

# The impact of the marital relationship on the experience of caring for an elderly spouse with dementia

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## **ABSTRACT**

Husbands and wives constitute a large proportion of carers of those older people suffering dementia. Many older people with dementia have had a long history of personal relationships, often having lived with the same partner for most of their lives. Following the life course approach, this study explores the ways in which a couple's marital experiences impinge upon the challenges faced when a spouse develops dementia in late life and is cared for by his or her partner. I start by surveying the relevant literature. The second section outlines a study of nine couples and includes brief case vignettes. In the third section I seek to test out hypotheses extrapolated from the material, with the theme of how perceptions of the caring situation are related to perceptions of the pre-morbid marital relationship, drawing heavily upon the case material. No single discussion is exhaustive, as any of these hypotheses are worthy of intensive study in their own right. I conclude with a summary of the findings and a reflection on how professionals might put these findings into practice.

**KEY WORDS** – dementia, spouse, carers, older people, life course

## **Introduction**

The people being cared for by their spouses in this study suffered cognitive impairments from many causes, most of which were classified as some form of dementia. Dementia is here used to indicate a global deterioration in an individual's mental faculties that occurs in the presence of brain disease, is progressive or chronic in nature (Jacoby and Oppenheimer 1991), and which results in behavioural problems and social and psychological disability. Rather than focusing on neurological features, I will take a perspective drawn from social psychology, 'which reveals dementia care as a true process of meeting between two persons' (Kitwood 1993: 51). It is not sufficient to locate

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the 'problem' with the sufferer, but to bring under scrutiny the process of communication between the person with dementia and 'the other'. This relational perspective encourages us to look at the agent's interpretations of an action based on past experiences.

The study should be seen in the context of the biological perspective on ageing which views ageing itself as unpathological (Hughes 1995), and dementia as a disease. Much of the following discussion follows ideas implicit in the life course approach, based on Erikson's (1994) typology of the eight stages of life, in which each stage is a dialectic between conflicts, and the study of which involves the blurring of the boundaries between psychology, history and biography. This implies that older people should not be studied solely in terms of their current 'problems' and welfare needs (Arber and Evandrou 1993). It provides a dynamic framework, focuses on change and continuity, and begs the question of how couples react to the challenges of dementia. It is this aspect of the life course approach that I shall be using rather than the rigid segmentation of life into ideal-types of characteristics for each stage.

Askham (1995: 87) reminds us that 'one of the basic relationships retained by most people after they lose the fundamental one of employment is that of marriage', and yet there is almost no research on older people's own perceptions of the meaning of marriage (Askham, 1995), or on the complex dynamics between satisfaction and marriage (Mansfield and Collard 1988: 30). Older married people are individuals engaged in a dynamic interplay, sometimes with a lifetime partner, negotiating the final stage of this relationship in light of a lifetime of mutual and individual experiences and future expectations.

Older married carers are also under-represented in the literature on carers of elderly people, much of which has emphasised the plight of filial caregivers (*e.g.* Lewis and Meredith 1988), much of it from a feminist perspective (Graham 1983). This agenda has led to retired spouse carers, especially husbands, being neglected. The stereotype of older people as recipients, rather than providers, of care goes against evidence that the proportion of older people who are carers is comparable with that of the general population. The OPCS survey of informal carers (Green 1988) identified 14 per cent of all adults over the age of 16 as carers, and 13 per cent of those aged over 65. Because of the definition of 'caring' used, it has been argued that this represents a significant underestimate (Arber and Ginn 1990).

There is a growing pool of research to which a study of older spouse carers can refer, yet few British texts deal directly with the spouse caring relationship. Exceptions are Thornton (1989*a*) and Fisher

(1994). Parker (1993) charts the dynamics and perceptions of caring relationships, partly through exchange theory, among younger people where one spouse has developed a physical disability.

Many studies address the experiences and effects of caring in general, and some make special reference to older spouse carers and dementia sufferers. Overall, spouse carers help more with personal care tasks, spend more hours caring (Green 1988), and have a greater commitment to caring (Stoller 1992). Care (especially from wives) is less likely to be supplemented by formal services. There have also been a number of studies comparing the experiences of caring husbands and wives (Stoller 1992; Pruchno 1989; Rose and Bruce 1995).

Many studies have documented the 'carer burden'. Usually the effects on spouse carers are subsumed in more general surveys of caring (Warner 1995) or in studies of family care for older people with confusion (Levin *et al.* 1989). However, as Stoller says (1992: 53): 'The focus on caregiver burden in the empirical literature has overshadowed the positive consequences of helping an ill or impaired spouse'. The effects of caring relate not only to the here and now but also to the context in which the caregiving takes place (the spouse's life course; both as a couple and as individuals). It would be wrong to subsume the role of the spouse carer automatically under the 'carer' umbrella, rather than that of the 'spouse'. The appropriate label will depend on the carer's interpretation of their own involvement, which, as we shall see, depends on the context of the relationship.

There are a number of other approaches to the caring relationship. Those cared for can be made to seem like passive recipients, with the effect of devaluing the carer (Kitwood 1993: 53). A contrasting approach is based on the concept of an equal exchange of mutual caregiving. In this ideal-type there is mutual dependence and role reversal where partners have 'complementary' disabilities. The delicate balance of capabilities which this implies (Wilson 1995) may be very temporary in a situation in which a partner has a deteriorating condition.

