

CHAPTER FOUR

THE EXPERIENCE OF CARING

INTRODUCTION

In the previous chapter, it was seen that, in accordance with situational constraints theories of poverty, respondents' access to material resources could go on to influence the costs experienced as a result of their role. This was explored by looking at such things as the role of material resources in influencing the practical demands upon carers as well as their ability to meet the direct and indirect financial costs incurred as a result of their role. This chapter further explores the experience of caring and its impact on the physical, mental and social well being of respondents. Chapter three also showed how respondents did not simply passively react to their material circumstances but actively adapted to them and that this adaptation was characterised by cultural continuity on one hand and age-specific change on the other. It was thus argued that generationally based cultural norms and age specific disability combined to lead to older people's uncomplaining adaptation to their adverse financial situation with subsequent implications for their caring role. This chapter looks in more detail at this interaction between material circumstances, culture and disability with specific reference to the caring role of respondents. The first section of this chapter discusses some of the problems in accurately evaluating the caring role. This will be followed by a consideration of the impact of caring on specific areas of the carers' lives including finances, physical and mental health social life and household routine. The final part of the chapter focuses upon age-specific aspects of the caring role and the way in which, like the financial management strategies of respondents, this role is mediated by disability, attitudes and culture as well as by material circumstances.

THE EVALUATION OF THE CARING EXPERIENCE

The experience of informal caring is an issue which has been very well addressed in a large number of research studies. Early research into the informal caring experience tended to reflect the negative perceptions of caring as outlined in chapter one, focusing on the 'burden' or 'cost' of such caring on care providers. It also tended to be positivist in its orientation, attempting to objectively measure these costs by means of quantitative techniques (chapter 2). As a result of the various methodological problems associated with quantitative research into caring, as well as the growth of post modern and

phenomenological perspectives (chapter 1 and 2), there has been a more recent growth in the popularity of qualitative studies into informal caring, its 'subjective burden' and the meanings and motives which are attached to this role. For example, contrary to the determinist assumptions of the positive perspective, it could well be the case that those carers who, for whatever reason, actively choose a high level of involvement go on to subjectively underestimate the impact of this involvement due to the reasons for this choice. Conversely, those who have this involvement imposed upon them are likely to go on to subjectively perceive it in a negative way. This has been substantiated in the previous chapter with the two unwilling co-resident carers in the sample, Mr Davis and Mrs Flude experiencing a high degree of subjective dissatisfaction with their role. Moreover, just as subjective feelings of poverty are reliant on both an individual's objective material position and also on previously acquired expectations and experiences (chapter 3), the subjective experience of caring is similarly mediated. For example, Twigg and Atkin (1994) observe that caring is embedded in the kinship and marital relationship and this affects the way in which society, welfare agencies and carers themselves interpret the meaning of their experiences. They go on to distinguish between three individual responses to the caring role. The first is the 'engulfment mode' in which the carer is highly involved 'burdened' and subordinates his or her life to that of the cared-for person. The second is the 'boundary setting mode' in which there remains an element of separation between the carer and their situation. Thirdly, is the 'symbiotic mode' in which carers gain in a positive way from their role to the extent that they would not wish their responsibilities to be taken away from them.

It is undoubtedly the case that objective and subjective perceptions of the caring role are not necessarily related, with the subjective impact of caring being influenced not simply by the actual degree of caring responsibility but also by factors such as the life history and expectations of individual carers. This research, nevertheless, hypothesised that such factors are not totally arbitrary or as individualistic as interpretevisists maintain but are to some degree related to wider social structures and are characterised by a considerable amount of homogeneity (chapter 1). For example, it was suggested in the previous chapter that cultural factors played an important role in mediating the way in which

carers experienced and managed their financial situation, serving to minimise their subjective feelings of deprivation and promote their financial caution. This culture appeared to be characterised by an age-based homogeneity as a result of the shared past experiences of the carers in the sample. It was therefore reasonable to expect that respondents' attitudes to their caring role, especially within the spousal relationship, would be similarly mediated with shared cultural assumptions on such things as the sanctity of marriage and its lifelong nature, serving to shape their subjective perceptions of their caring role. However, in spite of this potentially important influence of culture on the role and experience of older carers, the 'ageless analysis' of informal care research means that this issue has not been fully addressed. This neglect of older age has been apparent in both qualitative and quantitative studies of informal care with the former tending to focus on the role of women or 'young carers', while the latter has tended to neglect the influence of social divisions on caring, seeing the family as a homogeneous and undifferentiated entity, with the burden of care falling equally on all its members (Grad and Sainsbury, 1968)

Not only has research into the experience of informal care been characterised by an ageless analysis, it has also been characterised by a classless analysis. For, in focusing on subjectivity, it neglects the way in which individual meanings motives and choice are themselves constrained by 'objective social forms' and the systematic differences between individuals arising from these constraints (Webb, 1996). Consequently, it is naïve to assume that subjective feelings of poverty are totally unrelated to objective levels of material well-being, for while the two aspects may not always correspond, those who are objectively poor are more likely to feel themselves deprived than those who are well off. Similarly this research hypothesised that it is also naïve to suggest that the objective and subjective experiences of caring are totally unrelated for while they are not *inevitably* linked, carers who carry high levels of objective 'burden' or *more likely* to perceive this role in a negative way than those who carry less 'burden'. In the light of this hypothesis, it was an aim of this research to further explore this caring experience, the relationship between objective and subjective costs and the extent to which these costs were correlated to the carer's material circumstances. Moreover, in order to break

down the false dichotomy between objective and subjective caring ‘costs’ characteristic of previous research and explore the way in which these two types of costs are related, it was felt to be advantageous to combine an exploration of respondents’ subjective experiences with objective measures of their caring role. With this goal in mind a variety of open and closed ended questions and both qualitative and quantitative methods were used to measure the caring experience. The rest of this chapter will be devoted to the discussion of the findings from this exploration of respondents’ caring experience and will reveal the way in which this experience was mediated by age specific factors of disability and culture, as well as by material resources.

THE IMPACT OF CARING

Objective and subjective demands

As it was seen in chapter one, the older the carer, the more demanding their caring role is likely to be, especially when this caring takes place within a co-resident setting. Thus, older carers are likely to have been caring for long periods of time and for many hours a week. They are also more likely than younger counterparts to perform demanding personal care activities such as washing and dressing. This intensity of task and time in the caring role of older people is largely attributable to the increasingly serious nature of the illness or disability of the cared for person, who is also likely to be elderly. In accordance with these findings, analysis of fieldwork in this research revealed that, with exception of two respondents, all were involved in the performance of personal care tasks, a role which the General Household Survey uses as an indication of a ‘high’ level of caring involvement. Most respondents were also caring for significant lengths of time, with most claiming their involvement to exceed 50 hours per week and with over half of the sample having been carers for 10 years or more.

Table 4.1: Number of years in caring role

0 - 4	5 - 9	10 - 14	15 - 19	20 - 24	25 - 29	30 - 34	35 - 39	40 - 44	45- 49
14	2	7	1	4	1	1	1	2	1

It was seen in the previous chapter that the material circumstances of carers could help to alleviate these demands. However, contrary to the materially determinist hypothesis

underlying this research, only two carers, Mrs Flude and Mr Davis, felt that their co-resident caring role had been unwillingly imposed as a result of financial expedience (chapter 3). The majority regarded it as freely chosen. Moreover, in spite of their high levels of caring demands, carers generally subjectively perceived their role in a positive light and there was a lack of association between the objective and subjective costs experienced as a result of caring. So while the majority of the sample were performing very demanding caring tasks for over 50 hours a week and often making great personal sacrifices in the process, few maintained that they were wholly dissatisfied with their role.

Looking after her she's never been any trouble at all, she's not a demanding person, never has been (Mr Cicourel)

No I wouldn't say that Edna's illness has caused me any bother, inconvenience, yes, but that doesn't bother me (Mr Tunstall)

With the aim of ascertaining the extent to which respondents' material circumstances were correlated with the costs experienced as a result of their caring role, an attempt was made to quantify these costs. Carers were asked to rate, with the use of Likert scales, the impact of caring on various aspects of their lives including finances, physical health, mental health, household routine and social life, categories which were used by Grad and Sainsbury (1968) in their influential research into the 'burden' of informal care. However, while Grad and Sainsbury's (1968) scales permitted only negative responses when carers were questioned on the impact of their role, thus implicitly reflecting a negative concept of caring, positive responses were also permitted in the Likert scales in this research (chapter 2). The findings yielded from Grad and Sainsbury's study were unambiguous, leading them to conclude that informal care provided at home was significantly more burdensome to families than institutional care (chapter 2). They went on to outline in detail some of the costs experienced as a result of caring:

The mental health of more than one half of our informants was affected. They ascribed symptoms of emotional disturbance to worry about the patient, and one fifth of them attributed frankly neurotic symptoms such as insomnia, headaches, excessive irritability and depression to

concern about the patient’s behaviour. Social and leisure activities were restricted in a third of the families; 29 per cent had their domestic routine, housework, shopping etc. upset and a quarter of the families had had their income reduced by at least 10 per cent. In 10 per cent the family income had been cut to less than half its usual level; this effect on income and the similar proportion of families where the employment of others was affected clearly indicates the high cost of mental illness to the family (Grad and Sainsbury, 1969: 271)

In contrast to these findings, as the table indicates, the findings yielded by this research not only highlighted the fact that, contrary to oppressive concepts of caring (chapter 1), this role was not always experienced in a negative way but information on the objective ‘costs’ of caring were also ambiguous and inconclusive.

