

**CARE IN THE CONTEXT OF MARRIAGES IN LATER LIFE:
AN ANALYSIS OF EXPERIENCES AND PERCEPTIONS.**

**Submitted by Alison Hill in January 2007 for the Degree of PhD in the
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Summary

This study is concerned with care in the context of later life marriages. Taking a qualitative approach, it explores how forty spouses experienced and made sense of care within their marriages. From the data that these spouses provide in joint interviews, it identifies how they supported and cared for each other and how they sought to maintain their relationships and life styles in the face of disability. It also reflects on how within their care experiences these men and women strove to preserve not only their spousal roles and identities but also their autonomy as couples. Thus it emphasises that they experienced and made sense of care both as individuals and as couples and how this duality resulted in care practices and constructs that supported and challenged gendered care expectations.

This study also looks at the couples' support networks, in particular what care the spouses were prepared to accept from whom and teases out their reasons for their choices. This reveals that they understood care in terms of their relationships; it was about being a spouse, a relative, a friend and a neighbour. Hence, their acceptance and provision of care were underpinned by their values and moral principles, and in particular reciprocity and fairness, that structured their personal and formal relationships. Within this context the use of services offered them a morally acceptable means of meeting their care needs and protecting their informal relationships.

This study also gathered interview data from fifteen home service providers to examine how they experienced supporting older couples and how they understood the use of this service by such service users. From a comparison of these data with how the spouses perceived service-use, significant implications for social policy and care practice emerge.

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CHAPTER 1: INTRODUCTION

INTRODUCTION

This chapter explains what this study is about and places it in the wider context of care research. It also details the aims and objectives of this study and how their fulfilment should potentially contribute to a greater understanding of care within marriage in later life. Finally the chapter provides an outline of the structure of the thesis.

OVERVIEW

This study is about the care experiences of forty older spouses who live in the North East of Scotland and whose ages range from mid-sixties to nineties. It explores how these couples practise and understand care within the domestic arena and the more public sphere of their social lives in terms of relationships, roles and moral values. It examines how their supportive social networks help them address the demands of care, identifying who provides them with what kinds of support and how they make sense of such help.

This study is also concerned with the provision of home care to older couples. It analyses how nine home carers and a group of supervisory and managerial service providers from two neighbouring local authorities experience supporting older married service users and how they perceive their need and use of home care.

In contrast to the more usual practical / non- practical approach to understanding care, this study assumes a relational approach to ensure that the complexity of caring relationships can emerge. This reflects the basic premise that care in later life marriages cannot be fully understood in individual terms. In taking such an approach, the thesis does not privilege any one particular theoretical paradigm but instead draws on a range of concepts and debates. It looks to feminist theories and research, in particular the work of Graham (1983a), Ungerson (1983a, b, 1987), Mason (1987a,b, 1996) and Finch and Mason (1993) to understand issues of gender, carer identity, caring activities and relationships. In its exploration of the spouses' relationships with their kith and kin it draws primarily on anthropological research and network theories, including those put forward by Wenger (1984, 1990b, 1994) and Jerrome (1992). The arguments put forward with regards to service provision are underpinned by social policy and social work theories. Thus, its approach can best be described as eclectic.

The anticipated contributions of this study arise from its assumptions about care within marriage and how it investigates them. These assumptions are (i) care is a gendered experience, (ii) care within long-term marriages cannot be adequately understood in individual terms and (iii) older caring spouses are also friends, neighbours, relatives and possibly also service users as well as husbands and wives. Thus, it explores and seeks to explain care in relationship terms and employs joint rather than individual interviews to gather data from a couple- perspective and rejects the frequently used practical / non-practical framework in favour of a relational one. In

this way it intends to identify how spousal caring relationships intersect with other supportive relationships and how all the spouses' different caring relationships are influenced and structured by a range of interplaying factors including gender, interdependency, principles and moral values.