### **The sample and method of study**

Nine elderly spouse carers of partners with various forms of dementia were interviewed between December 1995 and February 1996; three were in late life marriages; three were husbands and six were wives. Three interviewees were contacted through Oxfordshire Social Services, two through the Oxfordshire Mental Healthcare Trust and

four through a Carers' Centre. In terms of Pearlin's three stages of caregiving (1992: 647), two interviewees were in the 'residential' stage, six were in the 'institutional' stage and one was in the 'bereavement' stage. The interviews were conducted in the interviewees' own homes, were qualitative in nature, and conducted with as little intervention as possible.

It was not possible to interview the spouses with dementia because of the severity of their impairments. To be true to the relational and life course approach, it would have been better to interview both parties in the marriage: the carer spouses' recollections about their partners' past may be subject to a perspective which distorts the other's life course.

This method allowed spouses to narrate their own story, and perceptions of events, allowing them to make allusions to the past spontaneously (Arber and Evandrou 1993: 25). This biographical approach is well documented. Kitwood (1990) uses it to chart his psychological biographies of those with dementia. Weiland (1989: 191) comments on how, in general, studies on adult personality and ageing are moving towards more diverse descriptive methods ('intrapsychic interdisciplinarity') which locates the focus of study in the life course.

Because of the relational nature of this study, the appropriate method to use is one that embraces an interpretivist perspective. As Mansfield and Collard (1988: 23) argue: 'other people's marriages exist in obscurity and that is their fascination... These hidden worlds of "other people's marriages" are neither clearly expressed nor easily understood'. There is no 'external' truth to uncover, only spouses' interpretations in interaction with each other and the outside world, and the teller's narrative that is formed by his or her assumptions and interaction with the researcher.

Methodology which relies on people's retrospective perceptions runs the risk that memories become distorted in the light of subsequent experience. However, the purpose here is to determine how people fashion present experience in the light of past events. What is significant, therefore, is not the 'accuracy' of those memories but how they are used. People may use the past in different ways according to the stage they are in when interviewed. Another limitation to this study is in the selection of the sample. Couples were accepted only if it was felt that the process of being interviewed would not be over-intrusive or distressing. The majority had experienced a 'crisis' situation which may have made them present their stories differently. An interview situation can also be construed as artificial. Interviewees' use of the past in this situation may not compare with natural and spontaneous reflection.

*Case studies*

The following is a brief account of the marital histories, drawn from fuller descriptions written from the life course perspective, as described by the caring spouses.

*Mr and Mrs A.* Mrs A is an 82-year-old woman who was caring for her 81-year-old husband in the final stages of multi-infarct dementia, at home, with the help of a very heavy package of home care from Social Services.

The couple had married 57 years ago whilst they were both training to be teachers, to their families' disapproval. She described their relationship as 'never dull' due to their 'wonderful, fiery' intellectual debates. During the war, being a Quaker pacifist, Mr A did farm work. This ruined his hands and his aspirations as a violin soloist. After the war they both worked full time as teachers. They had two sons. Until her husband became ill, Mrs A would do the family finances, child-care, cooking and housework, and he the gardening and shopping. They spent their leisure time alone together pursuing intellectual interests. They had a 'gradual transition' toward retirement and bought a music shop to run together.

Six years ago, while on their second honeymoon, Mr A began to be 'slow appreciating things' and was diagnosed as having dementia soon afterwards. Mrs A did all her husband's personal care until recently (having had hip problems) but won't allow anyone else to feed or shave him. Mr A is now in the terminal stages of dementia and is unable to move or speak.

*Mr and Mrs B.* Mr B, 82 years of age, has, until last year, been caring at home for his 85-year-old wife with Alzheimer's disease.

The couple met in 1936 and married at the ages of 23 and 26. He says it was her 'wildness' and 'impulsivity' which first attracted him. They spent the first year of marriage 'totally in each other's pockets'. Mrs B gave up her job but felt uneasy with her domestic role. They had a son. Mr B went to fight in the war and they didn't see each other for four years. On Mr B's return they decided to go into the hotel business together and lived in their hotel. They moved around many times as Mrs B would quarrel with staff. They made few friends, had little contact with family and spent all their leisure time together.

On retirement they bought a house and Mr B took over all the household chores. Mrs B began to get restless, aggressive and forgetful, though her husband did not notice at first because 'she's always had a

temper on her, but she used to be sweet afterwards'. Several incidents worried him, such as Mrs B walking past him and becoming hostile at the idea of going home. Mr B took a great pride in 'managing' his wife himself and performing all the personal and domestic chores, and outwitting her attempts to wander. It was after several episodes of wandering and aggression, that he realised he could not physically keep up with her, or maintain her safety. She was admitted to hospital, and then a nursing home. He visits her three times a week.

*Mr and Mrs C.* Mr and Mrs C are both 82 years old. Mr C suffered from arteriosclerosis of the brain and was cared for by his wife until last year, when he moved into a residential home. Since the time of interview with Mrs C, her husband had died.

The couple married in 1934 at the age of 21, having met at the factory where they worked. During their early married life they lived in poverty, worsened by an unplanned pregnancy. They both did factory work during the war and Mrs C's mother provided childcare. After the war she decided to train as a teacher, and maintained the home and child at the same time as progressing dramatically in her career. They spent little time together in the week because of Mrs C's work commitments, and her academic interests that her husband didn't share. Her husband developed epilepsy and struggled to continue his work until 50 years of age. She says they 'caught up' at weekends and on holidays.

