

**NARRATIVE, CHANGE AND IDENTITY**

**The Experiences of Men in Informal Caring Roles**

**Colin Jones**

**November, 2006**



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## SYNOPSIS

This study examines the experiences of men who undertake the care of sick or disabled relatives. The modes of entry into carer careers are discussed, and the actual components of caring are described. The efforts of male informal carers to present themselves as coherent and worthy moral agents are described. Adaptations to caring as manifested in fantasy and daydreaming are examined. The entry into caring is seen to occasion a certain disruption in the continuing self-narratives of the men in the study, which amounts to a thorough threat to identities. The role of narrative in the formation and reformation of the self is discussed. It is argued that caring has disrupted the usual relation to masculinity for male carers, and that this is an important component of narrative disruption. Its restitution is important to successful caring. Certain narrative styles are associated with certain responses to caring, and the relationship between these is adduced and examined. An association between the form of narrative reformation, attitude to masculinity and caring style is identified, and this is correlated with adaptation to, and success in, the caring situation.

## 1. INTRODUCTION

In previous decades, the subject of informal caring, here defined as health and personal care directed towards a particular person on the basis of a pre-existing social relationship, was under-regarded and under-researched. When I became interested in informal care by men, and contemplated a study of it, I could find little relevant information. Most work concentrated almost exclusively on the situations of women who provided care for infirm or elderly relatives. Another body of work concentrated on the measurement, analysis and possible prediction of the burdens of care, usually as experienced by those caring for the elderly. It was difficult to find official statistics on carers, and there seemed to be little official recognition of informal caring activities.

However, by the time I had completed the study, the situation was quite different.

A national strategy for carers had been launched (DoH, 1999), there was a government web site devoted to carers' issues, and there was evidence of increased research into carers and caring (National Research Register, 2002). In addition, the 2001 UK Census included a question on caring activity for the first time. Combined with data from the reformed General Household Survey, this provided useful statistical information. In the literature on caring, there was an increased awareness of the variety of care situations, and a recognition of formerly invisible categories, such as child carers, infirm carers and male carers.

In retrospect, I suppose that my own interest in aspects of informal caring was part of this increasing general regard for the subject. It did not necessarily feel like that at the time, and I did believe that I was rather alone in my interest. However, it is

impossible to escape from the spirit of one's times, and the personal derives from the public and cultural in some curious ways. More recently, I have been happy to see my small endeavours as part of a wider social and cultural shift.

This increase in interest and awareness is entirely appropriate, given the importance of the subject. Informal caring is a crucial part of overall healthcare provision, and strategies for community-based healthcare depend on it. It has been estimated that it manages a very large percentage of illness experience and, if purchased, would add hugely to healthcare costs. The 2001 Census established that 5.2 million people provided some informal care, with 1 million providing care for more than fifty hours a week. This accords with data from the General Household Survey, which estimated that 6.8 million people provided care in 5 million households. Gender ratios for carers in the 50 – 59 years population segment were reported at 24.6% for women, and 17.9% for men, which has remained approximately consistent across the decade. On the whole, informal caring is of vital importance to the functioning of formal health and social care systems.

My own interest in informal caring generally, and in the experiences of men who engaged in informal caring in particular, began with meeting some remarkable individuals. I met them through the circumstances of my work, which had very little direct concern with their caring activities. The first of these had been caring for a mentally ill wife, and a son with learning disabilities for almost forty years. For most of that long period, he had been responsible solely for all domestic and financial work within the family. He had cared physically and emotionally for his wife and son, and had not sought or received much outside help with any of this. Although he had paid

employment through some of these years, he had never been able to seek promotion or pursue career ambitions because of his family commitments. He described a life characterised by severe restriction and curtailment. He was not able to engage in any activity outside of the family, and did not have many opportunities for private projects. Somewhat understandably, he was occasionally unhappy, and had received treatment for depressed feelings.

Another significant meeting, a few years later, was with a man in his late 40s, who had been caring for a severely mentally ill wife for more than 20 years. His wife was said to be particularly, and almost uniquely, resistant to any form of ameliorating treatment. She had some periods of inpatient care. Most distressingly, she had long periods when she felt that people around her had been replaced somehow with potentially threatening replicas, and this included her husband. His life was given almost entirely to the care of his wife, and he had no real separate existence. He was a powerful mixture of anger, unhappiness, pride, guilt, fierce devotion, uncertainty about most things, absolute certainty about some things and huge loyalty.

I wondered, measuring their experiences against my own life, just how these men managed. I was curious about what might constitute the minimum circumstances for lives to flourish, to continue. I wondered just what they did to survive, what mental and emotional mechanisms they employed, how they justified their restricted lives and what they said to themselves about their situations. I remembered a few other men in similar circumstances, particularly the father of a friend, who looked after a paralysed wife for many years. I began to conceive of male carers as a social category, undergoing a set of circumstances that made them unusual. Without

knowing much about it, but using myself as a template, I imagined that the difficulties of caring must be compounded by issues such as comparative inexperience of care tasks, social acceptability, gender expectations, social invisibility and what I then referred to as the male mind-set.

As noted above, when I began to look for studies of caring, and for work on male carers, I could find very little. What I did find was not helpful. It seemed to be inadequate and inaccurate, contradicting what I had seen. There was no real engagement with the actual experiences of male carers, and some generalisations were made on the basis of some very small samples. Eventually, I read Arber and Gilbert's landmark article on male carers, which increased my understanding of some of the issues, and indicated a manner of proceeding (Arber and Gilbert, 1989).

The following study was conceived, in the first instance, to satisfy my curiosity about male carers, and to attempt to answer some of the questions that had occurred to me. I wanted also to investigate the role of what I then called coping mechanisms in that situation. Specifically, I was interested in how the ability to relate a coherent story about one's self and one's circumstances may be lost as the result of engaging in informal caring, and under what circumstances it might be regained. Intrinsic to this were two notions. The first of these is that narrative competence is a necessary condition of a life that is rewarding and liveable. Secondly, I held the notion that some people may, under certain circumstances, be helped to regain a narrative competence that they have lost. I hoped to find some clues as to how this might be achieved.

These notions were vague and undeveloped. It was certainly not the case that I brought a set of developed and congruent concepts to bear on the issues of male caring. Rather, I was more impelled by rude curiosity, and as that was relieved, I made use of some of the conceptual tools available to me in order to make some sense of what I had come to know. That, approximately, is what I thought in the period before preparing a research proposal.

Further thought made me decide to focus on the way that male informal carers constructed identity, as an important and continuing task of the caring situation. The focus would be tight, and would very largely exclude such obvious influences as social class, kinship networks, group affiliations and personal histories. The unit of analysis, so to speak, would be the accounts that men gave of themselves. This urged, or even imposed, a way of proceeding – certain modes of inquiry and of analysis.

Near the end of the study, I became a carer myself. That is, I undertook the principal care of an elderly person with dementia. This was not on the heroic scale of the men referred to above and below, but it was sufficient for me to experience some of the things I had been hearing about: unremitting fatigue, despondency, boredom, anxiety and so on. This was a salutary lesson indeed, and it gave me a crash course in the actuality of the caring situation. If I had ever had a tendency to academic dispassion, it was tested severely. I have not included any of this in the study itself.

## **2. LITERATURE REVIEW**

### **INTRODUCTION**

This study concerns the experiences of men who undertake the full time informal care of sick or disabled relatives. Accordingly, this review of the literature examines the concepts and practice of informal caring, and provides the social context for the caring endeavour. It goes on to review selectively the key research into, and perspectives on, male informal caring that have been advanced over the last quarter of a century. This raises the adjacent and pertinent issues of gender role behaviour and experiences, which are explored in the final section of the review.

### **THE CONTEXT OF INFORMAL CARE**

Surveying the literature of the past twenty-five years, it is acknowledged that, across all cultures and geographical settings, and regardless of prevailing theories of illness, a very large proportion of healthcare work is performed in informal settings. Kleinman (1985) has suggested that there are three areas of caring in all local health care systems: popular, folk and professional. He asserts that most healthcare takes place in the popular area, which includes self-care and care given in families. Wolfendon (1978) provides a rather different model, arguing that healthcare services might be obtained from four sections – statutory, voluntary, informal and commercial. According to this model, informal care is that given by family, friends or neighbours, and is usually directed towards a particular person on the basis of social relationship.

This is contrasted with formal care, which is organised to have a wide delivery to all people within defined categories of need. Informal care is said to be characterised by care styles that are diffuse, not well specified and fluid; care acts are not prescribed or limited a priori (Abrams, 1978). Clearly, given these characteristics, and the narrow person-focused nature of informal care, it cannot provide 'equal provision for all cases in particular categories of need, and neither can it adequately meet the needs of all those who .... receive its services'. (Qureshi and Walker 1989, p.21). Further, it has been agreed that informal care is different in quality from formal care because it is embedded in pre-existing social relationships, which give it a different meaning from the points of view of both carers and recipients of care (Abrams, 1978).

Although there has always been a considerable amount of informal care provided in families, its incidence has increased markedly over recent decades. There are a number of reasons for this. One of the most important is the increase in the proportion and total of elderly people. In 1995, the United Kingdom was, demographically speaking, one of the oldest nations, with over 16% of its population aged 65 years or more. It is estimated that by 2010, nearly half the population will be aged 45 years and over. At the moment, the 80+ age group is the fastest growing population segment, constituting more than 20% of the aggregate elderly population in industrial countries (Kinsella 1996; Suzman et.al., 1992; Warner et.al., 1998). These statistics are of significance because it is acknowledged that levels of morbidity and disability are much higher in older people. For example, it has been estimated that people over 65 years consume more than 45% of total health spending. There is also a tendency for the oldest of old people to consume health and social services at a rate that is disproportionate to their number (Suzman, et.al.,1992; Ranade,1993).

Another important factor in the increase in informal care is the development of community care policies by central government. It has been argued that the idea of home-based care has been present in both policy presentation and service provision since the foundation of the Welfare State, and that community care services were developed throughout the post-war period (Walker, 1992). Certainly, this is the case with regard to the mentally ill and the mentally handicapped (as they were referred to at the time), where there was continued pressure for the closure of long-stay institutions (DHSS, 1962, 1971, 1975). These closures were to be facilitated by the parallel development of day care and local residential units of various kinds.

A key underpinning philosophy to this was the notion of “normalisation”, a belief that the mentally ill and the mentally handicapped (as they were referred to at the time) have a right to live in, and be part of, the wider community (O’Brien and Tyne, 1981; Wolfensberger, 1983). This view, which widened eventually to include all those with disabilities, gained wide credibility and acceptance by the 1980s, and was used as the basis for service development (Beardshaw and Towell, 1990; Ong, 1993). The subsequent de-institutionalisation programme became almost synonymous with community care (or, in the popular idiom, care in the community). However, community care policies were much more various, seeking to extend the family’s role in the care of the elderly, the mentally ill, the mentally handicapped and the convalescent by adapting care at home support services. There was a growing tendency to shorten periods of hospitalisation following acute illness, surgery, childbirth and acute mental illness, so patients were returned to their homes much earlier than hitherto (Wilson, 1997; Ham, 1999; Bornat, et.al., 1993).

It is perhaps unfortunate that community care policies became associated, at least in part, with the critique of the Welfare State formulated by the New Right of the 1980s. This emphasised personal responsibility for care provision, and promoted what was identified as traditional family structures and values. It arose perhaps in response to the financial crisis, which threatened, or seemed to threaten, societies with established and complex state-organised welfare arrangements, where the costs of welfare and the subsequent burden of taxation were seen as economically unviable and ideologically unwelcome. This association is exemplified by the case of mental health, where the radical/liberal call for deinstitutionalization and desegregation of the mentally ill that began in the 1960s was adopted and expounded from a very different perspective and for very different reasons by the Right (see Busfield 1986; Pilgrim and Rogers, 1999; Scull, 1984)

To summarise, community care policies were justified on the grounds of a philosophy of normalisation, economic efficiency and social expedience, utilising ideas of moral obligation and the language of quality assurance. These policies were supported by the simultaneous implementation of community development initiatives and community-based social work. (Hodge,1970; Seebohm,1968; Barnes,1997). It is clear that community care policies were predicated on the mobilisation of the family and the community in general as providers of care. It is unfortunate that this took place at a time when the family itself was undergoing some profound changes, and that the very notion of community was nowhere defined or delineated (Barnes, 1997).

## CARE AND CARING

Although decades of community care policy and service provision were codified and encapsulated in the 1990 National Health Service and Community Care Act, this document did not provide a definition of care, and used the term with a variety of qualifiers: health care, social care, residential care, home care and so on (Barnes, 1997). However, an earlier document did manage to provide a statement of the central objective of care: to achieve maximum independence, acquire/require basic living skills and to achieve full potential (DHSS, 1989 rephrased in Barnes, 1997).

It is noted that the concept of care, and the allied concept of caring, is complex, and is informed by a variety of elements and modalities. Some of these have been delineated as follows (adapting Twigg and Atkin, 1994, p.7.ff). Firstly, care involves the performance of supportive tasks, doing things that people cannot do for themselves, including personal and intimate activities. This is distinct from the personal tending and servicing performed traditionally by women, especially mothers, for family members (Waerness, 1984).

Secondly, an important element of care and caring is kinship obligation. Care almost always takes place within the context of kinship. This has been studied extensively, and the normative rules of kinship obligation have been described (Qureshi and Walker, 1989; Ungerson, 1987; Parker and Lawton, 1991). This is connected to a third element, which is the very important area of emotional attachment. Caring *for* a person in the context of informal care has been seen as synonymous with caring

*about*. This is a more complex, problematic and ambiguous subject than is assumed usually.

A fourth and often-crucial element in caring is geographical proximity, including co-residence. It has been noted that 'sharing a household rapidly affects the experience of care, and co-residence alerts us to the important ways in which caring is not just about the performance of tasks, but the consequences of a relationship' (Twigg and Atkin, 1994, p.9). Other studies have indicated the importance of co-residence in determining which family member adopts the caring role (Qureshi and Walker 1989; Arber and Ginn, 1991). Other important elements in the care situation are physical labour – not all researchers emphasise the very heavy nature of some care work – and feelings of responsibility for the recipient of care. It is worth emphasising that informal care takes place typically within a pre-existing relationship. Carers are 'constituted as a subject by the relationship of obligation and care that they may have with a disabled person .... caring is embedded in relationships of obligation such as marriage, parenthood, kinship, in which people feel responsible for spouses, children or parents, and obliged to give care. These are not voluntary relationships, and those feelings of obligation have consequences for their lives .... '. (Twigg and Atkin, 1994, p.10).

## **MALE CARERS**

The body of research into care giving contains a comparative paucity of work on male carers. There are many reasons for this. Most of the early research focused on the

family care of either mentally handicapped children (as they were referred to then), or those who were physically disabled (Baldwin, 1985; Glendenning, 1983; Wilkins, 1979). None of these studies focused on the role of men in family care giving. Later studies were concerned with the care of aged parents. A very large majority of these studies concentrated on the experiences of women, and it was accepted implicitly that the burden of care always devolved to women, and that the task of informal care was women's work. (Brody, 1981; Finch and Groves, 1983; Lewis and Meredith, 1988; Nissel and Bannerjea, 1982).

Much of this early work delineated the gender-ordered rules of kinship obligation, which impelled women into caring (although later studies have shown this to be a much more complicated situation than was thought previously). This work allowed much strong assertions as 'by far the largest portion of routine tending of the elderly infirm is provided by daughters .... The support at a daily level is almost wholly given by women and is defined as an extension of their routine domestic role' (Allen, p.95 1985).

A few studies did include information on male carers. One group of studies was concerned primarily with redundancy and early retirement, from which information on male carers emerged, in the first instance, as a sort of by-product (Bytheway, 1987; Cliff, 1993). Noting that many of his research subjects became carers because they were available to do so, having no paid employment, Bytheway remarks that 'men can become heavily involved in delivering care .... In the most easily typified cases, this is when the dependant older person has sons but no daughters, and when the husband cares for his sick wife'. (1987, p.184). He notes that men are sometimes

impelled into caring situations in preference to women for purely financial reasons, where men undertake domestic work to facilitate the employment of women – ‘Economic necessity was forcing a redistribution of domestic labour’ (Bytheway op.cit. p.185)

Another group of studies of caring included some men among the research subjects. For example, Ungerson’s study of the care of elderly people included four male carers in a total of nineteen, and Briggs and Oliver’s study of care of disabled relatives included accounts of four male carers in a total of twenty (Ungerson, 1987; Briggs and Oliver, 1985). However, in these and similar studies, there has been a tendency to describe male carers as atypical, somehow constituting a thoroughly aberrant sample. It has been remarked that for men ‘the entanglement of caring for and caring about does not, broadly speaking, exist (and where it does, those men are usually regarded as atypical)’ (Dalley, 1988, p.17.) Other studies have described men in caring roles as not being “real” carers. This is because they are said to engage in less intimate or personal care than do women in caring roles and because men are seen to receive much more support, both formal and informal, than do women. (Arber and Gilbert, 1989).

The issue of intimate care is important. It has long been argued that men are significantly less likely than women to be providing personal care (Parker and Lawton, 1991). Ungerson (1983) has argued that the provision of intimate care is difficult for men caring for elderly female relatives because it violates strong cultural taboos that are attached to incest prohibition. However, Ungerson feels that cross-sex caring is not problematic for marital partners. More realistically perhaps, Parker has

found that intimate care provided for a spouse can be distressing for both partners, regardless of the gender of the carer (Parker, 1993). In addition, Bytheway has reported on men who do provide intimate care, sometimes for other men (Bytheway, 1987). Later studies have shown that over 40% of men caring for someone in the same household provide intimate care, as compared with 66% of women. This difference is much less among married couples, where proportionately 59% of husbands provide intimate care, compared with 71% of wives. In addition, there is a small gender difference reported in those providing intimate care for disabled children (Arber and Ginn, 1995). It may be concluded that it is perhaps less problematic for women to provide intimate care for men than it is for men to provide similar care for women, because caring acts can be conceptualised in terms of mothering or nursing roles. However, it should be stressed that this is a matter of relative difficulty, rather than freedom from difficulty.

As regards the disproportionate help said to be given to male carers, some studies have shown that although men do receive more informal help than women, this difference is slight (Arber and Gilbert, 1989). A close study of data from the General Household Survey of 1980 by the same authors, concludes that there are different patterns of formal help (such as home-help provision, Meals-on Wheels and community nurse visits) but that this is 'not due to a discrimination against women per se, but discrimination against households in which non-elderly married women predominate as carers'. (Arber and Gilbert, 1989, p.116). This accords with similar work, where it is concluded that: 'Male carers were slightly more likely to be getting any service, but service provision to people being cared for by a relative in the same

household was at such a low level that this difference is of minimal importance'.  
(Parker, 1991, p.30)

A few early studies have attempted to address the disproportionate gender balance among carers, but none of them investigated the specific issues of men in caring roles (Briggs, 1983; Charlesworth, et.al., 1984; Levin, et.al., 1983). Recognition of male carers as a worthy subject of study was provided by the work of Arber and Gilbert (1989). This study was based on a careful investigation of data from the General Household Survey of 1980, and on a critical reading of earlier studies. Its essential findings were matched by a similarly careful analysis of the General Household Survey of 1985 conducted by Parker and Lawton (1991). In this extended analysis, Parker and Lawton undertook a separate consideration of male informal carers. They argued that data from the Survey presented 'a considerable challenge to previous comment about men as carers'. (1991, p.4).

As an example of this considerable challenge, data analysis shows that some groups of men, notably those aged 65 years or more, were more likely than women in the same groups to become carers. This inversion of received ideas is due probably to the higher incidence of Alzheimer's Disease in women (Corder et.al. 2003). Within males, the age group 45-64 years is more likely to undertake informal care. Analysis goes on to show that men are more likely to provide care for spouses than for others, resulting in the surprising finding that men were 'substantially more likely to be caring for women than women were to be caring for men (73% and 34% respectively)' (Parker and Lawton, 1991, p.13). The comparative longevity of women seems to be a factor in this. Co-residence was seen to be important in propelling men into informal caring.

It is argued that co-residence over-rides the usual rules of kinship obligation, and men are much more likely to take up informal caring under those circumstances. Finally, in terms of duration of care, there was seen to be very little difference between males and females caring for more than 30 hours a week, while men were much more likely to provide care for 0-4 hours a week. Parker and Lawton conclude that, if like is compared with like, 'men and women carers are much more alike in their caring profiles than previous evidence might have led us to believe' (1991, p.31).

This work, combined with subsequent inquiries such as the Welsh Health Survey of 1995, has established the numerical and social significance of male carers. Arber and Ginn (1989) estimate that about a third of carers are men. The Welsh Health Survey of 1995 indicates that 39% of carers in Wales are men. Arber and Ginn (1989) show that equal proportions of men and women – about 4% - were caring for someone in the same household, and slightly more women than men – 11% compared with 8% - were caring for someone in another household. Both Arber and Gilbert (1989) and Parker and Lawton (1991) have argued that men in caring roles should be seen as real carers, despite what appears to be slightly different experiences in, and of, the caring situation. Despite this recognition, there are very few qualitative or descriptive studies of men in caring roles. In addition, most studies to date have tended to concentrate predominantly on care of elderly relatives, and have not been concerned with the experiences of comparatively younger men caring for comparatively younger spouses and children. This seems to be a significant omission.

## **GENDER AND CARING**

The concept and practice of male caring brings issues of gender into sharp focus. For example, there is an assumption that caring is “naturally” the work of women, or the assertion that giving personal care somehow contravenes societal and cultural norms about appropriate masculine behaviour (Graham, 1983). In view of this, it is entirely necessary to investigate ideas about gender, gender role and gender appropriate behaviour in order to comprehend fully the male care-giving experience.

Anthropological explorations tell us all human cultures distinguish between male and female, although the basis of this categorisation, and its depth, vary enormously. In the same way, the meanings and consequences that attach to sexual differences are various. Gender has always been of interest to social scientists, in one way or another. In addition, the growth of feminism and the foundation of women’s studies have occasioned a greater interest in gender differences. This has led to an adjacent but connected study of men, maleness and masculinity, conducted from a wide variety of perspectives and disciplines.

Most thinking about gender is based on the strong assumptions that there are biological differences between the sexes, that what is biological is “natural” and that these “natural” differences somehow underpin and inform social practices. In the past, this has led to a discourse on the morality of gender relations that was essentially prescriptive. In modern times, this thinking has occurred within a social-scientific framework, which is a Western invention or construction of comparatively recent date. Its history is delineated by Connell (1987), and is explored below. For many

people, it is perhaps reassuring to feel that the pattern of gender relations - the social relations of gender - is “natural”; conversely, it seems to be difficult, and even threatening, to see it as a social phenomenon, and there is some continued resistance to it. Probably, this is one of those cases where explanations appear to run counter to common sense and to empirical observation that scientists describe occasionally (Wolpert, 1992).

Gender relations are present, sometimes crucially, sometimes less importantly, in all social institutions and at all social sites. These include large conglomerates, such as the modern state, and smaller “natural” formations, such as the family. Gender relations are entirely pervasive. Connell (1987, p.132ff), in a study that is still entirely persuasive, has shown how they are present powerfully in such activities as using a street: there are differentiated work practices (on the whole, women push perambulators and men drive lorries); the street is a site for female harassment; conspicuous advertising is sex-typed; and so on.

It is clear that there is not much that is “natural” about gender ordering. Biological factors determine fully only a small range of human activities (less full determination, in the form of inchoate propensities and predispositions, may occur much more widely, but that is another issue). It has been argued that gender relations are constructed historically in specific social contexts. Construction here might be defined as ‘giving a particular content to a category, establishing particular contrasts with and distances from other social categories, and constituting an interest around which identity and action can be organised’ (Connell, 1987, p.137). This leads to

practices, which become institutionalised - that is, acquires and signifies custom, routine, repetition and enduringness (after Giddens, 1984).

In conclusion, it might be assented that the social relations of gender are 'not determined by biological difference, but deal with it .... 'Gender' means practice organised in terms of, or in relation to, the reproductive division of people into male and female' (Connell, 1987, p.140). In this view, gender is seen as a process rather than a thing, but the establishment of general categories by means of this process invites and encourages reification. The process, and the reified categories, acquire weight and solidity in the form of institutionalisation. It might then be stated that 'gender is institutionalised to the extent that the network of links to the reproductive system is formed by cyclical practices. It is stabilised to the extent that the groups constituted by the network have interests in the conditions for cyclical rather than divergent practices ..... What persists in the organisation or structure of practice, its effects on subsequent practice'. (Connell, p.141). The importance of this formulation, and the central role of practice, in understanding the male experience of caring is established below.

## **THEORIZING MASCULINITY**

When it was recognised that men did engage in informal caring in significant proportions, it was argued that male caring was different in both substance and style. Men were thought not to be engaged thoroughly in the care situation because they did not provide intimate care, and because they had help with caring tasks. It was felt that

they were not involved at the required emotional depth, and those few who were involved in this way tended to be seen as aberrant. This issue of emotional involvement was investigated by Ungerson, who argued that men were much more likely to provide care from a basis of love and affection than from a sense of duty or responsibility. The contradictory situation formed by these opposing issues was not clarified necessarily by more recent work which showed that those of either gender caring for an elderly person for a significant period of time were more likely to suggest that love was their main motivating factor (Dalley, 1988; Ungerson, 1983; Levin, et al, 1983)

As has been shown above and elsewhere (see, for example, Arber and Gilbert, 1989; Parker and Lawton, 1991) many earlier claims concerning male caring were simply incorrect or inaccurate. They would seem to be informed by, and presumably informed, certain stereotypical ideas about masculinity and male behaviour.

Male sex-role characteristics have been described variously over the comparatively short history of social scientific concern with gender. The early work of Terman and Miles (1936), conducted at least partially in response to social anxieties about the military fitness of American men, was important in establishing sex-role stereotypes. They collected lists of characteristics that seemed to differentiate between the sexes, and produced a conception of 'masculinity and femininity as two opposing types of personality, located at either end of a single, bipolar dimension' (Edley and Wetherall, 1995, p.95). This approach informed much later work, although there were attempts to reduce characteristics to a small number of core traits. For example, Brannon (1976) discusses four clusters of characteristics which epitomise masculinity:

avoidance of all feminine traits, and behaviours; acquisition of high status and success; showing strength and confidence; displays of aggression, violence, and daring. More succinctly, Pleck and Sawyer (1974) insisted that male sex-role could be summarised by the rather gnomic and rapidly ageing maxims “get ahead” and “stay cool”. Archer and Lloyd (1985) produced a list of terms that were positively assigned, with a high level of inter-rated agreement, to men. These were:

acts as leader, aggressive, ambitious, analytical, assertive, athletic, competitive, defends own beliefs, dominant, forceful, independent, individualistic, leadership abilities, makes decisions easily, masculine, self reliant, self sufficient, strong personality, willing to take a stand, willing to take risks

Other studies of that period confirmed high levels of consistent agreement among people in assigning these characteristics to men rather than women (Williams and Bennett, 1975).

A survey of recent ideas about maleness and masculinity reveals that it is theorised generally that men are socialised into the male sex-role. Socialisation might be defined as ‘the business of learning the normative standards of society’ (Lee and Newby, 1984). Role theory asserts that most people, for almost all of the time, behave in ways, which are prescribed socially. There are a number of theories of sex-role assimilation, ranging from the functionalism of Parsons, through social learning theory to cognitive development theory; the range of theoretical orientation is reviewed by Edley and Wetherall (1995). An important contribution to cognitive development theory is provided by Bem’s gender schema theory (Bem, 1974, 1981,

1993). This theory argues that gender distinction is the most important classificatory system for humans, and that all experiences, including a sense of self, are conceptual frameworks, formed as a result of past experiences; they serve to impose order on the chaos of objects and events of continuing life.

Sex-role theory provides a way of understanding the manner in which people come to embody the norms of their societies. It does not rely on biological factors, and can provide a fully social account of human actions, with a simple framework for comprehending the vital relationship between the individual and society. It allows a certain optimism about the probability of changing sex-role norms, and has a degree of plausibility as an explanatory theory.

However, there are many problems with it. Sex-role theory does rest on male/female biological differences, and fails to recognise the reificatory nature of the collection of gender attributes as a research strategy – ‘there is no description without a standpoint. The apparently neutral descriptions on which these definitions rest are themselves underpinned by assumptions about gender .... Positivist procedure thus rests on the very typifications that are supposedly under investigation....’ (Connell, 1995, p.69; and see Kessler and McKenna, 1978). Sex-role theory utilises an oddly realist concept of the self, in which the “real” self is suppressed in favour of the socialised, gendered self. This implies that the “real” self does not have its origins in society, but must be somehow pre-social. As Dahrendorf (1973, pp 13-14) indicated, still persuasively: ‘it would be wrong to see the role-playing social personality as an unreal person who has merely to drop his mask to appear as his true self.... His roles are more than masks that can be cast off, his social behaviour more than a play for

which audience and acts alike can return to 'true' reality'. A further difficulty is that sex-role theory fails to distinguish between norms as descriptive and norms as prescriptive. This has led to the characterisation of activities that vary from the norm as deviant and defective, and it exaggerates the extent to which men conform to the normative standards. The focus on the standard normative case has led to a neglect of anything else, and to the over privileging of a certain form of masculinity (see Connell, 1987).

Finally, sex-role theory seems to presuppose a stable object of knowledge - masculinity, femininity - that is constant across all cases and contexts. Some ethnographic work suggests that this is not the situation at all. Perhaps the most powerful, and most striking, example of this is Strathern's (1981, p. 178) analysis of the utterly alteric use of gender as metaphor by the inhabitants of the New Guinea Highlands. This use serves to 'detach posited qualities of maleness and femaleness from actual men and women. A person of either sex can behave in male or female ways'. In this culture, gender descriptions are connected strongly to the achievement of personhood; indeed, 'the sex stereotyping of modes of orientation is in many ways the precondition for the visibility of the "person" as a genderless locus of orientation. Individuals of either sex can be seen to act in a manner typical of the other .... The deviation of individuals from their gender type makes the "person" visible'. (Strathern, 1981, p.179; see also Strathern, 1978, 1991). This idiomatic use replaces the idea of sex differences, and explodes all usual definition of masculinity. This was further confirmed by the work of Poole (1981) and Meigs (1976), who concludes that, in her particular field of study, 'a person's gender does not lie locked in his or her

genitals, but can flow and change with context as substances seep into and out of his or her body' (Meigs, 1976, p.406).

Despite these manifest and long-identified difficulties with sex-role theory, some of its concepts and something of its language are retained for use in this part of the study, even while presenting data that seem to undermine it. This is because the concepts and language of sex-role theory inform everyday thought on gender issues, and are thoroughly ubiquitous. It provides normative standards, which people give assent to, whilst knowing that what is not normative is not necessarily unusual, or even desirable. It is, of course, good to think with. Its drastic simplification of the complexities of gender, reducing everything to a single duality and assigning all that is not standard to the category of deviance, has an easy appeal, and can be grasped quickly. Importantly for the present study, it was the mode of thought that all informants used to discuss and, I suspect, to think about, their experiences. Even when resenting its restrictions and resisting them strongly, informants still used the language and thought-style of sex-role theory. This, as will be shown later, could be seen as a major component of their difficulties in reconceptualizing their caring activities and experiences.

## **THE COSTS OF CARING**

Many studies have noted the physical, emotional and financial costs of informal caring. Some researchers have found a higher incidence and prevalence of psychological ill health, sometimes expressed as psychiatric morbidity, among

informal carers (Bebbington, et. al., 1986; Levin, et.al., 1989; Gillreard, et.al., 1984). A North American study has shown that, across all indicators of mental health, carers are 'more depressed, express higher levels of negative affect, are more likely to use psychotropic drugs, have more symptoms of psychological distress than the general population and suffer from physical health problems (particularly diabetes, arthritis, ulcers and anaemia)'. (Pruchu and Poteshnik, 1989, p.699). This should be noted in connection with the well-documented higher levels of morbidity and mortality in men, and the reported propensity of men not to register complaints about ill health of all sorts, and emotional ill health in particular.

Studies have also noted the social and financial costs of caring. This includes less, or severe reduction, of income. For some male carers, abandonment of paid employment to take up the task of caring can occasion permanent unemployment. Adoption of caring is also likely to cause a severe curtailment of social life and the range of usual informal social supports. Loss of friendship networks is reported widely in the literature (Arber and Ginn, 1993; Glendenning, 1992; Evandrou and Winter, 1993; Parker, 1985).

## **CONCLUSION**

It can be argued that difficulties and comparative slowness in recognising, describing and comprehending the experiences of male informal caring are part of the general difficulties of research into caring. Although there are many studies of caring, it has been asserted that 'concepts have been defined, variables selected, hypotheses

formulated, measures and scales constructed, samples selected, inquiries conducted and data analyzed – all as if the basic meanings and concepts of the home-care experience were known. Few, if any, have bothered to ask whether care and care giving have different meanings to those directly or indirectly involved in home care. None seem to have wondered whether caring and care giving are the same or contrasting modes of experience. Rarely, if ever, has anyone even raised the question of whether there may be different versions of the home's going-on as a sickroom, which would imply that measurement would necessarily produce multiple, possibly contradicting 'figures' (Gubrium and Sankar, 1990, p.8).