Table 4.2: The impact of caring

	FINANCES	PHYSICAL HEALTH	MENTAL HEALTH	SOCIAL LIFE	HOUSEHOLD ROUTINE
Better	5	2	3	3	4
Worse	8	9	14	12	9
No change/ Unable to Quantify	21	23	17	19	21

This ambiguity served to render impracticable the initial aim of the exercise – to compare these costs with the objective material circumstances of carers in order to see if there was a clear correlation between poverty and high levels of such costs. This ambiguity also throws into question the validity of similar studies with this goal in mind and helps to explain the contradictory findings yielded by these studies. Thus although all the carers in the sample were performing similarly demanding tasks, they often rated the burden of these tasks very differently due to their differing interpretation of the questions, their emotional and subjective feelings about their role and their previous life experiences. For example, due to their generally positive perceptions of their caring role, Mrs Hacker and Mr Dale were quite adamant that all aspects of their life had improved as a result of caring.

Many others were unwilling or unable to even attempt to quantify these costs. Thus, with regard to household routine, while most recognised that this had changed, with the carer taking over the role of the cared for person, only a minority were willing to maintain whether this was a change for the better or worse – it had simply changed. As Mr Cicourel said when asked about the impact of caring on his household routine:

Well I'm not a housewife and I never have been a housewife so I wouldn't know what routine means. My mother had a routine, Monday would be wash day and Tuesday would be cleaning day and so on, that would be a routine but with me I do things when they want doing not because they have to be done...I don't want to live in a pigsty but on the other hand I wouldn't become a fanatic about it

Similarly, while many recognised that their social life had declined as a result of caring, many did not regard this as a change for the worse as they did not wish to go out. Matters were further complicated by the fact that some carers felt that aspects of their life had simultaneously improved and worsened as a result of caring. For example, Mr Cicourel felt that while caring for his wife was mentally stressful, he would find not caring to be similarly stressful due to the fact that he would be worried that she was receiving an adequate alternative source of care:

As long as she's OK, I'm OK (Mr Cicourel)

Similarly, Mrs Reid felt that, in some respects her social life had got worse as a result of the restrictedness of her caring role. However, in other respects it had got better as her membership of a carer support group had broadened her circle of friends. Indeed Baldock et al (2001) suggest that rigid interview formats and preset questions are likely to undermine the accuracy of information elicited from older people:

Our attempts to pursue particular lines of questioning were frequently ignored or diverted to the respondents' agendas. It is possible that once the respondents decided that they would not be allowed to determine the content of the interview they would acquiesce to implied suggestions or answers (Baldock et al, 2001: 17)

Issues of assessment

A further important point to note with regard to attempts at measuring the needs of older people and the objective costs experienced by respondents is that, as with respondents' accounts of their financial management strategies, transcripts revealed the high incidence of the words 'cope' and 'manage' when speaking of their caring role and these words were always used in a positive rather than a negative context:

*We're managing, were managing but as I say its got harder, its got harder now
(Mrs Halsey)*

*We're coping aren't we, we could be better off but it could be a lot worse (Mr
MacLellan)*

This could be seen as evidence of the same resourcefulness and adaptation, which had characterised respondents' financial management strategies. This in turn may suggest that, just as carers were unwilling to admit to financial struggle and hardship, they may also be similarly unwilling to disclose the true costs of their caring role, serving to distort research findings aiming to objectively ascertain the extent of these costs. This picture of resourcefulness in the face of difficulties amongst older people is supported by a number of other studies (chapter 3). For example, Langan et al (1996) identified themes of 'making the best of things' and 'making an effort' to be prominent amongst the older people they interviewed. Similarly, in his theory of 'gerotranscendence' Tonstam (1999) maintains that older age sees a shift from materialistic and pragmatic view of the world to a more cosmic and transcendent one, normally accompanied by an increase in life satisfaction. Indeed, there is a long history of work in social gerontology that shows how, in later life and particularly with the onset of disabilities, older people engage in 'identity work' in order to readjust their 'sense of self' to new circumstances and to maintain their sense of self-worth (Thompson et al, 1990). For example, as Baldock et al (2001) observe with regard to the onset of disability:

Their main bulwark against the downward trend they saw as their own attitudes and feelings and the way they treated the disabilities of old age. Disability could either be fought and transcended or it could be accepted but ignored. In both cases there was a dominant view that it was mental attitude rather than physical reality that was important (Baldock et al, 2001:13)

This renegotiation of self-identity taking place as a result of the onset of disability is likely to be compounded for those in a co-resident caring role, especially within a spousal relationship. For this renegotiation will not only involve the older person's own sense of self but also their sense of self in relation to those closest to them (Barnes, 1997). Consequently, older people's reluctance to come to terms with the onset of disability (Baldock et al, 2001) may not only affect their attitudes to their own physical impairment but also that of the cared-for-person, leading them to attempt to underplay or hide the severity of this condition to the outside world (Twigg and Atkin, 1994). For example, Twigg and Atkin (1994) found that spouse carers tended to see caring as a natural part of the marital relationship and tended to put a barrier around this relationship against the unwelcome intrusion of outside agencies. In the light of these observations, it should be recognised that, in an interview, participant responses are only partial revelations (Kaufman, 1994) and that all that may be available to the researcher are 'the contours of the masquerade' (Biggs, 1999:72). This 'masquerade' is likely to be particularly apparent amongst older people for whom the maintenance of independence, autonomy and the appearance of being able to 'cope' or 'manage' is crucial in maintaining their positive identity and sense of self (Tanner, 2001). This, in turn, has implications for the assessment process used by service providers and the subsequent production process of personal care in which service users, carers and service providers all play a part (Twigg, 2000). Such assessments tend to be focused on the levels of dependence of the person being assessed and their ability to perform 'activities of daily living' (Barnes, 1997). However, as the above discussion suggests, older people may be unwilling to admit to such dependence.

Indeed, as Baldock et al (2001) maintain, contrary to assumptions underlying the trend towards client-centred and needs-led assessments, older people are often unwilling to admit to or express their true need for support:

Firstly, our study leads us to doubt how far many older people are indeed able to judge their needs and make informed choices, particularly after an illness or other event, which has caused a shift in their self, care abilities. Secondly, we conclude that the qualitative gulf between the

realities that users and providers inhabit is so profound that it will always be to an extent unbridgeable. (Baldock et al, 2001)

The observations of Biggs (1999) and Baldock et al (2001) on the tendency of older people to put on a 'brave face' are applicable both to all types of assessment and the accuracy of information gained from these. However, as the problems in quantifying caring costs in this research has illustrated, it is likely that relatively unstructured rather than structured methods of assessment are more likely to get through older people's 'masquerade' and transcend the qualitative divide between user and provider. For as it was suggested in chapter two, qualitative techniques emphasise the interactive process between the researcher and the researched, seeks greater equality and closeness and gives primacy to human action and lived experiences (Plummer, 1983). Such methods also have the advantage of allowing the respondent to help to set the interview agenda, thus facilitating their sense of involvement and allowing for the identification of emergent themes. There therefore follows an outline of respondents' qualitative accounts of the impact of caring on aspects of their lives.

Finances

Previous research has identified the extra financial expenditure incurred by disabled people and their carers as a result of disability (Nissel and Bonnerjea, 1982). Thus as researchers such as Green (1988) observe, informal caring and its time-consuming nature affects the ability of carers to take paid employment. They are less likely to be in employment than their non caring counterparts (Parker and Lawton, 1990) and those who attempt to combine caring with work face a reduction in hours, fewer opportunities for overtime, restricted career development and loss of pension rights. These costs were more explicitly quantified by Nissel and Bonnerjea (1982) who found that the direct cost of labour in the provision of family care to elderly relatives was £2,500 per year and the cost of earnings forgone was £4,500 although these costs would obviously be higher almost 25 years on. It might be expected that such issues of lost earnings are not relevant to older carers due to the fact that they are past working age. However, some carers in this sample recognised that their long-term caring responsibilities had a negative impact on their current pensions. For example, Mr Cicourel and Mr MacLellan had taken early

retirement and Mrs Hudson had worked part time in order to accommodate their caring responsibilities. Thus, as Evandrou (1996) points out, lower pension rights can extend the employment impact of caring well beyond the statutory retirement age. To compound this financial disadvantage, until recently, carers aged over 65 were not entitled to claim Invalid Care Allowance, a welfare benefit designed to support carers.