On retirement, Mr and Mrs C decided to fulfil Mrs C's greatest wish of returning to the town of her birth and doing voluntary work. Soon after the move, she noticed a change in her husband's personality. He kept falling and shortly afterwards his illness was diagnosed. Mrs C cared for her husband at home for four years, at the same time as pursuing a political career. For a long time, she had refused any offers of respite care or day care.

Things came to a head when Mrs C herself fell and fractured a hip, and her husband went into hospital and then a residential home. One was chosen that was fourteen miles away from the marital home because of his previous attempts to walk home. She visits him twice a week, using taxis or friends' cars as she doesn't drive.

*Mr and Mrs D.* Mr D is 85, and Mrs D 75 years of age. Mr D has Alzheimer's disease and has been living in a nursing home for two years.

The couple have been married for twenty years, having both been widowed. They were introduced by relations who wanted Mrs D to

'keep an eye on Mr D' but who subsequently disapproved of the marriage. They retired shortly after the wedding, and planned to make full use of their leisure and money. But marriage at a late stage in life was a big upheaval at first, and Mr D became very possessive of his wife. They shared all the domestic work.

Five years ago Mrs D realised 'Mr D wasn't quite with it' and 'started doing funny things', but she put this down to old age. His behaviour became more extreme and he was diagnosed as having Alzheimer's disease. Mrs D provided most of his care as he deteriorated, and kept a careful account of her experiences. She got little help from relatives. Mr D started at a day centre, but he kept walking out and Mrs D would have to fetch him, so she stopped this. She used a sitting service occasionally. Home helps came for a short time. Mrs D became involved with the Carers' Centre. After several respite stays in hospital, Mr D moved into a nursing home. She visits him three times a week in her car.

*Mr and Mrs E.* Mr and Mrs E married in 1978 at the ages of 50 and 60 years respectively. Mr E developed cerebro-vascular disease in 1990, following a stroke. His wife cared for him at home until he moved into residential care eighteen months before his death in 1995.

They met through their work. Mrs E had been divorced from her first husband who had been ill at the time. She does not know if Mr E had been married before. He had had slight brain damage. Five years after marriage they retired. They shared the chores and spent all their leisure time together, shunning the company of others.

Mrs E first noticed a change in her husband when he began to be oblivious of conversation, and started stumbling. She says his illness took a long time to diagnose. He deteriorated, began to attack her and became doubly incontinent. She was offered no help and provided all the care and supervision herself, often sleeping for only two hours a night. She became involved with the Carers' Centre. Eventually Mr E was offered respite care which led to a permanent admission to residential care.

*Mr and Mrs F.* Mr and Mrs F are both 80 years old. Mrs F was diagnosed as having Alzheimer's disease seven years ago. Her husband cared for her at home until 1993 when she was admitted to a nursing home.

The couple met at first aid classes before war broke out. Mr F was called up and fought in France. They married 56 years ago during a short period of leave, hurriedly as Mrs F was pregnant. Mr F came

home from war injured and his wife nursed him. The family lived in poverty as he couldn't get a good job. 'Mrs F was a first class housewife'. They had little to do with friends or relatives, and spent all their time together as 'good companions'. On retirement they moved to the sea-side, as this was Mrs F's ambition.

In 1986 Mr F first noticed that his wife was beginning to forget things. He went to his GP but was given no helpful advice as Mrs F wouldn't agree to an assessment. He cared for Mrs F himself as he thought he couldn't afford a home help and had no knowledge of Attendance Allowance. Mrs F started wandering. They moved to be nearer their son. A care manager became involved. Eventually Mr F collapsed and matters were taken out of his hands. Mrs F was admitted to hospital and subsequently a nursing home, he visits her often, but says he feels desperately lonely at home.

*Mr and Mrs G.* Mr G had been caring for his wife, who has Alzheimer's disease, at home from 1990 to 1994. Since then she has been living in a nursing home.

The couple had been courting for eight years before they married in 1940 when she was pregnant. Mrs G had been a tailoress. They saw very little of each during the war as Mr G went to fight in India. On his return, they 'took up normal married life', had two more children and undertook traditional domestic roles. Neither of them had much extended family, and they spent most of their leisure alone. Mr G maintained strong connections with his male friends. When the children left home, Mrs G went to work with her husband in their small business. On their retirement they moved to be nearer their sons. Mr G became very involved with voluntary work.

Mr G thought that his wife was becoming deaf, until his daughter-in-law suggested that her unresponsiveness might be due to a dementia. Eventually, Alzheimer's disease was diagnosed. Mr G cared for his wife at home, with the help of his daughter who lived nearby. She would help with the 'intimate tasks'. He praised the efforts of the care manager. They had home care for a while, and Mrs G attended a day centre. After several respite care stays in a nursing home, Mrs G was admitted permanently. He goes to visit her often and feels well supported by their children, and his male friends. He has subsequently got involved with the Carers' Centre which he described as his 'voluntary work'.

*Mr and Mrs H.* Mr H is 76 and Mrs H 73 years of age. Mrs H has been caring for her husband, who has vascular dementia and Alzheimer's



disease, for three years. At the time of interview, he was an in-patient at a psychiatric assessment unit and was awaiting a place at a suitable nursing home.