This criticism requires some sort of response. It is probable that another care equation study, providing another multivariate analysis, would not be a sufficient response. It is hoped that the present study, recognising the complexity of the care situation, may go some way towards providing a more grounded response, thereby adding a little to what is known and increasing the number of possible routes to further inquiry.

## **REVISITING THE LITERATURE**

Given the period in which this review and the actual research took place, it has been necessary to revisit the literature in order to identify any new and different views of male caring that might challenge the essential argument of the thesis. Given the speed of contemporary change, governmental concern about informal care and the shifting fashions of intellectual discourse, I rather supposed that this would be the case. However, on examination, this appears not to be so. Even though some of the

references could be updated to take account of new editions, or replaced, and a few – very few, as it happens – be added, I still feel confident to assert the continued relevance of the thesis, and feel that it still presents a compelling argument.

The experiences of male informal carers remain as unexplored and under-theorised as they were when I first began to contemplate the subject. In truth, there has been some new work, and I discuss some of this below, but not the entirely necessary paradigm shift recommended by, for instance, Gubrium and Sankar as early as 1990. A review of the published literature from 2000-2005 shows that the situation is little changed. As previously, there have been a large number of papers dealing with the prediction, measurement, comparison and, eventually, alleviation or amelioration of what is referred to as carer burden (for example, Chappell, et.al., 2002 or Clyburn, et.al., 2000). This, as indicated above, is to miss the point. Other work approaches the caring experience from a considerable remove, not engaging with how carers experience their situation, and what they think about it (for example, Mitrant, et.al., 2005; McClendon, et.al, 2004; Atienza, et.al., 2001)

As regards the few cross-gender studies of caring, male carers are still seen as somehow aberrant. It is reported consistently that male carers have better health than do female carers, that men provide less intense and intimate care, that ‘female gender was a significant predictor of experiencing difficulty with providing care and perceiving unmet need with care provision’, and that women caregivers experience greater emotional challenges (see, for example, Navaie-Waliser, 2002; Thompson, E, 2000).

Frankly, this is disappointing. Thompson (2002) repeats the argument for a paradigm shift in the study of male carers. He argues that ‘the adjective “male” announces a predisposition to reframe caregiving as something different – generally something less – when the caregivers are men (Thompson, 2002, p.21). He asserts that researchers have ‘rarely stepped outside the typical gender difference approach, and looked within to ask how gender constitution, societal reaction, and men’s involvements and relationships shape their ongoing experience. What do men experience, and why? The imagination that underpins discovering what men, and what *different*, men do feel, and contemplate as caregivers has been neglected’ (p.21). Thompson concludes that studies of male carers have laboured under a set of redundant precepts, which have served to form any subsequent perceptions. For example, most studies perceive men as a homogenous class – ‘Although significant diversity exists, men are aggregated into the category “male caregivers” and the gender stereotype is the sole model of manhood imagined.’ Men who do not fit the stereotype are defined as acting out of character as men. This is typical of most studies.

An unexpected and perhaps unusual example of this tendency is provided by Bowers (1999) in a study of the caregiving experiences of widowed men, in which it was predicted that male caregivers would describe themselves as androgynous or “feminine” because of the caregiving experience. This hypothesis is underpinned by an unacknowledged precept that caregiving and masculinity are incongruent and incompatible. In fact, the study found that these men described themselves as more masculine, challenging the idea that men are less involved in, and expert at, caring. It asserts instead a ‘situational flexibility’ in men’s behaviour (Bowers, 1999, p.652-653).

Similarly, Carpenter and Miller (2000), in a review of the period 1980 to 1999, could find only eighteen usable studies of male carers. In none of these have researchers been able to 'capture the dynamic process underlying the male caregiver's experience that may be separate from, albeit related to, the female norms that have dominated the literature' (p.100). A survey for this Afterword of the period 2000 to 2005 reveals a similar picture.

In the light of all this, I reiterate my claim that the findings that follow continue to have relevance and pertinence. To go further, it may not be even the most preliminary of steps towards the paradigm shift in the study of informal male carers; however, it may constitute a small step towards the establishment of a viable, meaningful examination of the experiences of such men. Clearly, there is a need for much more work in the area, and it might begin where this thesis ends.

This Literature Review has concentrated on selected facets of the informal caring situation, and has not referred to other associated topics. For instance, it does not deal particularly with issues of the care of the mentally ill, with the life-long care issues of those with Learning Disabilities, with the care of children generally and with care provided by children. All of these are important subjects. Further, it does not consider the care of sick or disabled men by other men, although this is referred to in passing. This sort of concentration is perhaps inevitable, given the constraints of space and the circumscription of the central subject. It reflects also the nature and particular variety of the informants in the study. What the review does establish is the context of male informal caring, and what has been thought about it to date. It examines issues of masculinity as they relate to informal caring, and to the associated

strategies employed by male carers. Further, the role of narrative in the formation and maintenance of identity is discussed, with special emphasis on the reformation of damaged identities through narrative reconstruction. This, I would argue, provides stable and sufficient ground for the whole study.

### **3. METHODOLOGY 1: CONSIDERATIONS**

#### **INTRODUCTION**

The principal aim of the study is to explore and delineate the experiences of men who undertake the informal care of sick or disabled relatives. The focus is on the subjective experience of caring, and on the meanings that carers bring to that experience. This also involves the elucidation of shared and common patterns of experience.

There are a number of different research methods that might be used to gather this sort of information. Among these, the general scientific method is reported to be the most sophisticated method of acquiring knowledge that has been devised (Polit and Hungler, 1995), combining features of induction and deduction to produce knowledge that is reliable and valid. This positivist - empirical approach is based on the firm principle that the only reliable knowledge about any phenomenon is reducible to knowledge of particular instances of patterns of sensation. Probabilistic generalizations based on observations of these patterns are ordered logically to form theories. Such theories facilitate the prediction of future sensory patterns, and can be tested by further observation (after Harré, 1981).

This view is based on some fundamental assumptions:

1. There is an objective reality, existing independently of human beings.
2. Scientific reality is determined by the nature of objective reality.

3. Objective reality is consistent, orderly and, eventually, predictable.
4. All phenomena have antecedent causes, which can be discovered.

This is put more succinctly, and in a more developed manner, by Barrow (1988):

1. There is an external world, separable from our perceptions.
2. The world is rational: 'A' is not equal to 'not-A'.
3. The world can be analyzed locally - that is, one can examine a process without having to take into account all the events occurring elsewhere.
4. There are regularities in nature.
5. The world can be described by mathematics.
6. These presuppositions are universal.

This is, of course, a view of things. It is not timeless, and has an interesting history (Shapin, 1994; Woolgar, 1988). It is also a rather localized and contingent view. The aims of the scientific method are, roughly, exploration, prediction and control. Exploration records the incidence and dimensions of phenomena. Exploration is a method of organizing and integrating ideas about the interrelation of phenomena. Prediction and control allow deduction and action, based on earlier findings. Science as an activity is purposeful, systematic and intensely self-aware, producing theories that are clear, logical, consistent, precise, testable and parsimonious. It has, of course, produced much interesting and useful work, some of which is extremely important to contemporary life.

Nevertheless, the scientific method has its limitations. For instance: flawless scientific inquiry, adhering strictly to all requirements, is very largely impossible; no single study can produce definitive data; moral and ethical issues impose severe restrictions on the scope of research; some problems, particularly those concerning values, are not amenable to scientific research; the measurement of phenomena is often very difficult. However, it is in the area of human psychological functioning that standard science is most limited. Each human is more or less similar regarding biological functioning, and more or less unique regarding the aggregate of personality, mental capacities, life history, social environment and value system. Science has found it difficult to capture and report on the essential human experience, including both affect and meaning. It is thrown into difficulty by the ability of humans to respond idiosyncratically, to think about thinking and to second-guess experimental intention. Science can proceed only by a huge simplification or fracturing of human experience.

These limitations are exemplified by a large body of quantitative research into what is usually referred to as 'carer burden'. Much of this work, over the past two decades, has necessitated the design and development of special instruments to measure the subjective and objective burdens of caring (see, for example, Zarit, Reever and Bach-Peterson, 1980; Poulshock and Deimling, 1984). Many studies focus on the relationship between level of burden and a particular outcome of care, such as length of caring, perseverance with caring and the various termination points of caring (Beigel, Sales and Schulz, 1991; Montgomery et.al, 1985; Gilhooly, 1986). Some of this work is of a high level of complexity, taking into account a wide range of

variables, and producing a multivariate analysis of hypothesized co-variations between carer attitudes and the termination of care.

Unfortunately, this work has not been designed to address the human problems of caring, and has not sought to understand them. Gubrium (1987, 1990, 1991, and 1992) was one of the first to suggest that this led to a widespread poverty of understanding regarding the basic processes and meanings of the caring experience. He argued that this experience might defy measurement and quantification because of its human complexity, which involves concepts of self and other, gender role, family functioning, social values and expectations, cultural norms, economic issues and the very personal meanings of care for the caregiver, the recipient of care and for significant others.

Gubrium argued that quantitative studies might be possible only when some basic research on the phenomenon of caring has been performed. He suggested, and delineated provisionally, a programme of ethnographic research to explore its dimensions, constituting “basic” research in concepts and understanding. (Gubrium, 1990). Over a decade later, it is clear that this prescription remains pertinent. It is clear equally that it has not been addressed in any comprehensive manner.

It is because of the limitations of quantitative research with its evident lack of utility in gathering the necessary data, and in the light of Gubrium’s suggestions given above, that this study is located firmly within the qualitative research paradigm. This seems to provide a more appropriate way of approaching subjective human

experience, although the difficulties associated with the concept of distinct and separate research paradigms are understood and accepted (Silverman, 1983; Hammersley, 1992).

## **QUALITATIVE RESEARCH**

Qualitative research has a long and ramified history, ranging from pre-modern travellers' tales, through the exertions of colonial ethnographers and the proliferation of mid-twentieth century community studies to all sorts of post-modern experimentation. However, the term is homogenising, and "qualitative research" subsumes a bewildering array of theories and practices, none of which belong to any particular discipline. Qualitative researchers are said to use 'semiotics, narrative, content, discourse, archival and phonemic analysis, even statistics. They also draw upon and utilize the approaches, methods and techniques of ethno-methodology, phenomenology, hermeneutics, feminism, interviews, psychoanalysis, cultural studies, survey research and participant observation, among others' (Denzin and Lincoln, 1994, p.3; and see Atkinson, 1995, for a critique of this sort of listing).

This variety permits (and, indeed, encourages) some very loose definitions: 'Qualitative research is multi-method in focus, involving an interpretative, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and

collection of a variety of empirical materials - case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts - that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected methods .....’ (Denzin and Lincoln, 1994, p.2).

Any part of this definition might be open to critical debate (see Silverman, 1993, pp24. ff) but, eventually, some defining characteristics of qualitative research can be listed:

1. Preference for qualitative data.
2. Preference for naturally occurring data - that is, observation rather than experiment.
3. Focus on meaning.
4. Preference for inductive research rather than hypothesis  
(an adaptation of Hammersley, 1992, pp 160-172).

Even this rather modest list of characteristics might be open to criticism. For instance, it could be argued that to suppose there can be “naturally-occurring data” is to subscribe to the remnants of naïve realism; and it is possible to go further with this criticism. Perhaps qualitative research is seen best as a historically constituted collection of interpretative practices that are available to researchers on a pragmatic, practical basis. The history, or histories, that are attached to each of these practices reveal the tension, contradictions, difficulties and plain muddles that constitute the qualitative paradigm.

The position taken in this study acknowledges the necessity to ‘scrutinize systematically the methodology by which findings ..... were produced, and, in particular, to consider how the activities of the researcher may have shaped those findings’ (Hammersley and Atkinson, 1983, p.236). However, it also recognized that ‘the goals of research will not be served by slavish adherence to the historical accidents and arbitrary boundaries that separate methodological traditions and particular research methods’ (Atkinson, 1995, p.123). It is argued that ‘whatever high-flown rhetoric is adopted about uncovered meanings and understandings of discourse and narratives, what is required for a discussion of empirical work is some means of translating data from the field - interviews, observations, documents - into an explanation of the topic in hand, which can be conveyed to others and understood by others’ (Melia, 1997, p.35). Accordingly, the research strategy described below uses some well-developed techniques to ‘make the world of problematic lived experience of ordinary people available to the reader’ (Denzin, 1989, p.7). The commensurability between the aim, the epistemological starting point and the explanation of the data is open to critical examination and debate.

## **IDENTIFICATION OF INFORMANTS**

In the first instance, potential informants for the study were identified through a survey of the caseloads of Community Nurses (formerly District Nurses), Community Psychiatric Nurses and Community Nurses in Learning Disabilities. These nurses

were employed by a (then) Community Health NHS Trust, and provided services for a whole county. The survey was permitted and facilitated by my then employment at the Department of Nursing in that organization.

A survey document was sent to 300 nurses without any preparation of recipients. They were selected from a slightly larger total population (505 nurses), to prevent duplication and to ensure representation of all geographical areas within the county. This necessitated the use of four separate sampling frames. The response rate within the specified time limit for the survey was 74%. Nurses were asked to identify:

1. the number of patients on the caseloads cared for solely or principally by a man;
2. the number of those men caring for an aged parent;
3. the number of those men caring for a spouse or child;
4. the number of those men under 60 years of age;
5. the number of those men under 45 years of age;

The results were as follows:

1. 251 male carers were identified
2. 106 of these were caring for an aged parent
3. 145 of these were caring for a spouse or child
4. Of the 145 men caring for a spouse or child, 47 were under 60 years
5. Of these 145 men, 6 were under 45 years.

A large amount of previous study has concentrated on the experiences of the older male carer, typically caring for an elderly parent or elderly spouse. In this study, it was decided to include younger carers where possible. A sample of 8 responding nurses was selected randomly (every 11<sup>th</sup> item from an alphabetical list). They were asked to make contact with the youngest man caring for someone on their caseloads. Those nurses who identified more than 4 male carers in the initial survey were asked to contact the 2 youngest men. The men thus contacted were given letters inviting them to participate in the study (see Appendix 1 for specimen contact letters). The nurses telephoned contact information - name, address and telephone numbers - of those men who agreed to participate. I contacted them by telephone, and arranged to meet them in their homes.

This process produced 10 possible informants. I was able to contact only 7 of these, and 6 of them were willing to participate in the study. A further round of selection produced 8 possible informants, 6 of whom agreed to participate in the study. This gave a total of 12 informants, with a wide range of ages, all of whom were caring for a sick or disabled wife. At a slightly later date, I added 2 further informants. These were selected at random from those who were caring for an aged parent, and from those few who were caring for a child. This gave added breadth to the range of informant experiences, and is an example of purposeful sampling of the maximum variation type (Patton, 1990). This gave a final total of 14 informants.

This combination of random and selective sampling produced an interesting group of informants. In the first place, this represents an opportunistic sample, available to me

because of my employment circumstances, but thorough representation is impaired. For example, only those men caring for a person receiving formal community nursing attention could be selected. Further, the sampling method did not ensure adequate representation of all geographical areas within the county (although this was achieved by happy accident). However, within these constraints, the sample does seem to provide a useful range of caring experience in a variety of settings. Certainly, it provided sufficient and useful data. Further consideration of the sampling strategy is given below.

At initial interview, informants were further assessed according to criteria originally formulated by Tremblay (1957), but utilized by Johnson (1990). These were:

1. exposure to relevant information
2. possession of relevant information
3. willingness to participate in the study
4. ability to communicate relevant information
5. possession of a degree of objectivity and impartiality.

Clearly, only the first three of these could be assessed before interview, and the remaining two seem to be a sort of counsel of perfection, not easily judged or assessed.

At this stage, account was also taken of the inclusion of contrasting cases to gain as wide a perspective as possible, in accord with the precepts of Miles and Huberman

(1984). As shown above, some informants were selected strategically, with consideration being given to the content of study. As Tremblay asserted in this regard: 'we are not randomly sampling from a universe of characteristics under study. Rather, we are selectively sampling specialised knowledge of the characteristics' (1957, p.689). This long-standing idea has been found to be useful across a range of research projects (Patton, 1990).

This scheme of informant selection utilizes two complementary strategies described by Glaser and Strauss (1967). These are, in the first instance, to minimize the differences between cases to focus on the essential properties of any particular category (being a male carer); and in the second instance to maximise the difference between cases to 'increase the density of the properties relating to core categories, to integrate categories and to delimit the scope of the theory' [(Hammersley and Atkinson, 1983, p.44) (select a range of male carers in a variety of care situations)]. This scheme provides some assurance of theoretical representativeness (as opposed to statistical representativeness) (Johnson, 1990, p.27). The researcher should select informants 'from segments of social system that are meaningful in terms of .... explicitly stated theories, hypotheses or hunches (e.g. substructures, typologies, categories, network subgroups) as to the working of the society, culture or phenomenon under study. As long as these theoretical assumptions are valid, so too will be the ethnographic sample of informants' (Johnson, 1990, p.27). As Mead has indicated: 'The validity of the sample depends not so much upon the number of cases as upon the proper specification of the informant'. This clear specification allows each informant to be 'studied as a perfect example, an organic representation of his complete cultural experience' (Mead, 1953, p.646).

All informants were white, British and of working class origins, although many of them had middle-class aspirations, and some of them had been educated out of their original class positions. They were all able-bodied, and had extensive employment histories.

## **DATA COLLECTION**

It is perhaps worth noting that informant recruitment and data collection did not proceed in an unproblematic manner. On the first morning of the data collection period, I sat in my office with a list of 10 informants' telephone numbers. I was, in comparative terms, eager to get on with data collection, and I wanted to arrange as many interviews as possible. I became dismayed increasingly to get no answers as I rang the first 7 numbers on my list. I got an answer to my eighth call, but the informant was out, and the person I spoke to did not encourage me to call back. I did speak to the ninth person on the list, but he had decided not to participate in the study. I began to wonder about the viability of the whole project. However, I did manage to contact everyone, and did arrange interviews.

All interviews were conducted in the home of informants. Most interviews lasted for about 2 hours. Some informants were interviewed once only. Others were interviewed on 2 occasions (Mr C; Mr D; Mr E; Mr H; Mr L; Mr P). Interviews were recorded using a mini-disc recorder with a special microphone for recording two or more speakers. Two interviews were conducted unavoidably in the presence of the

recipients of care, who remained asleep throughout (Mr E; Mr C); two further interviews were conducted with the occasional and fleeting presence of the recipients of care (Mr B; Mr D). The experiences of the recipients of care, although interesting, were not the focus of this study, and no account is taken of them. This permits a more intense focus of the experiences of carers.

There were some factors that may have exerted influences on the data collection process. Firstly, I had some previous experience of interviewing. For most of my professional life, I have been required to interview people in a variety of ways on a very regular basis. In my earliest employment, I took formal medical, familial and personal histories from all patients admitted to neurological and psychiatric departments. At the time, this was seen both by me and my employers, as an entirely straightforward, unproblematic process. The collection and codification of information, and its use in the construction of “case-ness” and case-notes, was perceived as the elicitation and storage of so much clinical reality. From very early on, I became aware that the work of Goffman and others might problematize the process, but did not alter my interview style as a consequence. In a later period, I trained in one of the psychotherapies, and eventually spent all my working days in individual sessions. I was very interested in the techniques of the therapeutic interview, and in the process of being a therapeutic agent.

More latterly, I spent a significant proportion of my time dealing with complaints and litigation from the users of NHS services. This almost always involved interviews with patients, relatives and assorted members of staff, ranging from simple information gathering to formal negotiations of settlements. At the same time, I was

involved in the selection process for senior NHS clinicians, and sat on interview panels on a regular basis.

This occupational background made the interview situation less difficult than it might have been. At interviews for the study, I felt some slight initial trepidation, which evaporated quickly. On the whole, I believe that I had no difficulty in gaining rapport or in eliciting information. I felt at ease in the situation, and was glad that I had previous experience of things like reflective listening and the use of open questions. However, this previous experience did occasionally impinge on the research interviews. I found myself utilizing those earlier styles. Without thinking much about it, I began to form tentative hypotheses about psychodynamic processes, and had to remind myself that I was engaged in data collection of another sort. Similarly, there were occasions when I found myself in complaint investigation mode, beginning to compose letters to various people, and constructing appropriate apologies to aggrieved parties. All of the time, I noted things I might have helped with in one way or another. I was a little amused, and even fascinated, by this propensity, and I learned to watch out for its appearance. It never quite disappeared, and I came to regard it as a sort of enduring testament to those responsible for my earlier training.

Another factor that impacted on the process of data collection was the ease and apparent fluency with which the average informant discussed personal issues. I expected to work hard to gain personal information, and assumed that men would, on the whole, be reticent and uncomfortable about divulging much about themselves. I was surprised by just how much, and how soon, most informants revealed about their intimate feelings. I was surprised equally by the ease with which issues concerning

masculinity were discussed. Some informants needed to encase this information in a humorous, self-deprecating mode of delivery, which seemed to serve defensive purposes, but many did not.

It was not at all difficult to elicit information. A few informants started slowly, but became more effusive and expansive as the interviews progressed. The oldest informant (Mr B) was the most reluctant to talk about himself, and I attributed this to the social environment of his upbringing until I spoke to the informant closest to him in age (Mr E), who spoke for seventy-five minutes in response to one rather general question. Other informants inhabited the middle ground between these two.

Despite the provision of information sheets and a brief explanation at initial contact, most informants regarded me as a representative of some sort of local authority, perhaps the Health Authority or Social Services. There was a feeling that I might report to an even higher authority, such as the NHS Executive. Most informants seemed to be motivated by altruism, and participated in the study because they felt it might contribute to an amelioration of the carer predicament. None of them expected to derive any personal gain. I was accepted with unfailing kindness, courtesy and consideration. It was evident that all informants went to some lengths to accommodate me, and to provide clear information

## INTERVIEWS

Data for the study was collected at individual extended interviews, details of which are given below. It is noted that the individual interview is a thoroughly ubiquitous activity, and we live in what has been termed an “interview society” (Silverman, 1993, p.19). The interview seems to formalize some natural human inclination - “to ask questions of other people, and to treat their answers with some seriousness” (Schuman, 1982, p.21). It has become important in such diverse fields as journalism, entertainment, medical practice, criminal and juridical processes, psychological treatments, candidate selection, marketing research and confessional exercises. This ubiquity both informs, and is reflected by, the wide use of the interview in social and cultural research. Kvale (1996, p.8) provides some theoretical and technical reasons for this wide use. The precise epistemological status and the usefulness of data obtained at interviews remains contentious. In many ways, this is a sort of localised sign of wider and more profound debates about epistemology in the social sciences. Early theorists and practitioners saw the interview as an unproblematic method of gaining access to information held by those interviewed. This information was thought to be imparted in a direct, uncontaminated manner. Interviewers could regard themselves, and act, as impersonal collectors of facts, rather in the manner of early nineteenth century natural scientists. It was thought that valid, reliable data could be gathered if attention was paid to the random sampling of subjects where appropriate, and to the administration of standardized questions which allowed tabulation and statistical analysis.

This view has been subject to attack from two other positions. Firstly, researchers have been reminded that the interview is a social event, governed by all the usual rules, structures and conventions of social encounters. The ability and willingness of research subjects to provide information is affected by these. Interview data should be interpreted 'against the background of the context in which they were produced'. (Hammersley and Atkinson, 1983, p.126). According to this critical view, reliability and validity depend on the achievement of intersubjective depth in the course of profound and prolonged interviews. This is an essentially humanistic conception, stressing the interactive, interpersonal nature of the encounter.

Another position provides a critique of both the early "positivist" model, and the later interactionist revision. This asserts that interviews provide data which express the conversational practices and interpretative procedures present in what both interviewer and interviewee are doing through their verbal and non-verbal interaction. Accordingly, it is not possible or even desirable to judge interview responses as true or false reports on reality. Rather, such responses can be treated as displays of perspectives and moral forms, a selection from the entire repertoire of available narratives.

In many ways, the effect of this critique is to render the interview more or less useless as a data-gathering tool. It can be relied upon to provide data about itself and its operation in a very limited context; its situatedness is entirely constraining. Although there might be a certain attraction in this proposition, with its evocation of an anomic, iconoclastic nihilism, it is not at all adequate.

In this study, the view is taken that these propositions should be employed carefully as critical devices, and that attention should be given to the circumstances of response production in the interview situation. Whilst rejecting any realist conceptions, it has been argued persuasively that interviews can capture something of individuals and society – ‘we take it that two persons can communicate their perceptions to one another. Knowing full well that there are both structures and pollutants in any discussion, we choose to study what is said in that discussion’ (Glasner and Loughlin, 1987). It is perverse to maintain that interviews can provide only knowledge about themselves, and that a ‘life can only be understood by the same means that it is lived’ (Melia, 1997, p.34). It is the task of the social scientist to render lives explicable and open to analysis. Social science must - eventually - provide material that is susceptible to practical reasoning and critical analysis; it must be able to convince others. It has been argued that it may be ‘counter-productive to get further and further into a philosophically interesting mire which keeps us from the plausible story’ (Melia, 1997, p.34). As Strong (1979, p.250) asserted: ‘the best we can hope for ..... is a plausible story’.

## **TRANSCRIPTION**

All interviews were transcribed in longhand, and then typed. Far from being the boring, laborious process described in some textbooks, I rather enjoyed the work of transcription. This is not, I think, an example of perversity on my part. I appreciated

the opportunity to listen again to the informants, and was able to engage in some early sorting of data. I enjoyed the actual process of turning audio recordings into writing, with all the attendant difficulties of accounting for the vagaries, nuances and oddities of spoken communication.

This process raises issues concerning the reliability and validity of interview transcripts in research. It is accepted that transcription involves a process of “translation” from the oral to the written form, each mode having its own distinctive rules and practices. Therefore, it is understood that transcripts ‘are not copies or representations of some original reality, they are interpretative constructions that are useful tools for given purposes’ (Kvale, 1996, p.165). Clearly, the process of transcription exerts some particular effects on data. Transcripts are, of course, decontextualized, and this produces an immediate difficulty – ‘If one accepts as a main premise of interpretation that meaning depends on context, then transcripts ..... make an impoverished basis for interpretation’. (Kvale, 1996, p.167). The spatial, temporal, social and interpersonal aspects of the actual interview are difficult to convey in transcript. Vocal intonations, facial expression and the language of bodies in interaction add nuances and intimations that are almost entirely missing in transcripts.

It is difficult to see how this could be otherwise. Interview transcripts can never provide a relatively stable, non-contextual, transparent and unproblematic relation between representation and reality. Just as interviews can be seen to construct reality in intersubjective space, so transcripts construct another version of events, another

context to generate meaning, another reality - 'Different transcripts are constructions of different worlds, each designed to fit our particular theoretical assumptions and to allow us to explore their implications' (Mishler, 1991, p.271).

However, it is reasonably certain that interview transcripts can provide useful data for research purposes. It might even be the case that some elements of meaning remain constant across, and through, the mesh of contexts. It is important that analysis of transcripts should involve a sensitivity to the contextuality of meaning, and to the intrinsic relation of meaning and form. In such an analysis, informants' answers are not viewed as reality reports, but are considered for the ways that they construct aspects of reality in collaboration with the interviewer: 'The focus is as much on the assembly process as on what is assembled' (Holstein and Gubrium, 1997, p.127). There are many examples of this sort of analysis, in which both the reality-constructing process and the conveyed subjective meanings are examined (Holstein and Gubrium, 1994; Riessman, 1993; Silverman, 1993).

## **DATA ANALYSIS**

It had been my intention to use the NUD.IST 4 software package for data analysis, and I began that process. I was familiar with the use of NUD.IST, Ethnograph and Text Analysis, and had unlimited access to them. However, I discovered that I was much more comfortable with less technical procedures, and used some traditional

methods of data organization. I had gained a close familiarity with the data through the transcription process, and wanted to maintain and use that familiarity.

Accordingly, I made multiple photocopies of typed transcripts and used some different forms and many different colours of text-marker in the coding process. Eventually, I cut relevant segments from the text, and stuck them onto large sheets, which grew into separate “concept files”. This suggests a cumbersome and messy process, but I felt entirely comfortable with it, and it gave me a firm control of the data. I used NUD.IST 4 both before and after my analysis of data for the present study, and I do not think I was at all disadvantaged by not using it. On the contrary, I think I had a greater ease of data management, although this would not have been the case with a larger amount of data.

I began coding the data according to some very general categories: events, activities, strategies, emotion and reflections. These were answers to the questions: What happens? What do you do? Why do you do it? How does it feel? What do you think about it now? These categories were taken, and extensively modified, from a study of the experience of families with children who have Duchenne Muscular Dystrophy (Gagliardi, 1991). Essentially, this was a process of data organization, designed to facilitate the retrieval of data fragments of note. It also allowed the further operations of identifying relevant phenomena in the data, collecting examples of those phenomena and analyzing those phenomena to find similarities, differences, patterns and structures (Seidel and Kelle, 1995; Coffey and Atkinson, 1996). Codings became more focused, further dividing phenomena, as the process continued. As common

patterns of experience emerged, I focused more on singular and untypical events in carer careers.

Coded data was thus thoroughly decontextualized and disassembled. This created “pools of meaning”, enabling the further identification of patterns and regularities. It was also possible to identify contrasts, differences, irregularities and counter cases. Codes can be seen to act as heuristic devices, allowing certain modes of investigative thought. Codings were seen to imply (or create) systematic relationships between concepts and categories, and these formed the basis for interpretation. The interpretative framework was provided by the data itself. For the main part, this process was in essence an organizational process. However, it did produce some interesting patterns of experience that are detailed fully in the relevant chapters.

## **THE SELF IN THE STUDY**

The reflexivity of the research process is recognized and acknowledged in this study. It is understood that a strong assertion of objectivity has been largely replaced by a description of subject position; all writing, all research, is situated. It is also understood that the research interview is a joint project, dependent for success on the establishment of inter-subjectivity. Interviews are not merely or simply a matter of gathering information, and what can be known is dependent on the interactional process. Such factors as race, nationality, gender, age and personal histories of both interviewer and interviewee affect this process and the material that might emerge

from it. As Hastrop (1992, p.118) has indicated: 'The magician is part of the plot; her achievement is not 'pure production' ex nihilo. It is a production from a particular position'. In order to comprehend fully my research product, it is necessary to describe at least some elements of that position. As Leach has asserted, 'Ethnographers must admit the reflexivity of their activities; they must become autobiographical' (1989, p.45). Accordingly, there has been a range of experiment with autobiography in ethnographic writing (see Okely, 1992, for an account of this trend). Currently, provision of some autobiographical material is accepted practice in social science research reports, and in the findings of "hard" science as well.

I have been involved in studies where the pertinent question would not have been 'How did you get involved in this work?' but 'How could you have avoided it?' Given the nature of the studies and my own personal characteristics and proclivities, there seemed to be a certain inevitability about my involvement. Superficially, this did not seem to be the case with this present study; and then, on reflection, it very clearly did. I provide here some biographical material in an attempt to situate my involvement and my position more precisely. I note that I have selected a particular strand of biography from a variety of available and utilizable strands, and have not attempted to do more than plot a few points on that strand. This process imposes an order, a sense of purpose and progress, a sort of plausible psychological realism, that I did not consciously intend, and do not necessarily want to own. The appearance of coherence and cogency is an artefact of the process, and I am aware of the entirely constructed nature of the self that I report. I am also aware - intensely aware - that it would have been possible to make a selection to construct a counter case, utilizing much of the same material.

I was born in the immediate post-war period, into a society and among people that were exhausted. I was nurtured partially but importantly in an extended family that was predominantly female. Aunts were conspicuous, accessible and accommodating; uncles were shadowy figures, of very little consequence, or they were absent, doing whatever men do when they are away. Post-war austerity was more wearying and constraining for adults than for children who knew nothing else, and a childhood spent on the edges of the countryside, on the edges of the working class, was more vivid, more rich and sensual, than might be imagined. Most of my early memories are of women, working slowly but continuously, in a domestic setting. Food was prepared, laundry processed and things were cleaned to the accompaniment of a continuous conversation. I heard it around and above my head, while I was at play. I heard both the sense of the spoken words and, if I wanted to withdraw from it a little, I heard it as pure sound, a sort of mellifluous murmuring.

I was born into a literate family, one that liked to read, hear and tell stories. I liked to tell them myself, and learned that a judicious application of exaggeration improved stories immensely; I remember that I was not discouraged from this. I learned to read early, and learned to escape from all sorts of unpleasantness into a book. Everyone in the family read a great deal, including all the men.

Later, when I passed the 11+ examination, I was the only boy in my area to go to the local (mixed sex) Grammar School. I travelled every day with a party of girls, most of them slightly older than me, and I heard a lot of female conversations. I was taken up and 'adopted' by some of these, and this always gave me a greater ease of access to girls than that enjoyed by most of my contemporaries. It goes almost without

saying that in all this I used and took advantage of the inherent privileges of being male when I wanted to, and didn't reflect on it at all. What did make me different, I think, was the difficulty I had in sharing the fear and distaste for things feminine that was expressed by my peers. It was difficult (but not impossible, unfortunately) to join in the general denigration of things female, and the vulgar condemnation of signs of active female sexuality. It was disappointing not to be able to share my clear sense of girls as equally worthy friends and allies.