This study also assumes that care within marriage involves taking care of the spousal relationship, life style and home. Accordingly, it adopts an unusually broad understanding of care that incorporates activities that are not conventionally defined in care terms but are vital to independent functioning of households. This means that it is able to reveal the breadth of caring within marriage and the contribution that support with activities – such as home and garden maintenance, driving and socialising – make to care experiences of older spouses alongside that of traditionally recognised care activities. The value of such information lies in its implication for community care policies and development of adequate and appropriate service provision.

A potential problem with the assumption of such a broad definition of care is that it could result in a lack of focus. To minimise this risk, this study does not overtly emphasise this broad understanding of care in its recruitment material but rather in whom it is interested, namely older couples who are coping with a disability. Whilst this may lead to an under-representation of couples who are mainly involved in offering support with activities not conventionally defined as care, it does not prevent their participation. Furthermore, it allows this study to remain open to finding out how and what older spouses define as care.

Finally, this study assumes that local authority home care and similar services play an important practical and conceptual part in how care in later life is experienced and understood. The identification of how home carers experience supporting older married service users and how they perceive their use of this service should expose the strengths and weaknesses in homecare provision for such service users. Thus, this study should contribute to the development of suitable service provision and care practice for older couples.

LATER LIFE SPOUSAL CARING RELATIONSHIPS IN CONTEXT

The full extent of the older carer population in Britain was first revealed in the 1985 General Household Survey (GHS). This showed that 18 per cent of the total carer population and a quarter of the co-resident carer population were aged 65 years old or more (Green 1988). The 1995 GHS similarly found that older carers made up 20 per cent of the overall carer population and 28 per cent of the co-resident carer population (Rowlands 1998). In Scotland, 26 per cent of the co-resident carers in 2001 were at least 65 years old (Scottish Executive 2002a). Analysis of the results of first Scottish Household Survey in 1999 revealed that the incidence of limiting chronic illness rose steeply for men in their 60s and for women in their 70s but amongst older people aged over 85 more women than men were in poor health and had difficulty performing everyday activities. Furthermore, within the 85 plus age group, 41 per cent of men and 31 per cent women who did not live alone were found to care for someone within their household

(MacDonald et al. 2000). Most of these carers can be assumed to be caring for their spouses since men and women of this age, if not living alone, tend to live with their marriage partners (MacDonald et al. 2000). However, whilst the proportion of men aged 65 or over in 2001 who were providing co-resident care exceeded that of women, the demography of this age group meant that more women than men were caring (Source: Scottish Executive 2002a).

Although marriage is the most common kind of co-resident caring relationship in later life in Britain, the officially identified number of older spousal carers is probably an underestimate (Milne et al. 2000, Parker 1998). This is because older spouses tend to view the provision of non-specialised and undemanding forms of care as an ordinary part of their marriage rather than as care and so they tend not to identify themselves as carers. Furthermore the subjective experience of spousal care is poorly understood and has attracted only limited research attention. Nevertheless, studies that have focused on this subject have repeatedly found that interdependency is a key influence on how older spouses make sense of and experience care (Milne et al. 2001, Thornton 1989, Wilson 1995). Wilson (1995) captures the essence of this interdependency in the title of her study 'I'm the Eyes and She's the Arms' whilst in her study Thornton (1989) highlights older spouses' acceptance of caring as a 'taken-for-granted way of life'. Allen et al. (1992) and, more recently, Milne and Hatzidimitriadou (2002) have reported that the roles of carer and care recipient in some later life caring relationships are indistinguishable because both partners are engaged in looking after one another. Moreover, in cases where partners feel there is an overall sense of fairness or reciprocity in their relationship, psychological interdependency and balance may persist, even when actual caring interdependency no longer does (Kahana and Young 1990, Wenger 1990a). However, to assume that interdependency makes caring easy would be wrong. Siegel (1990: 72-77), in her exploration of growth in later life, claims that spouses are affected both positively and negatively by changes in each other's well-being as these can lead to an increase in 'bonding and sharing' and, due to anxiety, to an increase in conflict.