The couple had been 'childhood sweethearts' but had 'gone their own ways' during the war, each having had other relationships. Mr H had gone to fight in the war while his wife had worked in Navy inspection. Following marriage in 1948 the couple had two sons. Mrs H 'ran the home' while Mr H pursued both his career in engineering and an interest in sport. Occasionally they would go out together socially. Upon retirement, Mr H spent much of his time caring for his wife's elderly aunt and tending his allotment. Mrs H got a part-time job because she liked 'to be with people'.

In 1990 Mrs H had a hip replacement operation, and at the same time her husband had a knee operation. She was unable to visit her husband in hospital, but heard reports from her family that he 'was a changed man' as he had lost his concentration and interest in life. After she had recovered and they came home, she cared for him as his condition deteriorated. He became jealous of his wife going out and lost his practical skills. His illness was diagnosed one-and-a-half years before the interview and had deteriorated very rapidly. A care manager became involved and a day centre and homecare were tried, but Mr H was not compliant. Finally he was admitted for respite care. His wife visits him regularly. She has no transport and is very anxious about the impending move because of having to travel further to visit him.

*Mr and Mrs J.* Mrs J is 76 and her husband 81 years old. Mr J has had schizophrenia for much of his adult life and has recently developed memory problems. Mrs J has been caring for her husband at home in between respite care stays and regular day care.

The couple married in 1980. It was Mrs J's first marriage and her husband's second. He had been divorced many years previously and had spent much time as a patient in psychiatric hospitals and bed-sitters. He first became ill after fighting in the war. Mrs J had worked full time and cared for her disabled mother. They were introduced by Mr J's brother who wanted Mrs J 'to keep an eye on him'. Before they met Mrs J had decided that she 'wanted to marry for my retirement'. Mrs J's family were disapproving of the marriage, and some of Mr J's family disowned him. Mrs J says she thought she could 'cure him' through her Christian faith.

Mrs J has spent the entire marriage tending her husband. Over the last eighteen months his condition has worsened both physically and

through the development of severe memory problems. Mrs J's health has been failing, and she has had 'periods of desperation'. She feels she has no other life apart from her caring role, as her friends and relatives have been 'put off her' because of her husband's condition.

### **Hypotheses**

Using the reported experiences of the spouse carers, this section is an exploration of hypotheses about the ways in which a couple's marital history and experiences impinge upon the caring experience. My purpose is to present an analysis of the dynamics of the marital relationship, shedding light on some assumptions that are made in the literature.

*Hypothesis 1 For older spouses, because the idea of caring is part of the marriage contract, it is unproblematic and there is no conflict of roles*

This argument is asserted in much of the literature (see Johnson 1985: 165). The supposed lack of conflict is often seen to result from older carers' economic inactivity. In examining this argument, it is necessary to consider expectations of marriage, perceptions of present roles and the potential for conflict. This hypothesis suggests a number of questions.

*What were the interviewees' expectations of marriage, as perceived through their present stage in the life course?* Interviewees' recollections revealed two main orientations: those who described the marital contract solely as one to care for their partner, and those who mentioned pre-marital love and marriage enabling them to live together (at a time when cohabitation was taboo).

Mrs J explicitly stated that she had married to be a carer and to 'heal' her already ill husband. Mrs D said, 'for me, a wife was a carer'. Mr B and Mrs H explained that they had each got married without much of a view to the future, to be with their partners. Mrs H said 'You just didn't expect this sort of thing. I saw my husband as my strength, I never thought I'd be caring for him'. Mrs C said she had originally felt 'sorry' for her husband and married partly 'for better, for worse, in sickness and in health', and partly for love and companionship.

Of course there will have been many other expectations of marriage, which may have been tied to a couple's orientation toward the future. For those marrying around the time of the war, expectations may have been rather different, as many would have been very uncertain as to their long-term futures. A greater expectation of caring was evident

among the three marrying in late-life. This is explained partly by a sense of realism, as they were marrying older people potentially requiring care. All three had extensive caring histories, and they may have wanted to continue this role with new partners. What is important for this discussion is the diversity in perceptions of marriage and caring.

*Do the interviewees see themselves now as spouses or carers?* From the interviewees' description of their present role, a dichotomy emerged between those who primarily felt themselves to be a 'spouse' (whose tending was just part of this role) and those who primarily identified themselves as a 'carer'. All three spouses who married in later life cited a commitment to caring as their major expectation of marriage. All three husbands identified themselves as 'spouse', citing their major expectation from marriage to be love. This does not mean that they thought of these categories of spouse and carer as being mutually exclusive. All six wives thought of themselves as 'carer' and they would often make allusions to their husbands being 'dead', like Mrs D who felt like a 'widow'. These phrases were more likely to be used by those, for example Mrs E and Mrs D, whose husbands had become aggressive.

*What conflicts are present in marriage and caring as separate entities?* The concept of marriage is not unproblematic and without tensions for those who see tending as subsumed within the norms of marriage. 'The marital relationship, like all other personal relationships is in a constant state of flux, and the participants move in and out of conflict, negotiation and agreement' (Mansfield and Collard 1988: 30). There is competition between the individual benefit of each spouse, and that of the relationship. These interpersonal dynamics can also be affected by inequalities between the spouses in power or resources.