Much later, when I was still inexperienced enough to have large hopes, I joined one of the caring professions. This was supposed to be a very temporary arrangement, and it was motivated by necessity, curiosity and sheer carelessness. In that setting, I was taught a little of how to care for sick people, and I performed some physical activities associated with this on most days. In some departments, I went through the motions of providing care, and in one or two desperate places, where things were thoroughly routinized, I went through the motions of going through the motions.

I was never taught to care about sick people. I suppose this was assumed to be a motivating factor in my choice of occupation. However, caring about was not seen as entirely unproblematic and I was cautioned and counselled repeatedly not to fall into the occupational trap of caring too much. For most of my colleagues, this was not an issue. Regarding myself, I could see easily how I might care too much about particular patients. It felt like a normal response, but I learned quickly that unrelieved fatigue, frustration, occupational powerlessness and routine exposure to high levels of distress could become the cornerstones of professional distance, amounting sometimes to real affectlessness.

The event that brought the issues of caring for and caring about into sharp focus for me was the experience of being solely responsible for the total care of a very young child for an extended period. This occurred for a variety of reasons, all beyond my immediate control. Suddenly, some of the issues I had read about in feminist literature became sharp and immediate reality. I note here the absence of time, energy and opportunity for self-projects, the unremitting nature of domestic work, the unrelieved fatigue and consequent boredom, the narrowing of horizons, reduction of options and lack of opportunity for what Simone de Beauvoir has called “transcendence” (1969). This experience was crucial to my personal and intellectual development. I do not think I added new ideas to my stock, but rather amplified, clarified and ordered things I had known in an inchoate way for some time.

What all this might amount to is, of course, a matter of interpretative opinion. I have tried out a few of them in my time. For what its worth - and these days, I don't think it worth much at all - I feel that the legacy of the past, as it might impinge on the present study, is as follows. I have an abiding sense of men as other, and a feeling - mostly happy - of partial exclusion from their company. I know all the rules for taking part in male society, but feel none of them strongly. I see men as strange, slightly exotic creatures, not particularly valuable, but as objects of curiosity, worthy of study, similar to me in some surprising ways, and utterly alien in others. Perhaps as a result of this, and in so far as it is compatible with the demands of family and occupation, I have maintained an outsider position, never being really part of anything - not one of the boys, and clearly not one of the girls. I am at least an apathetic joiner of things, and have engaged in a sort of serial apostasy, leaving just about everything.

When I was introduced formally to the practice of participant observation, I realized that I had been doing it all my life. I have worked in a predominantly female profession, and spent quite a lot of time in female company; in it but not of it, of course.

I have always been fascinated by the stories people tell about themselves. One of my earliest memories is of listening to old men reminisce about the Great War as they worked on their allotments. In adult life, one of the most interesting and compelling features of healthcare work is the chance to hear people's accounts, sometimes very intimate accounts, of themselves; it is a true privilege. Additionally, the healthcare endeavour is rich in anecdote - explanatory, expository, cautionary and so on - and constitutes a dense web of narrative. The fascination of all this is difficult to describe, but I like it particularly, in conversations and interviews, where 'the light cast by substantive references, allusion, details fade and we find ourselves surrounded by humanness' (Benjamin, 1988, p.3).

This is the approach I have brought to the study, which inhabits the intersection of several long-standing interests: the study of men, who are both different and the same; the mechanisms that people use to cope with extreme situations, on both social and individual levels; a profound dissatisfaction with what has been called care in the community; and a continuing search for personal meaning and verification in the experiences of others. As Okeley argues: 'The reflexive I of the ethnographer subverts the idea of the observer as impersonal machine. The autobiographical insertion is different from the stamp of author's authority: not simply 'I was there', but the self and the category whom the others confronted, received and confided in.

The people in the field relate to the ethnographer as both individual and cultural category, whether or not the ethnographer acknowledges it' (Okeley, 1992, p.24). It is with that in mind that I provide these autobiographical notes.

## **4. METHODOLOGY 2: NARRATIVE**

### **NARRATIVES, SELVES AND IDENTITIES**

The essential purpose of interviews in the study was to gather information about the experience of caring. The idea of narrative is central to this, as much of the material gathered took the form of narratives of one form or another. If interviews are a ubiquitous form in our society, then one of the usual and “natural” products of the interview, the narrative account, is even more pervasive. Mischler (1985) notes the propensity of interviewees to produce narratives in response to even narrowly framed questions, and shows that the ability to provide succinct, concise answers is “learned” in the interview situation.

This pervasiveness is worth exploring in terms of the growing literature of the last two decades. It has been argued that the evolution, development and structure of the brain accounts, at least in part, for the human propensity to experience life as a narrative sequence, and to engage in narrativisation (Fuller, 1982). That there is a close relationship between experience and narrative, and that ‘conventions of forwardness, so deeply entrenched in our syntax’, encourage narrativisation has been noted for some time (Steiner, 1977, p.167). Barthes (1966) asserts that there has never been a human society without narrative. Many authors noted the importance – the primacy, even – of narrative to human psychology (Bruner, 1986; Carr, 1986; MacIntyre, 1984; Ricoeur, 1984, 1985, 1988). Narrative has been seen as ‘the primary scheme by which human existence is rendered meaningful’ (Polkinhorne, 1988, p. 11) and as ‘the organising principle for human action’ (Sarbin, 1986, p.9).

Thus there is an established perspective which asserts the primacy of narrative in the human attempt to order and make sense of experience. Bruner has argued that narrative is one of the two basic modes of thinking – while the paradigmatic (scientific, abstract) mode is best for making sense of principles that are abstracted from context, narrative understanding carries the weight of context, which makes it a far better medium for relating human experience (Bruner, 1986). Consequently, Bruner has viewed narrative as the principle by which ‘people organise their experience in, knowledge about, and transactions with, the social world’(1990, p.35).

However, it is argued that narrative accounts do not, and can not, provide accurate reflections or unproblematic representations of the world. Rather, the constituents of reality are gathered and assembled during the process of narrativisation, and this, probably, is the only reality accessible to humans. Indeed, language itself, as a raw material of narrative, is ‘understood as deeply constitutive of reality’ (Riessman, 1993, p. 4). Narratives are crafted, profoundly rhetorical, interpretive constructions that are full of presumption and assumption. As Riessman observed: ‘Human agency and imagination determine what gets included and excluded in narrativisation, how events are plotted and what they are supposed to mean’(1993, p.2).

Narratives are important also in the construction and maintenance of personal identity. Narratives structure perception, organise memory, and ‘build the very events of a life’(Bruner, 1987, p. 15). Personal stories ‘are the means by which identities may be fashioned’(Rosenweald and Ochberg, 1992, p.1). There is a very strong sense in which individuals become the autobiographical narratives they relate, and these

individual constructions ‘typically mesh with a community of life stories, “deep structures” about the nature of life itself’ (Riessman, 1993, p.2). There are several available versions of this process, all perhaps owing something to Ricoeur’s earlier treatment of narrative identity (Ricoeur, 1986). The exact parameters of this are still open to debate, but it is reasonably certain that personal narrative brings some disparate elements together in something like a plausible and purposeful whole which is referred to as the ‘self’. This is one of the important ways in which humans structure and configure events, an ‘act of imagination that is a patterned integration of our remembered past, perceived present and anticipated future’ (McAdams, 1993. p.12).

Kerby (1991, 1997) proposed a view of the narrative construction of selves in which the self is the product of language – ‘the implied subject of discursive practice’ (1991, p. 4.) – and is not either a ‘substantial entity having ontological priority over praxis or a self with epistemological priority, an originator of meaning’(1991, p. 4). Identity, according to this view, is not fixed or permanent, but depends on the coherence and continuation of one’s personal narrative. For most people, for most of the time, the question of personal identity does not arise. However, ‘questions of identity and self-understanding arise primarily in crisis situations and at certain turning points in routine behaviour’(1991, p. 6). What is revealed at such times is the ongoing need for narration of experience in order to exist as a meaningful human subject, and the crucial function of narrative in generating a continuity of self.

Kerby proposed a model of the human subject based on a tripartite division: (1) the speaking subject, or material agent of discourse; (2) the subject of speech, or purely linguistic subject of discourse; (3) the spoken subject, or subject produced through or

by discourse as a result of its effect on a reader-listener. As an example of this, in a case of self-narration of the past, 'the speaking subject is myself qua language user and "repository of images"(and hence conditioned and restricted by that language, by tradition and by past experience). This narrative then sets up a subject of speech, the character signified by the pronoun I and involved in a certain narrated life situation. What makes this narrative personally historical or autobiographical is that I correlatively become the spoken subject of narrative – just as a spectator might identify with some character in a play or film (1991, p.105). Thus, if the speaking subject 'is a subject of semiosis, a material subject of signifying activity, then it ascends to selfhood only via the products of its activity – as the self of its own narrative enterprises' (1991, p. 138).

Narrative construction and relating has been seen as important where some sort of disruption has occurred – 'where there has been a brush between ideal and real, self and society' (Riessman, 1993, p.3). It has long been noted that individuals experiencing biographical disruption, such as chronic illness, reformulate and reconstruct coherent selves in narratives (Bury, 1982; Riessman, 1990; Williams, 1984). The significance of this sort of strategy has been explored in cases of multiple sclerosis (Monks and Frankenberg, undated). Other authors have noted the propensity of interviewees in social science research situations to shape narrative accounts to provide justification and reason for particular actions or decisions. There is a small but influential literature on this sort of account, which amounts to the construction of selves as rational, moral beings, as has informed methodological developments in narrative analysis (Baruch, 1981; Moore, 1974; Voysey, 1975).

The narrative maintenance of selves might be disrupted by changing life circumstances. Breakwell (1986) provides a still cogent and entirely durable general model of identity, threat and coping, which illuminates a wide range of human experiences. This model eschewed a firm definition of identity, preferring a description of its structural components and dominant processes. It has ten central propositions:

1. The structure of identity is a dynamic social product of the interaction of the capacities for memory, consciousness and organised control.
2. The structure of identity has two planes: the content dimension and the value dimension.
3. The structure of identity is regulated by the dynamic processes of accommodation, assimilation and evaluation, which are deemed to be universal psychological processes.
4. The processes of identity are guided in their operation by principles, which define desirable states for the structure of identity.
5. Identity is created within a particular social context within a specific historical period.

6. A threat to identity occurs when the process of assimilation-accomodation and evaluation are, for some reason, unable to comply with the principles of continuity, distinctiveness and self-esteem.

7. Any activity, in thought or in deed, which has as its goal the removal or modification of a threat to identity can be regarded as a coping strategy.

8. The choice of coping strategy is determined by an interaction between the type of threat involved, the salient parameters of the social context, the prior identity structure and the cognitive capacities available to the individual.

9. Coping strategies are influenced by the demands of cognitive consistency requirements and social comparison processes.

10. Where coping strategies fail, the structure of identity will change in ways incompatible with the constraints normally imposed by the principles guiding the processes of identity.

This model has particular and continuing relevance for, and utility in, the study of the experiences of male informal carers.

## **NARRATIVE ANALYSIS**

Investigators have been advised, in the first instance, not to read narratives for content alone, and to avoid 'the equally dangerous tendency to read....as evidence for

a prior theory'(Riessman, 1993, p.61) Instead, it is recommended that the structure, the form, of narratives be examined. This strategy recognises and allows for the constructed nature of narratives, and their social function as speech acts or performances.

Formal analysis might be conducted from a variety of perspectives and disciplines (Cortazzi, 1993; Toolan, 1997). Among these, Labov has developed a sociolinguistic approach to narrative that is applicable to personal narratives collected 'artificially' – in research interviews, for example; as opposed to the sampling of naturally occurring discourse where informants can talk uninterruptedly for extended periods, and where talk constitutes a performance of some recognisable type. Labovian analysis has been used widely in social science investigation; notably, Cortazzi (1991) has applied it to the study of occupational narratives in education, and Riessman (1990) has used it to study the experiences of divorced people. Coffey and Atkinson (1996) show how even a simplified and brief application can produce interesting and significant findings.

Labov's approach is established in two key papers (Labov and Waletzky, 1967; Labov, 1972). His approach may be classified as sociolinguistic, and is perhaps influenced by the morphological approach of Vladimir Propp (Propp, 1968). Labov hypothesises that fundamental narrative structures can be discerned in the narrative accounts that can be found in ordinary, everyday speech. These semantic structures are related to two broad functions: their referential function, which deals with the recapitulation of experience in an ordered set of clauses which match the temporal sequence of the original events, and the evaluative function, which is 'the means used by the narrator to indicate the point of the narrative, its *raison d'être*: why was it told,

and what was the narrator getting at' (Labov, 1972, p. 366). According to Labov, the minimal requirements for a narrative are two sequential clauses that are temporally ordered. He identifies two kinds of clause: narrative clauses, the order of which cannot be altered without changing the described sequence of events, and free clauses, which can be arranged and distributed in and across a narrative sequence without altering it too much. Labov's analysis is both formal, examining the pattern of invariant structural units, and functional, examining the referential and evaluative function of narratives in social use.

Labov asserts that oral narratives have a six-part structure:

Abstract: What is this about?

Orientation: Who? When? Where? What?

Complication: What happened next?

Evaluation: So what?

Result: What happened finally?

Coda: Ending

(Adapted from Cortazzi, 1993)

The Abstract is an optional unit, often reduced to a very minimal clause, and sometimes omitted completely. It indicates the start of a narrative, and initiates it, usually by stating a general proposition, which the rest of the narrative will exemplify and amplify.

The Orientation provides the necessary context, and any pertinent background details.

The Complication consists of a series of narrative clauses, usually in the past simple

tense, but sometimes in the historical present. It supplies the substance of the narrative. The Evaluation suspends the formal movement of the narrative by providing its point. Labov notes that every good narrator works to deflect continually the question 'So what?', and the Evaluation forestalls this, and shuts it off. In Labov's developed theory, the Evaluation is divided into various types, and its regular appearance throughout longer narratives is described. The Result provides the resolution and final outcome of the narrative action. The Coda is another optional unit, signalling the end of the narrative, and the return to the usual turn-taking conversational mode.

Narratives are analysed by breaking them up into constituent clauses, which are usually numbered in sequence, and by identifying each clause according to the above schema. One of the abbreviations A, O, C, E, R and Cd are placed beside each clause to mark this identification. For example, one informant in the study describes a visit to a Retail Park:

A 1 I went there myself, only once

O 2 me and my mate went in his car

O 3 down the M4

C 4 we had a look around

C 5 went in most of the shops

E 6     there's not much there really

E 7     nothing you can't find in the town centre

R 8     and we came away

R 9     without buying anything

Cd 10   why bother, um?

It has been argued that 'many narratives do not lend themselves to Labov's framework' (Riessman, 1993, p. 59). It is noted that Labov's scheme does not 'map onto....all narratives with perfect regularity', and that analysts need not 'search obsessively for the equivalent narrative units and their defining characteristics' (Coffey and Atkinson, p.61). There is also said to be a difficulty concerning the identification and accumulation of narrative sequences that are embedded in longer interview material, and that there a few rules for 'partitioning more complex stretches from interviews' (Riessman, 1993, p.60). However, the same author notes that 'one can locate stories and other narrative segments in a stretch of talk and inductively build a framework' (Riessman, 1993, p.60).

It is worth noting that the Labovian analysis of narratives produced at interviews has been criticised by Wolfson (1976, 1982). Wolfson argues that narratives elicited at interviews are essentially summaries, and are not fully performed conversational

narratives. Conversational narratives are performed when the norms for evaluative interpretation are, or are presumed to be, shared; they are elaborated, spontaneous and thoroughly performed. However, this view is rejected by Cortazzi (1993, p.57ff) who provides examples of performed narratives elicited as research interviews and other similar situations. This accords with Mishler's observation that it is difficult to prevent informants from providing fully performed and elaborated narrative accounts, sometimes in response to closed questions (Mishler,1986)

The following brief example illustrates the Labovian method.

- A 1 It was one of those things you have to do
- O 2 I did a bit before
- O 3 during the strike
- O 4 but I hated it
- O 5 I've been coddled all my life
- C 6 so I had to clean and cook and shop and look after her
- C 7 she had to have a bath every day
- C 8 I had to bath her
- C 9 but the shopping was worse
- C 10 and I used to panic
- C 11 with more than one thing cooking
- R 12 but I got over it

R 13 I got used to it

E 14 even a bit good at it

E 15 a fuss about nothing really

Cd 16 but that was that

In this example, Mr D provides a brief account of his entry into caring. He followed it with a more expanded account just a few minutes later. He was responding to a question about the beginnings of care-giving, and produced a few narrative segments of this sort, before settling down to produce a much longer account. In this example, he provides a general proposition as an Abstract: "It was one of those things you have to do". The Orientation follows, consisting of four short clauses which detail Mr D's previous experience of domestic work. This is followed by six narrative clauses which describe his caring experiences. Somewhat unusually, according to Labov's formulation, the Result precedes the Evaluation; in context, this reversal seems entirely appropriate. The Coda takes the form of a rather formulaic concluding phrase.

An interesting feature of this example is that it could serve as the Abstract to Mr D's whole narrative of caring, and very probably it does. It has all the elements of an Abstract by outlining the story that is to follow. In fact, Mr D's full narrative does follow the structure and course of this fragment. In addition, in Labov's terms, the Abstract functions to 'answer questions which relate to the referential function of effective narrative' (Labov, 1972, p.370). Specifically, it says something about the

whole narrative, and why it should be related, and the fragment meets this requirement.

A further short narrative, also provided by Mr D, illustrates some other features of Labovian analysis.

A 1 as usual

A 2 I wasn't prepared at all

E 3 typical

O 4 she was in the same ward

O 5 and I was in work

O 6 and I had a phone call saying

E 7 you've got to come

E 8 and get me out of here

C 9 and I had a thing for a stairlift

C 10 because I inquired about it

C 11 and uh my mate's mother up here had one

C 12 but she moved to (a nursing home)

C 13 and she wouldn't go on it

C 14 so I said

E 15 don't sell it

E 16 I'll have it

- C 17 so I bought it
- C 18 it was all going on
- C 19 he had to take it out
- C 20 and all
- C 21 but she told me
- E 22 I'll have a bed here
- E 23 in the front room
- E 24 but I am coming home
- E 25 definitely
- C 26 so she came home
- C 27 and we didn't have the stairlift then
- E 28 no preparation
- E 29 as usual
- E 30 not ready at all
- R 31 so me and my mate took it out
- R 32 and put it in here that afternoon
- E 33 so it wasn't too bad
- Cd 34 and I started to look after her at home

In the narrative, Mr D relates a complex narrative in response to a question about his level of preparedness for caring. He had told me a earlier that his wife disliked her

stay in hospital, and has discharged herself a little prematurely; he makes oblique reference to this. In the narrative, he combines the story of her discharge with the connected story of the hurried acquisition of a stairlift to form a narrative of unpreparedness. The unreadiness of the stairlift and its rapid installation, act as a kind of metonym for a general unpreparedness. Despite being wrapped in a comic self-deprecation, it is a story of obstacles surmounted and ultimate success.

The segment also illustrates a more complex use of Evaluation. At line 3, Mr D adds an Evaluation comment to the Abstract. This is classified as an External Evaluation, breaking the narrative flow to express a current evaluation of past events. The reported speech at lines 7, 8, 22, 23, 24 and 25 might also be categorised as External Evaluation by Labov, because they interrupt the narrative flow. However, they do continue the action in important ways, and are not entirely evaluative. This slight discrepancy is noted by Toolan, who argues that it reflects ‘an assumption that plot is core, that the clauses of narrative action are the heart of the matter, the inner narrative, and that evaluation is to a degree external, and always intrusive’(1997, p.159). This point is discussed at length by Culler (1981, pp. 184-187) who notes that Labov’s analysis works well as long as the “story” can be distinguished from “discourse”; that is, the referential function is separated from the evaluative. Culler demonstrates that some of the most powerful evaluative devices are ‘not comments external to the action but actually belong to the sequence of action’(p.185). He shows that narrators employ discursive strategies, which embellish and aestheticise, sometimes creating chains of cause and effect at variance with the actual sequence of events.

In fairness, these strategies are recognised and identified as evaluators by Labov, who is not unaware that ‘guided by prior awareness of tellability–requirements, our evaluations shape our plots’(Toolan, p.160). Labov notes that evaluation might be a narrative clause ‘in that an action one reports has the primary function of emphasising the dramatic character of the event’(1972, p.373). Interestingly, Pratt asserts that “literary and natural narratives are formally and functionally very much alike”, and that natural narratives employ all the devices of literary works – ordinary or negative parallelisms, comparison, repetition, balanced structures, hyperbole, the commonly accepted rhetorical figures and all those methods, which emphasise the emotional effect of an expression”(Pratt, 1977, p.66, and p.68, here quoting Sklovskij, 1917)

These strictures might illustrate some of the limits of Labov’s method, and explain some of the difficulties in its application to certain texts. However, the utility of the method as a tool of analysis is not much diminished, especially when formal analysis is only part of a wider inquiry.

## **A NARRATIVE ACCOUNT OF CARING**

As indicated above, informants’ narratives were not gathered as discrete and continuous wholes. Rather, following Riessman (1990, 1993), they were assembled from narrative segments embedded in more extensive interview material. Informants produced narratives in response to interview questions. On the whole, these answers

were complete narratives in themselves, and were often extended. In interview, I was careful not to interrupt the narrative flow, but did so occasionally to clarify particular points. At the end of some narratives, I asked questions to pursue certain lines of inquiry, and these often led to the reformation and repetition of some narrative sequences, with or without greater elaboration.

There was no particular difficulty in discerning the overall shape of a caring career from these separate narratives. This was the case whether the informant was a particularly beguiling storyteller (Mr E, Mr G), an unskilled verbal performer (Mr B or Mr D) or a polished rhetorician (Mr C, Mr P). I tried always to retain an awareness of the means by which informants attempted to “direct interpretation by the way in which they organised their narratives, including parts and their relation to the whole”(Riessman, 1993, p. 60).

All this is exemplified by a narrative account of caring provided by Mr H. It is shorter than the other accounts, but contains all the usual features.

1. Its been five years
2. I've looked after my mother
3. in one way or another
4. for just over five years
5. she was never sort of settled
6. after Dad died
7. about, about ten years ago

8. she was a bit down for a while
9. and then she got um a bit forgetful
10. muddled
11. well that went on for a while
12. it was trivial, you know
13. she didn't forget important things
14. only small things
15. nothing to get worried about
16. so we let her be
17. then about five years ago
18. five years ago
19. she got much worse
20. we used to find her wandering about
21. didn't know what day it was
22. where she was going and all
23. she used to get muddled with the cooking
24. and everything
25. very clearly she couldn't look after herself

26. so I moved in here
27. I'm separated
28. so there was only me
29. but then people used to ring me at work
30. Mrs Jones at the farm
31. to say that Mum had wandered in there
32. in a bit of a state
33. or she was asking for directions
34. up to the shops
35. and people would ring me up
36. so I took early retirement
37. it was on offer
38. it wasn't a bad deal
39. so I took it
40. stayed at home to look after her
41. and I've been doing it for five years now
42. five years
43. so I suppose I moved into it gradually

44. like I was doing a lot while I was still working

45. so when I did it fulltime

46. um it was nothing new, you know

47. but um it was still a shock

48. funnily enough

49. there was a difference

50. I have to admit

51. I would think twice before taking it on

52. but I've started

53. and there will be an end

54. but I wasn't really ready for

55. I hadn't expected

56. well you lose a lot

57. and I was all ends up at first

58. there wasn't much to hold on to

59. I never thought I'd miss the office

60. but well I did

61. the things settled a bit

62. I got to grips with it eventually
63. I felt a bit lost at first
64. like all the landmarks
65. all the landmarks in life had gone
66. well not all
67. but some important landmarks
68. and it takes a while
69. to get yourself back
70. get back to yourself, you know
71. its like you make new routines
72. and you get used to them
73. the new things become part of you
74. part of your life
75. you have to give yourself time
76. to get used to it
77. like you lose yourself a bit at first
78. but then you find yourself again
79. sort of thing

80. you don't realise how much of you is bound up with what you do

81. do you

82. so I do all the cleaning, cooking

83. all the housework really

84. all of it

85. shopping, everything

86. there's that

87. and then I do nursing care

88. I have to organise washing, dressing, eating

89. you know she can

90. she certainly could anyway

91. manage all of that

92. but you have to tell her

93. prompt her

94. well until recently

95. because things have got worse recently

96. especially as regards the um toilet

97. the incontinence

98. which has got much worse recently
99. so I have to sort that out
100. I mean its difficult
101. because it's your mother
102. difficult because it's a woman
103. and difficult because
104. well its not pretty work is it
105. and I've never done anything like it before
106. so all of that really
107. I still bath her every day
108. and sort out the toilet stuff
109. it sounds a bit odd
110. I was talking about it the other day
111. it's a bit odd
112. but I am different
113. this is difficult to talk about
114. a bit embarrassing really
115. but in doing all this

116. I have kind of found different parts of myself

117. well used them a bit more

118. and I sort of like myself a bit more now

119. I suppose work was always very competitive

120. at some level

121. and you were encouraged by the situation

122. to be sort of ruthless in a way

123. sort of uncaring about others certainly

124. I mean if you let someone have the advantage

125. they'd use it

126. so on one level

127. the usual kindness and courtesies

128. the usual supports

129. were gone, gone completely

130. but this is different

131. and I've discovered

132. it suits me better

133. to be different

134. you know, kinder, patient, gentle

135. all of that

136. I'm not boasting here at all

137. I should have took a different career

138. I really should

139. I suppose what you're doing

140. is encouraging your feminine side

141. no not feminine

142. but the part we keep down

143. us men

144. in order to get on

145. to do our jobs

146. and all

147. I mean that

148. and I've found

149. this new style suits me better

150. I think I feel different

151. I mean feel differently

152. but I suppose when I was working
153. I was the centre, the central character of my own story
154. sometimes the hero
155. sometimes the villain
156. sometimes the victim
157. but then I lost it
158. I lost the plot
159. almost completely
160. so I wasn't much of a figure
161. in my own life
162. I got it back though
163. and I got to be a hero
164. of my own story again
165. at last.

Although constructed from narrative fragments, Mr H's narrative account of his career as informal carer can be analysed using the Labovian scheme. A brief analysis might identify lines 1-4 as an effective Abstract, detailing the nature and scope of the whole narrative. Lines 5-16 serve as an Orientation, providing pertinent background

details and listing the *dramatis personae*. It could be argued that lines 17-109 represent the bulk of the narrative action. This is followed by a firm Evaluation at lines 109-130, and a Result at lines 131-164. The final phrase at line 165 provides an attenuated Coda.

A more detailed analysis could note the appearance of evaluative clauses throughout the entire narrative, and would identify the long passage at lines 42-81 as definitely evaluative. However, the difficulty of distinguishing between narrative and evaluative clauses has been discussed above, and even this passage contains narrative movement, adding new narrative information at lines 44-46. Also of note is the repetition of the phrase “five years” at lines 41-42, echoing the same usage at lines 1-4. This seems to be a particularly literary strategy, exemplifying Pratt’s contention discussed above. There is a similar repetition of material at lines 68-69 and 77-81 in the closing lines of the whole narrative. This ending, at lines 162-165, provides a remarkably polished closure to the whole narrative, and shows considerable rhetorical strength.

Mr H presents a moral tale and a success story; these two elements are linked. He describes the disruption that caring occasions, and the very real difficulties of engagement with the daily tasks of care. He describes his perseverance through these difficulties, and a sort of personal transformation as a result of this. The structure of the narrative is adapted to underpin and inform that process, and it is emphasised by the use of “literary” and other rhetorical devices. The narrative describes a familiar trajectory in biographical work – basically, an interesting decline, use of persevering strategies at a low point and an eventual recovery or restitution, sometimes to a

status superior to the original position. This is the form associated with myth, and it is the structure of stories associated with many religions. It has been identified as the core structure of personal stories recounted at meetings of Alcoholics Anonymous (McAdams, 1993; Cain, 1991). Mr H also locates his narrative within an ideological setting, and against a moral background, drawing on notions of right and wrong, of responsibility, of appropriate sacrifice and proper reciprocity. The identification of narratives as moral tales is explored in a later chapter.

Although it is both useful and instructive to read narratives for form, the main strategy of analysis in the study concentrated on the content of informants' accounts. Although I examined all the accounts in the Labovian manner, I have not used any of that material in the following chapters. As indicated above, it was possible to discern the different shapes and structures of the accounts without recourse to formal analysis. However, it is certain that the initial Labovian analysis provided me with a more intense familiarity with the content of the accounts, and this allowed an easier discernment of shape and structure than would otherwise have been possible.

## **5. ENTERING INFORMAL CARE**

### **INTRODUCTION**

Human life is structured with expectations about duration and course. These expectations are formed culturally, and can be seen to constitute both a specific cultural unit and a powerful collective symbol. In Western thought, lives are seen as individual, orderly projects, with an emphasis on linearity; the life course is expected to be largely predictable, knowable and continuous. When these expectations are not met, people experience disruption.

Disruption of one sort or another occurs regularly in human life. It is commonplace to observe that the most momentous events erupt in the midst of mundane circumstances. Life rolls along in its accustomed way, and then the unexpected breaks in, sometimes happily, sometimes tragically; the contrast is felt to be surprising, even slightly surreal. Humans know that the unexpected can enter lives at any moment, often with devastating and enduring effect, and a huge individual and collective effort goes into the day to day management of that knowledge. This is most usually manifested as an overlooking of, and disregard for, the possibility of unpredicted events. But however well this unknowing is employed, however much distance is achieved, the unexpected comes along, and those it affects might reflect that they could have predicted it all along.

That human lives are sometime disrupted by serious illnesses or debilities is very well known. The extent of that disruption and the varieties of accommodation to it are comparatively well documented (Greenhalgh and Hurwitz, 1998; Kleinman, 1988;

Bury, 1982). This disruption can have important consequences for persons other than the immediate sufferer, and its eventual ramifications can be extensive. An important aspect of this concerns the expectation that the sick person will receive on-going care within the family. This informal care giving can be disruptive, often massively and rarely minimally, to those who undertake it, and the assumption of care giving can constitute a significant turning point.

### **MODES OF ENTRY**

The caring situation can be entered gradually or comparatively suddenly, although this is perhaps an over-simplification of a complex situation. A gradual assumption of the caring role is said to occur as the result of co-residence with a person whose condition is subject to inexorable deterioration. The carer assumes more and more responsibility for the sick person until full carer status is achieved. On the other hand, some carers are impelled into the caring role by the sudden illness or disability of another person, with whom they may or may not be co-resident at the start of care.

The informants in the study described a rather more complicated situation. Five of them entered caring by the gradual route outlined above. Two of them were caring for elderly persons with Alzheimer's Disease, and had assumed more caring responsibilities with the typical deterioration of that condition. One of these was co-resident with the recipient of care, who was his wife. The other became co-resident with the recipient of care, who was his mother, due to her deteriorating condition.



This move was facilitated and given further imperative by his changed matrimonial circumstances.

In addition, three men were caring for wives with multiple sclerosis. Each of them had assumed more care responsibility with the fluctuations and ineluctable deterioration associated with that condition: "From walking on sticks to Zimmer to wheelchair", as one carer described it. All of them were co-resident before and during the illness. All of them dated their full-time caring activity from particular times when significant deterioration had occurred. Before that, they had provided elements of care, but did not think of themselves as care-providers. Two of them gave up employment to engage with full-time care at this point, and the third had retired already.

One carer occupied a sort of intermediate position between those who entered care gradually and those who entered suddenly. He was responsible for the care of his handicapped son. He described himself as an "assistant carer" for many years; his wife had provided most care, until her comparatively recent death impelled him into more responsibility. He had discontinued employment to do this. Although he had been co-resident with his son since birth, and had engaged in a multiplicity of care tasks, he dated his assumption of the caring role from the death of his wife. He characterised his entry into caring as "sudden, but not without preparation".

Eight of the informants describe their entry into care as "sudden". It occurred in response to the sudden illness and consequent debility or disability of their wives. In these cases, lives were thrown into disarray by an unpredicted event. However, for

seven of these men, full time caring was delayed by the hospitalisation of their wives. This amounted to a few weeks, in most cases, and several months in some. Although life had been suddenly and seriously disrupted, the exigencies of the caring situation were not yet apparent. This period of hospitalisation allowed some preparation for the assumption of caring responsibilities. Some men received formal preparation from healthcare professionals, usually in the form of lifting and handling instruction. Others needed some practical preparation for caring, including the conversion of part of domestic space into sick room facilities. In some instances, this involved the large-scale transformation of homes (see below).

All informants describe this period before their wives returned home as characterised by anxiety, uncertainty and chaotic disruption. They date the transformation of their lives from this time, although they did not become carers in the active sense of the word until much later. It can be shown that the distinction between gradual and sudden entry to caring tends to overstate the differences within a complex process of change. Those who entered care suddenly did not assume caring responsibilities for some time after their wives became ill. The intermediate period was characterised by preparation for caring of some kind. On the other hand, those whose entry to caring was gradual described a situation where they experienced a sudden realisation of the situations, and recognised for the first time that they had become full-time carers. It was as if they had been too close to, and too preoccupied with, the caring situation to recognise it fully. This recognition is described as occurring suddenly, and as being something of a shock:

“I turned around and - Christ! - here I was!” (Mr A)

and

“It came to me that I was well different all of a sudden. Right in the middle of it, really, no going back” (Mr N)

Nevertheless, the distinction between gradual and sudden entry to caring is both real and valid. It can be an important factor in the overall experience of being a carer. For example, Parker found that carers whose spouses had been affected suddenly spoke more often about the way that the caring experience had brought fundamental changes to their lives and to them as persons (Parker, 1990, p.120).