In addition to loss of earnings are the ‘one off’ and ‘recurrent’ costs faced by carers (Glendinning, 1992) such as clothing, bedding, laundry, heating, transport, special food, housing, home adaptations and aids to mobility and daily living. Respondents in this sample spent large sums of money on such items. For example, with regard to ‘one off’ expenses:

I had both my hips done and I can't even get up the stairs. I had to have a stair lift fitted, we had to pay for it ourselves (£2000)...and then I couldn't get in the car. Colin bought a newer car and he got a bigger one with higher seats so I can get in and when we go out he has a platform to help me get in and out (Mrs Lane)

I've had a stair lift since 1991 and I couldn't manage without it. I bought it. The local authority will loan them but they make such a lot of fuss about it (Mr Dale)

A source of ‘recurrent’ expense for respondents was in the payment of charges for services such as home care, day care and meals on wheels (chapters 3 and 5). For example, in their survey of the financial status of carers the Carers National Association found that three-quarters of carers aged over 70 were paying for services out of their savings (CNA, 2000). Thus Mr Tumin described how, out of his weekly household income of £160, he had to pay the running costs for his stair lift, home care bills, regular respite care bills of around 60 pounds a week and the rental of his lifeline phone of £3 per week. These ‘recurrent’ costs as well as ‘one-off’ and ‘indirect’ costs incurred as a result of disability (chapter 3), could be a significant drain on the resources of respondents. As Mr Hall said of the running costs for his invalid scooter:

It just cost me £224 for two batteries for my scooter that was getting bugged...I got it three years since. Doesn't belong to nobody else, its all mine. (Mr Hammond)

However, perhaps surprisingly, some carers thought that their financial situation had actually improved as a result of caring. For Mr Davis and Mrs Flude, this was due to the fact that co-resident caring enabled them to pool limited resources (chapter 3) while for others this was because of the receipt of attendance allowance and disability living allowance (chapter 5). It should also be recognised that it was not always possible to distinguish between the costs incurred as a result of caring and those incurred as a result of the impairment of the carer or cared-for-person (Glendinning, 1992). Consequently it was difficult to quantify exclusively care related financial costs, although it is evident that, for some households, these were considerable.

Case study 4.1: Mrs Hudson – the long-term carer

Mrs Hudson was aged 64. Her caring role had spanned 42 years, the whole of her physically and mentally disabled son's life and she had never been able to work full time as a result of this. Therefore, like other long-term carers, she experienced a 'feedback effect' to her current financial situation

"I would probably have had a better job if I hadn't had to work round David (her disabled son) so I would have had a better pension" (Mrs Hudson)

She had also incurred further expenditure on various aids and adaptations including a stair lift and, although she was a homeowner and had savings, felt ill equipped to meet these costs. When seen for a follow-up interview she had finally been persuaded to have her son permanently admitted to a sheltered housing scheme. However, she was very apprehensive about this impending admission and was concerned at how she would cope financially following his departure, for she would lose his disability living allowance, mobility allowance and income support payments.

Physical health

A major potential cost incurred as a result of caring is its impact upon the physical health of carers. As such, older carers are at an increased risk of experiencing health problems or disabilities themselves, especially if they are aged over 75 (Arber and Ginn, 1991) with the General Household survey finding that over half of older carers have a long standing illness or disability (Milne et al, 2001). Evandrou (1996) observes that this risk of ill health is particularly high amongst those who are caring intensively within a co-resident setting, especially within the spousal relationship. Specific health outcomes include physical strain and muscular-skeletal problems (Henwood, 1998). Many respondents in this sample spoke of health problems such as angina and arthritis and their impact on their caring role:

When he first went into hospital I was younger but these last two years I started to feel my age. I'm 84 next Tuesday so I can't grumble. But I can't do what I want to do and that's what's upsetting me (Mrs Roach)

The health or disability of the cared for person could also have an important impact on the physical health of the carer, serving to exacerbate the demands of their role. As such, the illness/impairment of those in receipt of care were often severe and wide-ranging, the most common being dementia (nine households), stroke (seven households) and angina/heart attack/heart problems (seven households). Mr MacLellan observed the way in which his wife's level of impairment could in turn affect his own health:

It has got worse this last 12 months since she did her shoulder. She broke that just to be awkward and they didn't do a marvellous job on it. Well you can see. She can't use it sometimes, she can't feed herself. She's struggling but we've been coping anyway. With the continual lifting it's difficult, it's painful...well this prostate job has upset me more than anything (Mr MacLellan)

Indeed, although not directly addressed in the interview schedule, the issue of health featured heavily in the interview transcripts with many carers speaking at length of their own or the care-recipient's ill health. This preoccupation of older people with health is substantiated by much research which has found that while material well-being is an important factor in determining the quality of life of the young, issues of health were more important in determining the life satisfaction of older people (Baldock, 2003). However, as Milne et al (2001) maintain the relationship between caring and physical disability and illness is a complex one and it is unlikely that this relationship is totally causal. In accordance with this, in spite of the physical health problems experienced by respondents, only nine maintained that these had been caused or exacerbated by caring with most carers seeing them as an inevitable product of the ageing process:

I'm not as fit as I was 10 years ago but that's the same with everyone (Mr Cicourel)

I have been looking after her for eight years. My health hasn't been affected but you don't get better as you get older, I'm full of aches and pains. I've had a

problem with my thyroid; I had a cyst on it so they took it out but years ago they used to say you couldn't live without your thyroid. My GP said to me one day, I'm amazed you're still here (Mr Caplow)

I wouldn't say the wife has caused it. It's age catching up and I get breathless when I'm walking and if I walk downstairs my knees start to give way. I can walk up steps better than I can walk down them (Mr Tunstall).

Similarly, Mrs Hudson reported that the physical strain of caring had increased over time both due to her diminishing health as well as that of her son:

Well it does because you're not so quick and he's got bigger and bigger because I used to be able to take him upstairs but I couldn't now...when my husband was alive it would take two of us, one at the back pushing and one at the front pulling but then I was left on my own....(Mrs Hudson)

Previous research has identified the way in which socio-economic status, as well as age can be an important factor in influencing the incidence of ill health and disability (Oliver, 1990). For example, the Black Report (1990) found there to be a close relationship between the incidence of ill health and material deprivation. Similarly, using car ownership, housing status and income as a measure of material circumstances, Arber and Ginn (1992) found that older people with good circumstances were less likely to experience ill health than those with poor circumstances. This materially-based gradient in ill health will have an obvious impact on caring for, on one hand, it is likely to exacerbate the demands on poorer carers while at the same time reduce carers' ability to cope with these demands. Due to the relatively small size of the sample, it was not possible to affectively test this class gradient in health status. However, it was possible to 'look behind' these statistics by exploring the way in which carers perceived and experienced ill health and how this went on to affect their material circumstances and caring role. For example, one explanation given for the high rates of illness and disability amongst poorer social groups has been the unfavourable environmental factors to which they are exposed. These factors and their potential impact upon health were alluded to by Mr Phillips, a retired steelworker, who attributed his long-term health

problem of emphysema to such unfavourable environmental factors (he died of this illness shortly after his interview took place):

Nine years ago, the doctor said to me I'd got emphysema and that my lungs were damaged. I said yes, I've swallowed enough steel dust in my time, 48 years in the forge.

Other research has argued that lower socio-economic groupings are not only more vulnerable to ill health but also are more likely to pursue unhealthy lifestyles, which could in turn exacerbate problems of ill health (Calnan, 1987; Blaxter, 1990). From a materialist perspective it is argued that this is due, not to ignorance or irresponsibility but to situational constraints upon actions such as the inability to afford a healthy diet (chapter 3). This research revealed that the restrictedness arising from a co-resident caring role could have a similar impact:

I smoke a pipe. It's the only thing I can do. I'm bored stiff. It's not that I like to smoke a pipe in particular but I do because I'm bored stiff. I never take it out of the house, if I go away I never bother with it. It's only boredom that makes me do it (Mr Davis)

Sometimes if you're sitting around doing nothing you'll eat far too much (Mrs Field)

However, like the relationship between physical health and caring, the relationship between social class and ill health was a complex one as ill health could not only be seen to be a product of material deprivation but also a cause of it. For example, Mrs Halsey told of how her husband's illness had led him to be unemployed for many years, thus having a detrimental impact on their current financial well being. Mr Caplow had similar experiences:

They decided to make me redundant when I was 59, they wouldn't let me go back because of my health. They offered me a job cleaning windows but I couldn't do that going up ladders so I didn't take it and two years later they closed it up (Mr Caplow)

Similarly, Mr Davis, due to long-term mental health problems had not been in paid employment since he was 35 leading him to be financially dependent upon his mother since that time.

Mental health

Although the role of caring in causing physical incapacity is unproven, the relationship between such caring and mental health is much more conclusive (Parker, 1990; Draper et al, 1996). Thus the British Panel Survey has suggested that caring has a significant impact on the emotional health of carers (Henwood, 1998) and is especially true for those providing intensive co-resident care (Evandrou, 1996). Stress among carers is widely reported and is particularly associated with depression, with around one third of those caring for a disabled spouse being found to experience clinical levels of depression (Levin et al, 1994; Ballard et al, 1995). Moreover, Milne et al (2001) found that one-third of carers surveyed felt that their mental health was influenced by caring with nearly two thirds reporting stress and half reporting depression. In accordance with these findings fourteen respondents in this research reported the negative impact of caring on their mental health.

