contact the review team at hulbertnj@cf.ac.uk.

Nick Hulbert-Williams.

## APPENDIX 6.5: IPOS 2007 CONFERENCE ABSTRACT

important to determine the relative contribution of certain types of beliefs to adjustment. Moreover, it would also be important to discern the role religious beliefs play in various aspects or stages of the stress-appraisal-coping process. For example, do certain types of beliefs render some cancerrelated stressors non-threatening? CLINICAL IMPLICATIONS: Interventions with an emphasis on enhancing self-efficacy might also include some remediating the precursors of efficacy such as social support and fostering religious beliefs if the patient endorses those beliefs as a coping resource. OF ACKNOWLEDGEMENT RESEARCH FUNDING: National Cancer Institute (CA88603 and CA94914).

#### P1-144

Anxiety, Depression, and Quality of Life in the First Six Months after Cancer Diagnosis: the Contribution of Personality, Appraisals, and Emotions \*Hulbert-Williams NJ , Neal RD , Wilkinson C ,

Morrison VL<sup>2</sup> <sup>1</sup>Cardiff University, North Wales Clinical School, United Kingdom, <sup>2</sup>School of Psychology, University

of Wales, United Kingdom

PURPOSE: Early identification of those failing to adjust to a cancer diagnosis is imperative to enable optimized provision of psychosocial care. Psychological variables are undoubtedly important for this purpose; however, research findings to date have found inconsistent results. This is perhaps a methodological issue: many studies use crosssectional designs, recruiting long after treatments are completed; and, few studies are truly theory based, thus failing to explore all potentially relevant predictors. We addressed these methodological issues in a theory-driven study (using Lazarus's Transactional Model) exploring the contribution of personality, illness beliefs, appraisals, emotions, and coping to reported anxiety, depression, and quality of life in newly diagnosed cancer patients. METHODS: 154 participants from three NHS Trusts were recruited shortly after diagnosis of a primary breast, prostate, lung, or colorectal cancer. Participants were approached within 2-8 weeks of diagnosis and completed questionnaires at baseline, three months, and six months. Questionnaires at all time points assessed a range of personality variables (LOT-R, NEO-FFI); health control beliefs (MHLC); coping (BriefCOPE); cognitive appraisals and emotions (Smith & Lazarus's Appraisal Components Questionnaire); adjustment (MiniMAC); quality of life (SF-12; FACT); anxiety and depression (HADS). Clinical data (stage of illness, treatment plan and intention at diagnosis, secondary care psychological services referral and treatment, waiting time, and performance status at diagnosis) were

extracted from hospital records. RESULT: Data are currently being inputted for analysis using teleform technology. Repetition of all psychological predictors at each data collection stage will not only allow for tests of association and prediction, but also stability over time, under the increased stress and uncertainty during the first few months after diagnosis. T-tests and/or ANOVAs will be used to explore differences based on clinical and demographic data. Standard and cross-lagged correlations will be carried out between all predictor (e.g. personality, control beliefs, appraisals etc.) and outcome (e.g. anxiety, depression, quality of life etc.) variables. Theory-informed regression models (based on Lazarus's Transactional Model) will be conducted to determine the predictive validity of specific variables above and beyond that offered by illness specific variables. All results will be analyzed and presented at the conference. CONCLUSIONS: RESEARCH IM-PLICATIONS: This will be one of the first truly theory-driven studies within psychosocial oncology research to explore, using improved methodological approaches, the role of clinical data, individual differences, cognitions, emotions, and coping in response to cancer diagnosis. The findings will be useful in informing future research hypotheses and in further development and understanding of Lazarus's Transactional Model. CLINICAL IM-PLICATIONS: Findings from this study will be useful for the identification of which psychological variables are most predictive of distress and quality of life, at which time points after cancer diagnosis. This information can be used by clinicians to identify those at risk of poorer adjustment and increased distress at an earlier stage, thus enabling better provision of psychosocial care and optimizing patient well-being through treatment and remission. ACKNOWLEDGEMENT OF RE-SEARCH FUNDING: We are grateful to the North Wales Research Committee for a small grant to support this work.

#### P1-145

Studying of Depressive Disorders in Patients with Acute Leukemia

\*Ibragimova SZ, Makhmudova MR, Eshimbetova SZ Institute of Hematology, Uzbekistan

PURPOSE: The treatment of the patients with cancer is often complicated by the development of psychopathological frustration. Modern protocol of chemotherapy allows achieving a good outcomes, however such therapy entails occurrence of the stressful situation, leading to serious complications in mental sphere and behavioral ramifications. Depressive infringements cause of slow recovery, refuse of treatment, increases the

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Psycho-Oncology 16: \$1-\$287 (2007) DOI: 10.1002/pon

## APPENDIX 6.6: EHPS 2007 CONFERENCE ABSTRACT

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Exercise declined from Time1-Time3 (p <.001;eta2 = .075). Baseline exercise accounted for 20% of the variance in exercise at two-year follow-up. Intentions and E-SE added 6.2% (Time1) and 9% (Time2,ps <.001). Controlled for these measures, neither SABC nor specific self-efficacy (Block3b) added to the prediction. Block3c added 5.4% when baseline predictors were used (R2adjusted = .28; Coping Planning: Beta = .23,p <.01; E-SE:Beta = .20,p <.05; Action Control: Beta = .17,p = .065) and 2.6% for Time2 predictors (Action Control: Beta = .24,p <.05;E-SE: Beta = .18,p = .054).