## **CARER SELECTION**

The sudden mode of entry into caring is interesting, because much of the process is compressed, allowing a more focused examination. For example, in all instances of sudden entry into caring, it was clear immediately that the informants would become the sole or primary providers of care. There was little or none of the negotiation of roles within the family as described by some authors (cf Ungerson, 1987, p.37, p.53). What was negotiated at this time was the provision of help from the wider family to facilitate the husband's caring role. This provision was both regular and ad hoc, allowing husbands to engage in short duration tasks outside the home, such as weekly shopping or visits to GPs. Stabilisation of the conditions of the recipients of care and establishment of caring as routine, occasioned the renegotiations of this help, resulting usually in its reduction.

The issue of carer selection is complex. As discussed above, it is demonstrated that there is huge pressure for informal care to be provided for sick and disabled people by

their families (Qureshi and Walker, 1989; Parker, 1990). Despite the well observed contention that 'we are dealing with relationships so entangled, ramified and minutely varied that they cannot be ordered at all or can be ordered only by an effort quite out of proportion to my conceivable results' (Abrams, 1978,p.2), it has been possible to identify some of the roles of kinship obligation for the selection of informal carers within families (Qureshi and Walker, 1989; Ungerson, 1987; Parker and Lawton, 1991).

It has been shown that the rules for carer selection are gender-ordered, producing a clear and consistent preference for women to occupy caring roles. However, in practice these rules are often confounded by other factors, other variables, which allow particular choices of carer to be made within particular families. These factors can include such things as perception of the relative quality of relations between potential carers and the cared for, perception of the relationship between carer and cared for, geographical distance and material conditions, such as adequate finances or possession of a spare room.

More importantly, the fact of marriage cuts across the usual rules to produce a preference for spouses to engage in caring, regardless of gender. This is an important finding, and it has been shown that the comparative scarcity of research into spouse carers has led to the ignoring of male carers, and the under-representation of women in accounts of disability (Parker, 1990, p.1, p.7).

In many ways, the preference for spouse carers is predicated on a set of strong cultural assumptions. Within the literature on caring, marriage is regarded as 'the supreme

caring relationship, rivalled perhaps only by the mother/infant bond' (Ungerson, 1987, p.51). Caring for a sick or disabled person is seen as one of the most fundamental responsibilities of husbands and wives, and all married informants in the study referred to this in some way. The words of the Marriage Service in the Book of Common Prayer specifying "in sickness and in health" came readily to all of them, even to those entirely innocent of connection with the Church of England or other Christian denomination.

Although many of the men in the study had female relatives – daughters, sisters, sisters in law – who might have taken on primary caring duties, this was never the case. In most instances, it seems not to have been a consideration, and some husbands showed a fierce determination to be the sole provider of care for their wives, even to the extent of taking on some more formal healthcare activities. This does not support Ungerson's original assertion that 'the obligation of marriage are cross-cut, and can be contradicted, by the obligations of gendered kinship' (Ungerson, 1987, p.53).

Specifically, it is asserted that where a husband is caring for a wife and there are daughters or daughters in law ostensibly available for caring 'There will always be tension as to who should shoulder the main responsibility for care' (Ungerson, p.53). In the study, nine of the twelve informants had daughters who might have provided care for their sick or disabled mothers. None of them were exempt from consideration of the grounds of geographical distance, previous carer obligation of other significant factors. Two of them were nurses, and these women did provide slightly more assistance at times of crisis or particular difficulty. One of them, in the early stages of her mother's illness, was said to have provided quite a lot of advice

and care-management. However, at the time of data collection, both women confined their input to once weekly or less frequent visits to the parental home. This seemed to be the general level of engagement of all the daughters, although some ad hoc emergency help would be provided when necessary. None of the informants expressed any desire for any one else in the family to undertake all or part of the care of their wives. In contrast, quite a few of them expressed strong dissatisfaction with the level of input provided by the healthcare services.

## **LIMINALITY**

The assumption of informal caring can be seen to confer liminal states on the carer (as does illness on the recipient of care). Liminality is a concept derived from Van Gennep's early ideas about rites of passage. These are defined as those rituals which accompany every change of place, state, social positions and age. Van Gennep collected and collated many examples from different cultures and societies to demonstrate that 'beneath a multiplicity of forms, either consciously expressed or implied, a typical pattern always occurs' (Van Gennep, 1960, p.191). This pattern is tri-phasic, with elements of separation, transition and incorporation. It can be elaborated further : 'I propose to call the rites of separation from a previous world, preliminal rites, those executed during the transitional stage liminal (or threshold) rites, and the ceremonies of incorporation into the new world post-liminal rites' (Van Gennep, p.21).

Van Gennep's formulation has been utilised by anthropologists for some decades, (see, most notably, Turner, 1967, 1968, 1977). It has been applied to the domain of healthcare with some success (Helman, 1990) where it has been argued that illness of all sorts involves a rite of passage. For example, hospitalisation (or seclusion in a domestic bedroom, or merely absence from work on the grounds of illness) can be seen as rites of separation. The ritual nature of hospital admission procedures adds weight to this interpretation. The period of inpatient treatment (or recuperation at home) is liminal, while recovery and assumption of normal activity are signs of reincorporating into the usual world of health.

A similar process can be seen to apply to those who engage in informal care. As Turner has observed, in some instances, the liminal period may be protracted and 'may cease to be a mere transition and become a way of life, a state' (Turner, 1972, p.37). Informal carers have many of the characteristics of liminalities. They 'evade ordinary cognitive classification.... They are 'dead' to the world' (Turner, p.37). They occupy a different space from most people and can be numbered among the invalid, the unclassified, the chronically ill and the dead. Socially and structurally, they are invisible. The liminal period is one of abeyance, standing outside usual time and normal routines.

Some informants commented on their liminal status in interviews:

"Most of the stuff I do here is, invisible, like I'm invisible, nobody sees, nobody knows, like I've disappeared" (Mr J)

and

“I don’t have a function, other than this. I’m out of place, out of joint. I don’t count.

“I’m somebody that looks after somebody” (Mr D)

Van Gennep’s formulation and Turner’s subsequent elaboration (Turner, 1977) provides a useful way of conceptualising the situation of informal carers, adding resonance to the usual descriptions of social marginalisation.

## **DISRUPTION**

Even after many years, informants remembered, and could recount in often vivid detail, their early caring experiences. Narrative accounts of these experiences were fast, detail-laden and had a strong emotional tone.

Some informants – ten in total – abandoned employment to undertake full time care.

This change added considerably to the disruption of early caring.

“She was there (in hospital) for three weeks, flat on her back, wouldn’t let her move, do anything at all, and, because, uh, I didn’t know what was going to happen after, so, well I wasn’t at work and I had a phone call and they said there were voluntary redundancies going and when I went there they said we don’t know your circumstances but we’ll make you redundant because they thought it would make it easier, better, if I had to claim”. (Mr D)

“So she deteriorated fast and they more or less told me to finish work to look after her... I had my own pension, and her bit of pension, but anyway I lost my own health then, went downhill, and that put me on Invalidity though I was still looking after her”. (Mr E)

“She got worse and worse, so I took early retirement, it was on offer, it wasn’t a bad deal, so I took it and stayed home to look after her”. (Mr H)

“I stopped work – took early retirement eventually, they were good to me at that firm”. (Mr K)

Of these remaining four informants, two had retired before taking up informal care, one stopped part-time work (although he was well over retirement age) to look after his wife, and one was on sick leave but negotiating early retirement with his employees.

Many informants employed the same nautical metaphor, or one adjacent to it, when describing the early days of caring; for instance:

“I was all at sea at first, everything was messed up ... different, I didn’t know if I was coming or going”. (Mr B)

“I was all ends up at first, there wasn’t much to hold on to, I never thought I’d miss the office. I felt a bit lost at first, like all the landmarks, all the landmarks in life had gone” (Mr H)

“It was all a bit unfamiliar. You lose your bearings”. (Mr L)

“I was all at sea. Like it was different because well it was anyway difficult and because you’d lost all your bearings and all the usual things had gone, you do lose your bearings for a while”. (Mr N)

The allusion implies comparison with being in a small boat with a malfunctioning compass, out of sight of land and being threatened by turbulent, inhospitable seas; this is clear enough. Other informants give a more direct description of emotional turmoil:

“I was concerned, you know, concerned all the time, and tired, I was tired” (Mr B)

“It was a shock, a bloody big shock, I can tell you. It was a bit scary, I can tell you” (Mr J)

“Difficult, busy, very tiring. I was very tired and very scared, all the time”. (Mr N)

“Well it was a shock. To tell the truth, I just did everything automatically for a while, I wasn’t there”. (Mr M)

The key theme of being out of place was a consistent component of informants’ reports, and was an important part of the overall disruption. These accounts of being out of place are also accurate and pertinent descriptions of the liminal state.

“You go into a different circle then. You go into the disabled circle. You know, not the able circle, even though you are a carer, its funny, it is really, you are nowhere” (Mr A)

“See, you’re in a woman’s world when you are doing this. Not that its women’s work, the stuff you do, but is women what do it you see and its geared up for women, all the services and everything ... so here I am, on my own in a woman’s world, really” (Mr K)

“You go into a new world, you do, a whole new world” (Mr C)

Some informants provided a clear description of the social invisibility that is a characteristic of those in the liminal situation:

“It’s the isolation, it’s the boredom, its well I guess what you fellows call social um social what is it social exclusion” (Mr M)

“Most of the stuff I do here is invisible, like I’m invisible, nobody sees, nobody knows, like I’ve disappeared” (Mr J)

It is clear that entering informal care was experienced as a major disruptive event in the lives of carers. The sense of disjunction and marginalisation is conveyed strongly in informants’ accounts. Consciousness of the effects of disruption seem to add to the disruption itself, as a reflexive nexus that is difficult to tolerate.

## **THE SICK ROOM**

A further source of disruption in the adoption of informal caregiving is the transformation of the home, or part of the home, into some type of sick room. This

has a practical utility: homes have to become fit for the practical aspects of care giving and have to be transformed into units for the household production of care (Albert, 1990, p.20). The range of this transformation was huge, from the simple rearrangement of household furniture to accommodate a wheelchair to the construction of a multi-roomed annexe, with purpose-built bathroom for a disabled person. Most usually, there had been some conversion of ground floor living space, involving the relocation of the sick person in that area. Some men had gone to considerable lengths to create special areas, and one had reversed entirely the usual upstairs-downstairs functions of his house. Another man had established and installed a sophisticated intercom system throughout the house, allowing his wife to summon him immediately. Many men had installed chair-lifts, sometimes under difficult circumstances:

“I was in work and I had a phone call saying you’ve got to come and get me from here I had a thing for a stairlift because I inquired about it and uh my mate’s mother up by here had one but she moved to (a nursing home) and she wouldn’t go on it so I said don’t sell it, I’ll have it so I bought it. It was all going on he had to take that out and all but she wanted to come home so she came home well we didn’t have a stairlift then but me and my mate took it out of that house there and put it in”.

Mr D’s somewhat fractured narrative perhaps reflects the disruption and turmoil of his wife’s unplanned and rather precipitate return home from hospital. He describes here the dismantling, relocating and reinstalling of a stairlift in the period of a single afternoon. The creation of a sickroom can be a major disruption for informal carers. It is acknowledged that home is an important polysemic cultural symbol, capable of

almost infinite complexity, extension and usage. It exists both as a loaded cultural image and as actuality. Basic to it are elements of security, protection, comfort, retreat, independence, dependence, interpersonal interaction, development, emotional tone and biological process. A feeling of being at home is localised and general, specific and diffuse. A feeling of not being at home is one almost universally commiserated with, even by nomadic people. It has been noted that home represents a shared 'system for order and each person's interpretation or version of shared community values about space, organisation and being' (Rubinstein, 1990, p.38)

Some of these meanings inform the idea of "home care", which is contrasted explicitly and implicitly with institutional care. The latter is criticised for not being, by its very nature, homelike. The home is felt widely to have a therapeutic effect and function implicit to it, in addition to any practical or technical advantage it might confer. This is a general opinion, taking no regard for the relative qualities of particular homes and particular institutes. In addition, the function of home as a site of caring for the sick 'may play an important part in modulating illness or redefining a situation as not one of illness' (Rubinstein, p.39)

However, the conversion of home, or part of a home, into a sickroom can be disruptive, and allows the eruption of disorder into carefully constructed and maintained domestic worlds. This disruption can be severe in itself, but can have difficult ramifications: changes occur in daily routine, use of space, noise, odour, access to utilities, accommodation, access for visitors and décor. In many instances, and especially in small modern homes, a bed for the recipient of care is erected in the sole living room. This occasions considerable spatial disruption, and disrupts patterns

of leisure activities. For carers, the former site of relaxation and pleasure is turned into a workplace.

This relocation of the workplace in the home is potentially a difficult issue for male carers. All of the men in the study were used to the rigorous separation of work and home and, for one reason or another, many of them felt this new situation to be difficult or awkward. Many men expressed trepidation and feelings of awkwardness because they saw themselves as intruding on a female domain:

“You’re in a woman’s world when you are doing this” (Mr. A)

This was a consistent theme for many of the informants when they described their early experiences of caring. Many of the difficulties of both working at home and of providing care to a dependant person that were identified by informants were very similar to those delineated by women in their critiques of housework and child care. The unendingness of housework, its repetitious nature, the lack of stimulus, social isolation and lack of job satisfaction (for example, Oakley 1981, pp 173-175) were also reported by informants. The “intensification of responsibility” discussed by Oakley, where housewives have to act as their own supervisors and set their own standards, was also identified by informants.

The description of isolated work at home given by Rowbotham is very similar to the informants’ descriptions:

‘There is no distinction between workplace and leisure... it stretches over the whole time of existence... its space is the whole of a woman’s life. A woman does not go to

work, she wakes up to work. Home is work and work is home. Within the space of the house and the time of day there are certain tasks to be done. The tasks are the boundaries of a woman's work in the home. Each operation is broken into small parts. Each one is quite distinct and separate.... The day is carefully delineated, the operations are repeated again and again but the context changes every day'. (Rowbotham, 1981, pp 70-71)

Rowbotham asserts that 'housework can never be a normal job routine because emotion erupts in its midst' (p.730). She refers here to the labour of childcare, but her description applies equally well to the care of the sick or disabled. Even more pertinent is Rowbotham's use of the following quote:

'Her helpless child is her jailer. Its total dependence is its total power, it dictates her moods by its moods' (p.79)

Some informants made explicit reference to the mother-child dyad when describing their own situation:

"I run the home as woman with small children would run it". (Mr E)  
and

"My situation is almost exactly like a young wife with a baby and an absent husband. I get all the isolation, loneliness, boredom and all". (Mr M)

## LOSSES

The adoption of full time caring involves multiple losses. These are additional to the losses already incurred as a result of the serious illness or disability of a relative (most usually a spouse).

All informants expressed unhappiness at social losses of one sort or another, and suffered particularly from the social isolation of the lone-carer situation. For example:

“You lose all your friends, you lose all your friends. They are all gone”. (Mr A)

The elegiac tone of Mr A’s observation, with its effective repetition, was common among informants.

“Everything’s gone. Everything, just about. I mean, work, social life, friends, holidays, weekends away, shopping together, all that’s gone... It’s hard to go anywhere and friends don’t call that often”. (Mr N)

Informants lamented the loss of autonomous leisure activities and the social contacts associated with them:

“Well, I used to go out five nights a week. Or to the rugby, on a Saturday, and all that stopped” (Mr B)

“I was never in, I used to get about a bit, go for walks, you know, go up the mountain, up the club, everywhere. But then I was stuck in here”. (Mr C)

Informants also regretted the loss of shared leisure and social activities with their wives:

“Social life just went. We didn’t have separate social lives, but I gave up watching cricket, going out walking, that had to stop. We couldn’t go and see our friends, or at least rarely. They used to come here some afternoons, but, well...”. (Mr G)

and

“I used to go to the club perhaps two nights a week, Anne used to come with me. I used to watch rugby, up here, or we just used to go for a walk, you know, up the canal or something, but its different now” (Mr K)

While missing social contacts and leisure pursuits, some informants had terminated those few still available to them.

“Her sister used to come round on a Friday so I could go for a drink, but I got fed up with that, like I’d lost contact with the club and all, and it was pointless going there, I wouldn’t just go for a drink because I’m not that fussed, and I got to be a bit out of place over there, you know, lost the continuity of club life, so I packed it in” (Mr J)

and

“No social life at all. That can be a bit different, and I do get upset about it, but what can you do? I could, if I wanted, get someone in for an evening, but what would I do? One evening, every, every few months. It’s not worth the trouble”. (Mr M)

## **NARRATIVE DISRUPTION**

The entry into informal caring occasions widespread disruption in the lives of carers. On a fundamental level, it can be argued that this disruption extends to the personal narratives that carers employ to make sense of themselves and their situation. Caring disrupts the formation and utilisation of narratives; put simply, the old stories will not serve to explain the new situation. There is a disjuncture between self and ideal self, between experiencing self and managing self; and the continuity between past and present, between present and imagined or anticipated future supplied by narrative is broken.

This has been referred to as “narrative loss”. Mattingly (1998, p.52) shows how chronic illness and suffering ‘often generate a narrative loss as well as a physical loss as patients restructure lives in new ways’. Accordingly, it is argued that the adaptation of informal caring occasions a sort of narrative loss, perhaps amounting to a diminution, temporary or relatively enduring, of the competence to create narratives that incorporate the new caring experiences. Such a restructuring would have to refigure carer identity, deal with the multiple losses inherent to the caring situation, establish connections with the past and, at least, permit some ideas about future developments.

The idea of narrative loss and its recovery is similar to, but not at all the same as, the notion of narrative competence in modern psychotherapy, where narrative is seen to turn ‘experience into a story which is temporal, is coherent and has meaning...It creates out of fragmentary experience an unbroken line or thread linking the present

with the past and the future' (Holmes, 1993, p.150). In this formulation, narrative competence is linked to the possession of secure attachments with roots in very early childhood. Although this in itself may be contentious, the assertion that 'A person's core state is a condensate of the history of their primary relationships. If this history is available to them in the form a personal narrative, then they are likely to feel secure' (p.150) seems to illuminate the carers' situations.

It is clear that in the midst of sudden disruption occasioned by the serious ill health of a close relative, assumption of unfamiliar and perhaps uncongenial caring responsibilities, cessation of paid employment, loss of continuity and so on, carers are too busy – too disrupted – to engage in much narrative formation to begin the narrative reconstruction of their lives. They have to exist in that uncomfortable, chaotic, restless state, where half-formed thoughts circle repetitively and almost endlessly in the mind, and where nothing is settled – a state that everyone must experience at one time or another. At this time, narratives are broken, disjointed and inchoate.

The first step in the reconstruction process occurs comparatively early, and consists of the formation and retailing of narratives of disruption. Basically, these are accounts of what has happened, and are characterised by a high degree of distress, which seems to be a major organising factor in such stories (Becker, 1997, Cohler, 1991). The recounting of narratives of disruption is necessary to explain, order and regulate the experience, to incorporate it into an over-arching life story.

This first step is followed in some, perhaps most, cases by the formation of narratives about coping with disruption: these may be stories of struggle followed by success or failure. These will be examined in chapters 10 and 11. However, it might be hypothesised that those carers who do not move on from narratives of disruption are much more likely to seek formal professional care for relatives; this remains conjectural, and could not be confirmed in the present study.

Informants were able to describe this early state, but had all moved on from it. Some of them were removed from the early experiences of caring by a period of ten years or more. However, a few informants made some comment about the early difficulties, which seemed to describe the experience of narrative disruption and loss:

“You lose the plot, well actually the plot loses you doesn’t it and you have to run like hell to catch up with the story” (Mr N)

“Takes a while to get yourself back, but then you find yourself again, sort of thing”.  
(Mr F)

These comments describe a situation where disruption affects the experience and organisation of the self – a self constituted largely through its own narrative competence. This indicates the importance of narrative in producing both a coherent sense of self and a coherent self (see Ewing 1990). This is not to assume that narration provides coherence in the face of severe disruption, which would be to suppose that there exists a pre-narrated self, which requires coherence of some sort. Rather, it is to assert that selves as social/symbolic entities are produced and maintained through discursive strategies.

## CONCLUSION

It is evident that entry into informal caring can be an extraordinary and disruptive event. The ramifications of this disruption extend beyond emotional life to encompass leisure activities, domestic space and the very organisation of the self. The concept of liminality, derived from Van Gennep's study of rites of passage, provides a useful and illuminating way of viewing the caring experience. From this perspective, it is certain that entry to informal caring confers a species of liminal status on carers. The loss or impoverishment of narrative competence is seen to be important in the early period of disruption. Recovery or restitution of that competence seems to indicate an important coping mechanism: it can also be seen as an agent of accommodation and change.

## 6. INSIDE INFORMAL CARE

### INTRODUCTION

Men enter informal care with few preconceptions, slight preparation and not much guidance. The initial disruption settles down quite quickly, although its reverberations and ramifications do not, and the long work of caring begins. It is recognised as being a long-term project from early on, and this is one of its difficulties. Carers settle into a routine of caring that is largely of their own devising (although, of course, hugely determined) and this comes to constitute a world. The mechanism of routinisation closes like a trap: caring work would be difficult or impossible without an orderly routine, and life is felt to be atrophied with one. Carers have to construct a life in the space between the teeth of this trap. Largely, they do so with success, but not without difficulty, struggle and particular pain; eventually, some of them achieve a sort of transcendence (see Chapter 11).

This chapter details the daily experiences of male informal carers. It contains a survey of caring activities, some intensely practical and some less obvious or visible. Some of the survival strategies used by carers are noted. Attention is given to both the use of narrative in survival, and the effects of this on narratives. The principal work of narrative is to enable the individual carer to interpret his experiences, and draw all the disparate strands into a cohesive whole. It has been noted that individual histories are constructed in a work of imagination that emphasises various connecting points, and transforms them into a coherent story (Ricoeur, 1983). This can be an essential task of caring, as of human life generally.

## **EXTENT AND SCOPE OF CARING**

Informants reported that they were involved in a wide range of activities that might be subsumed under the general heading of informal care. These may be divided into four broad categories: domestic work, nursing care, treatment and emotional care. In practice, these categories are not particularly self-evident or discrete, and there are huge overlaps between them. Such activities as the purchase and preparation of food, feeding a sick relative and cleaning up afterwards can be seen as a single process, crosscutting categorisation. The notion of categories of caring activity arose in interviews, when it was convenient to discuss domestic work and more direct caring separately. The categories provide a simple plan for a survey of carer activity.

### **a. Domestic Work**

Informants described having sole responsibility for all housework and household activities, with the partial exception of one man, who employed a part time cleaner.

Common activities were:

Meal planning, shopping, food preparation and cooking

Washing, other laundry work and ironing

Kitchen work, including dishwashing

General cleaning and household maintenance

Gardening and exterior work

Much of this involved the acquisition of new skills for most of the informants. For others, it constituted an extension of their usual range of activity. There was usually some early difficulty:

“My first attempts at dinner were a bit off beat. I had to learn, I just had to learn to cook” (Mr G)

“One thing I wasn’t good at, hanging the clothes out, though I got the hang of it later, she likes them neat and tidy on the line, well if I hang them out every Tom , Dick and Harry style, you know” (Mr J)

“I used to panic if there were too many things cooking” (Mr D)

Some informants found real difficulty in shopping for food:

“Shopping, going shopping and meeting your mates from work! (Mr L)

“I used to be there when they first opened because I hated being seen there, I’d be there when they first opened, and I’d be home in half an hour” (Mr D)

“It was a bit embarrassing. Especially if I bumped into one of my mates in the supermarket, like he’s with his wife, but I’m on my own and I’m like comparing the price of Mr Sheen with Pledge or whatever it was, and I used to curl up” (Mr K)

All informants reported that the effects of practice had improved their performance in all aspects of housework:

“I’m a conscientious ironer. I take pride in it” (Mr D)

“I do it better now, I make it a bit easier for myself by having a race with myself, try to improve my performance time for hoovering” (Mr K)

“I’m used to it now, cleaning, washing, cooking I’ve done it for so long it’s a part of me now, I can’t remember otherwise. I’ve even got a bit house proud, you know, fussy about it, like that women on TV comedy series “ (Mr M)

“I take some pride in it now, and get a bit of satisfaction from it. Especially the cooking – I’m one of those Delia Smith disciples” (Mr H)

However, despite a few positive comments of this sort, and despite evidence of skill and ease with housework procedures, almost all informants commented on the boring, repetitive nature of domestic work:

“This is boring, you expect that, you can get um demoralised, you have to keep reminding yourself why you’re doing it” (Mr P)

“I’ve got to do it, its got to be done, but...! (Mr M)

## **b. Nursing Care**

Informants reported engagement in a wide range of nursing care activities. A few informants no longer engaged in some activities, because of partial improvement in the conditions of their relatives. Others had engaged in more of these activities, in response to deterioration in the conditions of their relatives. Most persisted with the full range. The most common activities were:

Dressing and undressing, or assistance with these

Lifting in and out of bed

Lifting in and out of wheelchair

Lifting, carrying and transporting

Washing, bathing and showering

Seeing to toilet needs

Feeding or assisting with feeding

Hair care

In addition, two informants applied some basic cosmetics to their wives. Others had contemplated this, but felt insufficiently skilled. The problems of providing personal and intimate care are discussed below.

### c. Treatment

A significant number of recipients of care in the study were having complicated regimes of medication. Carers were responsible for the administration of these, and the difficulties of organising the correct dose at the correct time was referred to by some of them. In two instances, this involved very complicated scheduling.

In addition, a few carers were, or had been recently, engaged in other forms of direct treatment. Four of them managed on-going catheterisation. They had been taught to remove and insert catheters as necessary, and had developed some expertise at this. One of them had developed a significant theoretical knowledge by reading extensively across the relevant literature, as supplied by healthcare professionals. Other carers were responsible for the regular administration of suppositories, either as transmission vehicles for medication or as aperients. Five carers administered some form of regular exercises, as prescribed by physiotherapists.

None of the informants found this engagement with treatment to be at all difficult. In fact, a few of them, especially those who tended to be younger, found some reward in it. It seemed that the application of instrumental medical procedures conferred a sense of achievement and mastery that other aspects of caring did not provide.

#### d. Emotional Care

All informants referred to the emotional care of their relatives, and described the difficulties of meeting the emotional needs of unhappy, labile, dependent, disabled persons, who were often in pain. This was seen as on going work, entirely implicit in all daily activities. However, two informants made explicit reference to emotional caring, and described a purposeful engagement with activities that would promote emotional health. One of them noted:

“...and I try to spend a good bit of time doing something with her, otherwise it can be very boring, she was always a bright, active girl, deserves more than just watching TV, so we might play a boardgame or do a crossword together, read a seed catalogue and plan the garden, that’s another. I go out and find stuff like that” (Mr M)

Other informants recognised, and allowed time for, the need for expression of feelings, although this might be painful:

“We hold one another, we talk about it and um we usually have a cry” (Mr D)

#### **PLANNING AND PREPARATION**

Informants described the necessity to plan their caring activities. This was recognised as more or less essential, but was time-consuming, and oddly de-energising.

“It takes on career proportions... it has to be programmed, chess game. You know if you’re not eight moves ahead in chess you can forget it, at least eight, well it’s like that.” (Mr C)

Another informant described the planning necessary to get his wife to a hospital outpatient’s appointment at 9.30am, involving a journey of only fifteen miles:

“We have to start getting ready at four o’ clock, or at least I do. That’s when I get up, get myself ready, get Anne up, washed, dressed, downstairs, breakfasted – all of this takes an hour or so on a good day. I have to get her into the wheelchair, and get the wheelchair in the van. The journey’s the easy part, but then it’s a reverse process at the other end. And you have to remember so much, like to take a drink, because she can’t have one before, and so on, and so on. An afternoon appointment would be easier, but they don’t have them then” (Mr A)

This planning and preparation is similar to the “watchfulness” described by Parker in her study of caring and disability in marriage (1993). This activity ranged ‘from making sure that other members of the household did not leave things on the floor for the spouse to trip over, through being around in case anything went wrong, to quite complex medical decision making about the spouse’s state of health and the need for intervention’ (Parker, 1993 p 18). It is noted that although this watchfulness is not visible, it is a very important component of care.

## **PERSONAL CARE**

Issues concerning the provision of personal or intimate care have been important in discussions of the experiences of male informal carers. In the following section, I use “personal care” to refer to all care of the person that involves close physical contact other than lifting and supporting. It refers to a range of activities from hair dressing and dental hygiene to post-toilet cleansing.

It has long been argued that male carers do not, or are much less likely to, engage in intimate care. Male carers, on the whole, were said to enlist the help of others for this. It was hypothesised that cross-sex care violated some powerful cultural taboos, which served to exclude men from aspects of the intimate personal care of females. Those who did engage in it were seen as somehow aberrant. However, it was asserted that cross sex care was largely unproblematic for carers or recipients of care if it took place within the context of a marital relationship (Ungerson, 1983 and 1987)

This has proved to be contentious, according to more recent research. It has been shown that over 40% of men caring for a co-resident person provide intimate personal care, compared with 66% of women. However, the difference is much less when the co-resident person is a spouse. In this situation, 59% of men, and 71% of women provide personal care (Arber and Ginn, 1995 p.28). In addition, it has been shown that provision of personal care can be distressing for marital partners (Parker 1993, p.14ff). The assertion that fewer inhibitions ensnare cross sex help between spouses with personal tasks like bathing and toileting ignores the fact that many carers and recipients of care have a huge mutual investment in sexual attractiveness, which may

be impaired by some care tasks. It has been demonstrated that intimate care provision of this kind can have a negative effect on a couple's sexual relationship (Borsay, 1990, p.108) Finally, a study of the caring activities of redundant steelworkers has shown men engaged in all sorts of intimate care, sometimes for other men (Bytheway, 1987).

At the time of the interview, all the informants in the study were providing some form of personal care. Two of them had provided higher levels of care in the recent past, but this had been reduced (not eliminated) by improvements in the conditions of their spouses.

With an important exception noted below, the informants found it surprisingly easy to talk about the provision of intimate care, perhaps in contrast to the reticence of Bytheway's interviewees from an earlier period (Bytheway, 1987). I had anticipated much greater difficulty in gathering this sort of data. However, despite this apparent ease, almost all informants used a large degree of verbal circumlocution in their descriptions, and employed an extensive array of euphemisms.

Provision of intimate personal care was always the occasion of embarrassment in the earlier stages of carer career:

"It was difficult. I had to do it. Never done anything like it before. Odd, embarrassing.... Embarrassing more than difficult and I was, you know, awkward, clumsy" (Mr B)

Difficult, yes. Embarrassing. We've never been that inhibited, uninhibited, which is it? But you don't realise what you can do until you have to" (Mr D)

However, at least two informants found no embarrassment at all:

"The nurse said to me how will you manage, I said I managed for nearly ten years before you came here. She said I thought it would be embarrassing for you, and I said it don't hurt me, I've seen her bum before, and if I could have seen as much of it when we were courting as I do now I'd have been a happy man" (Mr E)

and

"Not difficult at all, we've always been close and sort of easy with one another" (Mr F)

As indicated above, some informants found the provision of personal care difficult, because they were not used to doing it, and had no skill or dexterity:

"....difficult because well it's not pretty work is it and I've never done anything like it before " (Mr K)

"There was embarrassment, and um I wasn't much good at any of that to begin with, no practice see, I've never done anything like it before" (Mr L)

The informants provided personal care as part of the total care of their relatives. They found it difficult, but assumed that it was their responsibility. None of them had sought assistance with it from any other informal carer, although two men had received assistance from their daughters during periods of acute illness. Two of them said they would pay for professional assistance if they could afford it; for both of

them, this was a pipe dream, akin to fantasies about winning the Lottery. Two informants had a fierce determination to be the sole provider of personal care to their wives. Both had strong subscription to the ideology of the companionate marriage, and showed strong positive affect for their wives. However, it should be noted that both wives were near the end stages of terminal illnesses, and this had an effect on the husbands' perception of the caring situations.