I think that caring does take a toll on you because you tend to get tired and then you get stressed and worried and that takes a toll on your physical health (Mrs Reid)

Sometimes it gets you down doesn't it, I mean I lose my temper, I'll admit. You do get so fed up with it, it gets on your nerves, it does get on your nerves. You can't do a damn thing about it (Mr MacLellan)

The issue of abuse was not addressed in the interviews. However, such mental stresses are strongly associated with the incidence of abuse with Levin et al (1994) recognising that older carers can both be the victims and perpetrators of abuse, especially when caring for a person who is confused. Much of the abuse in this context relates to co-abuse where the carer abuses the cared-for person and the cared-for person abuses the abuser (Manthorpe, 1995)

This mental strain can partially be the product of the loneliness of being a carer, especially when the cared-for person is no longer able to sustain a conversation (Levin, 1989). For example, Mrs Halsey spoke of the way in which she felt unsupported and stressed as a consequence of her husband's physical and mental incapacity:

It's physical strain and mental strain as well. All the joint decisions, I could talk it over with Brian but after five minutes he's forgotten what he's talking about.

For many carers this mental strain was exacerbated by the behavioural problems of the cared-for person. Such problems have been found to be associated with high levels of stress and include such things as repetition, restlessness, unsafe acts, wandering, lack of purposeful activity and aggression (Levin, 1989)

I can't leave her on her own because she forgets to do things, I can't trust her. It's the stress part of looking after her that effects you, you can't really settle down (Mr Carson)

It wears me down naturally. It's alright in the day time but at night time she'll have me out of bed anything up to six or seven times. It's the night time that punishes.. I don't physically suffer, no only tiredness if you can call that physical. (Mr Tumin)

I can't leave him. For one thing he gets very frightened, I think if he doesn't think I'm there.... I have some pills, some antidepressants because Dr West thought I was really depressed about my husband (Mrs Field)

In addition to the management of behavioural problems, the performance of personal care was a further source of stress for carers. Personal care involves such things as the provision of help with bathing, dressing, lifting, toileting, walking and taking medication. Such activities are often seen as the defining feature of informal care. Commentators have emphasised their impact on carer's life and health (Glendinning, 1983), while other studies have described in detail the personal care tasks performed by carers (Glendinning, 1983; Parker, 1993). Such personal care has been identified by Twigg and Atkin (1994) as having an important impact on the difficulties experienced by carers. This is partly

because of its intimate nature which can run counter to culturally prescribed expectations about acceptable physical contact (Ungerson, 1983). In addition, it often gives rise to embarrassment and the need to utilise techniques in social distancing. For example, cross gender tending has been found to be problematic, especially if it is provided by males for females and Parker (1993) found that such problems of physical contact even extended to spousal relationships. As such, contrary to the findings of Borsay (1990) who maintains that intimate care comes naturally to spouse carers, researchers such as Kitwood (1993) have observed the distress and alienation which caring for a disabled spouse can bring. This distress was echoed by some of my spouse carers, both male and female, as, Mr Cicourel recounted his embarrassment at having to provide intimate personal care such as washing and dressing to his wife

You see it was frustrating because washing a woman isn't like washing a man and then she was in the menopause as well

Incontinence has also been found to be one of the most stressful aspects of caring (Levin, 1989), giving rise to stigma for both the carer and care-recipient and also causing practical difficulties in coping with extra laundry and in the acquisition of incontinence aids.

Putting him on the pot you know that's really the most unpleasant thing, to make sure he uses the lavatory before he goes out. I just stand there saying go on, go on. That is something I wish I could do without (Mrs Field)

A second feature of some personal care tasks such as feeding, dressing and toileting is that they need to be provided on demand or as the need arises.

I'm on hand 24 hours a day. I mean when we go to bed at night, sometimes she can manage to get out of bed so she can get on the commode, sometimes I'll have to get her out and then wait and put her back. Somebody's got to be with her, you couldn't leave her on her own (Mr MacLellan)

This puts an additional pressure on the carer who may also face the dilemma of determining the extent to which assistance should be given in the interests of preserving the independence of the care-recipient:

Well the home carer, she'll wash her in the morning, sometimes, not always she'll manage to get her in the bath on her own and I'll leave the door open in case she needs me but she does manage to get in and out by herself. She doesn't get right in the bath, she's only got a seat to sit on about half way down and then I'll go and wash her back down and shower her and all that. She doesn't like that; she likes to be on her own if she can manage (Mr MacLellan)

Miss Howard further highlighted this dilemma between care and control:

You've got to allow her her freedom. She's still an adult. If she wants to get up and walk around why shouldn't she? You just try and protect yourselves from yourselves

Social life

Associated with the stress arising from behavioural problems and personal care tasks is the further problem of 'restrictedness', that is, the feelings of frustration, boredom and claustrophobia arising from the constraints that accompany the informal caring role (Bebbington et al, 1986). Twelve carers reported that caring had a negative impact on their social life. For example, Mr Cicourel spoke of his frustration at the time limits placed on his leisure activities due to his need to get back home to his wife:

You see Elaine, if you continue with your sports or whatever, you become frustrated because there is a time limit... I might have a week when she won't eat and she won't drink or it might take twenty minutes to give her a drink. So I can't commit myself to saying I'll be there at half past nine or ten o'clock and because of that I think I'm making myself a nuisance and that's why I don't bother (Mr Cicourel)

As such, intensive caring demands can restrict the carer from leaving the house for any length of time. This often results in social isolation as carers become detached from their social networks and lose touch with community supports (Wenger, 1992) and this isolation is a particular feature of caring for someone with behavioural problems (Wenger, 1994). As Twigg and Atkin (1994) observe, this restrictedness takes three major forms. Firstly it arises from the carers need to ensure the care recipients physical

safety, with this problem being reported by several carers respondents, especially when the cared-for person is confused:

I can't leave her on her own; twice she's fallen down when I've just gone in the kitchen to make the tea (Mr Hunter)

Secondly, it arises from the general anxiety of the carer about what might happen in their absence:

I don't leave him on his own because you don't know...he's very unpredictable and he can be sat quite still on the settee for one minute and then if I go in he'll be out of the seat and crashing into the chair. No he's very unpredictable (Mrs Hudson)

A third aspect of restrictedness is 'secondary restrictedness'. That is, the carer may be reluctant to pursue an independent life without the cared for person. This secondary restrictedness is particularly apparent amongst spousal carers who may feel guilty about enjoying themselves without their spouse (Twigg and Atkin, 1994). In accordance with this, while 9 carers in the sample maintained that their social life had got worse, they often said that they didn't mind as they didn't want to go out without the cared-for person:

Even if I had someone to sit with her I wouldn't know where to go on my own. I wouldn't want to go in town and things like that (Mr MacLellan)

Well we have always done everything together and it has got that we can't do the things that we want to (Mrs Williams)

Freedom is nice if you can share it (Mr Cicourel)

Even though Mr Caplow's wife had recently died, he also expressed reluctance about pursuing a social life on his own, as he said of his local community centre:

A week on Tuesday they're going out on a trip to Cleethorpes and they asked me if I wanted to go but I said oh I don't know because they all split up you see and it leaves you on your own. I mean you don't know people, you think you do but you don't. I mean I was walking down there and there were two ladies I knew who

walked past me and they never even spoke. They knew where I was going because I was going to the same place. You notice things like that (Mr Caplow)

In this respect, the perceived legitimacy of the independent activity was of great importance to spouse carers with such things as shopping being regarded as preferable to more frivolous social activities:

I can leave her for an hour to go shopping which I have to do, I don't have any option (Mr Tumin)

Well I don't leave her long do I? If I dash to the shops and dash back, I leave her for half an hour at the most (Mr MacLellan)

These feelings of guilt exhibited by spouse carers at going out without the cared-for person, contrast with the views expressed by Miss Hudson and Mr Davis who, as filial carers, had developed a separate and independent life prior to the need for caring, which was not the case for spouse carers (Parker, 1990). As a consequence of this they expressed the greatest degree of subjective deprivation as a result of their sacrificed social life:

My day generally starts in the morning and finishes at half past eleven in the morning when I get her lunch and if its late she doesn't like it, if its five minutes late she doesn't like it.....I'm a church organist. I've had to pack up seventy per cent of my music because she doesn't allow me out of the door. She's a very, very selfish person...I resent it, you would if someone said you could go out and be back for eleven, looking at your watch coming back, you would (Mr Davis).