Similarly, the concept of caregiving is not without inherent tensions. Skaff (1992) describes the mechanisms whereby stressors in the caregiving situation can lead to aversive effects on the well-being of the carer. For healthy physiological functioning, 'self-mastery' and 'self-esteem' are crucial. Loss of identity or 'loss of self' can occur as a result of engulfment in the caregiving role (related to limited social contact and lack of social roles outside of caring) and is found to be associated with a low self esteem and depressive symptoms. As in any other social relationship, there is the potential for a conflict of interests between the role and the individual.

*Where spouse and carer are seen as synonymous, what conflicts are at play?* Taken separately, the roles of 'spouse' and 'carer' contain inherent tensions and, as a result, problems arise for service-provision. Yet, taken together (which they were by many of the spouses interviewed), there

is the potential for greater conflict. A history as a spouse whose role is based on love, is seen by some commentators and service providers to make the present caring role less demanding personally. However, a deep commitment to the welfare of the other and memories of what the spouse used to be like, can undermine the welfare of the carer. As Mrs C said 'The closer you are to the person you're caring for, the more it hurts'. Thus 'loss of self' could be greater for spouse carers. Mr G said 'I should have asked for help years ago, as I was being driven into the ground. But she was my responsibility'. Mrs H recalled saying to herself, 'Come on, you're married. You have to put a brave face on'.

When a carer still has marital conflicts to work through, caring may be more difficult. An example is Mrs J's unease about being a second wife. Her insecurities with this role, she said, caused her to 'say things she was ashamed of to an ill man'.

*Hypothesis 2 Intimate care comes 'naturally' for spouse carers because of the intimacy involved in marriage*

Such an assertion was made by Borsay (1990: 114). 'The management of disability in marriage is smoothed by ageing, and the suspension of conventions pertaining to bodily care'.

All of the spouses with dementia had high personal care needs such as toileting or bathing. Many of them also had behavioural problems making these tasks harder. For example, Mr D was fearful of the water and would resist his wife during bathing. A variety of responses to these aspects of caregiving were presented. At one extreme, Mrs A put her distaste to one side and adapted to the new situation: 'These practical things have never been a passion for me, especially managing incontinence, but I'm a pragmatic person and do what has to be done'. On the other hand, some carers seemed to hold a deep conviction that cross-sex care was immoral, though necessary. Mrs C said '(bathing my husband) just doesn't seem right to me. You see I've got Victorian values'. Mr B recalled standing outside the shower room door, unsuccessfully coaxing his wife to bathe, because 'she's always been a very shy person'.

One other reason for discomfort in performing intimate tasks was a feeling that because of a changed personality the spouse was no longer the spouse of their shared history. Mrs E commented in the third person plural about the unpleasantness of having to manage her husband's faecal incontinence, saying 'You know you're their wife but you're dealing with a stranger'.

These comments illustrate that among the spouse carers interviewed, personal care tasks were problematic partly because of the intimacy

involved. This was true for husbands and wives alike. There is a complex interplay between taboos against cross-sex care which may have been stronger earlier in the century, degrees and types of intimacy which have been previously experienced in marriage, and spouse carers' perceptions of the continuity or lack of continuity with the past. These perceptions may be partly fashioned by the length of the pre-morbid relationship.

*Hypothesis 3 A source of unhappiness in these relationships is that the 'intact' spouse looks at the congruence/incongruence of development through the life course*

From the human developmental perspective (Riegel 1973), many of the reported negative consequences of spousal caregiving can be put down to the effects of dementia on human development and the lack of capacity of the sufferer to share meaning and consciousness with the partner. Wright compared caregiving spouses' perceptions of marital quality and coping with healthy married couples. She found that 'Alzheimer's Disease couples can be characterised as having committed-dependant relationships with divergent developmental outcomes: adaptation and control for the caregiver, and distortion and disorder for the afflicted. In contrast, well spouses evidence shared meaning in interactions and concordant developmental outcomes' (Wright 1991: 236).

Several of the interviewees referred to feelings about continuing to 'develop' whilst their partner was deteriorating. Mrs A said that she felt 'guilty' for her feeling of relief that the illness had happened to her husband and not herself. Mrs C, who felt that all her achievements had come unusually late in life said, 'I got everything I wanted late in life – except my husband'. Through her marital history she had seen her husband as, 'a very quiet supportive man who wanted me to pursue my own ambitions'. She missed having someone to 'catch up with' and be an 'emotional companion' outside her 'public' role. She said, 'Leaving them behind hurts so much and there's no end to it'.

Some people talked of their frustration, guilt and feelings of inadequacy in not being able to understand their spouses' interactions, or to believe what they were saying, when this had been a feature of their relationship. Mrs C said of Mr C's confusion, 'I didn't know whether he was telling me the truth. I felt disloyal when I couldn't believe him'. Some spouses imbued their spouse's actions with perceived meaning from their previous life histories. Mrs J put her husband's unappreciativeness down to him 'never really loving me'. 'To be loving is to be giving. If you're not giving, it's not love, despite

this illness'. Mrs C understood her husband's obsessive behaviour in the light of his life-long 'Victorian preoccupation with the regularity of his bowels'.