Only two of the informants could remember discussing the provision of personal care with their wives, although for most of them this would not have been possible in the earliest days of caring. One of them seemed to make this decision, at least in part, on the basis of some strong convictions:

“Just because our relationship was so strong, it seemed the right thing to do, no sort of politics or, personally and professionally I've had the experience of other carers, and what I do, I'm aware that what I do is a bit different, that many um male carers or men in general wouldn't consider it, but it was the quality of our relationship, because we had, we felt we were lacking in privacy, all the people coming to the home, and, privacy is of considerable value to us – they're all OK all very helpful, but we wanted to keep more privacy, something with each other. We are aware of the necessity at some stage of having to say to somebody do this for me for a period of time, so it's not a clear refusal of help” (Mr C)

The other informant described a much less considered discussion, involving a healthcare professional:

“One of the nurses said can you do it, and asked my wife if she was happy for me to do it, and I did it. Wife wasn’t worried. We were always close” (Mr G)

One area of particular difficulty for some of the informants was dealing with menstruation. In practice, at the time of interview, this was an issue for only two informants. The wives of the other informants had ceased to menstruate due to age, illness or the side effects of chemotherapy. However, a few informants referred to earlier difficulties, and some of them expressed relief that this was not a continued feature of care. Managing menstruation has been noted as an area of difficulty for both carers and recipients of care (see Parker 1993 p 14). Both informants referred to above adopted a sort of stoical resignation, and got on with the practical necessities:

“Got to be done, its got to be done, that’s all. You just have to get on with it” (Mr A)

“Part of the difficulty for me is I know it must be difficult for her. She says its OK but... Well you just have to get on with it, there’s no alternative. Who else could do it?” (Mr L)

## **ROUTINISATION OF CARE**

All informants described the need to establish a routine of care. This has an instrumental aspect and seems to derive from the human propensity to order and

regulate the apparently disordered and unregulated, perhaps in an attempt to achieve predictability and symmetry. The intrinsic value of the routinisation of care tasks is almost self-evident: achievement of a routine allows certainty, fixity and predictability in the location, timing and sequence of tasks. This permits a greater feeling of certainty in both process and completion of tasks: the work can be seen to be done, and its end is signalled clearly. This reduces the potential infinity of caring to a series of manageable, finite tasks. Caring work can be predicted, prepared for, performed and completed, allowing the carer to, in a sense, move on to other things. That “in a sense” is important, because carers are not able to move on at all, and this is one of their most consistent complaints, but the sense of progression, or the illusion of it, is comforting. Similarly, routinisation can never render the care situation predictable, but it allows the illusion of it. We all live by the strength of our individual and collective illusions, so the power of this is not to be doubted. All informants were able to give very clear, very detailed accounts of their caring routine over a 24 hour period, full of the thickest of thick description (Geertz 1973 ;Denzin 1989).

It has been noted that carers often ritualise the caring routine, ascribing significance, power and meaning to the “correct” performance of tasks. This action is in addition to the purely instrumental purposes of getting the job done in an efficient way (Albert 1990 p 28ff). Ritual may be defined as ‘those aspects of prescribed and repetitive formal behaviour, that is those aspects of certain customs which have no direct technological effect and which are symbolic’ (Loudon 1966 p101). However, the instrumental, technological aspect is not necessarily that important; Leach observed that ‘any form of secular activity, whether practical or recreational, can be stylised

into dramatic performances and made the focus of a ritual sequence' (Leach 1972, p.974.). The ritualisation of caring tasks is also a feature of professional healthcare work and may be significant for other professional groups (Bosk, 1980; Katz 1981; Moore and Myerhoff 1977).

A few informants described an intense routinisation of care that could be seen to amount to a species of ritualisation. This was not discussed in an explicit manner. However, it was clear that routinisation had reached a point where it was possible to "go through the motions" of caring where there was strict adherence to the outward ritual form, while the inner purpose and meaning might be lost. This accords with anthropological studies of "empty" ritual in other cultures (Humphrey and Laidlaw 1994) Informants did refer to this in interview:

"I don't know, it took me ages to get a routine going, get it really established, and now I have, it sort of runs me, and I'm, I'm often bored to death, desperate for something else, something different " (Mr K)

Other informants were explicit about the repetitive nature of caring:

"It goes banging on, day after day, the same things in the same order" (Mr F)

"You get it done, that's all, it's a wheel, a what is it? A treadmill" (Mr J)

One informant described the loss of meaning sometimes consequent on that repetition:

“This is boring, you expect that, but more than that, you get um demoralised, it all becomes meaningless, well you have to keep reminding yourself of the meaning, you have these conversations with yourself” (Mr M)

Another informant reported a dislike of breaks in the caring routine occasioned by holidays or respite care, because:

“It’s hard for me to come back and start it up again. It’s hard. Because you’ve been away, because its difficult to re-establish it, both for me and for her, and because well it’s not worth messing it up, and anyway I won’t do it again” (Mr A)

It has long been asserted that men who engage in informal care are much more likely to receive help and support than are women in similar situations. There remains a wide presumption that male carers receive more help, both from the formal health and social care services and from informal carers – family, friends, neighbours and so on – who are not co-resident. These assumptions and presumptions are shown to have limited accuracy (Arber and Gilbert 1989b; Arber and Ginn 1995; Parker 1990). Any difference in levels of help to male and female carers is small, particularly in cases where carers and recipients of care are married couples.

Informants in the study reported receipt of much less formal and informal help than might be expected. Some of this may be due to the manifest ability of these men to provide consistent, good quality care. It may be due in part to the determination of some of the informants to be the sole provider of care to their wives. Informants were much more engaged with caring, and much more expert at it, than one might expect

from the literature. However, as noted earlier, these informants might well constitute an unusual group in that respect.

The help that informants did receive was of narrow range. It was provided by a variety of persons, both paid and unpaid, in a variety of ways. One informant paid for a certain amount of help with direct care:

“I pay £100 a month, and for that I get an hour in the morning and an hour at night, where someone helps me with washing and dressing. It was too much for one person, and there’s no one else” (Mr A)

This was entirely untypical; no other informant paid for help with direct care in this way. Another informant paid for the services of a part time cleaner. In comparative terms, he was particularly able at all aspects of domestic work, and employing a cleaner was perhaps an action that he would have taken anyway, regardless of the health of his wife. His choice had something of an aesthetic quality to it:

“We’ve had a lady in to do the um cleaning, because I can clean but she does it better. I can do it but I’m not satisfied with it because I can walk in the door and say to myself there’s the difference, that’s what would be missing if I did it. I’ve done it all my life, but she does it better” (Mr J)

The wives of two informants received a large amount of health care, because they were at the time of interview, both seriously and terminally ill. This necessitated nurse visits up to three times a day, but the nurses provided very little in the way of

help with personal care. It was clear to the informants that this sort of care might be arranged, but neither of them took advantage of it.

Three informants were able to send their relatives to day care facilities on one weekday. All of them facilitated this, even though it required slightly more care work in the preparatory phases of the day's activities. The day was not seen as an opportunity to rest, or to engage in personal activities, but was construed as an opportunity to engage more thoroughly in domestic work:

“She goes to the day centre on Fridays, and that’s the chance I get to do the shopping”  
(Mr B)

“She goes to the day centre on Wednesday, and then I can get on with the cleaning, you know, pull the furniture out, do upstairs, clean the windows, that sort of thing”  
(Mr H)

“She goes to the centre up there on a Tuesday, ten until three, three thirty, and that’s when I do the shopping and give the house a good seeing to” (Mr L)

Two informants had been offered respite care for their relatives. One had never taken up this offer, but held it in reserve, for when his own health deteriorated. The other informant had, on one occasion, sent his wife for respite care, but this was not successful:

“Once they persuaded me, I was having a hell of a time, she was awful, they asked me to send her in for respite care, it was a big ward in..... Hospital, it was horrid. I left her there, came home and I sat here... anyway, I went up there on the Monday it was a Monday, and on the Tuesday I took her out, took her back home, and I wouldn’t do that to her again, I’ll keep her here. As it was, she wasn’t as clean as she should have been, and half her clothes were lost, it was no good, but still I couldn’t do it to her”

(Mr E)

“An assistant gives her a shower every Friday. She can do it herself now though” (Mr B)

“Care assistants come every other day to give me a hand with the bathing, because these days I can’t lift. I’ve put in for a hoist to help me, but these girls give me a hand until it comes” (Mr L)

Most informants received no formal help, and were helped minimally by families and friends. The extent of this is summarised neatly:

“Her sister comes on a Tuesday, so I can do the shopping. My son gives me a lift if he can. He does our washing, well sometimes it’s his wife, because they’ve got a machine to dry it, and he does a bit of gardening sometimes” (Mr B)

Most informants describe similarly loose, informal arrangements. The most common form of help was for a sister in law to combine a social visit with an element of “baby sitting”, allowing the informants to go shopping. Five informants describe this arrangement. It seems to have occurred naturally, when informants took advantage of a social visit to go shopping and this had developed into an informal arrangement.

Some men felt that they should allow their wives the opportunity for a private conversation with their visiting sisters, and absented themselves from the room to facilitate this. Three informants described evening visits from sisters in law, which were intended originally to facilitate some social activity for them, but all of them had discontinued this by the time of interview. A single informant used the visits of a friend, and of community nurses to do the shopping:

“I do go shopping. Mary comes on Thursday afternoons for an hour or so. We used to go together, but as her mobility became less we had to stop. And when the nurses come, sometimes, I go out quickly, to the local shops” (Mr C)

## **CARING AND FORMER EMPLOYMENT**

Men are said to engage with caring in a different manner to women. One aspect of this difference is that men are said to have a more business-like attitude to caring, and to draw on their previous employment experiences (Ungerson 1987 p 103ff). In addition, men are said to employ a different orientation to the production of care work, utilising such concepts as efficiency and output (Ungerson, p.104). It is perhaps worth remembering at this point that Ungerson’s data derives from only four male carers.

In the study, all informants engaged with all aspects of care. Three of them had developed a style of what might be called “care management” that seemed to derive

from their former occupational experiences. They were in the Managerial-Professional category, used to bureaucratic procedures and experienced at the management of people. All of them used their skills to obtain equipment and services from the local Social Services Department, and had engaged in a variety of work acquired practices, such as telephoning direct to heads of departments, using previously established contacts and persisting appropriately on some issues. None of them had any trepidation about changing hospital appointments to more convenient times, and all of them kept diaries or timetables to ensure that appointments and visits occurred at appropriate times and dates. This could be time consuming:

“All these things. People phoning, services who need certain things, repeating things, the next phone call is about the same thing, because they are slow in getting it to happen, somebody else is ringing because some hospital has got some agenda, and all that goes on, you get through the day without being bored”. (Mr C)

However, as regards the provision of direct care to relatives, none of these “managerial” men were particularly different from the other informants. Most of them attempted to organise care, but were handicapped by comparative lack of experience and educational background; they also displayed a greater degree of deference in their dealings with healthcare professionals.

Some of the older informants, particularly Mr B and Mr E, who were well into their 80s, had a propensity to take “breaks” throughout the day, when they stopped what they were doing, and had, at least, cups of tea. This might well have been a remnant of previous occupational practice, but it is equally likely to be a product of increasing

age. It should be noted that none of these men removed themselves from the care situation to take their breaks, and always involved their wives in the break activity.

It would not be surprising if male carers utilised the vocabulary and style of former employment in some aspects of their caring work. It would not be particularly surprising if they derived a certain satisfaction and sense of agency from their ability to order care provision. Many of the informants had extensive, and in some cases completed, employment histories. Most of their adult lives had been spent in the workplace; the experience had influenced much that they did and much that they were. However, they discussed paid employment comparatively little, although it was always an available measure for their caring activities. One informant referred to this explicitly:

“...in 1976, there were three men killed in the pit – I’m still, I’m starting to fill up now.... When I went in there, the manager said to me what are you like working around dead men, I said well I never done it before. He said well as soon as you want to come from there you can – that type of thing, what I’m trying to get at, until you’ve had to do it you never know do you, and I worked there all day then, there were three killed there, the sights of it, they were trapped, they were, they were trapped, and the weight of it was coming on them all the time and squeezing them, and all the blood was coming through their pores, you know.. Well, it hit me for a while after that, but I, I was team captain, and I had twenty men, say, in my team, and you lead by example more or less... but what I’m getting at is you never know what you can do until you do it, and I used to say that was the hardest thing I ever done until I started looking after her “ (Mr D)

## PSYCHOLOGICAL EFFECTS

That caring can exert a deleterious effect on the well being of informal carers is well documented (Bel et. al., 1987; Briggs, 1983; Cantor, 1983; Hirschfield, 1981; Parker, 1985; Hooyman, et. al., 1985). Although such effects include disrupted social life, depleted economic status and poor physical health, most recent studies still show that deterioration in emotional health as the most prevalent and pervasive consequence of caring(see Nolan, et. al., 1990). Some of the most stressful aspects of caring include the unremitting nature of the work, hard physical labour, lack of rewards, social isolation, lack of privacy and inadequate off duty periods.

However, humans are resilient and endlessly adaptive, employing a range of protective strategies and adaptive devices. Information in the study described, usually indirectly, many of these. The descriptions and sometimes the language employed, were very similar to those of strategies noted in an established literature on inmates of other forms of total institution (Cohen and Taylor, 1972; Goffman, 1965; Bettelheim, 1971). On examination, there are many similarities between the experience of informal carers and those of long term prisoners. For example, Cohen and Taylor note the stress in prison life occasioned by constant surveillance and lack of privacy. More specifically, there is reported to be a lack of opportunity for solitude, for “time out”, which is seen as a necessary condition for ‘indulgence in private fantasies, for obtaining a sense of individuality’ (Cohen and Taylor, p.79). In addition, there is a reported lack of space for intimacy, where people can achieve maximum personal affinity. These, of course, are all features of the caring situation, and were discussed by informants at interview.

An important strategy for coping with the demands of caring involves time management. This is also reported as a problem for prisoners and for factory workers (among others). In all instances, there is a tendency for people to create their own subjective clocks, and to divide up time into convenient, easily manageable stages. Carers describe the completion of tasks and series of tasks as important milestones in the day. In common with the reported activity of factory workers, they punctuate their day with interruptions and markers, breaking up the day into parts that are more easily assimilated; tea or coffee breaks, cigarette breaks, meal breaks and so on. Sometimes this amounts to no more than the ticking off of completed tasks on some mental time sheet. Whatever form they take, such contrived incidents serve to break up the day, and to protect against a too close apprehension of the extent of available time. In a sort of contrast, other informants described a time management strategy which consists of total immersion in the work at hand, with close attention to minutiae, where a kind of unconsciousness of time is sometimes achieved. These sorts of strategies have long been noted among inmates of various sorts (Ray, 1959,1960; Bettelheim 1971; Cohen and Taylor, 1972)

Another common survival strategy is the adoption of resignation. This can amount to a sort of retreatism, referred to in Goffman's classic work as "situational withdrawal", where the person 'withdraws apparent attention from everything except events immediately around his body and sees them in a perspective not employed by others present' (Goffman, 1965, p.61). This is noted also in studies of prisoners. The strategy was employed by some informants. It seems that it might be employed by all

informants at one time or another. For two of them, it had perhaps become an established defensive stance, and characterised much that they did:

“I just keep my head down, get on with it, do you understand what I’m saying? Keeping a low profile is part of it, but.... Um, I suppose I’ve withdrawn a bit, just concentrated on what I’m doing here” (Mr A)

“Her sister used to come on a Friday, so I could go for a drink, but I got fed up with that, like I’d lost contact... it was pointless going there” (Mr K)

Another form of defensive strategy might be referred to as “secondary adjustments”, which are small habitual attempts to make life more bearable (Goffman, p.56). In total institutions, these are ‘practices that do not directly challenge staff but allow inmates to obtain forbidden satisfactions or to obtain permitted ones by forbidden means’; they provide the inmate the ‘important evidence that he is still his own man, with some control over his environment; sometimes secondary adjustment becomes almost a kind of lodgement for the self, a cheering in which the soul is felt to reside’ (Goffman, p.56). Similar processes can be seen in the adaptations of the informants. One of them reported a secret and almost savage glee at purchasing and eating a cake while shopping at the supermarket:

“Like I’m fooling no one, but it feels like I am. I mean, Anne wouldn’t care a bit, not at all. But it feels like I’m getting one over see. Like I’m robbing no one, it’s my money but its become important” (Mr L)

Another informant described spending longer than was absolutely necessary on the repair of household items, which he took to his shed:

“A bit of time for me, twenty minutes, that’s it, but it’s all I get. I’ve got the alarm, she can call me anytime, but I enjoy those few minutes, it’s my guilty secret”

(Mr. C)

Other informants, in common with the reported activities of inmates of total institutions, gathered a little time for themselves by engaging in hobbies. For most informants, this was too difficult. However, a few of them reserved hobby activities for the evenings, when their relatives watched television. One informant made rather beautiful trays with intricate veneer inlays. He has started this since taking up full time care, and it seemed partial compensation for the loss of his social life.

Some few carers were involved actively in carers’ associations, or other groups for the relatives of people with specific disorders. This included taking on campaigning activities. In anthropological terms, these groups can be seen as similar to the cults of affliction for past, present and prospective sufferers and their relatives, as recognised across numerous studies (Boddy, 1990; Constantides, 1977; Turner, 1968). It also accords with the behaviour of prisoners, who mount campaigns to draw attention to the injustices of their particular cases, sometimes with success. In those cases, it has been noted that ‘the ego of prisoners refused to accept the estrangement it was subjected to. It therefore turned the experiences connected with the loss of its feelings into an object of its intellectual interest’ (Bluhm, 1948, cited in Bettelheim, 1971, p.104). It is clear that some informants were involved in a similar process.

It is possible to identify three different styles of adaptation to imprisonment. These are: a. doing time, where prison is seen as a suspension of life, and inmates avoid trouble, make few friends and few adjustments, intending to get out and get on with life as quickly as possible; b. jailing, which involves cutting oneself off from the outside world, and attempting to construct a life in prison; c. gleaning, which is adaptation to prison to effect changes in life so that the future can be better – for example, getting an education (Cohen and Taylor, p. 152ff, 1972).

This is not entirely or immediately applicable to the experiences of informal carers, but it does convey something of relevance. Caring might involve elements of all these coping styles, and this typology can be seen as a repertoire of behaviours and attitudes that carers might adopt at various time. In addition, it might have some consonance with the typology of caring styles and outcomes given below (see Chapter 10).

Those in extreme or extraordinary situations are said to employ a variety of psychological defences. Although the precise epistemological status of psychological defence mechanisms or, indeed, of the category “psychological”, is uncertain, it is perhaps worth noting some of them. Prisoners are said to employ elements of rationalisation, emotional detachment and selective amnesia (Bettelheim, p. 187ff). In addition, there is a reported tendency for prisoners to account for their present sufferings as some sort of atonement for personal failings, or for those of families and friends. These formulations were also a feature of informants’ accounts of caring. Carers usually struggled to achieve an element of emotional detachment.

“I try not to think about it too much. You know, just do it, but not really think about it, dwell on it” (Mr A)

“It doesn’t bear thinking about. If you let yourself, you can get down, really down, there’ll be no coming back. Once you start, once you open that door, it’ll all come out. Better not think about it, and get on” (Mr K)

For at least one carer, there was an element of atonement:

“I’ve not, I mean, I’ve done things I’m not proud of, well I suppose we all have, but, well, I wish it was different, so if I do this now, properly, entirely right, it might just make up for it. I told her that once, and she thought it was daft, but that’s the way it feels” (Mr J)

For other informants, the element of atonement and reparation was a less explicit part of their accounts, but strands of it were present. This was usually part of some wider search for meaning and significance, where informants attempted to make sense of the misfortune that surrounded them. One way of making sense is to assume that misfortune is, somehow, a punishment for previous offences, and that enduring it atones for those offences. Several informants played around with those notions, but not strongly or enduringly.

Further to the delineation of defence mechanisms, it has been noted that persons in extreme situations have rich fantasy and dream lives. These seem to be entirely plausible modes of escape and relief from a difficult present. The use of fantasy by informal carers is discussed more fully in Chapter 9.

There is another important adaptive strategy. Those in difficult enduring situations are said to employ ideologies or “philosophies”, however rudimentary or ad hoc, to explain, explore and endure their circumstances. In many ways, difficult situations are testing grounds for personal ideologies, and their relative worth can be measured by their utility. Difficult situations may test some long held views to destruction. This may necessitate adoption of a new one, or reformulation of one long abandoned; it may be necessary to engage in an extreme modification of one’s world view.

As far as could be ascertained, none of the informants held any strong, explicit ideology. A few of them were nominally Christians, but none of them attended any sort of church. They held some vague, unsystematised beliefs, entertained considerable doubts, held largely rationalist views and had engaged in purely instrumental praying at difficult moments. This is typical of much Christian belief in contemporary Britain, as described by Chadwick (1987). One informant held a more or less connected series of beliefs that asserted the value of human relations, had a reverence for the natural world and entertained the notion that happiness could be found in types of personal fulfilment. These beliefs had certainly affected his approach to caring:

“...but life was going on. Then there was a major disruption. What helped was um we were the sort of people who wanted to live in a cottage, make things out of wood, sell them you know? That was the ideal. We didn’t want to be managers or PRs or whatever. So the circumstances we’re in now didn’t dramatically alter that. We wanted to be knitters and so on ha ha, spending a lot of time together. So, I guess, we were more able to come to terms with the life change we got, because in a way we

were already going down that road, that path. I think a commitment that allowed us to, prevented us from letting the whole thing fall apart, because we were going to our cottage, going to spend time together, not going to work – my shed, my workshop, we were nearly there in fact we're still doing it" (Mr C)

Most informants held – or came to hold – a view of life, and an orientation to it, that was characterised by a sort of wry, detached stoicism, formulated with some precision and enduring resonance by Hoggart (1977, p.92) who observed:

'When people feel they cannot do much about the main elements in their situation, feel it not necessarily with despair or disappointment or resentment but simply as a fact of life, they adopt attitudes towards that situation which allow them to have a liveable life under its shadow... The attitudes remove the main elements in the situation to the realm of natural laws, the given and the raw, almost implacable, material from which a living has to be carved'.

This is perhaps expressed by informants' use of small, wry, clear-eyed phrases like:

"You just have to get on with it" (Mr B)

"That's the way it is. It won't be different. You just have to put up with it and get on". (Mr A)

“..lower your sights a bit, because if you don’t you’re going to be disappointed. See, it’s a long game, and you’ve just got to go along with it, take the rough with the smooth, don’t let it get you down” (Mr M)

Hoggart identifies this sort of stoicism as a characteristic of an older, fast-disappearing, working-class culture. In fact, it was characteristic of all informants to some extent or other. Certainly, it was held strongly as a world-view by the four carers who were sixty years and over, but it was expressed also by the six men who were in their 30s and 40s. By any definition, all the informants could be described as having working class origins. A few of them had middle class jobs, and more than a few had middle class aspirations, but none of this seemed to influence their outlook in any distinctive manner.

All informants who were caring for spouses alluded to the ideology of the companionate marriage, initiated by romantic love, fuelled by mutual esteem, cemented by joint obligation and scheduled to last a lifetime. Some of them identified specifically the ideology of marriage as a motivating factor in providing care:

“We did get married, you make your bed and you lie in it, for better or worse, and that’s what I’m doing “ (Mr A)

“But caring is a part of marriage, I believe that” (Mr E)

“It’s marriage, isn’t it? You get married, for better or for worse, in sickness and health. If you’re married to someone, you have to look after them if necessary, whatever” (Mr N)

These ideas provided some sustenance in the caring process, and were a source of motivation to continue with care. The ideology of marriage seems to provide a nexus point for the different but related ideologies of love and duty. Informants indicated that these were both strongly motivating factors. However, they maintained a view that love and its circumstances was the main motivating force in taking up caring, but that duty was the principle motivating force in its continuation. This perhaps modified slightly Ungerson’s earlier assertion that male carers are motivated more by love than by duty – ‘Men would be unlikely to care for someone whom they could not legitimately claim to love on an intimate basis’, and ‘men explained their behaviour in terms of feelings and, in particular, how they felt about the person they were caring for’ (Ungerson, 1987 pp 98-99). Informants in the present study seem to describe a situation which is slightly more complicated.

## **NARRATIVE ISSUES**

As might be expected, most of the data gathered at interviews with informants consisted of narratives of caring. All of the informants were thoroughly engaged with the caring situation, albeit at varying stages, and had learned to produce narratives of their daily work routines:

“You learn to do it, especially you learn not to care about time, she’s my primary concern, but you don’t sleep properly, it’s a sort of suspended animation, you’re asleep, but you’re there, you know, there”. (Mr E)

“Sometimes it seems difficult, sometimes it goes smoothly, you know, sometimes run a bit awkward, you know, the timing don’t come together” (Mr F)

“You’ve made new routines and you get used to them. You have new things to do, and you get used to them. The new things become part of you, part of your life” (Mr H)

“Gradually and not so gradually I took it all over, got used to it” (Mr L)

Manifestly, all the informants were coping with the demands of the caring situation – that is, they were producing acceptable and consistent standards of care and associated domestic work. None of them had ever been identified as unable to cope by friends, relatives or healthcare professionals. However, an occasional note of edginess, indicating difficulty and intimating the possibility of failure in caring, coloured particular narratives, such as Mr E’s story about his continued lack of sleep due to his constant vigilance (given above) or:

“I want a break, I really do, but if I get one it’s hard to come back and start up the routine again” (Mr A)

“What’s happened to me is that in ways I’ve been reduced down to basics” (Mr N)

Some informants told humorous stories about their coping difficulties. Clearly, these served a distancing, defensive function. Most usually, the stories focussed on a comic inability – or, more correctly, on an inability made comic – to perform certain tasks. Some of these stories had attained the status of well-worn anecdotes, and had been added to personal stocks of available narratives. By the time of interviews, the incidents were relegated firmly to the past – Mr D's adventures as an incompetent wheelchair pusher in Padstow, Mr J's misadventures with the washing line, Mr K's Olympic style feats at the supermarket – and were well on their way to becoming legends. They were hand-crafted, well-polished and rehearsed; longer exposure to them would, I am certain, have allowed me to identify continuing embellishment and ornamentation. They were genuinely funny stories. The men who retailed them had regained, or were regaining with every retelling, the competence to describe and therefore construct their own lives. They were regaining something like agency and perspective, returning to the centre of their own narratives, becoming important figures in their lives.

For other informants, this was not always the case. They also told narratives of failure to cope, but these were not so humorous. They were in strong contention with circumstance, and were unsettled. They still produced good quality care, and were at pains to emphasise that the actual work of caring was not particularly the issue. The difficulty was much more profound:

“I get it all done, but yes, I suppose I don’t like it and I never will... I can’t see how you can be comfortable with it “ (Mr L)

“I... I’m feeling a bit sorry for myself, that happens, you know, from time to time. I mean, everything’s different, and I’m a bit, you know, the same. I get all these feelings about it, not good ones” (Mr K)

“Oh I do it all, but I don’t like it and never find it, um, you never get a sense of a job well done” (Mr H)

All informants told coherent narratives about coming to terms with the disruption of caring. They had passed beyond the raw, undigested experience of disruption to a position where the narrativisation of that experience was possible. However, some of them were not – not yet- able to achieve a critical distance, a narrativising stance, a full narrative competence. As Becker describes it, because ‘closure on the disruption that occurred has not yet been reached, they are full of subjunctivising elements’ (Becker, 1997, p.196). These informants were in the process of trying out narrative possibilities. They had not yet utilised available key cultural constraints such as ‘order, personal responsibility, control over the environment, continuity and transformation’ (Becker, p.196). This, at least in part, accounts for the tense, confused, angry and unsettled tone of those narratives quoted immediately above. In Becker’s terms, those suffering the effects of disruption ‘anticipate or wish for closure that embraces normalising ideologies.... When living up to normalising ideologies appears to be out of reach, or when the story has a strong contrapuntal element of resistance to those ideologies, people explore alternative endings through subjectivity (Becker p. 196)

## **CONCLUSION**

This chapter has examined the continuing experience of some male informal carers, and has detailed the extent and scope of caring activities. Adaptive and defensive strategies utilised by carers have been surveyed. A crucially important interpretative and adaptive strategy is narrativisation. The chapter has shown that carers have been able to narrativise their experiences of disruption. Some have progressed from this to a narrativisation of coping with caring, and have produced sophisticated anecdotes on the theme. They have achieved some distance from their immediate experiences. Others have been less successful, and the continuing experience of disruption and distress colours their accounts.

## 7. MORAL TALES OF INFORMAL CARERS

Narratives of caring are, among other things, moral tales. That is, they detail the reasons, justification and motivations of engagement with informal care. These things have strong moral elements, drawing on culturally constructed notions of “correct” behaviour and feeling. However, such narratives are never completed, probably not even when the end of caring exerts strong closure, and they remain in continual need of revision and repair. They are part - a crucially important part - of carers’ continuing attempts to make sense of the caring experience, and represent an on-going construction of the decision to care.

Of course, these narratives are, almost by definition, entirely subjective accounts. Their “truth” or other verity could not be questioned very closely, and they do not necessarily display accuracy, inclusivity, balance or dispassion. To expect them to do so would be to miss the point. Putting the ordinary problems of remembering and of autobiographical remembering to one side (Olney, 1980; Lambeck, 1996), these narratives should not be seen as reports of “reality”, but as constructs, entirely situated and congruent with a particular set of circumstances, not necessarily pertaining to or drawing on a general view of “truth”. They serve to present the narrator as a reasonable, well-conducted, appropriate moral agent, who has made a careful and correct decision about the care of a sick or disabled relative. Of course, a similar moral presentation has been recorded where carers have made the decision not to continue with care, and to hospitalise sick relatives (Taraborelli, 1996).

Such narratives – moral tales – have become established as a subject of study in social science. For example, Baruch’s insightful study of the parents of children with either congenital heart disease or cleft palate showed how narrative accounts serve to present these parents as morally adequate agents. Such parents are at pains to stress the reasonableness, consistency and competence of their parenting decisions. They ‘produce accounts which display their status as moral persons by appealing to an inter-subjective reality according to whose standards they performed adequately.’ (Baruch, 1981, p.282). A similar phenomenon has been observed in the parents of disabled children in Voysey’s innovative and still relevant study (Voysey, 1975).

To widen the scope a little, moral tales have been identified in areas other than childcare. For example, Moore shows how Church of England clergymen of the “progressive” variety produce accounts, which serve to demonstrate the appropriateness, rationality and worth of their occupation. Much of this is achieved through the construction of a context in which their work was incontrovertibly valid and rational (Moore, 1974). Similarly, Emmison has examined the narrative accounts of sportsmen, and identified a means by which the experience of defeat is managed successfully. He shows how narratives reaffirm the particular logic of the sporting order, and how an ‘entire....moral order’ is ‘talked into being’ in them (Emmison, 1988, p. 24).

These moral tales both derive from, and produce, a sort of cultural mapping, and they assist people to make sense of their worlds. They reflect particular interpretations of culturally sanctioned moral ideologies, and show attempts to grapple with them, most usually by adherence to some or all of their principles. It has been noted that ‘a

moralising impulse is present in all narrative accounts; there is no other way that one's reality can be endorsed with so much meaning' (Becker, 1997, p.17). In addition, this moral element inherent in narrativisation was examined by MacIntyre, who argued 'without the accountability of the self those trains of events that constitute all but the simplest and basest narratives could not occur; and without that same accountability narratives would lack the continuity required to make both them and the action that constitute them intelligible' (MacIntyre, 1984, p.216).

Narratives gathered from informants were concerned with two basic areas of moral responsibility, centring on reasons for undertaking, and persisting with, informal caring. Firstly, there was a concern with the duties associated with the companionate marriage. This comparatively recent version of marital union is based on personal attraction, romantic love and enduring compatibility. It requires strong affective ties, and demands emotional exclusivity; it is regarded as the site and source of personal happiness, and is a lifelong commitment.

All informants who were caring for spouses gave acceptance of the moral precepts of this ideology as the most important reason to engage in care. They identified the requirement to care for a sick or disabled partner as an important marital duty, and recognised no limit to the extent or duration of that duty.

"Caring is a part of marriage, I believe that." (Mr. E)

"You get married, for better or worse, in sickness and in health. If you're married to someone, you have to look after them if necessary, whatever." (Mr.N)

“There’s no real choice is there? It’s something you must do, an imperative.”

(Mr. C)

This duty applied even when the recipient of care was unable permanently to discharge their own marital responsibilities, was unable to reciprocate in any way at all and was changed considerably as a result of illness. Such changes might include emotional, psychological, physical and personality features, sometimes amounting to a large transformation of the person.

“It’s difficult, but she is still the little girl I married, though it’s difficult to see, hard to remember now.” (Mr. A)

“It’s not her fault. She doesn’t know what she’s doing, what’s going on, poor thing. I have to remind myself of what we had, because it’s all gone now, but well she is my wife, I did marry her, and I must look after her, come what may.”

(Mr. E)

The very real difficulty of caring for someone who has been changed irrevocably by illness was recognised by informants, but did not constitute a reason for the cessation of care.

“One thing, her mind isn’t affected by it, no I haven’t lost a companion. We still have a good relationship. I don’t know how I would have coped if she was affected

that way, but well um you'd find a way, wouldn't you? I mean, it's my job to look after her. She's my wife and my responsibility, whatever happens."

(Mr. G)

"Yes, all the time I have to remind myself. But I don't put limits on it, I'm not sure, if it was the other way around, if it was me that wanted looking after, I'm not sure if she would have done it. I think it would be too much. Mind, I'm not sure if she should even have to try ... perhaps there are limits, I don't know. Anyway, that's not the way it worked out." (Mr. E)

The second area of moral responsibility for informants concerned the issue of home care as opposed to institutional care (I use "institutional care" to refer to any formal provision of care in non-domestic settings). To provide some context, it is worth noting that, apart from acute medical care in the early stages of illness, only a few informants (n=3) had any experience of the institutional care of their relatives. Those without this experience still held and expressed strong views about it. For three informants, the issue of long-term institutional care was not relevant, because their wives were in the end-stages of severe illnesses. Nevertheless, even these men had views about the preferability of home care.