I was looking forward to taking up new activities in retirement, well of course that's gone by the board now, I've not been able to do any of those, my own social life has gone by the board (Miss Howard)

Household routine

Like research into the financial management strategies of older people, existing research on the division of household tasks during retirement tends to yield contradictory findings. For example, resource theory presupposes that within co-resident relationships, power is held by the person with the resource advantage and that changes in these relationships occur as a result of fluctuations in the resources possessed by cohabitees. As a consequence of this, it is argued that male retirement and the loss of the male breadwinner role leads to a similar transformation of domestic roles and blurring of traditional gender role divisions as a consequence of this (Pina and Bengston, 1993). However, other research stresses the continuity in household roles after retirement. According to this perspective, men continue to perform typically masculine tasks (Vinick and Ekerdt 1992), while women, in contrast, maintain traditionally feminine roles, such as cooking cleaning and laundry. However, despite its conflicting arguments, as Kulik (2001) maintains, a common theme in all of this research is that it assumes that retirement is a unitary and unchanging period, during which roles remain unchanged. Contrary to this perception, while, respondents did experience a blurring of the gender role divisions which had characterised their younger lives, this role adaptation tended to be a gradual and insidious process and was primarily facilitated by the disability of the cared-for person rather than by changing material circumstances. As such, while this role transformation often commenced following male retirement, it tended to become more pronounced with the passage of time:

When I stopped work, I started cooking and shopping and all those things (Mr Denis)

She did all the housework, only when I retired I used to help around the house a bit, but now she can't do a thing, if she washes the pots, I have to watch her, I have to do everything....if it had happened sooner it would have been harder but I retired at 62 which gave me quite a few years to gradually come in (Mr Carson)

As this post-retirement role transition tended to be accelerated by the increasing disability of the cared-for person, it was therefore most pronounced amongst very old carers. The

fact that such older carers were not only likely to be disabled themselves but were also likely to have previously adhered to traditional gender role expectations, made their efforts at adaptation all the more notable. As the following male spouse carers described of their changing marital roles:

She used to do the shopping and things like that, cooking and looking after the house, I was just the provider, the gardener and the helper but she developed this arthritis of the spine which meant that shopping was getting very, very difficult, so I just took over. (Mr Tunstall)

She's not done any shopping for twenty years. When she was OK she did. I mean we had a family, that's why she never worked as she was looking after a family. I mean I do it all now, cooking, cleaning, the lot (Mr MacLellan)

She was OK ill she was about 75, until then she did all the housework. I didn't find it very hard to adapt, I'm very adaptable, and it didn't bother me taking over. It's folk's attitude. It's men's attitude towards housework. You either get it done or you let it go to rack and ruin (Mr Caplow).

I do what I can. I don't let her do cooking and things like that. I'm afraid she has burnt herself on occasions. When I was working it was difficult. Mind you you can forget about that now. These past few years I do everything...its hard work housework you know, housewifery whatever you call it (MrHall)

Much feminist research maintains that women are more likely to be highly involved carers than men (Finch and Groves, 1983), yet this was not substantiated by this sample. Thus all but one carer, a woman, were caring on a full-time basis and all but two performed personal care tasks such as washing, dressing and feeding. Neither was there a significant gender difference in the duration of caring the men being involved in caring for an average of eleven years as compared to fourteen years for women.

Although there was much cross-over in the roles performed by older male and older female carers in the sample, feminists argue that there is still likely to be a significant

gender difference in the way this role is perceived due to previously ascribed characteristics. Thus Finch and Groves (1983) maintain that men and women are socialised differently. Apparently, older care-giving wives view their role as natural, affective and a continuation of their previously held nurturant role. Conversely, husbands see their caring role as alien and more task-centred because of their former work in the external world. While this issue of gender difference in the subjective perception of caring was not directly addressed in the interview schedule, such differences were not directly expressed by the older carers in this sample. Indeed, in accordance with postmodernist claims that older people experience a liberating release from former social roles, many male carers appeared to positively enjoy some typically female tasks. Similarly, the views expressed by women did not tend to adhere to the caring and nurturant characteristics ascribed to them by feminists. For example, as one spouse carer, Mrs Reid, said:

Some days I think that its nice to have someone to talk to, then other days I think that I've spent my whole life caring for people

Another carer, Mrs Flude, a woman in an unhappy marriage, said that she felt that caring for her husband allowed her to finally be in control in their relationship, feelings far removed from the nurturant female motives identified by Finch and Groves (1983). Thus, as Miller (1987) observes, a central aspect of care-giving is being in charge of another person, which is an extension of the male authority role. Moreover, as Lewis (1998) observes, Finch and Groves' theory does not place adequate weight on the diversity in the roles of older people. Thus, it has already been seen that many of the women in the sample became much more instrumentally-orientated in later life due to a blurring of traditional gender roles.

Neither were carers' younger lives always characterised by the traditional gender role divisions attributed by feminists, especially in the case of long-term male unemployment. For example, Mr Davis had not been in paid employment since he was 35 due to mental health problems. He had spent most of his life looking after his mother upon whom he was also financially dependent leading to an effective reversal of traditional gender roles. He described his mother's longstanding lack of interest in domestic affairs:

My mother has never been a cook, never been interested in food and as I said, she's always had this hypochondriac attitude towards herself. But she's laid back, she couldn't care less. Providing she is getting fed she's quite happy. It doesn't matter about anybody else. I've said it for years, there's only her on this planet

Similarly, due to her husband's long-term unemployment, Mrs Halsey had always been assisted by him in domestic tasks:

Yes, he'd do all sorts of things; say if I cooked the dinner, he'd wash the pots and things like that. I'd do the washing and he'd help me to carry the washing down and put it in the yard

While Mr Cicourel, had assumed responsibility for domestic tasks and childcare throughout most of his married life due to his wife's long-term illness with multiple sclerosis.

For the first 10 years I tried to be mother and father to the kids and I tried to do as much as I could for them, I could have packed my bags and gone but if I had done that what would have happened to them

ROLE TRANSITIONS AND RECIPROACITY

The preceding findings on the impact of caring suggest that, the experience of caring in older age differs markedly from experience of younger carers and that, as with the financial management strategies of respondents, it is an experience which is mediated by age-specific factors of culture, attitude and physical pathology as well as material resources. The qualitative component of the fieldwork also revealed the high incidence of reciprocity and interdependence in the caring relationship and continuity and change in the experience of caring.

Continuity and change

Not only has previous research and its generally burdensome perception of caring tended to ignore the many positive benefits which carers may gain from their role. Such research has been criticised for taking a static approach to the caring role, providing a historically specific snapshot of a caring situation and taking no account of the changing

circumstances of the carer or cared-for person. Such changes are likely to be particularly important in the lives of older people due to such things as the onset of retirement disability and ill health. This impact of the life-course on older people's lives has been well researched and can be divided into two broad patterns. In the first instance, retirement is characterised by continuity of previous life activities and that this continuity provides a strong anchor that strengthens the individual's sense of security and order. Thus it is argued that after retirement most older people continue traditional patterns characterised by clear differentiation between gender roles (Brubaker, 1986). In contrast the second approach views late adulthood as a period of transition and development (Erikson, 1994). Postmodernist theory also maintains that retirement leads to a role transformation. In this vein, Gilleard (1996) claims that it results in a dislocation of previous social identities and a subsequent liberation of older people who are enabled to construct identities of their choosing. In a different vein, the family stage theory argues that families change and develop over time in predictable ways and that in older age there is a shift in gender role perceptions and men and women begin to assume increasingly similar tasks (Guttmann, 1970). However, as Kulik (2001) observes, not only are these research findings contradictory but they do not take account of any development of roles within the retirement period, tending to see it as being a unitary and unchanging life stage rather than one characterised by both continuity and change.

With regard to continuity in older age, contrary to post-modern postulations of increasing social and cultural diversity in older age (chapter 1), this research suggests that older people are likely to retain many of the attitudes and traditions, which were prevalent in their formative years and will also have lived through historical periods, which differ radically from contemporary society. These generationally specific attitudes and experiences will in turn affect the way in which they perceive and manage their current situation and that these perceptions and management strategies will be characterised by a degree of uniformity. Thus it has already been seen in the previous chapter that older people's cautious approach to money differed markedly from the management strategies of their younger counterparts and this could be partially attributed to their early life experiences and the attitudes deriving from this. For example, although only in her early

sixties, Mrs Halsey readily identified herself as an ‘older person’ and cited the experience of two world wars as shaping the attitudes of her generation:

We’ve been married since 1958. We’ve always been careful, if we can’t afford anything we go without. People of our age group who have lived through two world wars have learned to be careful with their money (Mrs Halsey)

Other respondents spoke of gender role expectations in their formative years with Mr MacLellan implicitly referring to the ‘gender deal’ (Carlen, 1988), that is, a tacit agreement between men and women based upon the twin ideals of a wage earning male and informal care giving within the family by a female. Mr MacLellan went on to link subsequent changes in these expectations to wider material factors such as improving standards of living and technological innovation:

When we got married that was the way it was, nobody expected your wife to go out to work in those days, you got married and you had a family and usually the woman had plenty of work in the house. In those days there weren’t the things that they have today, washing machines and all that kind of thing, the washing would take them two days and then there’s children. I think if a woman’s got children I think she’s got plenty to do to look after them.