Huston and Robins (1982) claim that partners in a close relationship affect and are affected by each other's behaviour, attitudes and beliefs about one another and their relationship. From this perspective, and as the foregoing references illustrate, spousal care is about the interpersonal – the caring relationship, or marriage and its properties – as well the activities, attitudes and feelings of individuals. This implies that care within long-term marriages in later life cannot be adequately understood in individual terms.

Wenger (1984b, 1990b, 2001) explains that older people have supportive social networks that are made up of their families, friends, neighbours and service providers. Thus, it can be argued that spousal caring relationships need also to be understood within a network context.

In Britain, home care, that is either provided or arranged by the local authority, represents one of the most important sources of such provision to older people (Scottish Executive 2004a,b, Sinclair et al. 2000). The Scottish Executive (2001a point 2.12) describes this service in its

report 'Fair Care for Older People' as 'personal care' plus 'domestic care'; 45 per cent of staff time being spent on the former and 55 per cent the latter. At the time of this report and during the interviews for this study both personal and domestic care were means-tested but in 2001 free personal care was introduced. Almost two-thirds of home care provision is delivered during the week; the peak daily periods for the delivery being morning and lunch-time with a little over a tenth of home care being delivered after seven o'clock in the evening (Scottish Executive 2002b).

The majority of home care providers are middle-aged women and women represent also nearly three-quarters of the home care user population (Scottish Executive 2001a, 2004a,b). In March 2004 around 70,000 people in Scotland received home care; 70 per cent of these service users were women, 81 per cent had physical disabilities, 84 per cent were aged 65 years or over and 65 per cent lived alone (Scottish Executive 2004b). What percentage of home care users were married couples is unclear because of the classifications used within the available statistics. In 2004, around a third of home care service users in Scotland were described as not living alone. Twelve per cent of these were described as living in households where the service was provided to more than one person, with a further 22 per cent being described as living in households with someone who was not a service user (Scottish Executive 2003, 2004b). Most of the former are likely to be married couples and some of the latter also. The reasons why older couples represent only a minority of home care service users include demographic, social and ideological factors but also practice and policy ones. In their research into coping with dementia, Levin et al. (1985 and 1989) found that older couples were less likely to be offered and to receive support from home help than older people living alone or with other supporters. Milne et al. (2001), over a decade later, identified in their caring in later life that home care services are not only targeted towards older people who live alone but also assessment and allocation procedures tend to assume an 'individual' focus. Whilst such services stand accused of failing older couples at the level of assessment and allocation, whether this is also the case with regard to service delivery is much less clear for this remains a largely unexplored subject; a question that this study aims to address.

AIMS AND OBJECTIVES

The overall aim of this study is to provide a greater insight and understanding of care within long-term marriages in later life. Atkin (1992), in his study of differences between informal carers, claims that relationships affect the experience of care and the response of service providers. This study originally sought to examine how different types of dyadic relationship influence the experience of care in later life but at quite an advanced stage in the course of interview recruitment only three non-spouses had been identified, only one had been interviewed and there were no indications of the recruitment of non-spousal participants becoming more fruitful. Therefore, the overall aim was modified to concentrate on care within

marriage in later life. Five interlinked objectives, detailed below, were derived from this modified aim.

Objective One: To Demonstrate the Breadth of Care within Marriages in Later Life.

This objective aims to show that care within marriage is about sustaining the marital relationship and lifestyle as well as supporting individuals. Accordingly, this study assumes an unusually broad definition of care that embraces all different kinds of help and support couples require to live independently within their communities. Thus it reflects on the contributions that help with home and garden maintenance, socialising and day-to-day travel as well as personal care and domestic activities make to the independence of older couples. It also asks whether current community care policies and provision are adequate or whether they leave older couples with unmet needs that place their independence at risk.