In this regard, informants constructed and used a polarity of home care against institutional care. Without exception, all positive values were attributed to home care, and all negative ones to institutional care. There was very little objective assessment of advantages and disadvantages, although the failings of institutional care were attributed sometimes to lack of resources rather than to any inherent difficulties.

“I wouldn’t send her to one of those places, never” (Mr. K)

“An awful place. The doctors, the nurses, they do their best, but it’s so big, they’ve got so much to do, and resources, that’s another thing, how can it be as good as home? It just can’t, can it? Even with all the resources in the world, it must still be impersonal, at it’s very best, but these places, they’re not at their best now...” (Mr.J)

“Hospitals are too technical, too cold, you’re just a number, a case. I’m sure they do their best, but how can you give individual care and attention? Like you can at home? It’s just not possible, and I want her to have the best.” (Mr. H)

Those informants with experience of institutional care could make direct comparisons.

“Up there, in .....hospital, she’s in a room of her own. I paid for a television, but well that’s not company, is it? She’s more isolated up there than here at home. She was fed-up when she went in and bloody suicidal after a week of it.” (Mr. A)

“It was awful. They lost her stuff, her clothes were all muddled up, I don’t think she got enough to eat. I mean, the ward sister was nice enough, but I said is this the best you can do, because I can do better! Like I say, I’ll never do it again.”  
(Mr. E)

Informants were very insistent on the superiority of home care, to the extent that they seemed to be engaged in an effort to convince themselves of it. Their vehemence might well be a measure of their uncertainty about the correctness and appropriateness of their decisions to provide care at home. Certainly, informants felt that their caring activities were scrutinised more intensely because of their gender, and that the whole idea of men providing care was questionable in the minds of most people.

“Some say, some people say that it’s not right for men to do it. That’s all rubbish. I can do all this as well as anyone, better than some of those care assistants. I’m sure of it.” (Mr. E)

“You feel, at first anyway, that the health staff are sort of checking up on you, in a minor way, because you’re a man and might not be up to it. I was a bit resentful at first.” (Mr. C)

“People are surprised. They wonder, of course they wonder, if, if what you do is OK. Can you do, it because men are um not used to it.” (Mr. D)

“Everyone thinks it’s a bit abnormal, not a man’s job. We’ve talked about that, you know what I think, but I’m not surprised they doubt your capacity to do it, because I doubted it myself when I first started and sometimes I do need to know I’m doing OK. Well, you wouldn’t want to be less than good at it, would you, for the sake of the um person. If a nursing home could do it better, there’d be less point in it.”  
Mr. K)

In addition to these concerns, some informants expressed some entirely personal reasons for providing, and continuing to provide, informal care.

“I wouldn’t try it again. Respite care is alright for some, they like the break, but I don’t, I don’t like it. I missed her when she was in there, missed her a lot.”

(Mr.E.)

“When she went in for respite, we paid for a week. I phoned every day, and went to visit every afternoon and most evenings. Eventually, I took her home, it was on the Thursday. The staff there said this is no rest for you, they all laughed, but I wanted her home.” (Mr. J)

“God knows! This is my wife and my house and I’m responsible for them. If I failed, how could I live with it?” (Mr. G)

“If I didn’t do it, if I had someone in, or worse, put her in somewhere, I’d be letting her down, I think. And myself. I would have failed, failed as a husband. Anyway, I’d miss her, I know I would.” (Mr. L)

These accounts express a quite usual need for the company of loved ones, a desire to fulfil one’s duty and a strong sense of guilt at failing to meet moral imperatives. However, the situation may be more complex. It has been noted that ‘men can gain satisfaction from the bodily presence of their wives, and their ability to act as protectors and rescuers is enhanced when their wives’ dependency is at its greatest’ (Rose and Bruce, 1995, p. 126). Male carers are said to take a certain pleasure – more so than women – in the accomplishment of caring competently. It could be concluded that the institutionalisation of wives would reduce or remove that pleasure, adding to feelings of loss and loneliness. Thus male carers can be seen to occupy an uncomfortable space, where partial adjustments to the caring situation are removed by

the termination of active caring, and loss is followed by loss. This seems to generate a certain ambivalence about caring, where its end is both feared and desired. Informants gave occasional expression to that ambivalence.

“You get to the point where you’ve had enough. I just want to leave. But you can’t. Where would you go, what would you do?” (Mr. A)

“When it all ends, how it all ends. I can’t let myself think about it. Too upsetting. But the thought of going on like this in unbearable too.” (Mr. C)

This ambivalence might also suggest that informants were not entirely or uniformly satisfied with their decisions to engage in informal caring. Narratives reflect an uncertainty about the correctness, both moral and practical, of the decision to provide care at home. They represent the continuing assessment of that decision. Within the narratives, past decisions and ongoing processes are considered and evaluated; views of significant others are discussed and incorporated or rejected; alternative courses of action are reviewed.

Some of this unease is indicated by the polarisation of home and institutional care, and by the use of strongly critical language to describe institutional care: “awful”, “bloody horrible”, “cold” and so on. It has been suggested that this sort of extreme formulation, and its accompanying repetitions – “Horrible, bloody horrible, it was horrible” (Mr. E) – are employed when people suspect that their accounts might be received unsympathetically (Pommerantz, 1986). The use of this strategy gives further indication of the constructed nature of the informants’ accounts.

These accounts use other, similar, structuring devices. Just as the idea of home care is constructed and justified against a strong typification of institutional care, so informants construct their own roles against an idea of “other men” who do not, and would not, engage in care.

“...what I do is a bit different, but many um male carers um men in general wouldn’t consider this sort of care.” (Mr. C)

“Some men won’t do it, I know. It’s not a man’s job, and they walk away from it. Irresponsible, it’s irresponsible. And they are not men to have that attitude, not really men, just wimps, or worse.” (Mr. E)

“But I would say I’m an exception because I’m able to do it. Exceptional, you have to take that into account. I don’t think every man would be um some men um you get a few like me.” (Mr. J)

“I’m sure you get other men, well I know some, who just won’t do it, they just opt out. Well I think that’s irresponsible. I don’t see how they can do that. You’ve got to be a bastard.” (Mr. K)

“But you get others, others who, when it comes to the crunch, just run away from it. I think I was like that in my um imagination, I thought I was that sort of person, you know, too scared to deal with things. Turned out I wasn’t. That’s how I see it now, cowardice. You’ve got to be tough to do this, to put up with it. Opting out is easy. Some men do it, no trouble at all.” (Mr. D)

In these accounts, informants construct an idea of “other men”, who do not, or will not, engage in care, and they define themselves against this idea. This is strongly polarised, as might be expected in this version of an extreme case formulation. “Other men” are defined as irresponsible, cowardly, not tough, bastards, wimps or worse, possibly feeling guilty and unexceptional. In explicit contrast, men who engage in care are responsible, dutiful, brave, tough, able, not reprehensible, probably not feeling guilty; they belong to a small group of exceptions and are exceptional. This seems to be a restatement of traditional masculine values that is partly defensive, and perhaps indicates the strain imposed on masculine identity by the care situation.

The separation of male carers from other men is similar in some respects to the notion of “Mr. Wonderful”, as formulated by Rose and Bruce (1995) and developed by Taraborrelli (1996). This refers to the reported finding that male carers are praised and described with warmth and positiveness by those who come in contact with them. Their caring achievements are applauded, and they are seen as exceptional men. Rose and Bruce (op. cit.) report that women in similar situations receive no praise at all for engaging in the same sort and degree of work, and will not be noticed unless they fail at caring in some way.

Taraborrelli (1996) argues that the construction of “Mr. Wonderful” has the effect of isolating individuals from the generality of men, and supposes that it is by this means that society manages the possibility that all men have the potential to be successful carers. It is argued further that successful male carers threaten the idea that caring skills are largely and inherently female. It is easier and less dangerous to reclassify some male carers as “exceptional” rather than allow the possibility that caring skills

are not exclusively feminine (Taraborrelli, op. cit., p. 172). Of course, reluctant or unsuccessful men can use the same argument to explain that reluctance and lack of success.

Most informants were pleased to be thought of as successful at caring, although the pleasure was almost imperceptible at times. A few informants were too preoccupied with acute dissatisfaction in general to have much interest in success or failure. However, some informants were aware of the phenomenon of the “Mr. Wonderful” ascription, and commented on it.

“But you get a lot of praise for just doing the stuff that’s taken for granted in women.” (Mr. J)

“Of course, a lot of women do this, with less concern for onlookers, with less surveillance. They get less praise, too.” (Mr. C)

“Her family are amazed at what I do. I’m always getting a pat on the back, you know, he’s marvellous, but I say, she looked after me for years, twenty years or more, just like this, but none of you said a thing.” (Mr. D)

“I don’t know any man, not even my brother-in-law, who couldn’t do this if they really had to. There’s nothing special about it, and I hate it when people act as if you’re, you know, Mr. Wonderful or something. It’s not that special. Women do it all the time. (Mr. B)

This shows an awareness of gender-ordered ideas about caring, although it does not amount to a thorough rejection of the “Mr. Wonderful” idea. In practice, this might be very difficult, if not impossible to do. It does demonstrate that moral narratives of caring have to be constructed within generally accepted and available gender roles. In most societies, there are highly circumscribed repertoires of available roles. These might include some unusual and contrary formulations, but access to them is accorded somewhat differently across age and social class (McAdams, 1993). Certainly, contrary formulations were not widely or realistically available to most informants. In fact, nearly all men have to order and narrate their caring experiences within a narrow range of types and stereotypes, one of which is the “Mr. Wonderful” formulation. It is better perhaps, and easier, to fit uncomfortably into a recognised role than to adopt an unrecognised one.

The ascription of “Mr. Wonderful” might be seen to have other functions. The exceptional status it confers binds carers even more closely to the care situation, making abandonment of care, or strong expressions of dissatisfactions with it, very difficult. The ascription might be seen to be somewhat coercive, as well as congratulatory. It could constitute a subtle coercion, involving threats to self-esteem, reputation and ideals.

Finally, it is worth noting that male carers can gain some personal enhancement from the care situation. They are very largely exempted from the pressures (and rewards) of ambition and competition. Although the boundaries of their lives are narrow, they gain a solid purpose and a sort of emotional security, perhaps similar to that

experienced by husbands of agoraphobic women (Hafner, 1977a and 1977b) These factors may provide further reasons for continuing with care.

In conclusion, it is clear that narratives as moral tales deal with the decision to engage in informal caring, and the dilemmas consequent on that decision. They negotiate the difficulties of gender-appropriate roles and behaviour, the duties of the companionate marriage and the ambivalence about continuing with care. Such moral tales serve to present carers as reasonable, well-intentioned and competent agents. They represent a continuing evaluation and ongoing construction of the decision to engage in caring. Moral tales are an important part of the caring experience, and on their utility depends much of the success of the caring endeavour.

## **8. DREAMS OF LEAVING: THE FANTASY LIVES OF CARERS**

### **FANTASY AND FANTASISING**

The tendency of inmates, those inhabiting total institutions or otherwise subject to restricted activity to engage in rich fantasising, was noted above. The wild, vivid, essentially improbable nature of such fantasies has been recorded, and duration-dependent change from specific and concrete content to non-specific and vague content has been described (Bettelheim, 1971, p.154 ff). Those who engage in the informal care of sick or disabled relatives live in circumstances of restricted activity and significant reduction of stimulation of all kinds. It might be hypothesised that this situation would produce a similar level and style of fantasising as that reported by inmates.

Daydreaming, fantasising or engaging in any form of stimulus-independent thought (all hereafter subsumed under the general term 'fantasy', unless quoting directly) seems to be a thoroughly ubiquitous activity. It is said to occupy a large proportion of waking time, and is conceived as a process central to normal human functioning, exercising 'important functions in the adaption of the organism' (Klinger, 1971, p.4). Its significance is explored in Singer's revealing account of his fantasy life, where he delineates the interaction of fantasy with what might be referred to as ongoing reality (Singer, 1981, p.17 ff).

Fantasy is comparatively under-researched, and does not admit of easy or succinct definition because of its tendency to merge with, or to become, such activities as

'laying plans, reminiscing, analysing past events, anticipating future ones, asking oneself questions, engaging in brief reflections, entertaining disorganized imagery and ... experiencing night dreams' (Klinger, 1971, p.6).

Singer's attempt to define "daydreaming" (he prefers that term rather than 'fantasy') is useful; '... a shift of attention away from some primary physical or mental task we have set for ourselves, or away from directly looking at or listening to something in the external environment, towards an unfolding sequence of private responses made to some internal stimulus' (Singer, 1981, p.3). This definition still leaves a few problems; for example, is it possible to perform routine physical tasks and to engage in at least short bursts of fantasy? However, a constant refining of this sort would lead to an unsatisfactory negative definition, arrived at by excluding all properties of instrumental, task-orientated activities. For these present purposes, fantasy may be defined as verbal reports of 'all mentation other than orienting responses to, or scanning of, external stimuli, or operant activity such as problem-solving in a task situation' (Klinger, p.10).

The history of research into fantasy is interesting, despite that until comparatively recently, there was very little of it, and most speculation about it derived from psychoanalysis. Indeed, psychoanalytic explanations of fantasy retain substantial currency in Western culture, and inform much lay thinking on the subject. These utilize Freud's "hydraulic" model of mental activity, and rely on the notion that the activities of humans centre on the gratification of instinctive drives. It is implied strongly that 'much of our daydreams and fantasies, as well, of course, as our night dreams and indeed many of the more extensive characteristics of all human thought,

are reflections of our fulfilment of a limited number of desires, primarily the tissue-related sensual needs or the cyclical aggressive drive within us' (Singer, p.103). Essentially, this suggests that fantasy is a form of wish-fulfilment, a remnant of some childish strategy to gain drive-gratification. This, in turn, leads to the idea that fantasy is a form of escapism, underwritten by Freud's erroneous assertion that 'happy people do not make fantasies, only unsatisfied ones do' (Freud, 1925, p.176).

The comparative dearth of adequate research into fantasy was remedied in the second half of the last century, when behavioural psychology developed an interest in it. This was part of the second phase, the so-called "cognitive revolution", of behaviourism. Research into fantasy became necessary when it and other imaginative techniques were used as therapeutic tools in such treatment strategies as desensitization (see Wolpe, 1973). This led, at least, to a reconsideration of psychoanalytic theories. Thus, Klinger (1971, p.279 ff) catalogues a variety of work on the effects of hunger, thirst, sexual arousal, sexual deprivation, aggression, sleep variation, restricted activity and fear on the incidence, vividness, organization and other structural properties of fantasy. He concluded that 'drives by themselves exert little direct influence on the content of fantasy, but fantasy in turn has little influence on the levels of drive ... Thus, fantasies are usually not manifestly wish-fulfilling and are probably never directly drive-reducing, although their tendency to drift and distract may be less conducive to a worsening or maintaining a state of drive such as anger than such alternatives which remind the angry individual of the anger-instigator' (p.354). In addition, it has been recognised that fantasy can diminish anticipatory anxiety about unavoidable pain (Rowe, 1963). This diversionary, tension-reducing function of fantasy can be important.

Klinger's innovative and comprehensive theory of fantasy, concludes (among many other things) that an individual's current concerns - that is, states of involvement with goals which have not yet been attained or abandoned - are more likely to influence the content of fantasy: 'Just as instrumental behaviour is governed by the attraction of attainable incentives, so the content of fantasy tends to reflect the incentives for which the individual is striving' (p.353). In addition, it is observed that fantasy sometimes depends less on prospective incentives than on important previous events. A large body of research on working through unsettling or overwhelming events, either favourable or unfavourable, is referred to by Klinger, and it is speculated that under these circumstances, fantasy helps with a necessary modification of the self. For example, 'the fact of undergoing certain experiences changes a person's social status or social stimulus value sufficiently to require the individual to work through to a new self-concept or a new set of role behaviours. Thus disfigurement, losing a job and divorce all create tasks of self-redefinition' (p.304). It is agreed that self-redefinition is necessary for social functioning, thereby accruing the obvious rewards of social competence. This tangible incentive places the task of redefinition among current concerns - 'the current concern of self-redefinition would be expected to potentiate fantasy elements relevant to it and therefore relevant to the unsettling event that precipitated the need for it' (p.305).

This accords with the narrow range of fantasy content observed by Singer in adult humans, where 'even the task-irrelevant daydream ... is somewhat narrow in scope' (p.162). This narrowed scope can still maintain a utility. Fantasies can constitute rehearsal for future actions, and suggest new ways of responding; they may 'generate

a serious re-examination of ... options in life', and provide 'a challenging opportunity for renewal and the exploration of new possibilities' (p.174).

This has obvious relevance to the situation of informal carers, where there is the need for large-scale status adjustments and self-redefinitions, including the maintenance of self-worth in somewhat unpromising circumstances. In addition, informal carers are faced with the continuing problems of care provision, have to negotiate a changed and changing relationship with the recipient of care and must attend to the demands of a future, however distant, which will demand readjustment, reskilling and further self-redefinition. Klinger's idea of "current concerns" is particularly valuable.

Research into fantasy has some obvious difficulties. It is an entirely interior and private phenomenon, not observable or otherwise directly accessible to the researcher. It depends on the reports of people who are in turn depending on their capacities for introspection. This in itself is methodologically problematic, and there are associated difficulties about adequate recall, selective remembering, honesty, narrative compression, exclusion of material and other forms of editing, both conscious and unconscious. There is also the difficulty of conveying thoughts, the Jamesian "stream of consciousness" into neat, linear sentences. The attempts of well-equipped novelists - Faulkner, Woolf and, perhaps pre-eminently, Joyce - to do this has been assessed, and it is clear that they rely heavily on certain literary conventions, while adding a few new ones (Humphrey, 1968). Whatever the success of this project, there remains a huge gulf between what can be imagined and what can be inscribed or spoken, especially regarding the mode and character of that imagining (Pope, 1978).

In addition, there is a high cultural value on active, willed reason, and a correspondingly low value on stimulus-independent thought of all kinds. This adds to the problem of ordinary reticence in revealing private fantasies, the content of which might be felt to be too revealing of the individual fantasiser. There is also the idea that fantasising is something that might well be particular or peculiar to one's self, and that to reveal its extent or content might be to expose oneself as maladaptive, aberrant, of suspect worth and insufficiently engaged.

## **COLLECTING DATA ON FANTASIES**

When planning interviews, I had no clear intention to ask questions about fantasies. However, in the early stages of data collection, I read some excerpts from John Bayley's second memoir of his life as the husband-carer of Iris Murdoch, who suffered from Alzheimer's disease. In the book, Bayley discusses his fantasy life at some length, some of it pertaining to the caring situation. However, in the excerpts, there was just one recorded fantasy. After an incident where he had to retrieve a confused and wandering Murdoch from the street, and explain his actions to some passers-by, Bayley fantasised that he had kidnapped her: 'Woman abducted in broad daylight. I, the kidnapper, a man of iron nerve, had easily persuaded the bystanders that I was in charge of a poor demented creature' (Bayley, 1999, p.202).

I found this intriguing. It described precisely the mechanism that humans use to endure difficult or boring situations; the actions remain the same, but the context is transfigured. I remembered Orwell's description of his adolescent fantasising as 'a

continuous story about myself, a sort of diary existing only in the mind. As a very small child I used to imagine that I was, say, Robin Hood, and picture myself as the hero of thrilling adventures, but quite soon my story ceased to be narcissistic in a crude way and became more and more a mere description of what I was doing and the things I saw. For minutes at a time this kind of thing would be running through my head: "He pushed the door open and entered the room ... With his right hand in his pocket he moved across to the window" ... This habit continued until I was about twenty five'. The actions would remain the same, but their context would change; not 'The man entered the room', but 'The well-motivated assassin entered the room...'" (Orwell, 1975, p.181.) I recalled Singer's account of his fantasy life as "Singer the Composer", and as a composite character known as "Poppy Ott" (Singer, 1981, 19.ff). Such sources indicated the ubiquity of fantasies, and were in accord with the reported experience of inmates of various sorts. They opened a different perspective on the caring situation, and revealed a submerged but important coping strategy.

I determined to ask informants about their fantasy lives, if the opportunity to do so presented itself and if it seemed appropriate. Most informants signalled some initial embarrassment at discussing fantasies, and I was careful not to pursue it too strongly. All of them knew exactly what I had in mind, and were able to give a few examples. Two of them rather warmed to the topic, and talked at length about their interior lives. Another two found it too embarrassing, and I did not pursue it with them at all after a tentative initial inquiry.

This strand of data collection produced mixed results. Informants did not necessarily possess the personal fluency, security and ease which must allow someone like John

Bayley or Jerome Singer the confidence to engage in smooth, self-deprecating revelations. They were responding to a rather tentative inquiry as part of much larger interviews, and were being addressed by a comparative stranger. I appreciate that I would have been able to gather a greater depth of data from most informants at subsequent interviews, but there was no real necessity to do so. With hindsight, I would have been intrigued to know if capacity for fantasy was at all connected to eventual adaptation to the caring situation

## **CARERS AND FANTASIES**

On initial examination, it did seem that the fantasies of male informal carers contained evidence of wish-fulfilment. For example, they reported a wide and constant incidence of fantasies about somehow leaving the care situation.

“I just dream about leaving ... That she’s OK and my job’s done ... That everything is OK, and I can go”. (Mr D)

“I go out to the shops as usual but I keep going, keep going, down to the motorway, down to Dover, cross the channel, just keep driving”. (Mr A)

“I imagine, not on purpose, you know, I imagine I’m walking on that ridge there (indicates hills behind the house) just me, in the wind and the sun, on a good day,

what you might call a good day for blackberrying, not too hot, not too cold, nothing to worry about, and all you've got to think about is blackberrying". (Mr B)

In addition, all informants reported the pleasant and, I imagine, very common fantasy that centres around the sudden acquisition of a large sum of money, usually by winning the National Lottery. It should be noted that these fantasies are not particularly fantastic: leaving a home that contains a wife who is well, driving a much-travelled holiday route or going out to pick blackberries. These are all activities that informants had engaged in, and were familiar with. As such, fantasies about them constitute an escape to the pre-morbid, pre-caring situation, a retreat to the past.

Fantasies about the past were very common among informants, and had a distinctive pattern.

"Well, most of my daydreams, ones that come on their own, most of them are about the past ... Sometimes good things, sometimes bad. I go over it in my mind ... I think about the good times, when I was first married and all that". (Mr E)

"I do daydream about the past, how it could have been if it wasn't for all this, how it should have been. Like I think of what I should have said instead of what I did say".

(Mr G)

This re-examination of the past was very common. It accords with the observation of Klinger, who reports that recent and important past events often yield 'a great deal of re-constructive fantasy in the form of replaying scenes, perhaps with intermittent self-

criticism and the imagining of possible alternative ways in which the action might have been conducted. The process seems sometimes undertaken for purposes of self-assurance, sometimes as a defensive re-interpretation of what happened' (Klinger, p.301).

Much of this fantasising about the past involved positive affect. In this regard, it has been noted that few investigations have recognised or explored 'the frequency with which fantasies contain rumination about happy events that went before' (Klinger, p.300). These are very different from straightforward wish-fulfilment fantasies which, by definition, must entail an imaginary satisfaction of unmet needs. In the instances noted above, fantasies seem to represent a re-savouring of original experiences, presumably to compensate for the current dearth of similarly happy events. This seems to be another version of the "management of the past" by carers, which is discussed below.

Other reported fantasies are self-aggrandising, in a manner which may be wish-fulfilling.

"I might imagine I'm a chess champion and I choose to live like this, in this restricted way, because of eccentricity. You might read it that way in a Sunday supplement ... In reality, at that level, I'm a mediocre player, I know that". (Mr C)

"Like I went down to the bottom supermarket very early, it opens early, well in those days it did, and the streets were empty, no-one around at all, it was like a film, I don't

know, like 'High Noon', like that, I'm walking along like the sheriff, and I imagine that's what I'm doing, tell myself a story in my head, briefly, you know, and then you have to think about something and it stops". (Mr D)

"It's telling yourself a story, like when you were playing as a kid, but without acting it. Its boredom, I think, like um I'm a secret agent on a mission, but actually I'm going up to the baker's, usual boring trip. But I think we all do it". (Mr K)

It is important to note that none of these informants were in danger of confusing their fantasies with reality. Apart from a distracting and entertaining function, such fantasising can be seen to fulfil a need for creative expression and organisation (Singer, p.29). The element of aggrandisement could be seen as a compensation for perceived lack of importance, powerlessness and depletion of agency in carers' lives. However, these aggrandising functions were few. The largest proportion of fantasies reported by informants concerned current preoccupations and worries. These usually had a thoroughly realistic content, and were concerned with daily activities.

"Most of my daydreams, and my night dreams too, if it comes to that, are all about what I'm going to do next, sort of planning out the next day or even the next hour, but I don't set out to do that, it just happens". (Mr L)

"... find yourself thinking about what you have done and what you have to do. Sometimes it slides away into um complete rubbish, nonsense, really, sometimes not". (Mr G)

“I don’t have wild or extravagant fantasies about anything, well not often, not like in childhood. What I usually find myself daydreaming about is day to day activities here, just sort of running it through my mind, but not purposefully”. (Mr H)

“... just a sort of running commentary on what I’m doing, with a change of context here and there to make it interesting, you know, the activity is the same, but I imagine a different setting for instance”. (Mr L)

The “slide away into ... rubbish” noted by Mr G above was described widely. Many reported fantasies began in firm reality, but were elaborated into the fantastic and improbable.

“Its our situation. I’m maybe thinking about how to get the bed downstairs to wash it and then suddenly, like a night time dream, we’re in some sort of prison, and I’m plotting an escape, and the bed is somehow part of it. A Colditz sort of thing. I mean, you’re not unconscious, you know what’s going on, and then you come back to yourself and think what a load of rubbish”! (Mr C)

“Starts OK, but then I might imagine I’m sort of super medic inventing a medical breakthrough. A sort of story I’m telling myself. It comes on its own. But its embarrassing to talk about.” (Mr K)

This demonstrates the tendency of fantasies in adult life to coalesce around current concerns and be restricted in scope. Nevertheless, they remain fantasies, and do occasionally admit the improbable and the bizarre. It seems clear that fantasies serve

several important functions for male informal carers, as they do for all humans. Firstly, and most obviously, fantasies can make life more bearable. Some of them are associated with pleasant affect; they are divesting, distracting and amusing. They may provide people with alternative environments to one that is unpleasant and unrewarding, perhaps containing reminders of painful circumstances. To this extent, they are certainly escapist and wish-fulfilling, but benignly so. This seems important enough, but fantasies can serve many additional functions. They can be seen as rehearsals for future actions and, by their inherent looseness and fluidity, may suggest or provoke innovative and alternative ways of dealing with situations. Even the most incongruous, improbable and comic functions might indicate the humour in situations, thereby defusing them. The disparity between rich fantasy and impoverished reality can serve as an incentive towards the transformation of a life.

As indicated earlier, fantasies seem to assist in the process of redefining selves in changed circumstances. They also have some important significance for self-organisation: '... fantasy processes constitute a continuous cycling of ... elements that are most likely to be relevant to the individual's present life situation. In the course of fantasy, a person works over, recombines and sometimes reorganises the information, often creatively. Fantasy thus serves as a channel for performing preparatory work fortuitously between emergencies. Since fantasy content is normally adrift, it provides continuous reminders of concerns other than those he is working on which he needs to bear in mind ... Fantasy and related respondent processes ... carry an important burden of self-organisation in the individual's overall adaptive mission'. (Klinger, p.356)

Finally, the devaluing of fantasy and stimulus-independent thinking has been noted. However, it might be recognised that 'our own private experiences and images, our own symbolic observations of the natural world or our mythological elaboration of it, is as much part of our reality as the physically measurable stimulus field that surrounds us' (Singer, p.30). It is the adaptive task of humans to honour, understand and utilise these private experiences, rather than to ignore or banish them (see Singer, 1981; Bachelard, 1971). For the men in the study, fantasy was an important mental tool. It helped to create an atmosphere of positive affect in an otherwise fraught situation. Perhaps more importantly, it allowed the initiation of new aspects of the self, and it was important in the redefinition of the self that may be crucial to successful caring ( see Chapters 10 and 11).

## 9. CARING AND MASCULINITY

### INTRODUCTION

Gender identity has four essential components according to Harris (1995) who provides this equation: gender identity = biology + dominant cultural norms + sub-cultural influences + unique personal circumstances. Masculine gender identity is acquired in part through the process of socialization, which may be defined as ‘the business of learning the normative standards of society’ (Lee and Newby, 1984, p.265). A key aim of this is the formation and acquisition of gender identity, defined as ‘an individual’s own feelings of whether or not he is or she is a woman or a man, a boy or a girl’. In this context, gender identity is self-attribution of gender (Kessler and McKenna, 1978, p.8). To go further, male gender identity is ‘the subjective sense men develop about their own and others’ masculinities’ (Harris, 1995, p.10), and can be seen as the individual man’s interpretation of lived development of how his social group sees masculinity.

This enculturation process has been referred to as the making of a “cultural native” (Bem, 1993, p.140). According to Geertz, the salient characteristic of native consciousness is the inability to distinguish between reality and the cultural construction of reality. The reality of things is taken for granted, and passes as unproblematic and natural (Geertz, 1993). Harris describes the necessary depth of gender self-identity: ‘Each man constructs his own identity in relation to specific gender notions deeply embedded in his culture. These notions are coded into messages with specific configurations that spell out specialized patterns of conduct.

To learn a role, it is not enough to acquiesce to routines immediately necessary for its outward performance. A young boy must be initiated into the various cognitive and affective layers of the norms appropriate to that role. Each role carries with it a socially defined appendage of knowledge and repertoire of acceptable and unacceptable behaviours' (1995, p.9).

The idea of a set of gender-ordered roles regarding acceptable and appropriate conduct is important to the present study in many ways, and some associated research can be used to illuminate the situation of male carers. For example, Bem and colleagues conducted a series of laboratory studies in which people who described themselves as conventionally gendered according to objective measures and descriptions were asked about their feelings regarding the performance of tasks that are defined culturally as not appropriate to their gender. It was demonstrated that people in these situations reported negative feelings about themselves (Bem and Lenney, 1976).

In further experimentation, it was shown that this pattern 'extends beyond .... trivial activities .... to .... more profound activities' (Bem, Martyna and Watson, 1976, p.1020). One experiment required subjects to stand firm in their opinions when faced with a group giving opposing opinions, and to behave nurturantly towards a baby and a lonely peer. The results showed that 'conventionally gendered women and men managed to do well only at whichever of these behaviours the culture defined as appropriate for this sex. In other words, conventionally masculine men were independent but not nurturant, and conventionally feminine women were nurturant

but not independent' (Bem, 1993, p.157). Clearly, this has some significance for the study of men who undertake caring roles in this particular culture.

In addition, there are a number of studies of retirement, early retirement and redundancy that are pertinent to the present study. These detail the social and psychological consequences of paid employment, including threats to, and deleterious effects on, male identity. Men in caring roles often abandon full-time employment prematurely, and enter the unemployed state in a precipitate manner, there being little time for contemplation and adjustment. This alone is sufficient to occasion a crisis. The importance of work in maintaining and enabling male identity is established by a large body of research (Gradman,1994). It is noted that even planned and predictable retirement occasions loss of colleagues and the social support they provide, loss of opportunity for competition, achievement, status, power, self-reliance and, of course, loss of income (Ochberg, 1987; Weiss, 1990). Other studies have noted that men can perceive retirement (in its wider sense of not working) as an intrusion into the "feminine" world of the household and family (Willing, 1989). This is said to lead to all sorts of uncertainty about appropriate masculine behaviour. The successful negotiation of these difficulties is said to involve a modification of masculine identity, which is an idea with special pertinence for the present study.

## **INFORMANTS' ACCOUNTS**

Informants were aware, often with painful intensity, of the usual gender-ordering of informal care. They knew that their situations were rather unusual, and there was

often an acute awareness of being present in a “female” domain. The whole experience of providing care was referred to repeatedly as a “woman’s world”.

“I’ve considered I’m in a very female orientated world – very aware of that before we started.” (Mr.A)

“That sort of thing is women’s work, best done by women really. They are better at it”. (Mr L)

“I’m sort of saying it’s women’s work, and all that, but only because women usually do it”. (Mr M)

A few informants compared their situations with that of mothers with very young children.

“I run the house, like a housewife, caring for children”. (Mr E)

“... my situation is almost exactly like a young wife with a baby and an absent husband ... I can see why young mums complain, get depressed, or whatever”.  
(Mr P)

Other informants (and, later in the interview quoted above, Mr M) gave the rather more considered opinion that some tasks were considered masculine or feminine, regardless of the gender of the person who performed them.

“... it’s a woman’s world, in essentials. It’s um nursing, which is mostly thought of as a woman’s job, although some men do it, I know”. (Mr M)

“It might be normal, usual, for a woman to do it, but men do that work too, professionally. And you know I’ve done some of it, cooking, cleaning, laundering and all, I’ve been eighteen years doing it professionally”. (Mr J)

This accords with the observation that ‘we call some women ‘masculine’ and some men ‘feminine’, or some actions or attitudes ‘masculine’ or ‘feminine’ regardless of who displays them’ (Connell, 1995, p.69) and with the ethnographic studies referred to above. Some informants rejected the idea of caring as a properly gender-orientated domain.