Cultural norms such as the ‘gender deal’ do not therefore exist in a vacuum but are part of the ‘ideological superstructure’ of capitalist society and as such are merely a reflection of its economic infrastructure (chapter 1). Consequently, recent changes in industrialised society, including the destruction of heavy industry and subsequent sources of male employment coupled with a corresponding expansion in the service sector and female sources of employment, all suggest that the ‘gender deal’ is an arrangement less likely in modern society than it has been in the past.

Against this context of cultural continuity in older age is also the high incidence of change. Retirement, the death of friends and relatives and the increased incidence of illness and disability, for example, lead to a transformation in the lives of older people and their material situation (Arber and Evandrou, 1993).

Table 4.3: The incidence of long-standing illness or disability by age (n=19266)

0-20	20-29	20-39	40-49	50-59	60-69	70-79	80-89	90 +
17.9 %	19.3 %	23.0 %	30.3 %	43.5 %	53.8 %	61.8 %	62.6 %	71.7 %

Source: secondary analysis of the General Household Survey, 2000-2001

The increasing incidence of disability in older age is well illustrated by the above table. Indeed, the lives of all the respondents in this sample had been greatly affected as a result of the disability or ill health of the person for whom they cared. For example, the previous chapter showed how this disability could lead to a blurring in the traditional gender role divisions in household financial management strategies which had characterised respondents' younger lives. This impact of the life-course on post retirement caring was explored in initial interviews by asking respondents the length of time for which they had been caring and the impact that ageing had upon this role. These issues were further explored by conducting follow-up interviews with a number of carers from the initial sample. For while the time span between first and second interviews was brief, it nevertheless helped to illuminate how, in later life in particular, the passage of time could affect the caring role. Some thought that the process of ageing had made their job easier due to the absence of conflicting work and childcare responsibilities and due to increasing targeting by formal provision. Thus as Mr Cicourel who had been a carer for 20 years said:

It was back in 1987 or 1988 when a district nurse decided that I should have more support and that's why I get a nurse every morning now to wash her (his wife) down and so forth. You see now it's a lot easier for me than it has been for the last 15 or 20 years

However, for most, ageing had made caring harder to perform. This was partly as a result of the relative poverty brought about by retirement with most carers maintaining that they had become financially worse off since they retired making it harder for them to purchase the aids and services, which would help them in their role. Broader factors incorporating access to informal support were also seen as affecting the role of older carers interviewed. Thus most spoke of how their informal support networks had

diminished in later life through the death or ill health of spouses, relatives and friends, through the geographical dispersion of children and through the loss of work colleagues (chapter 5). As Mrs Halsey said when asked how her caring role had changed since retirement:

Harder, love, harder. He used to do a lot of things for me. If I went out shopping or anything, he'd do things in the house he, he can't do it now. When we used to decorate he'd do all the ceilings, I'd do all the papering, he can't do that now, he can't do anything really. (Mrs Halsey)

The increasing incidence of disability and ill health were also a significant factor of change in post retirement caring careers with the greater incidence and severity of disability in older age serving to progressively intensify the demands on older carers. The incidence of ill health and disability amongst older carers themselves could also have a significant impact on the caring experience and a changing dynamic within the caring relationship. For, on one hand, it could promote a practical interdependence in the caring relationship (case study 4.3). On the other hand, it could make the caring role yet more demanding, as the case of Mrs Halsey illustrates.

Case study 4.2: Mrs Halsey – a disabled carer

Mrs Halsey was a 62-year-old council tenant and had looked after her husband who was 65 since he had a stroke in 1991, which left him paralysed down one side. During their 40 years of marriage, Mrs Halsey and her husband tended to pool their limited household income and make joint decisions on its expenditure. Due to her husband's long-term unemployment they also played a joint role in household tasks. However, since the onset of her husband's illness Mrs Halsey had to assume sole control for financial and household management and she found this to be both a mental and physical strain:

"So all the pressure of running this house and seeing to everything is all on my shoulders now when we used to do it together. It's not only physical; it's mental as well".

In addition to these strains, Mrs Halsey herself had developed physical problems and it had now become necessary for her to wear an oxygen mask 24 hours a day, due to breathing difficulties. Indeed she was rarely able to leave the house:

"I have a lot of panic attacks and if I panic I can't breathe so that's why I've got this, I should only be on it a few hours a day but with things that have been happening, I'm practically on it 24 hours a day"

Not only did the increased incidence of illness and disability in older age have a significant impact on respondents and their caring role, as Qureshi and Walker (1989) have maintained, this disability was experienced differently to the way it is experienced

in younger people. Thus, in accordance with the life course perspective, older peoples' past histories of independent living led them to regard the onset of disability as a source of humiliation, stigma a threat to their independence. For many older people, these perceptions of independence appeared to be closely linked with maintaining a positive sense of identity (Coleman et al, 1998) and could be compounded by the 'culture of coping' which characterized other areas of their lives. For example, not only are older people more prone to illness than younger counterparts (table 4.3), they are also less likely to ask for help on the onset of such ill health:

Table 4.4: Does not ask for help when ill by age (n=59)

AGE GROUP	16-29	30-39	40-49	50-59	60-69	70 +	TOTAL
percentage	13.6 %	10.2 %	15.3 %	16.9 %	15.3 %	28.8 %	100 %

Source: secondary analysis of the General Household Survey, 2000-2001

Langan et al (1996) uncovered a wide range of views about the meaning of independence for older people with common themes including the importance of deciding for oneself; the importance of financial resources; the limitations brought about by illness and frailty; the desire to receive necessary help without becoming a burden to others; and the development of strategies for reducing the impact of loss and decline. Evidence of such strategies were apparent amongst the respondents in this sample. Thus it was seen in the previous chapter how respondents actively adapted to their reduced financial circumstances through the utilization of financially cautious management strategies. Similarly, this chapter has illustrated the way in which older people had stoically adapted to their role, with some positively embracing the challenges and changes, which caring brought to their lives. For example, in spite of their traditional views on gender roles, many male spouse carers willingly adapted to the gender role reversal which caring had brought to their lives and even claimed to enjoy it:

In fact I don't dislike cooking do I. I like cooking and baking. In a day when she's not to bad and we can't go out, Ill find something to do like baking, cakes and one thing and another. Oh I like baking yes, and housework (Mr MacLellan)

There was also much evidence of the struggle for continuity in the context of change:

The routine of the house is exactly the same as when she ran it and it's just the same. I clean it the same. I shampoo the carpets and things like that...brought up in service she was very strict about the home and she got me into it being strict like that and I do everything for the home the same as she did (Mr Tumin)

This blurring of gender role divisions experienced by older carers, as well as the impact of material circumstances on their role serves to highlight the omissions of feminist analyses into caring which, in focusing upon issues of gender, have tended to overlook the influence of poverty and older age upon the caring experience. This apparent diversity of gender roles between respondents and the blurring of traditional gender divisions as a result of the ageing process serves to highlight the inadequacy of radical feminist assertions of the ahistorical and universalistic nature of women's caring and nurturant role (chapter 1). For as Marxist feminists maintain, such claims fail to take account of the dynamic relationship between production and reproduction, class and gender and capitalism and patriarchy, giving rise to diversity in gender roles both between and within societies (chapter 1 and 6). Indeed, it has already been seen that respondents in this study experienced variations in their caring role as a result of their material circumstances. It has also been seen that male exclusion from the workforce and the subsequent loss of their breadwinning role as a result of disability or retirement could also lead to a breakdown of traditional gender role divisions. As such, much early feminist research into caring is not only characterised by a classless analysis with its focus on gender being accompanied by a neglect of the materially based diversity in the experiences of informal carers. It is also characterised by an ageless analysis, serving to ignore the impact of ageing and the life-course on the caring experience. The next section will explore the way in which cultural continuity and age specific change contributed to the reciprocal and interdependent nature of the caring relationship of respondents in this research.

Reciprocity and interdependence

Not only has research into informal caring overlooked the influence of ageing upon the caring role, it has also tended to portray the experience of caring in generally negative

terms (Olsen, 1996). This portrayal has not only been apparent in early research into informal care (Grad and Sainsbury, 1968) but also more recently, notably in accounts of the experiences of caring amongst children which focuses on the negative consequences of their role such as physical damage and restricted social networks (Newman, 2002). Similarly negative connotations have been attached to the experience of care receiving which has been regarded as a dependency-creating concept, with the achievement of independence widely being regarded as an ideal to which all disabled people should aspire (French, 1997). However, the apparent devotion of most older co-resident carers to their role, regardless of their social class or material circumstances, helps to undermine these assumptions and the hypothesis of Arber and Ginn that the higher incidence of such caring amongst older people than younger people is due solely to their relative poverty and their subsequently reduced economic ‘leverage’ with which to resist this role. Instead it suggests that, as with the financial management strategies of carers, age-specific factors and generationally-based cultural norms can be an influence on the assumption and experience of co-resident caring. For example, the increased incidence of disability in older age may lead to a practical interdependence between older co-resident caring couples, encouraging them to assume and maintain this role. This is supported by Gladstone (1995) who suggests that, due to the fact that their marriages are based more on practical rather than affective ties, older people have to live together in order to ‘feel’ married. At the same time, their ‘culture of coping’ is likely to further reinforce the caring bond within the household while exacerbating isolation from outside agencies.