Some mentioned distress at the sudden loss of the development of the actual relationship or the ability to work out past conflicts together, and at the way in which they were suddenly not treated as a couple but as individuals. Mrs A spoke of how her relationship had matured over the years as she and her husband would engage each other in 'wonderful, fiery, intellectual debates'. Although she still pursues her academic interests she feels 'shut off from ordinary life'. She equates this with her marriage. Mrs D became very tearful whilst discussing her treatment by the Court of Protection. What had upset her most was their treatment of his and her money separately, and the suggestion that she was trying to 'get what doesn't belong' to her, even though she was his wife.

This suggests that hypothesis 3 is true. Developmental incongruence and unshared meaning in interactions are a source of strain for the caregiver.

*Hypothesis 4 For spouses to care effectively, they must suspend the past*

The relational perspective locates the interaction between the person with dementia and the carer within rules governing the interpersonal process (Kitwood 1993). The problem is that in interaction the person with dementia lacks the memory to interpret actions in the light of past events or relationships. The work of the Bradford Dementia Research Group suggests that to care effectively for someone with these cognitive impairments one should 'suspend' the past or 'de-family' both spouses. Instead the caregiver should 'hold' the person in a safe place where they will not be overwhelmed by emotion, or the need to refer to past memories to make sense of interactions. They should 'validate' or acknowledge the reality of the dementia sufferer's experience, and they should be 'facilitated' to take part in the social world (Kitwood 1993).

In spouse caring relationships, as we have seen from the developmental perspective, this may be a particular problem, because of the length and intensity of the marital relationship and the wish of the caregiver to work on issues left from earlier stage of life. Another problem is that there may be a tendency for a spouse carer who feels they have lost any continuity with an enabling marital relationship, to be more controlling. This may make the sufferer into a dependent object and undermine their attempts at interaction. This can be seen in Mrs E's description of her husband as 'one of them'.

This research suggests that, while hypothesis 4 may in part be true, in a caregiving relationship it is not enough to suspend the past. The vacuum must be filled if the sufferer is not to be viewed as a passive object. It is also important to acknowledge the developmental expectations for the spouse (discussed under hypothesis 3).

*Hypothesis 5 Spouses who have been cared for in the past by their partner, feel their caring is ‘paying them back’*

Bytheway (1986) shows explicitly how older husbands’ caring can be motivated by a deep sense of reciprocal obligation and a concern to respond to the needs of the care-receiver. This study provides examples of where this applies to both genders. It is too simplistic an analysis to state that it is only husbands who reciprocate their wives’ caring role, as wives in this cohort are seen to have roles in the domestic sphere. Many of these couples did not have strictly segregated roles. Also, some spouses see themselves as reciprocating for their partner’s love rather than tending.

Mr F referred to his wife as ‘a superb housewife ... stronger and more intelligent than I, who nursed me when I returned from the war. Now it’s my turn to look after her’. He became angry at the intervention of one of the social workers as ‘she seemed more concerned about my welfare than my wife’s’. Mrs C felt her achievements were due to her husband’s enabling attitude throughout their married life, saying, ‘you can’t get rid of 61 years just like that’. Mr B commented that, although he felt that he had been ‘looking after’ his wife throughout their married life, in spite of her temper she had ‘doted’ on him and he was reciprocating this love with his tending role.

Reciprocity in personal relationships has been explained through exchange theory. Duck (1983) says that when the fairness of equity of a relationship is threatened, readjustments will be made by the partners to redress the balance. If there are no opportunities to redress the balance the partners may alter their evaluation of the situation. For example, doing household finances may take on greater value. On the impaired spouse’s side, if he or she is not able to re-evaluate the situation to establish equity this may lead to a devaluation of the carer or a self-devaluation. Duck says that one way for the pair to achieve equity in this situation is to acknowledge the partner’s past activities such as wage earner or homemaker: ‘in long term relationships we are prepared to extend a kind of social “hire purchase facility”’ (Duck 1983: 108).

What seems to be at issue in the relationships in this study, is a

retrospective ‘hire purchase’ facility. The impaired partner was not able to make the re-evaluations necessary to achieve balance and the options available for the spouse carers were more limited than in Duck’s theory. Depending on past roles and how they are now perceived, they can either self devalue, or devalue their partner, or feel that they are reciprocating for their partner’s past role. However Parker’s research (1993) reminds us that these readjustments are firmly based on normative beliefs about marriage and about the roles of husband and wife within that marriage. This is supported by these case studies. Many interviewees mentioned that they thought marriage used to be viewed differently, and that the vows they took to care for each other were seen as more binding then than they are today.

*Hypothesis 6 Older husbands caring for wives have an instrumental orientation because of their traditional breadwinning roles*

Finch and Groves (1983) suggest that men and women are socialised to respond to caregiving differently. Older caregiving wives view caring as natural and affective – as a continuation of their nurturant role. They say husbands see this role as alien and more task centred, because of their previous work in the external world. This theory can be criticised on theoretical grounds as sex role differences developed early in life may not continue into later life (Sinnot 1984). For example, women may become more instrumental and assertive as they get older (Gutman 1987). One could argue that the central aspect of caregiving is being in charge of another person, which is an extension of the traditional male authority role (Miller 1987).

Material from the interviews suggests that Finch and Groves’s theory is helpful and illuminating in many respects, but places inadequate weight on the diversity in the roles of older couples. Mrs C’s experiences may not be typical, but she saw her own role through life as ‘instrumental’ and her husband’s as ‘affective’. Mr and Mrs B’s choice to live in their hotel was a result of his wife’s satisfaction with domestic labour. Also spouses of both sexes talked of their tending and emotional sense of loss in similar ways (although the husbands were less likely to go into minute practical details about what tasks the caring comprised). Mr B said, ‘this illness has broken my heart. I didn’t want to let her go. She needs her husband’s love to look after her’.