“I have this particular view of um housework practice or domestic science, or whatever you want to call it, shouldn’t be a gender um thing. A few people we know wouldn’t see it that way, at least in theory. Other people ask me about it, and I say no problems, because the gender thing isn’t difficult for me, not at all. I think it might be difficult for other people, people who encounter us, but that’s not where the burden lies for me, not at all”. (Mr C)

“I’ve never thought of it that way, although I know some do. A lot of men won’t wash up, won’t wash up and um it’s silly, isn’t it? I always say if you can’t cook, you can’t eat. Some men do nothing and they lose out. The same with this. There are jobs to be done, and I don’t believe that women are just naturally better at them. That’s just a society thing. It’s just prejudice, like when we started having women bus drivers. I’ve never seen this sort of work as women’s, and now I’m doing it, I haven’t changed my mind”. (Mr F)

“I suppose unthinkingly because its not the sort of thing you give much thought to, I might have associated caring with women, but I’ve always known that men did it, I’ve known one or two in work. But I never thought of my work as a man’s job particularly, lots of women did it. When I did think about it, all that gender stuff is rubbish. I kept finding jobs that only men could do, front-line soldiers for example, but you can always think of an exception. Look at the Israelis. Or the Somalis. In fact, I think the only job that is really for one gender only is wet-nurse, you know, breast-feeding. Oh, and perhaps sperm donor. The rest is up to individuals”. (Mr. J)

One informant exposed a similar view to these, but went much further in questioning the usual gender-ordering of informal care.

“You can’t walk away from it. Some people say it’s not a man’s job, but looking after one another is anybody’s job. But look, some of this caring might be too difficult for women. I’ve seen some of them really struggling, little women with big men in this state, confused, disorientated, aggressive, stubborn, it’s too much for them. Some could do it, but others were struggling. I mean, could she care for me in the same way? I doubt it. She might want to, I’m sure she would, but you need a certain amount of strength. It’s been all I can do to look after her, exhausted me. I’m not sure if she could do it, or even if she should try”. (Mr E)

Informants who challenged the usually gendered view of informal caring gave a variety of reasons for their ideas. One of them cited the strong influence of a role model.

“My dad, he was a miner, he used to cook the dinner, every day almost, and always on a Sunday, you know, meat, roast potatoes, everything. I never thought that men shouldn’t, couldn’t, cook. And he was generally handy around the house. I think I must follow him”. (Mr B)

Mr B, The oldest of the informants, remembers here the actions of his father in about 1920. This shows that even in much earlier decades, it was possible to reject or refuse at least some stereotypical aspects of sex-role. It is admitted that Mr B senior must have been a little unusual in this, although Maddox (1995) describes that miner’s son D H Lawrence similarly engaged with domestic work.

Other informants felt that previous exposure to, and participation in, domestic work - that is, engaging in practice - helped them to more easily abandon traditional masculine roles in order to undertake care. They were uncertain as to the extent of this.

“I’ve always done housework, so it was nothing new to me. I always thought it was something I should do. But I’m doing it all now, it was easier when we were sharing it. As far as housework is concerned, I started young, I was um, probably about fourteen when my mum went to hospital, and I did a lot of the housework, a bit of everything. So it might have made it a bit easier to adjust to my present situation. I mean, I didn’t start from a deep antipathy to it”.  
(Mr F)

“My introduction to this sort of thing was in the Forces. I did a bit of medic work, stitched a few heads and so on. And I was used to a certain amount of

domestic work. So it wasn't too much of a shock - no, that's not true, it probably lessened the shock, because it was a big shock, it was sudden, lessened the shock of having to do this, because I'd already done some of it".

(Mr G)

"My job made it different. I was used to looking after people, in a way. Not sick people or the disabled or whatever, but I had some ideas and I could cook, clean. Do you see what I mean? It wasn't in the deep end, in that *respect*".

(Mr J)

However, this limited previous experience was not as effective in changing views of traditional male sex-role behaviour as was the actual experience of caring. A number of informants described the rapid reappraisal of former behaviour and ideology that was necessitated by the adoption of caring.

"I didn't do a great lot, I was coddled really, waited on hand, foot and finger all my life. Worked hard .... you know, and worked a lot of overtime, but after that, any spare time I wanted to play golf ... I always used to tease my mates, you know, when they went shopping or got the dinner. It's a sign of weakness in a man, I used to say. That was a joke. But then we had this, and it was a big change. Until you do it, you don't know, but it's the hardest thing I've ever done. I had to change my mind about a lot of things. It was difficult, but it was more, like, educational in a way. When I seen my mates now they say I bet you peel the potatoes these days, and I say no, I buy them ready-peeled. I make a joke, because I can't explain to them how much I've had to change, and how wrong I was". (Mr D)

“Before, I was never, I was never a bad husband, like I was never down the pub or chasing women or staying out late or not helping or whatever, whatever the hell it is you have to do to be a bad husband these days. I was never that sort of person. But I did have in my mind jobs for him and jobs for her, if you know what I mean. I saw it as shared responsibilities, different strengths. I mean, one of the stupidest things I thought was that I should go out to work and she should look after Adrian, because work was more difficult and arduous. She could have earned as much as me, and I could have stayed at home, but that didn’t come into it. I quickly learned that this was crap. For instance, I found I was less good at the masculine things and quite good at the feminine things, according to my old way of thinking. Well, I’d got it wrong for years!”. (Mr P)

One informant felt that the sudden adoption of informal caring had forced him to live out some of the ideological positions he had taken up regarding gender and sex-role. He was forced to convert easy rhetoric into action, with some unforeseen consequences.

“What got me over the masculine barrier was actually doing it. I thought about it, I suppose I theorized about it, before all this happened, but doing it is what made me understand it all. I thought if you are going to do it, well go ahead and do it. It wasn’t what I thought. It was more difficult than I thought, much more difficult, and I needed to adapt. There was a time when I thought it was going to be too difficult, but then suddenly I was doing it, I am doing it,

and of course its become much more rewarding, gratifying, than I ever imagined. But you have to let go of a lot to get there". (Mr C)

This touches an important theme in informants' accounts. They can be divided into two distinct groups: those who rejected a conventional view of masculine sex-role, and those who did not. Another way of describing the two groups would be: those who adapted to the circumstances of caring, and those who remained in deep contention with it. This latter group remained in a state of unhappiness and discontent, not able to come to terms with the caring situation and the changes it brought.

"... but I don't like it, and never find it, you know, particularly rewarding, not even much of a sense of a job well done". (Mr K)

"... everything is different and I'm a bit, you know, the same. I can't adjust to it. I just hate it". (Mr K)

"I don't like it, and I never will... I can't seen how you can be comfortable with it ... So here I am, on my own, in a woman's world really ... A nurse would do what I do and feel at home with it, but I can't say I do". (Mr L)

"I mean, the actual work is not difficult, but I found it a bit, well, um, embarrassing, for want of a better word. You know, a bit sort of demeaning in a way, some of it. Of course, when you take up this sort of thing, you are entering what is really a woman's world, aren't you? That's how I felt, like when you wander into a woman's kitchen and they're busy, you're just in the

way, intruding, yes, intruding on their territory. It's not my world at all. You lose your bearings. You're lost. I say I've accepted it, but have I, really? I got to do it, its got to be done. There's no one else, but I'd stop straight away if I could". (Mr M)

"All the stuff that made me, me, is falling away. My old ways, my old skills are not much use. Take the average day. There's nothing to have prepared me for it like there would be if I was a woman. So I have to take up woman's work, use woman's skills, but I'm still me. Do you see what I mean? But don't get me wrong, I do it all. I do it all well, conscientiously, I think, but it's not for me. And another thing, I'm everything in this firm: manager, quality controller, progress chaser, factory hand, cleaner and tea-boy. But I still come back to this: it's not work for a man. You can do it, but you can never be comfortable with it". (Mr A)

The other group of informants provide a very different set of accounts. They share the same experiences of disruption and more or less enduring unhappiness at the distress of a loved relative, but seem to have moved on - the spatial metaphor is necessary but unhelpful - to a much more comfortable and tenable position. Using a variety of languages and idioms, they describe the slow formation of a new mode of being themselves, and a new way of regarding the world. These changes were initiated by the entry to informal caring.

"Well yes, I've changed, its changed me. I'm more of a family man, no, I was always a family man, but, how can I say? I'm here all the time now, this is my base, I lose myself here, where I am ... The whole thing has made me, like,

more confident, as a person. I don't suppose I was ever timid, but I'm more sure of myself now, more capable, I can do things, funny to say, at my age, isn't it?... So, everything went wrong, could have stayed wrong, but we held on, we made some changes on the way, went through it a bit, and now things are, well not OK, but yes OK in a way". (Mr B)

Mr B struggles to articulate a fundamental change in his relationship to the world and to himself - "this is my house, I base myself here" - and a result of that realignment in a subjective increase in confidence and capability. What is described here is, simultaneously, a series of minor adjustments and a fundamental ontological shift. The effects of changing practice on status is discussed below. Similar themes are discussed by other informants in this age group.

"I've accepted it all much better than I thought I would. I've had to adapt, I'm a conscientious ironer now (laughs). I'm proud of it, that's a joke, but seriously, I've found new um parts to me, new capabilities. I was never, you know, helpless as a person, but now I'm different, very different. Its been a discovery, yes, and I've found new parts to me, like before I was only say Europe, and now there's America and Africa and all. I'm more of a person now. More caring, for certain. More tender. Well I guess it's always been there. Put it this way, I was always a strong man at work, you know, physically able, and I took pleasure in that, a certain amount of pleasure, and prestige too. But I don't know if I'd go back to it even if I could, I've got more going on here. I'd have to do something else". (Mr D)

“How am I different? Well life in ... makes you more deeply, um, more sorry for people. You are a more compassionate person, more caring, you realize all the tragedies that there are in the world”. (Mr. J).

I would say I'm a better person for all this. I wouldn't want it to happen, but it has made me better. Well, you know yourself, there's not much room to be a caring, compassionate man in this world, is there? You wouldn't last five minutes. You've got to be hard, shut things out, you've just got to do it to survive. But this has let me stop all that and develop another side. Well, perhaps I would have been able to do all that if I'd had a different job, a musician maybe, or a teacher, with small children”. (Mr E)

“... since I've been doing this ... I've discovered I'm a better person than I ever thought I was, not in a big-headed way, but I'm much more caring, got more capacity for love, if that doesn't embarrass both of us. I always thought I had nasty, unfeeling parts, but now I realise that was my man-at-work mode. You have to be like that to survive. But not here, not doing this, and I'm more comfortable with that ... I've learned that, and I've learned to be happy with little. And, don't tell anyone, there's ways in which I'm more confident now than I ever was, only sometimes, of course. Of course, I could have stayed the same. That would have been easier, but useless in the long run. I would have been more unhappy but I'm changed, I know it. I feel different, differently about me. I'm telling a different tale these days”. (Mr. P.)

“Well this is going to sound odd, I think, but there are some rewards in all this. Don't get me wrong, I don't want it, I don't want it at all, and I'd undo it if I

could, but there are some good parts. It seems funny to say that, but yes there are rewards. This is complicated, there's more to it, um, um, in all the caring I do, there's something I wasn't quite expecting. I mean, one of the things is that I've found out about parts of me that I didn't know about, and that's rewarding. I'm a much more feeling person than I thought, a much more caring person, and my feelings go a lot deeper than I thought." Mr. P)

"..... not easy to describe. It's like you make some new routines and get used to them. The new things become part of you, incorporated, part of your life. You have to give yourself time to get used to it all. Like, you lose yourself a bit, at first, but then you find yourself again.... But I'm different, you can't quantify it, but I'm different. It's difficult to talk about, a bit embarrassing really, but in doing this, I have found different parts of myself .... well, I sort of like myself a bit more now. I suppose work was always competitive, at some level, and you were encouraged, well not exactly encouraged, but somehow required by the situation, if you wanted to get on, or just to keep your place, you had to be a bit ruthless, a bit uncaring about others. I mean, if you let someone have the advantage, they'd take it, use it, so on one level the usual kindnesses were gone. You had to be on your toes all the time, watch your back.... But of course all this is different, and I've discovered it suits me, it's better to be different, for me anyway, kinder, more patient, room to be gentle, concerned, all of that. I'm not boasting here at all. I suppose what you are doing is developing your feminine side, that's how I would have described it once, but um, why should women claim all that. I've worked with some women who were as uncaring, as ruthless, as bloody-minded, as any man,

right hard cases, I can tell you, especially at that level of the Civil Service, so no, not feminine as such, but the part we suppress or repress or whatever it is to do our jobs effectively. To be thoroughly masculine, in the old traditional sense, would be just as stupid ..... Anyway, the new style suits me better. I think I feel different, I mean I feel differently, but I suppose when *I was* working I was the central character of the story of my life, sometimes the hero, sometimes the victim, but then I lost the plot, lost it almost completely, so I wasn't much of a figure in my own life. Like, when you asked me earlier, there's not much room for daydreaming in caring, not when you're doing it, but slowly, slowly, I found more room for the usual run of daydreams, but it is different .... I got it back, and I got to be the hero of my own story again, at last". (Mr H)

## **DISCUSSION**

The fore-going interview transcriptions show clear differences between informants regarding their orientation to, and embodiment of, traditional male sex-roles. These differences are associated strongly with other characteristics, and this indicates an important finding. One group preserves, espouses and exemplifies a rather traditional idea of masculinity, and does not accommodate well to the caring situation. I want to argue, perhaps only tentatively at this point, that this view of masculinity and these difficulties with caring are connected intimately. To state it clearly, I want to suggest that a failure to adopt and develop a more flexible style of masculinity leads

inevitably almost to difficulty and continuing failure in the care situation. To add to this, the group of informants under discussion is precisely the same as the 'Stuck' group of Chapter Ten that is, the groups are composed of the same informants.

A second group espouses and exemplifies a modified view of masculinity, asserting that despite current convention, no particular task or set of tasks is the special province of either gender. It is further asserted that some characteristics and activities might be classified as "masculine" or "feminine", regardless of the gender of the person who owns those characteristics or performs those activities. This group is the same as the 'Marking Time' group in Chapter Ten.

The third group is very different. Its members have, variously, made large modifications to traditional masculine sex-role, and have formed a new masculine identity, based on their experiences of the caring situation. They have a more comfortable accommodation to caring, and use the language of personal development to describe their experiences. This group is consonant with the 'Moving On' group discussed in Chapter Ten.

How are the changes in this third group to be explained? It is argued that practice creates social reality – 'Particular versions of masculinity are constituted in their circuits as meaningful bodies and embodied meanings. Through body reflexive practices, more than individual lives are formed: a social world is formed'. (Connell, 1995, p.64). To describe this process, Connell borrows the term "onto-formative" from the Czech philosopher Karel Kosik (see Kosik, 1976). Human practice is onto-formative, creating social reality. It is possible that the new practices of male carers -

the new body of reflexive practices of caring and tendering - create a new version of masculinity, a new social reality. Of course, there are constraints to this. As Connell has argued: 'Practice never occurs in a vacuum. It always responds to a situation, and situations are structured in ways that admit certain possibilities and not others. Practice does not proceed into a vacuum either. Practice makes the world. In acting, we convert individual situations into new situations. Practice constitutes and reconstitutes structures' (Connell, op. cit. p.65).

Connell provides an example of body-reflexive practice and the creation of new social reality, arguing that the changing division of labour in early child care has provided men with experiences that develop new male capacities, and form a new masculinity. This accords with the work of Segal (1990), who describes the formation of new masculinity in child care experiences. It is interesting to note the similarities between child care and the care of the sick or disabled: physical intimacy, proximity to waste products, the need for tenderness and empathy. The men described by Segal were engaged in full-time parenting, and described difficult as well as good experiences that were very similar to those of men who undertake informal care: social isolation, boredom, repetitive nature of care work, loss of status, lack of support and shifts in self-esteem.

I would argue that the informal caring situation can be similarly onto-formative, similarly productive of change. Engagement with a series of unfamiliar physical tasks, especially the provision of personal care, and a re-ordered orientation to work and social life could lead also to a reassessment and reappraisal of gender role. Men in this situation are given a lot of opportunity to reflect on their pre-caring behaviours,

and a characteristic of almost all informants was the spontaneous reappraisal of the experiences of women. To engage in intimate contact with other bodies, to bathe and clothe, to feed and comfort, is to 'develop capacities of male bodies other than those developed in war, sport or industrial labour' (Connell, op.cit. p.233). These practices involve changes in social relations and a re-ordering of symbolism; they can begin to constitute a changed social reality.

As has been noted, practice does not occur in a vacuum, and there are some discernible changes in gender order throughout the world. It might be argued, for example, that there is a general softening of much of traditional masculinity, although this remains partial and tentative. Men everywhere continue to 'draw the patriarchal dividend' (Connell, p.226), and the reformation of masculinity may allow men to 'experience some of the pleasures more traditionally connected to women's lives and 'feminine' pursuits, while nevertheless retaining privileges and power over women more generally, even if undesired' (Segal, p.290). Nevertheless, there have been changes in gender ordering. Some large institutions, for instance the education system, have worked with some success to create quality of access and opportunity, and (within the patriarchal state) there have been many programmes to address inequity. What has changed is not so much the 'material and institutional structures of patriarchy' as the 'legitimation of patriarchy' (Connell, p.226). There has been a shift in the terms of discussion: the denial of equality for women and the continued existence of patriarchy have now to be explained and justified. There is also a wider consciousness of gender issues, which is more profound perhaps than the concept of equal rights. This has included a shift in cultural attitudes too, and about, masculinity, which is signalled by such diverse things as the increase in male cosmetic use,

emphasis on male health issues, general acceptance of the dangers of emotional suppression, late age of some new fathers and a slightly wider tolerance of homosexuality. It might be argued that these are predominantly middle-class features, and this is a view worthy of consideration. However, working-class men are not at all excluded from the effects of this cultural shift. In fact, it may be argued that working-class masculinity already contained the potential for elements of care, comradeship and physical proximity - a circumstance noted in the mine-working experiences of Kevin Devaney (reported in Segal, p.288 ff), and in the accounts of the mutual solicitude and care shown by ordinary soldiers as noted by middle-class journalists who covered the Falklands conflict (see Bishop and Witherow, 1983).

Some profound changes in the activities and experiences of men have been occasioned by changes in the working environment. Most notable of these for informants has been the marked reduction in the steel industry, the collapse of coal mining and the decline of heavy industry. This resulted in widespread unemployment and redundancy among men, a situation only partially remedied and ameliorated by the introduction of new employment opportunities. One consequence of all this has been an increase in female employment, both full and part-time. Consequently, men who are not employed (for whatever reason) have engaged more in some aspects of domestic work (Bytheway, 1987; Cliff, 1993). In addition, it has been noted that domestic labour and childcare are more likely to be shared between partners, but this depends hugely on economic relations (Segal, 1990).

## **FURTHER CONSIDERATIONS**

If some of the foregoing serves to explain why some men adapt to the circumstances of informal caring, and are transformed by their experiences, is it possible to explain why some men do not adapt, and are not changed? It would be easy to argue that these responses are the products of individual differences, and leave it at that. This would amount to saying everything, and nothing. It might be easy to argue that it is in some ways more comfortable to refuse change. Certainly, this might well be the case as regards the modification of masculine attitudes and behaviours. As has been noted, men draw benefits from maleness across every social site, and that can include the caring situation (see Rose and Bruce, 1995; Taraborrelli 1996). In a wider perspective, it is perhaps easier, although increasingly less comfortable, to retain a traditional view of masculinity. However, none of this seems to provide a satisfactory explanation of why some men were able to adapt to caring, modifying their view of themselves as men, and some were not.

Perhaps the difficulties of the 'Stuck' group can be explained more satisfactorily by recourse to Bourdieu's theories of habitus and practice. The context in which these ideas are formulated in Bourdieu's well-known attempt to avoid the oppositions between objectivism and subjectivism, which he has identified as the root of the difficulties of social science. "Habitus" is defined by Bourdieu as 'systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organise practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or and express mastery of the operations

necessary in order to attain them. Objectively 'regulated' and 'regular' without being in any way the product of obedience to rules, they can be collectively orchestrated without being the product of the ongoing action of the conductor' (Bourdieu, 1992, p.53).

The habitus is not seen as determining practice. This would be to misunderstand the essentially improvisatory nature of practice – 'the art of the necessary improvisation' (Bourdieu, 1977, p.8); "social life, in all its complexity and variety, is not accomplished on the basis of rules, recipes and normative models" (Jenkins, 1999, p.71). Rather, Bourdieu asserts, "the habitus contains the solution to the paradoxes of objective meaning without subjective intent. It is the source of these strings of 'moves' which are objectively organised as strategies without being the product of a genuine strategic intention - which would presuppose at least that they be apprehended as one among other possible strategies" (Bourdieu, 1992, p.62)

According to this view, the decisions to undertake informal caring, and the continuing series of decisions to persevere with it, would be the end products of an improvisatory process - "the exploitation of pause, interval and decision" (Jenkins, 1999, p.71) - that feel "natural", and perhaps inevitable. This is important: "the practical world that is constituted in the relationship with the habitus, acting as a system of cognitive and motivating structures, is a world of already realized ends - procedures to follow, paths to take - and of objects ...the regularities inherent in an arbitrary condition...tend to appear as necessary, even natural, since they are the basis of the schemes of perception and appreciation through which they are apprehended" (Bourdieu, 1992, pp 53-4). Some of the fluid notions that might inform the decision to undertake care

are the force of the current ideology of marital obligation, the availability of a suitable carer, economic opportunity, the need to gain (or not lose) social and symbolic capital, exemplars of male sex-role behaviours, uncommitted physical space and personal availability.

However, this improvisatory process can lead to difficulty. Practices are not always able to cope with the exigencies of a changing life, and can outlive their utility – ‘cases in which dispositions function out of phase and practices are objectively ill-adapted to the present conditions because they are objectively adjusted to conditions that no longer obtain’ (Bourdieu, 1992, p.62). There can be conflicts and contradictions in the habitus, especially at times of rapidly changing circumstances.

It might be argued that, for the particular group of informants under discussion, the decision to undertake care runs counter to some other powerful dispositions in the habitus. Central among these was a strong adherence to a traditional masculinity. Unlike other groups, these informants were not amenable to a crucial adaption. They were caught in a powerful contradiction: loss of social and symbolic capital engendered by the failure to undertake care of a sick spouse was equivalent to the perceived damage to social and symbolic capital occasioned by breaches in “appropriate” masculine behaviour. In fact, the only viable way of accommodating this was to seek the hospitalisation (or other formal care provision) of relatives - a solution pursued by informants wherever possible. This action would also be in accord with the improvisatory nature of practice – ‘the spinning out over time of the process of adjustment between the constraints, opportunities and demands of specific social fields and the dispositions of the habitus’ (Jenkins, 1999, p.179).

The same set of ideas can be applied to the 'Marking Time' group. These are operating within a circumscribed time-frame, and they have to make only a few adjustments. Within a limited period of time, they will be able to resume something similar to usual functioning, and this usual functioning might or might not be informed by lessons learned whilst caring. It is imagined that caring is a transformative experience, and those undergoing it will be changed. However, while caring continues, it is both necessary and desirable to modify one's self-view to accommodate to circumstances. This is almost a definition of sanity and wholeness. Context is (almost) everything.

## **10. MODES OF ADAPTION: MARKING TIME, BEING STUCK AND MOVING ON**

### **INTRODUCTION**

Following the initial disruption of entry to informal caring, there is a period of consolidation, characterised by the establishment of caring routines and adaptive strategies of varying usefulness. As has been noted earlier, there is a transition from the experience of chaos to the formulation of chaos narratives, and on to the preparation of coping narratives. The varieties of coping narratives are discussed below. When caring continues, and will in all probability continue for some time, carers settle down to the business of long-term care provision. As one informant noted, this can be a very long haul indeed. (Mr C; see below)

Unlike the relative homogeneity of earlier periods, informants' accounts of this later experience may be divided into three distinct categories: those who have recognised or realised that caring must stop at some point, and that it will be a temporary - long-term perhaps, but still temporary - interruption of their lives; those who provide acceptable levels of care, but remain discontented with, and contend against, their situations, failing to develop a coherent adaptive strategy; those who adapt more or less successfully (but still reluctantly) to the caring situation, learn to find some positive features in it, and develop a different orientation to it.

## MARKING TIME

Some informants - a small but distinct minority of them - came to realise or recognise that their caring activities would end at some time. This end was inevitable, and it would occur in a future that was foreseeable, or only just foreseeable. This must have been evident particularly to two of them, because they were aware that their wives suffered from incurable terminal illness. Although they possessed this information securely and certainly, neither of them were sure of the probable duration of the illnesses, and could anticipate realistically, utilising recent medical prognostications, that caring might continue for more than twelve months. A third informant, caring for his elderly mother, made the reasonable assumption that she would predecease him, and that her Alzheimer's Disease would terminate her life somewhat prematurely.

These informants had entered, and maintained a different experiential and thought-world from the others, in which the salient characteristic was the recognition of the temporary nature of caring. This was, in very large part, a product of the particular illnesses of their relatives, but it was not the only important factor. It is certain that other informants might have arrived at similar conclusions; two of them were in possession of very similar information regarding course, duration and ultimate prognosis of their relatives' illnesses, and another two of them might reasonably have expected their relatives to predecease them. This small group of informants had achieved a certain way of regarding the situation, and had adopted a certain distinctive style of thinking and feeling.

However, even for this group of informants, recognition of the temporary nature of caring was not entirely unproblematic, and was edged with multiple difficulties. This is demonstrated by the manifest struggles with language, meaning and everyday logic in informants' accounts.

“Sometimes, most of the time, it seems like it won't end, I'll be doing this forever. Logically, thinking about, I know this is not true, it must end, and that end is not particularly far away, really”. (Mr H)

“Of course, it won't go on like this, it will be different. That is, at some point this is going to get worse. The shit will come and splash all of us, that's for certain. The professionals, the medics and the nurses have .... well, look, I know there'll be an end”. (Mr C)

However difficult it may be to hold and own that information, these informants do recognise that their situations are somewhat different from other informal carers, and they are able to explore this difference.

“If it was a plain disability, no fluctuations, like after an accident or something, it would be a different story. People in that situation are, people who look after people like that, have to get their heads down for a very long haul, don't they?” (Mr C)

“There’s progressive deterioration, so that gives you a perspective. It would be different if it stood still, because however much I don’t want to think about it, an end-point, an end, is brought to my attention now and again, and forcibly.” (Mr F)

“This is a deteriorating condition. It seems to go slowly, day by day, but actually its rapid, rapid. I’ve been warned, told to expect it, although timescales are um uncertain. It’s inevitable, and that gives everything a different flavour, like it or not.” (Mr H)

This recognition of the difference in caring situations is important, and it is clear that informants realise that different situations require and utilise a quite different set of adjustments and coping skills. Informants in this category describe a coping strategy based on the maintenance of a close attention to the tasks at hand as a sort of blocking device, and only a minimal apprehension of the end of caring. This combination was not necessarily exclusive to that group, but characterised it strongly. Possibly, even probably, it constitutes a strategy for managing ambivalent feelings about the end of caring. This end must be desired strongly on the one hand, and feared on the other, because it must necessitate the death (or further deterioration) of a loved relative. Some of this ambivalence finds expression in informants’ accounts.

“I think of it as continuity. I don’t think of the end, I don’t let myself, but I know it’s there. What I do now is keep on, head down and keep on.” (Mr C)

“I go on from day to day. This is my life now, this is what I have to do. I keep my eye on the job, and I try not to let it wander.” (Mr F)

“It’s like work, do you know what I mean, if I had to say paint a fence, like I was doing before you came, a big fence, well there’d be times, big lumps of time, when I’d forget myself in it, I’d be so involved in the actual painting, how it is going on, the state of the wood, all the little problems, all of that, I wouldn’t be thinking about the end, not until I was almost there, well not much. Same with this.” (*Later in the same interview*) “I’ve said I’d made no plans, and that’s true, but of course half my attention is there. I know full well I’m going to stop at some point. So I couldn’t really get fed up with this because of that, and because it would be well disloyal.” (Mr H)

Ambivalence of this magnitude is not handled easily. Its resolution is not possible, and the strategy used by informants to cope with it is similar to the mechanism of displacement, as described and delineated by psychoanalytic theorists, where ‘the individual shifts interest from one object or activity to another in such a way as the latter becomes an equivalent for the other’ (Rycroft, 1977). In ordinary terms, informants attempt to distract themselves by immersion in the activities of caring from thinking about the possible future, which is the focus for ambivalent feelings.

“When I get there, I’ll think about it. I can’t think about it now, I just can’t. I’ll be in a mess, I expect, but I’ll deal with it then. Not frightened, no I’m not frightened, but I’ve got to get through this first, and then we’ll see.” (Mr C)

“I do think about the future, just daydreams really. I don’t make firm plans, it doesn’t seem right. In some ways um I imagine I’ll um pick up a few things I dropped off to do this, hobbies, whatever. But it’s too dangerous to dwell on it.” (Mr H)

Informants emphasise the provisional and temporary nature of the caring period, describing it as bracketed off from the rest of life, as an unusual interruption. These are descriptions of the liminal situation. True liminality occurs as part of a process, a rite of passage; it must always involve a return, a recovery, a restitution, not to the pre-liminal state, but to a changed condition. This is recognised in informants’ accounts. The experience, the whole process, is described and summarised in anticipation of these events by one informant.

“Although this is all my life now, and looks like it will be for a long time, at some point in the future I’m sure it will seem like a temporary thing, and life will resume. But, and this is a very big but, I’ve changed too, I’ve been changed by it, so it wouldn’t be a matter of picking up where I left off, not at all, there’s some things I’ll never do again because I’m different. However, I look at it, all this has changed me.”  
(Mr H)

## STUCK

A larger number of informants formed the second category. These were different from the others in several key ways. First of all, they were in difficulties of one sort or another; they were not settled, and they were not happy; there was a restless air about them, a sort of muted agitation. I came to refer to them in my notes as those who were “stuck”. This was a word they used a lot, in different ways: “I’m stuck in here”, “I’m stuck with this”, “I’m stuck in a rut”; and I began to use it to describe them. Although I am sure that informants used “stuck” in the sense of keeping the same position, being unable to progress, as I explored their painful difficulties, I began to hear it in the more primary sense of impaled, transfixed, stabbed (as ordered and explained by the Oxford English Dictionary). They were indeed wounded, impaled, immobilised.

These informants were further characterised by a marked propensity to retell chaos narratives. It was as if, in some fundamental way, they were still attempting to come to terms with the disruptions of the entry to caring (although the mean average number of years of caring for this group was 5.5). All these informants had “progressed” enough to relate narratives of coping, but the relation of these was different from that of other informants. Informants in this group described their coping strategies and activities in sparse detail, and more appeared to be dismissive of them; they were treated more as an irrelevance. It was as if the details of coping were not as important as their own emotional responses to them.

“Oh I do it all, but I don’t like it and never find it, you know, particularly rewarding.”

(Mr K)

“Well I get it all done, but yes I suppose I don’t like it.” (Mr L)

“I mean, the actual work is not difficult, not that difficult, but I’ve found it a bit sort of demeaning, in a way.” (Mr M)

The lack of rewards in the care situation reported by most carers was a particular issue for this group, and they reiterated it.

“ .... never find it particularly rewarding, you know, not even a sense of a job well done.” (Mr K)

“ .... suppose people seem to get something out of it, something I don’t get at all. I suppose we’re different.” (Mr M)

Emphasis on emotional responses to the caring situation was manifested in other ways. In fact, the accounts of this group of informants were characterised by higher levels of emotional expression of all sorts, and by anger, frustration and pain in particular. This included a continuing contention with the care situation as a whole.

“Even after all this time it’s difficult to accept. A part of me, a good part of me, still doesn’t accept it. Anyway, I don’t think it’s a thing you can accept, or even should accept, it’s unacceptable, always a source of irritation um whatever, you never feel happy about it.” (Mr A)

Informants discussed and described the losses they felt they had incurred on entering the caring situation. These were very similar to those of all other informants, and detailed such things as autonomy, privacy, social life, marital mutuality and self-esteem. However, in addition to these, this group of informants described a sort of enduring loss of self they were unable to repair.

“My resources are limited, personal resources, and I can’t be myself, the only way I know. I can only be in reference to something else, if you know what I mean, not me, not myself as I used to be. Mind you, I wonder now if it was always a bit like that, and now I recognise it.” (Mr A)

“I, me, I got lost in it all. I was busy, busy, and when I turned around I’d just disappeared. What happened, what happened to me? Well, not much, not much.”  
(Mr K)

The situation described here is well-recognised in carer research, and may be characterised as “loss of self”. This is said to involve damage to feelings of mastery

and self-esteem; it ‘confronts people ..... with the inescapable proof of their inability to alter the unwanted circumstances of their lives’ (Pearlin, et.al., 1981, p.337). This view regards the self concept as an unstable part of personality, which is particularly amenable to change under certain stressing circumstances. (see Filipp and Hamer, 1986). The conceptual specifications for the idea of loss of self are given by Skeff and Pearlin (1992); the concept is discussed more fully in the following section.