Table 4.5: Marital status by age group (n=5177)

MARITAL STATUS	40-49	50-59	60-69	70+
Married	59.4 %	61.7 %	58.7 %	35 %
Cohabiting	7.7 %	4.6 %	1.6 %	0.2 %
Single	12.8 %	10 %	7.2 %	8.1 %
Widowed	1 %	4.7 %	18.7 %	50.3 %
Divorced/separated	19.1 %	19 %	13.8 %	6.3 %
Total	100 %	100 %	100 %	100 %

Source: secondary analysis of the General Household Survey, 2000-2001

Also on a cultural level, as Coleman et al (1998) observe, in spite of general declines in religiosity, older people are much more likely than younger age groups to implicitly, if not explicitly, adhere to religious beliefs and spirituality which offer a sense of continuity and meaning in the face of decline and death. Such beliefs may lead to an emotional interdependence and strong views about the sanctity of marriage and its lifelong nature. For example, Johnson (1993) maintains that older spouses, see caring as being part of the marriage contract in 'sickness and in health' and, due to their economic inactivity, unproblematic. Therefore, contrary to individualistic models of caring (chapter 1), caring amongst older people can be understood as an expression of the expectations that underpin marriage, particularly the assumption that a couple will remain together until death (Atkin and Rollings, 1992; Manthorpe, 1994). While on an attitudinal level, it is likely that advancing years and a long history of married life will bolster the marital relationship and the caring taking place within this relationship. This is borne out by official statistics, which show that older people are much less likely than younger counterparts to get divorced (table 4.5). Indeed, out of the 34 respondents in the sample, only two classified their current marital status as 'divorced'. A further two had been divorced and had subsequently remarried. This compares with national trends in which four out of ten new marriages are expected to end in divorce (Pahl, 1999)

In accordance with the above suggestions and contrary to much research into the costs of caring which tends to portray the caring experience in generally negative terms (Olsen, 1996), many carers claimed to derive positive benefits or 'symbiosis' from the caring relationship. Moreover, contrary to Twigg and Atkins' (1994) suggestion that their three models of caring; symbiosis, boundary setting and engulfment, were mutually exclusive, some carers apparently conformed to two or more models simultaneously. For example, Mr Wilson an 80-year-old spouse carer, while experiencing symbiosis in his role, also showed evidence of boundary setting, pursuing many leisure interests such as bowling and night classes. The fact that this pursuit was facilitated by the availability of domiciliary support serves to highlight the way in which the adoption of models of caring are not only individually derived as Twigg and Atkin (1994) suggest but are also mediated by

access to resources. Similarly, while many respondents conformed to the ‘engulfment model’ of caring (Twigg and Atkin, 1994), apparently subordinating their lives to that of the cared-for-person, contrary to the negative connotations attached to this model, they also experienced ‘role symbiosis’, due to the positive benefits experienced.

I can't lead a life of my own, its just all taken up with looking after Pete. I don't mind you see. We've been married nearly 50 years and we still love each other in sickness and in health (Mrs Harris)

Notable aspects of these positive benefits included their relationship with the cared-for person and the reciprocal exchanges taking place within this relationship. In this respect, Homer and Gilleard (1990) found that affectional bonds between supporters and dependants were an important factor in mediating the experienced ‘burden’ of caring. Similarly, Abrams (1978) maintained that the two most important subjective or individual influences on positive perception of informal caring involvement are the balance of affect and reciprocity in a relationship. With regard to the former, research has found that if the affective relationship between the carer and her/his relative has always been good then there are likely to be high levels of informal caring involvement and this involvement is more likely to be perceived in a positive light (Homer and Gilleard, 1990). Reciprocity which implies a system in which participants engage in mutual and complementary exchanges, is also seen to be an important influence on personal or individual level obligation and can involve such things as shared interests and financial help. Gouldner (1973) suggests that while such exchanges need not be of equal value at all times, the caring relationship will not be sustained if they are markedly unbalanced.

Barnes (1997) identifies three types of reciprocity. Firstly the fulfillment of a sense of duty and the repayment of debt owed for past assistance.

You just feel as though it's your duty to do it don't you (Miss Hudson)

This theme has been further elaborated by Bytheway (1986) who maintained that older male spouse carers were motivated by a deep sense of reciprocal obligation and a subsequent concern to respond to the needs of care-receiving wives as a means of ‘paying them back’. As Mr Tumin said of his wife:

I just enjoy looking after her, I'm grateful, she had to look after me, she looked after me for six months when I had my hip done, now it's my turn.

A second form of reciprocity can be seen to arise from the intrinsic psychological benefits gained from caring. For while feminists have tended to resist psychological interpretations of caring (chapter 1), many carers expressed such benefits including the sense of sustained purpose and a job well done, companionship and the opportunity to learn new skills:

It's not all bad. There's a certain satisfaction in looking after the patient and in knowing that you've done a good job (Mrs Flude)

Such intrinsic satisfactions could derive from interpersonal and altruistic factors such as pleasure in the act of giving. Intrinsic satisfactions could also be gained from intra-personal sources associated with the avoidance of guilt and the desire to feel wanted or needed. Mrs Hudson expressed such satisfactions:

It's my voice he probably recognises because he's not emotional, he doesn't bother. Years ago one doctor said he wouldn't care whose looking after him but I'm not sure about that because if he's been away and he comes back here he seems so pleased to be back and he does like me to sit next to him at night on the settee, so were on fairly good terms (Mrs Hudson)

A third type of reciprocal exchange identified by Barnes (1997) is the belief held by carers that they are able to protect the cared for person from what they believe to be negative consequences or outcomes and the perceived superiority of the care which they provided as compared to alternative forms of care. As Mr Cicourel said of his 20 years experience caring for his wife:

The doctor said it's surprising she's lasted so long. Well she's lasted so long because of the medication and because I've been looking after her. She wouldn't have lasted half as long as what she has done if she had been neglected (Mr Cicourel)

Correspondingly negative views were expressed by many respondents on their past experiences of hospital and residential care admission and the poor standards of care

provided in these settings. As Mr Cicourel went on to say of his wife's last hospital admission:

You see because she can't communicate, they left her and her face stuck to her pillow and when they turned her over the skin fell off the right side of her face. That's why for the past four or five years I haven't been on holiday.

Others spoke of the way in which the cared for persons behaviour became more difficult to manage following a short term care admission due to such things as the increased confusion arising from environmental disorientation:

He gets high and disturbed and I can't control him, I can't manage him. I'll perhaps take him up to bed one night and he won't get in bed, he just gets out so I bring him downstairs and we stop here all night (Mrs Hudson)

Case study 4.3: The Lanes & the Taylors – practically interdependent spouse carers

The experiences of Mr and Mrs Lane and Mr and Mrs Taylor served to highlight the high levels of practical interdependency in the caring relationship between older spouses. For while this interdependency was expressed by many respondents, in the case of the Lanes and the Taylors, it was impossible to distinguish between the carer and cared for person, a perception which was shared by the couples themselves. Thus, Mr and Mrs Taylor were aged 92 and 84 respectively and regarded themselves as being involved in a two-way caring relationship. Mrs Taylor had angina while Mr Taylor had ear nose and throat problems, meanwhile both had sight and mobility impairments. In accordance with their reciprocal roles, they shared household tasks with Mrs Taylor doing the cooking while Mr Taylor went to the shops and collected their pensions. Mr and Mrs Lane both of whom were 86 and who also had mobility impairments performed similarly complimentary household roles:

"He washes the pots; I do a bit of cooking. We both help one another and if we aren't well, we just sit down and let it go" (Mrs Lane)

The Taylors' complimentary roles could be seen as long standing and a continuation of gender role divisions adopted earlier in their marriage. In contrast, for the Lanes, this role interdependency started only two years previously after Mr Lane had a heart attack. Prior to that he had been the main carer for his wife who had been ill since 1995 following a knee injury. This serves to illustrate the potentially dynamic and transformatory nature of the post retirement period (Kulik, 2000). It also highlights the influence of disability on these role transformations, giving rise to interdependency and changing dynamics within the caring relationship.

The relationship between the carer and cared-for person was not only characterised by an emotional reciprocity but also by a material interdependence (chapter 3) and a practical

interdependence leading to a blurring of their respective roles. Thus although all of the respondents had been identified as carers by the welfare agencies from which the sample had been drawn, some did not share this perception, preferring to see themselves primarily in terms of their spousal, parental or filial relationship to the disabled person.