*Hypothesis 7 Older people have to live together to ‘feel married’*

Gladstone (1995: 507) has suggested that: ‘A partner’s absence from the family home may represent a symbolic as well as physical loss for



the spouse who remains in the community'. Gladstone implies that this is because the older generation are deemed to have more non-companionate marriages, their bonds being based more on practicalities than affect.

Most spouses in this study whose partner had been institutionalised felt very much as if they were continuing their relationship. Some felt they were continuing to 'care' (*e.g.* in 'advising' the home on care, or taking in clothes) and all suffered anguish. Mrs C spoke of mixed feelings when her husband settled into a residential home. She was pleased for him yet felt this undermined his need of her. She said, 'it's a terrible wrench. When he says, "God bless, love you" I want to scoop him up and bring him home'. Mr B had ambivalent feelings about visiting his wife at the nursing home because she didn't often recognise him. He said, 'I carry on visiting for the love of her. I want to go, but I don't want to because she doesn't know me'. He said that it is only now that he has the chance to dwell on things. He has tried various methods to get used to her not being there, such as re-upholstering the lounge, but to no avail. Mrs H said at first she had been relieved, but now 'I would give anything to have him home for one weekend and give it another go'. Mr F said, 'It's all right in the day... I still wake up at night and try to put my arms around her'.

This tallies with the finding of Stephens *et al.* (1991) that many spouses continue to fulfil a caregiving role after their spouse has moved into an institution and that caregiving stress may remain at a high level. This suggests that the 'stress' is partly associated with a sense of loss. I found little to support Kelly's theory (1981) that spouses who had strong 'personal' relationships felt more positively about the move to the institution. All the interviewees who had 'personal' relationships, had ambivalent feelings of guilt (some feeling they had been disloyal by being 'manipulated by professionals'), relief that their spouse was 'in professional hands' and a deep sense of loss and loneliness. Mrs D actually felt 'more married' following her husband's institutionalisation, as this role had been made more public for her after years of isolation at home.

*Hypothesis 8 Spouses in this cohort are reluctant to accept home care because of a feeling of self-sufficiency*

Research has found that spouse caring situations are particularly under-represented in the provision of home care services. Evandrou (1987) found from research into the findings of the General Household Survey 1980 that 74 per cent of home help services provided were

provided to lone older people and just 17 per cent to couples living on their own. Thornton (1989*b*) completed a study of a relief care scheme devised for older people, and identified one reason for a failure to reach spouse carers as being their difficulty in seeing their use of the service as legitimate. The present study suggests that spouse carers who think of themselves as spouses may not want to take up services aimed at 'carer relief'. Also, many of them mentioned a feeling of self-sufficiency within their families, and gave examples of informal caring by their forebears. These attitudes may be traced back to ideologies of charity which pre-date the welfare state. Mrs G said, 'We look at life as they did years ago. We look after our own. We're too proud to accept what's due to us'. Mrs C said, 'I was reluctant to make full use of the services available to me. Other people are more needy. I have never been a scrounger'.

*Hypothesis 9 Private/companionate couples find it harder to accept home care and sitter services because they think back to how they used to live*

The previous hypothesis suggests one possible reason for the low take-up of services for older couples. Yet many researchers seem to have neglected to locate such reasons in the life experiences of the couples involved. An important part of this is how privately the couple had lived in the past. Several of the spouse carers described their marriage in this way, saying that not only had they had a close emotional relationship, but that, practically, they had been totally self-reliant. This was especially true of those who had been geographically mobile, with their extended family living at a distance. It must also reflect the changing public attitudes towards paid domestic labour after World War II. This is a time when many of these couples were embarking on married life.

Mrs A said: 'We've always been very private people. Sometimes when the home helps look in your linen cupboard you feel your privacy is being invaded'. She had a sense of invasion as the room in which the home helps tended her husband was also their marital bedroom. Mrs D described how she had used home helps for a while to put her husband to bed. She had cancelled this service in the end, not only because of her husband not accepting personal care from a 'stranger' but because she felt that having people calling at her door late at night was particularly intrusive. She would rather put her husband to bed herself.

*Hypothesis 10* In marriages which were perceived as 'happy', recent onset of behavioural problems are particularly upsetting because they 'spoil' memories

Comments from several of the spouses interviewed suggested that this may be true. Mrs H recalled that her husband used to give her too much freedom to pursue her own friendships and interests, yet had become very possessive. She said that 'When women lose their husbands like this, they lose how they've thought about their husbands. It spoils your memory'. Mr B said he had been particularly distressed by the incidents when his wife was screaming at him in public because 'I didn't want people to think I had been a bad husband. I've always looked after her. We have, in fact, spent our whole lives in love with one another.' Mrs E said her husband's attempts to hit her with a stick when he became ill, made it impossible for her to think about 'the loving man I married'.