Sustained self-efficacy, coping planning and action control play an important role in the maintenance of behaviour change.

Keywords: Action control, behaviour change, maintenance

#### Reference

\*Sniehotta, F. F., Scholz, U., & Schwarzer, R. (2005). Bridging the intention-behaviour gap. Psychology & Health, 20, 143-160.

#### 421

#### Personality, appraisal, emotional reaction, and adjustment following cancer diagnosis

N. Hulbert-Williams<sup>1</sup>, R. Neal<sup>1</sup>, C. Wilkinson<sup>1</sup>, V. Morrison<sup>2</sup>; <sup>1</sup>Cardiff University, Nwcs, Wrexham, United Kingdom; <sup>2</sup>University of Wales, Bangor, United Kingdom

Research Question Early identification of those failing to adjust to cancer is imperative for targeted provision of psychosocial care. Psychological variables are undoubtedly important for this purpose, however, research findings demonstrate inconsistent results. This is perhaps a methodological issue: many studies use cross-sectional designs, recruiting long after treatments are completed; and, few are truly theory-based, thus failing to explore all potentially relevant predictors. In particular, Folkman and Greer (2000), state the need for more emphasis on cognitive variables. We addressed these methodological issues in a theory-driven study (Lazarus's Transactional Model) in cancer.

Method Used 154 participants from three NHS Trusts were recruited shortly after diagnosis of a primary breast, prostate, lung or colorectal cancer. Participants completed questionnaires at baseline, three months, and six months. Questionnaires assessed personality, health control beliefs, coping, appraisals, emotions, quality of life, anxiety, and depression. Clinical data were extracted from hospital records.

Results Data are currently being inputted for analysis. Analysis will be conducted using t-tests and/ or ANOVA for group comparisons; standard and cross-lagged correlations between all predictor and outcome variables; and, theory-informed regression models to determine the predictive validity of specific predictor variables.

Conclusions This will be one of few truly theory-driven studies within psycho-social oncology research to explore, using improved methodological approaches, the role of clinical data, individual differences, cognitions, emotions and coping in response to cancer diagnosis.

Keywords: Adjustment, appraisals, cancer

#### Reference

Folkman, S., & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: When theory, research and practice inform each other. Psycho-Oncology, 9, 11-19.

#### **APPENDIX 6.7: IPOS 2008 CONFERENCE ABSTRACT**

#### 38L-2

Understanding Patient Perceptions of Participation in Psychosocial Oncology Research. Nicholas Hulbert-Williams<sup>1</sup>, Richard Neal<sup>2</sup>, Clare Wilkinson<sup>2</sup>, Val Morrison<sup>3</sup>

'University of Wolverhampton, Wolverhampton, England, United Kingdom, 'Cardiff University, North Wales Clinical School, Wrexham, Wales, United Kingdom, 'Bangor University, Bangor, Wales, United Kingdom

PURPOSE: Most methodological papers investigating participation rates into psychosocial oncology research are centred around recruitment into clinical trials. Recruitment rates into studies are low but a substantial proportion of patients report a desire to participate. Few studies explore perceptions of participation in non-clinical trial research studies. This paper analyses some of the comments made by patients during participation in a questionnaire-based study of cancer adjustment. METHODS: As an adjunct to a larger quantitative study, 160 participants were given the opportunity to write freely about any aspect of their illness or participation in the study. Lung, breast, prostate and colorectal cancer patients were recruited, with sixty percent of these sample providing comments which were thematically analysed. RESULTS: Five super-ordinate themes emerged: causation and control; physical aspects of illness; psychological adjustment; transition and return to normality; and, participation issues. The latter theme will be the focus of this presentation. CONCLUSION: Some participants found the questionnaire presentation format difficult. Comments centred around question ambiguity, limited response formats, and the fluctuating nature of their illnessrelated thoughts and emotions over time. Many commented on study timing, predominantly, the incongruency between time of recruitment and treatment start dates. Many felt that questions related to the role of religion were innappropriate and worded so as to imply negative perceptions of God. The importance of religion as a source of support and coping was discussed. Few participants reported harms from participation and these were grounded in increased attention on their condition. Several participants reported benefits of participation, expressing gratitude and often suggesting the questionnaire as a framework for clinical discussion. RESEARCH IMPLICATIONS: The results from this paper will be of interest to those designing and evalutating new research studies. By analysing patient experiences of recruitment, their feedback can be used to potentially improve recruitment into, and increase perceived benefit from, participation in psychosocial oncology research. CLINICAL IMPLICATIONS: This analysis highlights patient desire to be included in psychosocial oncology research and will help clinicians with decisions within practice relating to the introduction of new studies to patients at this complex time. ACKNOWLEDGEMENT OF FUNDING: This study was part-funded by a small grant from the North Wales Research Committee.