In addition, informants gave vivid descriptions of their “stuckness”.

“Like, if life’s a journey, you know how people say that, life’s a journey, well if life’s a journey from say Essex to Wales, well when she got ill we pulled into a lay-by near Swindon, and we’re still there, still there. And of course part of you wants to go on.”

(Mr L)

“I go round in little circles. I’ve been having the same argument with myself for years, years. I think, I know, I should move on a bit, I think I know that, but of course I don’t do anything about it, not at all. I’m stuck.” (Mr A)

This describes a protracted liminality, in which most positive features have been lost. It is reported that many liminal situations have positive features. For example, there are anthropological reports of women enjoying the brief period of segregation at menstruation, when they are released temporarily from usual domestic responsibilities and duties (Reiter, 1975; Martin, 1989). In Western culture, it is commonplace to observe that some people enjoy the secondary gains consequent on adoption of the

sick role, and it has long been noted that the liminality conferred by mild, time-limited illness is not entirely negative (see Robinson, 1973).

All informants in the “Stuck” group gave strong expression to a desire to be relieved of the duties of care. The sentiment itself was common to all informants, but the strength of expression and its high emotional tone were particular to this group.

“If I won the Pools or the Lottery, and I could pay someone to do all the work, make a good job of it, as good as me, then I would, I bloody would.” (Mr L)

“I’d stop straight away if I could get someone else, someone proper, to do it.” (Mr L)

However, in these accounts, there was very little to suggest that informants wished to be relieved of care duties in order to move on to other things. Relief seemed to be an end in itself. Finally, there was a definite air of tension about this group of informants. At first, I thought it might have been a response to the interview process, but it was unlike the interview anxiety of other informants. I entertained the idea that the tension was located primarily in me, that there was something about these men that made me feel tense and I somehow ascribed my tension to them. Finally, I decided that these men were tense, and were also unhappy, at an enduring and sub-clinical level. As a measure of this, these men were the ones I would have responded to with offers of assistance and succour if I had encountered them in a different context; their covert appeals were very powerful.

## MOVING ON

The third category was the largest grouping of informants. The “Moving On” group had some characteristics and proclivities which were not shared with other informants, and these are detailed below (some exceptions to this are also noted). In common with other informants, they often found the duties of caring to be difficult, onerous, restricting and constricting. They had periods of unhappiness, and mourned for lost freedoms. Like other informants, they found relationships with recipients of care to be difficult, not necessarily reciprocal and anxiety-provoking.

Informants in this category also described some elements of the loss of self phenomenon described above, although with less frank despair than the earlier group. This is not particularly surprising. Skeff and Pearlin note the ‘intriguing lack of relationship between loss of self and self gain’ (Skeff and Pearlin, 1992, p.662). It is assumed usually that these are structural opposites, but now appear to be entirely independent constructs. As Skeff and Pearlin indicate: ‘Gain refers to the sense of personal enrichment or character building that comes from having coped with a difficult situation, whereas loss of self captures the constriction of self-identity or loss of the essence of oneself. Caregivers can, and many do, experience both loss and gain’ (1992, p.663).

However, these informants were different. All of them, from the youngest to the oldest, from the least articulate to the most skilled rhetorician, described a very similar set of responses to the caring situation, and a very similar set of personal

conclusions. At the core, all these informants had found the caring situation to be, however unwelcome or difficult, somehow rewarding. That is, they had come to find some rewarding features in a situation that was unpleasant, upsetting and not amenable to influence or control. This is expressed in the following extract.

“Well, like I say, this sounds an odd thing to say, but there are rewards. The housework, for example, I take some pride in that now, and get a bit of satisfaction from it, especially the cooking .... This is complicated, there’s more to it, um, um, in all the caring, all the personal work I do for Anne, there’s something I wasn’t quite expecting. I mean, I’ve found out about parts of me that I knew nothing about, and that’s been rewarding. I’m a much more um caring person than I thought, and my feelings go a lot deeper than I suspected.” (Mr R)

All informants in this group described something very similar, using similar language. They had found some rewards in the daily round of caring duties, and had come to rediscover and resolve aspects of their emotional lives.

“I’ve found new um parts to me, more capabilities, more um caring.” (Mr D)

“.... makes you think more deeply. You find you are a more compassionate person, more caring.” (Mr E)

“I discovered .... I’m more caring than I thought, got more capacity for well love I suppose. I’ve learned that.” (Mr P)

This increased capacity for emotional life was accompanied by an improvement in confidence about things generally. Some informants made explicit and repeated reference to what they perceived as improvements in their moral character, and all of them referred to the relief of being able to see themselves as “better” persons. This was difficult to understand, and difficult for them to articulate. It was as if they had been through a testing time - physically, emotionally and morally - and were relieved to find that their worst fears about themselves were not confirmed; they were not weak, and had some emotional depth. It was possible to hear that relief in their accounts.

“In a funny way, I think its all made me a better person, like well it’s difficult to explain. I’m a better person than I thought I was, put it like that. This is what I have learned, but what a terrible price to pay for it.” (Mr E)

As a result of this, these informants describe a certain content - not happiness necessarily, and a content constrained by the circumstances of having a sick or disabled relative in need of constant care, and having undergone the major disruptions of taking up caring. Informants were, unanimously, surprised by this.

“.... there’s ways in which I’m more content now than I ever was. I think about that a lot, and I don’t pretend to understand it, but I know I’ve been a fool in the past and looked for happiness in all the wrong places.” (Mr P)

“.... get a bit of satisfaction from it .... In a way, in an awful way, really, I’m more comfortable with myself, despite all the restrictions and the upset.”

(Mr R)

Two informants in this category made some attempts to understand and theorise about what had changed them. One of them felt that he had adjusted to the deprivation consequent on caring, and had learned to be happy with less. This is something of a truism, enshrining some common wisdom. The other informant had a notion, which he worked up to the status of idea during our interview, that masculinity had something to do with it.

“If I was only a man before, I was much less of a person than now, do you know what I mean? It’s like, like I’ve found another way to be me that suits me better .... We hold on to some things about being a man to our detriment.” (Mr R)

## **DIFFICULTIES WITH CATEGORIZATION**

Although the three categories given above developed comparatively easily during the process of analysing data - a process largely of reordering, of data reduction and data complication that served to develop pools of meaning - there were two informants who defied neat and conclusive categorization. The importance of resisting the temptation 'to ignore incidents, events, individuals, or chunks of data that do not 'fit' into the codes", and the idea that "the exceptions, misfits and 'negative' findings should be seen as having as much importance to the process of coding as do the easily coded data' (Coffey and Atkinson, 1996, p.47) is recognised, and the details of that difficulty are noted.

Mr H is included alone in the Marking Time category, but could have been included in the Moving On category. He showed all the characteristics of both groups, but was included in this category because he gave strong expression to the idea of the temporary nature of caring. This seemed to be a reasonable action, and it provided a comfortable thematic fit.

Mr G was more of a challenge. He could have been included in the Moving On category. Objectively, he was coping well, and had made many important adjustments to the caring situation. His life was beginning to open out again, and he had found some new interests. He was cheerful, stoic and realistic. However, he refused resolutely to find anything positive about his situation, and did not believe that he had gained anything at all from it. He understood the idea, but felt that it did

not apply to him. I was reminded of the term “partial discordant improvement” to describe psychiatric patients who, by objective standards, had improved, but reported no subjective changes - for example, people with travel phobias who commuted daily in difficult circumstances, or compulsive gamblers who did not place bets (Taylor, 1951). Mr G remains uncategorised, and data from interviews with him are not included in this chapter. This difficulty indicates the limitation of the categories used in the study, but does not invalidate them.

## **CONCLUSION**

Although there is a high degree of homogeneity among informants, it was possible to identify three distinct categories of entrenched and ramified responses to the caring situation. These are characterised by the use of certain narrative modes, by particular styles of thought and feeling and by orientation to the caring endeavour. Some difficulties with categorisation have been noted.

## 11. OUTCOMES OF CARING

The analysis of data identified a pattern, or group of patterns, of informal caring responses. It became possible to isolate different phases of the caring career and to identify varying outcomes. The identified stages of the caring process were common to all informants. Depth and substance of preparation for informal caring was various, but does not seem to be related strongly to the ultimate success or failure of the caring endeavour. There was also very little difference between those who came gradually to assume the tasks of full-time caring, due usually to a combination of co-residence and a slow deterioration in the conditions of relatives, and those who were plunged suddenly into caring. All informants experienced the acute disruption - emotional, financial, practical - occasioned by entry to caring. Similarly, all of them described the establishment of a caring routine and the eventual utilisation of more or less stable coping strategies, amounting to a set of interlocking techniques of body and mind.

Analysis reveals three basic types of caring response among the informants, and it is argued that these appear to be associated with three different outcomes of the caring enterprise. The three response-types correspond to the three styles of caring identified in the chapter on Modes of Adaption : Marking Time, Moving On and Stuck. A similar tripartite response is evident also in informants' attitudes to, and modifications of, a traditional masculinity, and in the structure of their narrative accounts.

This pattern is not easy to explain, and it is possible to approach the subject from different perspectives. For example, what people do has been explained traditionally by recourse to what might be called motivation theory. Early research in this area focused on the motivations to action occasioned by biophysiological needs and drives. Higher order needs - for self-esteem, achievement and so on – were thought to work analogously, producing motives that explained human action. This view has been superseded, although some attention is given still to universal human biological needs in motivational theorising (Strauss, 1992; D’Andrade, 1992).

What is absent from this early theorising is the ability to repeatedly ‘specify a limited set of universal motives, identify them in behaviour and explain situational variance in their expression’ (Strauss, 1992, p.3.). A more fruitful approach investigates how internalised patterns of thoughts and feelings are learned in specific cultural contexts, and how they are linked to one another to form aims. That is, to investigate how cultural models come to have motivational force (Quinn and Holland, 1987; D’Andrade, 1981, 1984, 1990, 1992). It is argued that cultural models not only label and describe the world, but also set forth goals, both conscious and unconscious, to elicit desires (Holland, 1992). This does allow the study of situational variance in behaviour, and is not limited to a narrow range of universal motives.

However, there are some difficulties with motivation and cultural model theory. For example, social messages may change, be thoroughly inconsistent or difficult to read. This, I think, is the case with social messages about male informal caring. A similar set of difficulties is associated with child-rearing practices, where cultural messages are too vague, too inconsistent and too contradictory to underpin confident practice

(Harkness, Super and Keefer, 1992). Further, internalisation of social messages does not always entail copying or embodying them, and it is always possible to conceive of, and produce, counter-practice.

Another way of beginning to explain different carer responses and outcomes might be provided by Bourdieu's theory of practice. Bourdieu argues that social reproduction must be accomplished through the internalisation of social facts, but the primary social facts are not norms but practices. His notion of the habitus, defined as 'an acquired system of generative schemes objectively adjusted to the particular conditions in which it is constituted' (Bourdieu, 1977, p.95.), provides a source from which people can extract a pattern of practice that can be used innovatively and flexibly in enacting new situations. This improvisatory element seems particularly important. Another strength of Bourdieu's idea is its transcendence of the dichotomy between determination and agency; the concept of the habitus allows behaviour to be both determined and chosen freely in what feels like a close approximation of lived process.

However, there are a limitations to Bourdieu's work. Importantly, his analysis is not centred on individual persons, and he never examines the habitus of particular individuals, nor provides any guidelines for doing so. Much of his work, for example on the Kabyle people of Algeria, makes large assumptions about the content of the habitus on the basis of social facts such as household organisation. Secondly, his perhaps necessary focus on the unreflective, "automatic" nature of ordinary behaviour ignores social action that is consciously and explicitly goal-directed (although not

necessarily or always “rational”, as exemplified by the suicide missions of religious cult members).

A much clearer understanding of the various responses and behaviours of informal carers can be achieved by applying the model formulated by Breakwell (1986) concerning strategies for coping with threats to identity. This retains persuasive explanatory purchase that allows a more dense and complex context for identity formulation. This model sees identity as a dynamic social product ‘which cannot be understood except in relation to its social context and historical perspective’ (Breakwell, 1986, p.9.). Breakwell recognises that the term is highly problematic, and that its definition varies according to underpinning theory and perspective. She eschews any firm definition, seeking rather to define identity through a description of its structural components and dominant processes.

Breakwell argues that identities can be threatened by many different things, but that threat ‘occurs when the processes of identity .... are, for some reason, unable to comply with the principles of continuity, distinctiveness and self-esteem, which habitually guide their operation.’ (p.46). This is illustrated by examples taken principally from the experiences of unemployed people, and from those in gender-atypical employment (both highly pertinent to the study of men in caring roles), but the model is intended to apply across a range of identity-threatening situations. However, it is made clear that the details of individual cases will make sense only when studied in specific historical, ideological and personal contexts.

In terms of this theoretical formula, male carers are faced with a large-scale threat to identities. This would coalesce around such factors as the performance of gender-inappropriate tasks, loss of social connection, loss of paid employment, loss of structures to maintain masculinity and renegotiation of relationship with the recipient of care. All this would have a deleterious effect on continuity across time and situation, the feeling of distinctiveness, the feeling of personal worth and of social value. That much is very clear from the accounts of informants. These sorts of threats have 'the power massively to transform the individual's interpersonal network, group membership and perception of ideological structures. They have such wide-ranging implications for all areas of living that it is possible to examine within their remit other roots of threat' (Breakwell, p.52).

In terms of Breakwell's theorising, informants in the "Stuck" group have selected an inappropriate coping strategy for the type of threat they are experiencing, and have persevered with it when it has failed to work. The determinants of coping strategy choice are: type of threat, social context, identity structure and cognitive resources.

In this case, it seems that the threat to identity posed by informal caring is more enduring than the selected strategy allows for, but the social context provides an ideology and an interpersonal network that not only propels the informant into caring, but insists that he persevere with it. In addition, it is recognised that strategy choice is governed by individual psychological resources. For example, 'it might be predicted that individuals with a very high level of self-esteem prior to the threat, which may even be levelled at self-esteem, would be more resilient to change, more capable of evolving coping strategies whether at the cognitive reconstrual level or at the level of

social action.... It is not unreasonable to assume that actual context and value of the identity structure prior to the threat will predispose the coping strategy' (p. 153).

On one level, the members of the "Stuck" group have utilised the strategy of denial (Breakwell, op. cit., p.81; Lazarus and Folkman, 1984). Denial, as a mental mechanism and as a strategy, can take many forms. In this case, informants knew the facts of their situations, but refused to accept them fully, or to accommodate to them. This is categorised as one of the four sequential layers of denial used against threats to identity, as delineated by Breakwell: 'denial of the need to change identity structures despite recognising that the position is threatening' (p.81). Although denial may be a common initial response to the disruption of caring, this group of informants has not moved on to utilise any accommodation and acceptance strategies. More usually, they develop attitudes of negativity, which can be identified as a particular coping strategy that allows a partial protection of identity structures through the wide denigration of almost everything else. Those few informants who were very critical of health service, social service, family and voluntary assistance can be seen to operate this strategy. As a means of coping, negativity is at best only partially successful. More usually, it fails, leading to negativity about the self, and an associated turning inwards of anger and frustration.

Although it is clear that these strategies offer little in the long term, and may even exacerbate a difficult situation, people persevere with them. Breakwell offers four basic reasons for persistence with suboptimal coping strategies:

1. It is difficult to know what an optimal strategy might be;

2. Choice of strategy has nothing to do with rationality or logic, and is dictated by an interaction of factors; the best available strategy may not be the best conceivable strategy;
3. The constructs which precipitate the choice and use of suboptimal strategies may perpetuate them - 'Unless the pattern of interaction between the four determinants of choice changes, it is difficult to modify the strategy used' (Breakwell, p.166);
4. Initial use of a strategy may trap the user into continued use; for example, social isolation and passivity have strong self-perpetuating capacities.

In contrast to this, informants in the "Marking Time" group moved comparatively quickly from early coping strategies to an acceptance strategy that may be characterised as "compromise change". Acceptance strategies serve to modify identity structure, and to do so with a minimum amount of harm or damage. They 'represent creative adaptations which may rely on preliminary redefinition or re-attribution tactics' (p.93). Compromise change is defined as a revision of identity content, 'comparable with the threat but salvaging everything possible in terms of continuity, distinctiveness and self-esteem' (pp. 95-96). In the study, this group of informants redefined themselves as informal carers, and engaged fully with caring, but had a sense of occupying a temporary position, where much could be kept in abeyance. These informants used an imagined version of the future to cope with the present, allowing themselves to be modified temporarily by its demands. This

strategy relies heavily on an apprehension and identification of the transient nature of threat – albeit a comparative transience, in some cases. This is important, illustrating the strength of this style of coping: a person may occupy a threatened position ‘in the social matrix which is stable and continuous, but the threat to identity it creates is.... transient....Consequently, residence in a threatening social position is not coterminous with the experience of threat’ (p.77).

The informants in the “Marking Time” group can also be seen to deflect, reduce or defuse threats to identity. Their ostensible and comparative success in this is due, at least in part, to a happy choice of coping strategy, although it is important to stress the low level of active agency in this choice. Most of these informants began by utilising other coping strategies, but abandoned them at some point. It is not unusual for people to adopt sequences of coping strategies, especially when threats to identity are enduring. Indeed, the ability to do so might well be indicative of optimal functioning.

Very largely, informants in this “Marking Time” group adopted the assimilation-accomodation strategy of fundamental change. In such cases, in the face of continued threat, persons abandon all or some of the continuity, distinctiveness and self-esteem that are the foundations of identity. For informants, this required a fundamental realignment of the concepts of masculinity and gender-appropriate behaviour. It is argued that ‘capitulation to the threat by changing self-definition actually removes the conflict.... The incompatibilities between old self-definition and current situationally determined definition are eradicated’ (p.97). This process is noted in studies of unemployment, where it is argued that acceptance of unemployment as a way of life is the terminal point in the process of adjustment to a life without work (see Hayes

and Nutman, 1981). This process might also involve a revision of the relative salience of the principles guiding assimilation - if 'the threat is not contravening all three principles, it is possible to rearrange priorities between them, shifting emphasis from the threatened to the unthreatened. This can mean that a change which abrogates continuity might become tolerable because continuity is attributed less importance than, say, self-esteem' (Breakwell, p.98).

The "Marking Time" group utilise a second important coping strategy. This is included, according to Breakwell's typology, among the strategies that rely on the process of evaluation, and it consists of a re-evaluation of the existing content element of identity. It is argued that the value attached to the various elements of identity is socially determined, usually through social stereotyping. No single value system dominates entirely, and counter positions are almost always available. The actual value of an identity element is not fixed or absolute, and the evaluation process entails some form of social comparison. This allows some small freedom for re-evaluation, especially when individuals learn that newly-acquired social positions have negative social value (as in the cases of unemployment or disability). Thus most informants engaged in a re-evaluation of the identity element labelled "breadwinner", and asserted instead "competent carer". Similarly, some informants re-evaluated "competitive sportsman", learned to deride it in some measure and asserted instead "uxorious home-maker". Breakwell describes a similar operation among women who undertake gender-atypical work - 'The nature of the work militates against feeling themselves to be feminine. They respond by rejecting their own femininity and decrying its value' (p.101). This process involves a refocusing on another element of identity, and inflating its value. In addition, individuals may engage in exercises of

self-efficacy to regain self-esteem; this inner self-esteem is said to derive from the experience of oneself as an active, successful agent in the world, regardless (almost) of the type of activity.

These strategies can be seen as part of a wider attempt to regain a degree of control by means of narrative reconstruction, and they contain the seeds of later narrative elaboration. Narrative, as noted earlier, is central to the formation of selves and identities: ‘through narrative we construct a morally valued and conceptually coherent identity and sense of self. Narrative conventions serve to stabilise and authorise stories, including those that make up personal history, through direct effects on remembering...and through effects on social acceptance’ (Kirmayer, 2000, p.153).

For most people in the ordinary course of their lives, questions of self and identity are not pressing, or even very important. However, ‘questions of identity and self-understanding arise primarily in crisis situations and at certain turning points in routine behaviour.’ (Kerby, 1991 p.6) At these times, identity can become fragmented through ruptures in narrative. What is revealed at such times is the continuing and continuous need for narration in order to exist as a meaningful human subject, and the function of narrative in generating some sort of continuity of self.

In these terms, informants in the “Stuck” group have not been able to construct coherent narratives - and, therefore, thoroughly coherent selves - to match their changed situations. They continue to utilise inchoate chaos narratives and other structures of knowledge and self: ‘we can articulate our suffering without appeal to elaborate stories of origins, motives, obstacles and change. Instead, we may create

metaphors that lack the larger temporal structure of narrative but are no less persistent or powerful....metaphors then may function as gestures towards a story that is not taken up ....metaphor therefore occupies an intermediate ground between embodied experience and the over-arching narrative structure of plots, myths and ideologies' (Kirmayer, p.155; and see also Kirmayer, 1992 and 1993).

Similarly, informants in the "Marking Time" group have constructed narratives that are predicated strongly on the idea of a deferred, suspended future. They accept their role as carers, and construct new identities accordingly, but these are used on a temporary basis only. This allows the continuation of many identity components across the disruption of the caring experience, and the abeyance of others. This strategy seems to avoid the necessity of abandoning too much of the previous identity formulation.

Finally, the "Making Out" group seem to have achieved or regained a large degree of what might be referred to as narrative competence. They have reformed their identities as fulltime carers, retaining some identity components, abandoning others and modifying others where necessary. This reformation has required a realignment of life-trajectory, which is perhaps the single most important part of the process - The idea of trajectory provides a view of narrative structure that fits the metaphor of life as a journey, and behaviour as the motion of the self through both space and time. This element is crucially absent in accounts from informants in the "Stuck" group.

What can account for these differences in narrative competence? It is difficult, on the basis of existing evidence, to ascribe these differences to psychological type, current

situation, past history, supporting network or any other variable. The process of narrative construction is never easy, never unproblematic. It has been noted that 'mundane experiences may undermine our efforts at self-construction. A minimal list of those threats to the narrative coherence of the self would include intrusions of bodily distress; cognitive dissonance that makes us unable or unwilling to assimilate unpleasant but necessary facts about our self; and a wide range of social constraints, including outright sabotage by others with conflicting goals' (Kirmayer, p.155).

This social aspect is important. People make what they can of their lives, but the construction or reconstruction of identity through narrative is never an entirely private or personal manner. It is, in large part, a social act. Human identities have strong behavioural implications, which when realised are subject to social evaluation and social moulding. Social factors affect also the internal process of construction: 'it becomes increasingly necessary for the individual to articulate the implicit narrative line in such a way that the actions in question become intelligible and thus acceptable....whether a given narrative can be maintained depends implicitly on the individual's ability to negotiate successfully with others concerning the meaning of events in relationship with each other' (Gergen and Gergen, 1997, p.177). It should be recognised that this process of social negotiation need not be visible and public because people appear generally to avoid the threat of direct negotiation by taking prior account of the public intelligibility of their actions. They select in advance actions that can be justified on the basis of an intelligible or publicly acceptable narrative. Much of the negotiation process is anticipatory or implicit.

It is probable that these processes and pressures account for the differences between informants' responses to caring. There are some indications from the existing evidence that this might be so. For example, the difficulties of Mr. A could be ascribed to the continuing negotiation to define the situation of Mrs A. that persisted in the discussions between family members, and in their interface with health and social care professionals. Similarly, it might be argued that the manifest differences in the definitions of masculine role in the micro and macro social situations of Mr. L disrupted his attempts to form a new identity and fulltime carer. This line of inquiry is, I think, worthy of further investigation.

People construct and maintain selves and self-narratives in the spaces between circumstance and desire, individual proclivity and social pressure, dreams of freedom and actual limitations, imagination and mundane capacity. Each individual is formed by these and other processes in unique context. Probably, our constructed selves are the best that can be managed under the circumstances.

## 12. CONCLUSION

This study has observed that modes of caring, outcomes of caring, self-attribution of masculinity and narrative style were associated with one another and interconnected in complex ways. Despite any possible objection to the epistemological status of this finding, particularly that it is an artefact of the study itself, I want to assert its' value and validity.

It is well-established that the construction and maintenance of narrative is essential to the formation of personhood. There are many studies of this, and some of the most pertinent examples are discussed in the Literature Review. Unfortunately, lives are unpredictable, and it is necessary occasionally for persons to engage in narrative reconstruction to take account of disruption and change. This was the case with the informants in the present study.

I argue that the success of narrative reconstruction equates strongly with the success of adjustment to the caring situation. This sort of formulation has been shown to be the case across a variety of examples. Crucial to this is a renegotiation of the idea and practice of masculinity. Masculinity was central to the self-conception and self-understanding of the informants. Masculinity here is not seen as a stable condition, but rather as something that must be negotiated and renegotiated. This renegotiation and narrative reconstruction can be a fraught processes, with much uncertainty.

It is difficult to know what is the difference between those men who successfully reconstruct a new self-narrative, and those who struggle with it. This might constitute an interesting additional study. I do not, from this vantage point, think that there are

any obvious indicators to this: not age, education, circumstance, previous occupation or personality structure. Equally, I am not at all certain that less obvious psychological differences might account for it. I take it that the ability to engage successfully in narrative reconstruction rests on the interaction of many different factors, but these remains to be established definitively. The extant literature is strangely silent on the subject.

At the inception of this study, I had some questions about the experiences of men who undertake informal care. Some of these questions became more formalised as the study proceeded. At the end of the study, some of those questions have been answered, but the inquiry process has generated many more. I know more than I did, but I am aware that I know very little. Some of the new questions are difficult to ignore. For example, were my informants a thoroughly aberrant sample, entirely untypical of male carers? I think, on the basis of the literature and on reported experiences of other researchers, that this is not the case, but this remains a conjecture only on my part. Further, what would the responses of those who abandon the care situation have been like? What sort of narratives would they produce, and how would they compare to those of enduring carers?

On the other hand, I feel that I do now know some things. I have a clear idea about what male carers do, on a practical level and on a day-to-day basis. I know something about the mental operations that carers employ, including explanations and justifications of the caring role. I know that it is possible to discern distinct categories of attitudes to caring and to masculinity that may be, without pressing the point, connected to styles of caring and general satisfaction with the care situation. I feel

that I know something more about the importance of narrative in forming and reforming both selves and lives. I know more about the manner in which the competence to form and maintain a coherent self-narrative can be lost, and how, under certain circumstances, it might be regained.

It is to be hoped that this little knowledge might, with development and expansion, be of some use to those who might attempt to alleviate or ameliorate the difficulties of those in the caring situation. For example, the tentative categories of responses to caring might be used to indicate, and perhaps predict, some of the more profound difficulties that carers may encounter, and offer some explanation of them. Similarly, the crucial requirement to form coherent narratives of care, allowing necessary adjustments and personal progress, might underpin more firmly any therapeutic interventions.

As for me, it feels as though I have been somewhere else, and seen some strange things. I return with a sense of familiarity – of banality, even – and of profound alterity. I have encountered, and re-encountered, the improbability of thinking rigorously, and the difficulties of reporting adequately on anything at all. A part of me feels that experiences are not at all amenable to inscription or sustained thought, and all attempts to do so are, at best, translation and transliteration. Another part of me dismisses all that as manifestly untrue. A sort of internal debate continues. Despite this improbability and these difficulties, I have produced a report on what I saw and what I thought about it. This is it.

## **APPENDIX 1.**

### **Specimen letter to Informants.**

Dear .....

Further to your recent conversation with one of our Community Nurses, and to our subsequent telephone conversation, I ask you to read and sign the following document.

Thank you very much for agreeing to participate in the study.

By signing below, you are agreeing to participate in a study of the ways in which some men care for sick or disabled relatives at their homes. You were asked to participate because you have the necessary and relevant experience of caring. The study is being undertaken as an important part of my doctoral studies at the School of Social Sciences at the University of Cardiff. Participation in the study will not effect in any way the treatment your relative receives from Gwent Community Health NHS Trust.

Your participation will consist of being interviewed on one or more occasions about your caring experiences. The interviews will take place at a time, date and place convenient to you. The interviews will be recorded, and may be transcribed. All information will be accorded the very highest level of confidentiality. This confidentiality will extend to the final written thesis, and you can be certain that no one will be able to identify you from the information it contains. You may see a final draft of the thesis before it is submitted. All material relating to you will be stored in a safe place, and will not retain any identifying elements.

You have the absolute right to withdraw from the study at any time, and no penalty of any kind will be attached to this. If there should be any problems with the study, you should contact Colin Jones at the address shown above. You may also contact Sue Gregory, Executive Nurse for Gwent Healthcare NHS Trust at the address given below.

## APPENDIX 2

### The Informants in the Study

1. Mr. A. Aged 46. Caring for 10 years + for a wife with Multiple Sclerosis. Has a son (22years) and a daughter (20years), but they are not co-resident. Lives in his own home – semi-detached property in an established residential area. He gave up a career in sales to care for his wife.
2. Mr. B. Aged 85. Caring for a wife who has had multiple strokes. Has been a carer for eight years. Lives in a small housing unit for retired couples. Has a son, aged 61, who lives about one mile away. Mr. B. is retired, and was formerly a skilled worker with the National Coal Board.
3. Mr. C. Aged 36. Caring for a wife with multiple cancers – a terminal condition. He has undertaken full time caring for just over one year. There are no children in the marriage. He worked at a senior level in the Public Sector, before taking extended leave to care for his wife, and he has been negotiating a redundancy package for some time. Lives in a small, terraced house in a large village.
4. Mr. D. Aged 58. Caring for a wife with damage caused by a successfully treated cancer. He took early retirement/redundancy to take up fulltime caring. He worked in heavy industry. Lives in his own home – a semi-detached property at the edge of an industrial village.
5. Mr. E. Aged 80 years. Has cared for a wife with Alzheimer's disease for fifteen years. He is a retired local government officer. He has a daughter, who lives about fifteen miles away. Resides in his own home – a terraced house at the very edge of a small town.
6. Mr. F. Aged 45 years. Caring for a wife with Multiple Sclerosis for four years. He was made redundant from his occupation as factory worker. Has one son, who lives in abroad. Lives in a rented flat, on a new housing estate..
7. Mr. G. Aged 66. Caring for seven years for a wife who has had a stroke. He is a retired senior mariner, but works very intermittently, on a part-time basis, advising on maritime matters. Lives in his own home – a well-appointed detached house in an attractive village.
8. Mr. H. Aged 49 years. Caring for his mother, who has Alzheimer's disease. Gave up a job in the legal system to undertake caring. Lives with his mother in a large, detached house in open countryside.

9. Mr. J. Aged 52. Caring for a wife suffering from a brain tumour. He retired from his occupation in the merchant navy. Lives in a rented, local authority- owned house on a large estate.
  
10. Mr. K. Aged 47. Caring for a wife with a neuro-degenerative disease. Took a redundancy package from his occupation as a clerk in an industrial plant. Lives in a rented, local authority- owned house on a large estate. Has been a full time carer for five years.
  
11. Mr. L. Aged 58 years. Caring for a wife who has had multiple amputations as treatment for recurring cancer. He is a former skilled worker. Has been caring on a full time basis for three years. Lives in his own terraced house in an industrial village.
  
12. Mr. M. Aged 50 years. Caring for a wife with extensive stroke damage. Caring full time for two years. Gave up employment as a caretaker. Lives in a new terraced house in a village.
  
13. Mr. N. Aged 55. Caring for a wife with Multiple Sclerosis. Worked formerly as an industrial process trainer. Has been a full time carer for four years. Lives in a semi-detached house in a well-established suburb.
  
14. Mr. P. Aged 45. Caring for a son with mental and physical handicaps. Worked formerly as an administrator in the public sector. Has been caring for almost five years. Lives in a small terraced house, owned by the local authority. It has been modified extensively to facilitate caring.

## APPENDIX 3

### Example of Coding Scheme: Modes of Adaption: Core Categories

<b>Narratives (Code Blue)</b>	<b>Activities (Code Purple)</b>	<b>Core Category</b>
Some rewards (5)	Keeping your head down (5)	
Terminal illness (3)	Concentration on task (5)	
Progressive deterioration (5)	Continuity (4)	
Liminality (5)	Refrain from planning future (4)	
'Marking Time'		
Coping narratives (5)	Aware of the future (5)	
Bearing it (4)	Displacement activities (5)	
Maintenance of self (4)	Not think about it (5)	
Masculine image (5)		
No rewards (4)	Seek relief (3)	
Dislike whole situation (5)	Seek assistance (4)	
Frustration (4)	Seek personal help (3)	
Anger (5)	Tension (5)	
'Stuck'		
Resentment (4)	Unhappiness (5)	
Can't accept it (5)	No distractions (4)	
Loss of self (5)	Always thinking about it (5)	
Loss of self esteem (4)	Living in the past (4)	
Going around in circles (4)		
Chaos narratives (5)		
Loss of masculine image (4)		
Rewards (6)	Doing it (5)	
Satisfactions (5)	Doing more of it (4)	
Capabilities (4)	New roles (5)	
Emotional depth (5)	New capabilities (5)	
Confidence (6)	New satisfactions (4)	
'Making It'		
Improved self (5)	Less defensive (3)	
Content (4)	Living in the present (4)	
Success narratives (6)		
Enriched masculinity (5)		

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