You don't think of yourself as a carer until you sit down and think about what you're doing (Mrs Reid)

Moreover, in accordance with the findings of Morris (1993), it was not always possible to maintain a clear distinction between the carer and cared-for person with many respondent households being mutually interdependent in their giving and receiving of care. For example, Mr Dale, a 94-year-old amputee, felt that due to his practical interdependence with his son, caring had a positive impact on all aspects of his life, describing how he and his son, who had cerebral palsy, performed mutually complimentary household roles. Mr Dale took charge of household correspondence and financial management while his son performed the physically demanding housework tasks, which his father was unable to do due to his mobility impairment.

He's very good with his memory. I have to rely on him sometimes. He went to the training centre five days a week. Anyway, when his mother died in 1986 I stopped him going and I've taught him myself. He's learnt more by not going and the advantage is, he's here with me all day and can help me out...I couldn't cope without him (Mr Dale)

As Lewis (1998) observes, spousal care is particularly likely to be interdependent in nature with the carer and cared-for roles often being indistinguishable from each other and perceived, by older people, as an extension of marital intimacy and companionship (Milne et al, 2001).

The practical, emotional and material interdependence between caregiver and care receiver has implications for the position of former carers who are likely to experience a great sense of loss as well as possible practical and financial difficulties following the termination of their role. However, as Milne et al (2001) observe, despite these potential problems, little attention has been given either by research or by service provision to the needs or support needs of former carers. This is perhaps a reflection of the assumption

that caring is an inevitably ‘costly’ experience and those divested of this role are therefore not in need of support. However, contrary to these possible assumptions, in follow-up interviews, respondents in this situation, claimed to experience, not a relief from burden, but a significant decline in their quality of life. This was partly due to their reduced household income, which had typically fallen by over fifty per cent. It was also due to feelings of boredom, isolation and a sense of loss, not only of the person but also of their caring role. Such a loss could have a negative impact on ex-carers’ self-identity and sense of mental well-being (Barnes and Maple, 1992). As Mr Hunter said, whose wife had recently been admitted to permanent care, when seen for his follow-up interview:

I’m in a state, I don’t care if I go to sleep and don’t wake up (Mr Hunter)

Case study 4.4: Mr Cicourel & Mr Caplow – the former spouse carers

Mr Cicourel who was 69, had been caring for his wife since she first developed multiple sclerosis twenty years ago, his role becoming progressively more intensive during this time as her physical condition worsened. Mr Caplow, an 87-year-old had also been caring for his wife for a long period, since she developed diverticulitis twelve years previously. Like Mrs Cicourel, her condition had progressively worsened and for the last 6 years of her life left her flat only once. When Mr Caplow and Mr Cicourel were seen for follow-up interviews their wives had recently died and, contrary to oppressive concepts of caring, they both reported a significant reduction in the quality of life as a result of this. One aspect of this decline was in their material situation:

“My income went down by half you see, my moneys dropped down to £72...there’s lighting and gas, the telephone still to pay out of that little bit. It’s easier to live as a couple than a single person on their own. It’s cheaper” (Mr Caplow)

“My income has dropped now to less than half of what we were getting, my income now is about £125 a week and not only that the tax is still the same, the poll tax is the same, the phone bills are the same and the electricity is the same, the gas is still the same...I still have to pay water rates and so on and plus when she was alive she was getting marriage allowance which was about £1,900 a year for income tax, whereas now that’s been taken away, so I’ve got a bit saved and that bit saved I’ve got to pay tax on now, that’s why I’m disgusted with the government...”(Mr Cicourel)

A further aspect of this ‘sense of loss’ was in the loneliness and isolation which they felt, in spite of their attempts to pursue an active life outside the home:

“I’m lonely, there’s nothing that fills the space. I go out three or four times a week to the church hall to play snooker but when you come back the place is empty” (Mr Caplow)

“I still play bowls and for a couple of hours I forget everything and then I come back to an empty house. A house is a house; it’s not a home” (Mr Cicourel).

The interdependency between givers and receivers and the positive benefits gained from the caring role are clear, yet provision for carers has been implicitly based on a negative concept of caring and a conflictual perception of the caring relationship as illustrated in

assessments which see the needs of the carer and the cared for as distinct. This is exacerbated by community care policy, which places emphasis on individuals rather than contexts (Milne et al, 2001). For example, in spite of its advocacy of social inclusion, integration and citizenship, the practical implementation of community care policy tends to reflect the individualistic approach of the medical model. This is because it places great emphasis on individual need and the achievement of independence with little reference to the individual's relation to others (Argyle, 2000a). This conflictual perception has been further compounded by the development of campaigning user groups such as those for disabled people and informal carers (Barnes, 1997). For while such groupings facilitate the collective identity of their members, these identities are often secured in opposition to 'others' and impose one dimensional analyses on overlapping identities:

The danger with current community care policies and practices is that rather than giving appropriate support to families with caring responsibilities, they are forcing people into separate and opposed camps (Barnes, 1997: 136)

Barnes (1997) goes on to maintain that these practical and emotional renegotiations cannot be effectively understood by separating for the purpose of assessment the needs of each partner. For while such a separation may be a useful administrative device to enable service providers to categorise client and carer and so determine to whom their prime responsibilities lie, it is not an accurate reflection of the interdependency and interpersonal relationships which characterise the lives of older carers.

CONCLUSION

Chapter three illustrated the impact of material resources on the role of older carers and its implications for contrasting theories of poverty and older age. It was thus shown that, in accordance with situational constraints theories, limited access to material resources affected the caring role through such things as the promotion of material interdependence and well as through the exacerbation of the objective and subjective demands on carers. However, contrary to the determinist assumptions of situational constraints theories of poverty, the impact of such resources was mediated by age specific factors of culture and disability. Indeed, it is significant in this respect that while, within this sample, relative

poverty could potentially strengthen the bonds between household members through the creation of a material interdependency, this markedly contrasts to the position of younger people in poverty in which family break-up has been found to be common. The latter phenomenon is commonly attributed, from a cultural –functionalist perspective to fecklessness and irresponsibility (Lewis, 1968) or from a situational constraints perspective, to economically derived issues, notably, the lack of motivation or incentive to enter marriage and remain within it (Liebow, 1967; Havas, 1995). These potentially diverse reactions suggest that both non-material and material factors are needed to help to explain the experiences of respondents.

This chapter has further pursued this theme and broader interpretation of resources with specific reference to the experience of co-resident caring. For example, the increased incidence of disability, which accompanies the ageing process, could be seen to lead to a progressive transformation in the lives of co-resident couples, serving to override the influence of other social divisions, with culturally prescribed norms on gender role divisions becoming gradually blurred in respondent households. Disability also had an important influence on the demands of caring and led to changing dynamics in caring roles and identities, however, this effect was not clear-cut. For, on one hand, the disability of the carer and cared for person could obviously intensify the demands of the caring role and have a potentially negative impact on the ‘costs’ of caring. Thus it was seen that coping with behavioural problems and personal care needs could be a source of great personal stress to carers and this stress was exacerbated by their own disabilities which rendered them less able to cope with caring demands. On the other hand, the disability of the carer served to potentially enhance the benefits which they gained from their co-resident caring role due to the creation of a practical interdependence with the cared for person.

This interdependence in the caring role serves to undermine oppressive and individualistic concepts of caring (chapter 1) and was further facilitated by cultural and psychological factors such as the positive emotional benefits derived from caring as well as the belief held by older people that they have to live together in order to ‘feel’ married

(Gladstone, 1995). Consequently, just as subjective perceptions of poverty are affected, not only by objective material position but also by culturally derived attitudes and expectations relating to perceivedly adequate standards of living, so the subjective perception of the caring role was similarly mediated for respondents in this sample. This meant that they commonly subjectively underestimated their objective degree of caring responsibility due to their apparent devotion to their role and to the cared for person. At the same time, their attitudes of self-reliance and ‘culture of coping’ meant that, just as they were unwilling to admit to material hardship, they were equally reluctant to admit to hardship in their caring role. The appearance of being able to manage was crucial to the maintenance of their positive identity and ‘sense of self’ (Tanner, 2001). Moreover, contrary to postmodernist claims of diversity and cultural heterogeneity, these attitudes appeared to be shared by the majority of respondents. In spite of these suggestions, it could be argued that the older carers in this research were in fact unrepresentative and that other older people who have chosen not to assume a caring role may display very different attitudes. However, it is beyond the scope and purpose of this research to examine the attitudes of older people in general, only those of the co-resident carers in this sample. Moreover, as preceding sections of this thesis have highlighted, existing research tends to suggest that many other older people do indeed share similar attitudes and experiences to those of respondents in this research. This is shown, for example, in the high incidence of co-resident care found amongst older people (Milne et al, 2001) and in their attitudes to the onset of disability (Baldock et al, 2001), to their material situation (Walker and Maltby, 1997) and to the maintenance of independence and self-reliance (Langan et al, 1996). As such, the complex interaction between culture and attitude, disability and material constraint rendered unique the way in which older carers managed and experienced their role and showed diversity from the management strategies used by younger counterparts. It will be a purpose of the next chapter, ‘*Access to Informal and Formal Support*’ to explore the success with which supportive services have responded to this uniqueness.