This broad definition of care also facilitates a deeper insight into the gender-based divisions within caring in marriage and into how older married men experience care. This leads to a clearer understanding of how older married men feel about needing and accepting help with activities such as DIY and driving that are associated with their spousal role and identity.

Objective Two: To Explore the Impact of Interdependency on How Long-Term Spouses Experience and Understand Care.

Research into care within marriage has repeatedly found that spousal caring relationships in later life tend to be characterised by interdependency (Allen, et al. 1992, Milne et al. 2001, Wenger 1990a, Wilson 1995). This second objective looks at whether and if so how spousal interdependency shapes the needs of older couples. For example, does interdependency link the individual spouses' care needs or does it create 'couple' needs? Also, in view of the dominance of 'individual centred' approaches within care provision, this study asks whether and how service providers recognise and respond to spousal interdependency. Thereby it identifies whether care practices and provision discriminate against older couples as service users.

Objective Three: To Investigate How Spousal Care Expectations and Interdependency Interface with Gendered Care Expectations and Practices.

The influence of gender on care within marriage has been extensively researched (Duncombe and Marsden 1993, 1995a, 1995b, 1998, Graham 1983a, Mason 1987a 1987b, Ungerson 1983a, 1983b, 1987, 1990). However, this study adds to this area of knowledge by examining whether and how interdependency within marriage impinges on gendered care norms and expectations within spousal care practices.

Objective Four: To Understand the Spousal Caring Relationship within the Context of its Supportive Network.

Objective four builds on Wenger's (1984, 1990, 1994, 1995, 2001) research into the social support networks of older people. It identifies who gives what support to older couples, what meaning they attribute to it and thereby what makes support from different sources acceptable to them. The comparison of data collated from the couples and service providers on informal care and service-use highlights inconsistencies or discrepancies between how the former and latter understand the function of these different sources of care. Such information should aid appropriate care and service planning both on a personal and policy level.

Objective Five: To Reflect on the Contribution of Home Care to the Care Experiences of Older Couples.

Home care is, in general, an under-researched care topic and, notably, no published research appears to have concentrated specifically on older couples and this service. This study explores how frontline home care providers, especially home carers, understand and respond to the needs of older married service users. In particular, it is concerned with the question of whether these service providers are aware of and respect the duality and complexity of the needs of these service users. The answers to such questions carry implications for both care policy and practice.

STRUCTURE OF THESIS

Following on from this introductory chapter, chapter two outlines the methods and methodologies that underpin this research and introduces the older couples and home care practitioners who took part in it. It begins by defining care as a gendered and relational experience and by explaining why this study chose qualitative and grounded research techniques to gather and analyse data. Then, it records how the participants were recruited and the difficulties encountered in the process. The chapter also considers how gender, age and accent can influence the generation of data and provides examples of where these characteristics appeared to impact on the sharing of information within this study. Having set out how the data were collected, the thesis moves on to analyse them and to draw out their implications for practice and social policy.

Chapter three examines how the themes of reciprocity, fairness and interdependency permeated the spouses' practice and understanding of domestic care and marriage. It details how the spouses coped with the disruption that their care needs brought to their division of domestic labour, including how they addressed their domestic care needs, what support they accepted from what sources and why they felt these to be appropriate. In this way it reveals the influence of social expectations and assumptions about care, gender and age-appropriate activities as well as the spouses' personal moral values on how the spouses experienced and made sense of their

need for assistance with these gendered and identity linked activities. Moreover, the chapter highlights the duality of the spouses' experiences and perceptions; they experienced and made sense of assistance or care as gendered individuals and as couples.

Chapter four reveals the duality of the spouses' experiences and the reciprocal character of their supportive relationships within the relatively public arena of their social lives. It examines how the couples managed the impact of disability on activities that made up their individual and shared social lives. Thus, it identifies the kinds of support and assistance that they received from within their marriages and from other sources and how they conceptualised such help. As it reflects on this the impact of the spouses' personal care needs, gender, social expectations and ageist attitudes on their choice of social activities and thereby social lives emerges. This chapter also shows how participation in social activities provided the spouses not only with respite from the routine of care but also with the opportunity to interact and exchange social support with their friends and acquaintances.