*Hypothesis 11* The only thing spouse carers experience is 'burden', they see no positive consequences of this role in the life course

This study suggests that this claim is unduly pessimistic. Although all of the interviewees mentioned the numerous negative personal consequences of looking after a spouse with dementia, several did mention positive effects in the context of their self-development through the life course. Mrs A said that she had always seen herself as an 'intellectual, impractical person' but now, through her 'nursing role', she had been forced to get to grips with the practicalities of life. Also she had had to come to terms with having strangers in her house (home helps): 'I know that it is really good for my character to have to accept these things graciously'. Mrs J said of her marriage: 'It's all been for the better, though it takes a perceptive person to see it. I thought that through my faith I could change him, but I've ended up changing myself. I've become more of a patient and accepting person.' 'Doing their duty' was a source of satisfaction for many interviewees: the fulfilment of the marital commitment to love and care for their partner (Stoller 1992: 52).

Several people mentioned that their spouse's illness had forced them to learn new skills. Mrs H took pride in her new-found skills in financial management. She said: 'I'd advise any young woman, learn to do it yourself – you never know what's around the corner'. Mr B enjoyed learning new domestic skills such as cooking. Mrs D's recent experiences, she said, had given her a practical and emotional self-

sufficiency. Up until now she had viewed marriage as a 'crutch' to get through life.

### **Conclusion**

The results of this study suggest that the idea, implicit in the life course approach, that people interpret their present experiences in the context of their whole lives is correct. The way people use the past affects their current perceptions and experience of caring. An important part of their experience of life has been their marital relationship. This has served as a benchmark for what happened when the challenge of dementia care arose. As Parker (1993: 83) says: 'the pre-existing quality of the marriage and indeed the pre-existing personalities of the individuals involved may be crucial in understanding what happens to the couple after the onset of disability'.

Caring, especially for someone suffering from dementia, has been shown to be a relational activity, governed by the same basic principles as all human interactions, but different in that the person with dementia has lost the mental powers to put the interaction in context. However, spouse carers have meaning systems in their interactions with their spouse which have been formed and refined over the years. As has been shown from the interview material, spouse carers tend to make sense of their partner's behaviour by reference to past characteristics. If they perceive an underlying tension in the pre-morbid relationship, challenging behaviour can be seen in relation to this.

Another strategy that is employed is a deliberate distancing of the present character of the ill spouse from that of the past one, especially if aggressive behaviour is a feature of the illness. Seeing the partner as an 'empty shell', 'not the person I married', may be a coping mechanism that preserves good memories of the spouse. The tendency to see the partner as 'dead' has also been shown to be a mechanism to make sense of the incongruity of development between the spouses. This is especially so if the marriage had been perceived as private, and if there had been an ethos of personal growth, development and 'enablement'.

The perception of spouse carers of their present role and their motivation to care can also be seen in the context of the previous relationship, regardless of whether this was close and companionate. Yet this connection is not simple. For example, some people who had had a close relationship saw their present tending role as an extension of this. They saw it as reciprocating for the love and affection they had shared with a spouse with whom they still felt an emotional bond.

Others with the same background, however, turned to a new institutional view of marriage and tending, grouping their commitment to care in the duties imposed in the marital contract, having felt that the emotional intimacy they shared with their spouse had come to an end.

There are other important themes which have emerged from this analysis of how spouses use the past. The effects of separation through the institutionalisation of a spouse and how carers cope are mediated both by the emotional closeness of the pre-morbid relationship and the degree of interdependency. The motive to care may be found in the continuation of a life-long tending role or in reciprocating for past received care. Among the late-life marriage spouses interviewed, extra difficulties emerged when the marriage was less readily accepted by outside parties, and when couples seemed to bring with them to their second marriages expectations of marriage from other relationships. Also of note is that these spouses had more of an instrumental or institutional view of marriage and tending.

These themes all point to the way in which the marital relationship is an important indicator of identity in late life, and how spouses use perceptions of change and continuity to construct their caring experience. However, this is not just a matter of theoretical discourse. Care professionals should note the context of the spouse caring relationship in the face of dementia among their clients. For good quality practice, professionals should get to know the couple and their background on an individual level. The assessment of both the client's and the carer's needs should have a personal, relational dimension rather than being just a bureaucratic procedure.

A picture of the couple moving through the life course should be a useful resource when deciding what form of emotional support is most suitable for the caregiving spouse, for example when a decision has been made for the ill spouse to move into nursing home care. This method should put family dynamics more firmly on the practice agenda, and help the professional to be attentive to needs for direct counselling. As Hughes and Mtezuka (1992: 233) say: 'a wider perspective on relationships and family dynamics in the lives of old people appears to be absent from the professional view of social work with old people, which effectively excludes longer term work, casework and groupwork'. By fostering the recognition of need which gives rise to such services being available to other client groups, this approach promotes anti-discriminatory practice and anti-ageism. A regard for the marital background should also enable professionals to be more sensitive and effective in giving practical information; for example when advising on money management or welfare benefits.

Finally, service planning is another area which may be enriched by a greater awareness of the issues raised in this study. Older spouse carers should be put on the service planning map and action on the low take-up of services should relate to their marital history. Such factors may include an unthinking use of the name 'carer' for the provision of some services, or services being described as substitutes for the carer role when, for many, a 'spouse role' can never be substituted. This regard may highlight the need for specialist services and support groups, as many services seem to be based on the assumption that all carers are middle-aged and female. This study has illustrated the special individual needs of older spouses in a tending relationship. These people can be supported more effectively if the ways in which their present roles have been defined are noted.

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