#### 381.3

## Towards an Evidence Based Guideline 'Detection of and Referral for Psychosocial Distress'

J. Nogossek<sup>3</sup>, J.C.J.M. de Haes<sup>1</sup>, M. Bannink<sup>2</sup>, M. A. van der Pol<sup>4</sup>

<sup>1</sup>Amsterdam Medical Center/University of Amsterdam, Amsterdam, Netherlands, <sup>2</sup>Erasmus Medical Center-Daniel den Hoed, Rotterdam, Netherlands, <sup>3</sup>Comprehensive Cancer Center South, Eindhoven, Netherlands, <sup>4</sup>Comprehensive Cancer Center Rotterdam, Rotterdam, Netherlands

PURPOSE: The guideline will offer healthcare providers evidence based recommendations for systematic screening of psychosocial distress and referral. METHODS: A multidisciplinary expert group of representatives from professional associations in (psycho-)oncology and from patient associations will develop the guideline according to the Dutch method of evidence based guideline development: Investigate obstacles and their priority encountered in the field, by online survey Define distinct questions based on obstacles given high priority Search for highest levels of evidence and for practices for each question Define recommendations based on findings Obtain approval from professionals in the field of (psycho-)oncology Publicate the guideline on www.oncoline.nl Develop indicators to monitor implementation The process of development and implementation of the guideline is facilitated by the Dutch Comprehensive Cancer Centers and the Dutch Cancer Society. RESULTS: 340 respondents - professionals of all disciplines in (psycho-)oncology and cancer survivors - of an online questionnaire prioritized obstacles from a list of 19 items considered prominent total group and subgroup analyses yielded a balanced set of obstacles with high priority as subject for the guideline the obstacles were reformulated into five distinct questions, which in turn were the starting point for a systematic literature search and search for best practice. Thus, recommendations will be made for: instrument(s) for psychosocial screening frequency and timing of screening communication about distress and the screening results with the patient rules for referral conditions for implementation. CONCLUSION: The identification by online survey of the most important obstacles in psychosocial screening and referral as encountered by health care providers led to a clear outline of the subject of the guideline. RESEARCH IMPLICATIONS: Based on the literature searches, what evidence is missing will become clear. Thus,

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Psycho-Oncology 17: \$1-\$348 (2008) DOI: 10.1002/pon

#### APPENDIX 6.8: STAR 2008 CONFERENCE ABSTRACT

STRESS IN CANCER DIAGNOSIS: IS LAZARUS'S TRANSACTIONAL MODEL SUFFICIENT?

Hulbert-Williams NJ, Neal RD, Wilkinson C & Morrison V.

Lazarus's Transactional Model is one of the most cited socio-cognitive models of stress in the literature, yet few validation studies have included samples undergoing major life event stress. Instead, studies use real-life daily hassles or hypothetical life events. This model was used as the theoretical underpinning for exploring stress after cancer diagnosis.

This paper explores whether the data supported the hypothesised relationships between different components in the model. Sixty three males, and 97 females were recruited. The sample included recent diagnoses of breast, colorectal, lung and prostate cancer (mean time since diagnosis =46 days). Participants completed a questionnaire including Smtih & Lazarus's (1993) measure of appraisal components, core-relational themes, and emotion themes.

For each emotion, two sets of regression analysis were performed. The first used the unique predictor combinations suggested in the literature in a forced-entry analysis. These were compared to the second set which used a stepwise approach. These were compared to assess comparative contributions of theory-driven and data-driven approaches.

In all but two analyses, both appraisal components and core-relationsal themes were required to best explain emotion. In 11 out of 12, data-driven analyses ( $R^2$  range = 14.9 to 52.0) outperformed theory-driven analyses ( $R^2$  range = 0 to 38.3). Concurrent analysis demonstrated the utility of all components in predicting of anxiety, depresison and quality of life. However, these analyses question the unique patterns of cognitive antecedents for each emotion. Further work, both longitudinal, and in other stressful situations, is required to enable refinement of this theory.

**Table 4.21**. Summary of regression models for each set of analysis (variables in bold indicate **significant** individual predictors).

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Depression Depression Depression Neuroticism Neuroticism Neuroticism Extroversion Extroversion Agreeableness  No additional variables entered in block 2		Quality of life	Quality of life	• •				
Depression Depression Depression Neuroticism Neuroticism Neuroticism Extroversion Extroversion Agreeableness  No additional variables entered in block 2		<del>-</del>	•					
Extroversion Extroversion Agreeableness  No additional variables entered in block 2			•	_				
Agreeableness  No additional variables entered in block 2		Neuroticism		Neuroticism				
No additional variables entered in block 2		Extroversion	Extroversion					
57.00/ A7.00/								
Total variance 57.0% 57.0% 47.0%		No additional variables entered in block 2						
	Total variance	57.0%	57.0%	47.0%				