All the spouses provided and received more care from within than outwith their marriages. Yet, as chapters three and four suggest, their friends, neighbours, family and service providers made a significant contribution to their care experiences. Chapter five focuses on the support that couples received from their support networks. It begins by attempting to identify the couples' network types and determine what support the spouses were prepared to accept from what sources, how they understood it and what factors underpinned and structured their acceptance of support within their informal and formal caring relationships. It explains how and why the couples differentiated between different types of care services and how they perceived their use of these different types of service. It also compares how the spouses viewed their use of domestic care services with the models put forward by Twigg (1989) and Twigg and Atkin (1994) as to how service providers conceptualise carers and considers whether it is appropriate for services to assume an individual focus when supporting older spouses in long-term marriages characterised by interdependency. This comparison, imbued with policy and practice implications, serves to link the foregoing chapters with chapter six.

Chapter six assumes an alternative perspective on care within marriages in later life, namely that of home care service providers. Consistent with research conducted by Warren (1988, 1990), Walker and Warren (1996) and Sinclair et al. (2000) into home help and home care services, this study focuses on the experiences, care models, training and support that home carers draw on to inform their practice and perceptions but unlike these studies, it assesses them in relation to older married service users. The potential influence of the home carers' approaches to practice and views on couples' use this service is highlighted throughout the course of this chapter.

Chapter seven critically appraises the methods adopted to complete this study and draws together the themes; issues and findings from each of the foregoing chapters to present the main conclusions of the study and makes explicit their implications for care policy and practice.

These are that care within marriage in later life cannot be adequately understood in individual terms or in isolation from other caring relationships but, in spite of and in contrast to this duality, home care operates an individual-centred approach to provision. To close, this thesis points to issues and questions that arose in the course of this study that require further investigation.

CHAPTER 2: METHODOLOGY AND METHODS

INTRODUCTION

This chapter analyses the methodology of study and methods it used to collate data. It begins by presenting an understanding of care as a gendered and relational experience before it discusses the choice of data collating techniques and the moral and ethical issues involved in their application. The chapter then moves on to focus on how this study approached the recruitment and interviewing of participants. It details the difficulties encountered in this process and how these resulted in the decisions: (i) to concentrate on how older spouses experience and make sense of care and (ii) to interview home care service providers. Finally, it considers the influence of gender, age and accent on what data were made available for analysis and whether those who took part in this study are representative of older caring couples and home care service providers in the general population.

THEORIES, METHODOLOGIES AND METHODS

Couples and Caring in Theory and Methodology

Theory and methodology are closely linked since how something is understood influences what kinds of questions are about it, how they are asked. In turn this influences what kind of information is provided and thereby how the matter is understood (Dill 1982, Hardy 1987, Millman and Kanter 1982, Oakley 2005, Seymour et. al 1995, Smith 1982). Care is highly gendered and a very familiar concept and experience but it is inconsistently defined and only poorly theorised (Graham 1991, Seymour 1999a, Thomas 1993). For example, care can refer to practical activity, emotions or feelings, a type of industry/form of employment and a defining aspect of identity or intimate relationships such as marriage and in each case care is structured by gender. (Duncombe and Marsden 1995a, Graham 1983a, Green 1988, James 1989, 1992, Qureshi 1990, Rimmer 1983, Rowland 1998, Thomas 1993, Ungerson 1983a, 1990). Thomas (1993) suggests that this inconsistency in how care is defined or understood is attributable to the tendency to present, as comprehensive, segments or partial representations of the totality of care that relate to a certain set of social relations. Thus, she urges research to identify clearly the segment of the totality of caring with which it is concerned. The segment of care with which this study is concerned is care as it is experienced and understood by older married couples. From a feminist perspective a couple may be considered to be and accordingly researched as a form of family (Seymour et. al 1995). Feminist theories of families recognise that families are made up of individuals with their own experiences, views, values and level of influence. Accordingly, they foster methodologies that examine and explore the differences between the experiences and views of the various family members. Thus, any gender differences in how older wives and husbands experience and understand care should be detected.

The recognition of the diversity of individuals and their experiences within families is undeniably, important. Yet, especially in respect of long-term caring couples, there is a risk of overemphasising or placing too much value on individualism. In such cases 'to do "justice" to the experiences of individuals, it is necessary to understand the complexities of relationships (Seymour et. al 1995:5).

Thompson and Walker (1982) claim that a couple is composed of but is always 'more than' just two single individuals; it is a relationship and as such has relational properties, such as power balance and mutuality. They also point out:

there has been a steady accrual of evidence that ...each partner's portrait of a relationship may be systematically biased, and that studying only one partner's perspective denies the complexity of relationships (Thompson and Walker 1982: 889-890).

Similarly, Maguire (1999: 214), in her methodological research, insists that to understand close relationships 'the researcher must use the dyad as the unit of analysis' because relational concepts or properties are central to the study of relationships.

Care, as well as being a gendered experience is also a relational experience. It takes place in and often is about relationships. This suggests that it cannot be fully understood in individual terms. It has also to be examined and analysed in terms of the relationship in which it takes place and to which it is possibly attributed as well as an individual experience. On this basis it is assumed that older spouses in long-term marriage experience and make sense of care as gendered individuals and as couples. Hence, this study adopts a dualistic understanding of care that explains it in terms of relationships and gender.

Social or human experiences, including the experience of care, are made up of / involve both the tangible and objective aspects and the interpretive, attributive or subjective aspects.

Accordingly, they can be understood and examined from both a quantitative and qualitative perspective.

This study assumes a qualitative research perspective and approach. It focuses on how older spouses subjectively understand care and how they make sense of their needs and care activities and draws on ideas or theories about gender and also caring relationships to analyse and explain their experiences. However, it could have assumed a quantitative approach focusing on the objective and quantifiable factors and concrete circumstances of their care experiences. For example it could have examined how much assistance and what kinds of assistance older spouses need and provide for each other, how much of their income and time is taken up on addressing their care needs, what kind of services they use, how much service input they receive and how adequately the latter meets their identified needs and assess how these factors correlate with different kinds of care experience. It could then have used data to suggest how older spouses' experience of care might be improved.

Quantitative research tends to require large numbers of participants to achieve reliability. Large-scale surveys such as the General Household Surveys as well as care studies have

gathered and analysed data about care in later life so that many quantitative or statistical data about this experience are already available. For example, as discussed in chapter 1, caring in later life marriages tends to be a time consuming, physically arduous task made up of a wide range of care activities with limited input from service providers (MacDonald et al 2000, Milne et. al 2000, Milne et. al 2001, Milne and Hatzidimitriadou 2002, Parker 1998, Rowlands 1998).

The availability of such information and requirements for gathering quantitative data raised the question, as to what this study, given its character and limitations, could actually contribute to the existing body of information, especially as it was anticipated that the recruitment of such numbers could be a problem. More significantly, this study did not assume a quantitative approach because it was unsuited to the questions it wanted to research, namely how older couples subjectively experience or understand and make sense of care within their marriages. To investigate this, it needed to find out what lays behind the statistics of care: Why do carers and assumedly older spouses, whose experiences of care are very similar in terms of amount and types of care they provide and service input they receive, actually experience care so differently? To answer these kinds of questions requires a qualitative approach that offers older spouses the opportunity to tell in their own words their stories and so reveal the whys within their experiences. In her reflections on quantitative and qualitative methodologies Oakley (2005:249-250) emphasises that research methods must fit the questions being asked and be sensitive to power relationships. Quantitative research methods have provided many of the data that prompted this study to ask how do older couples actually experience but to answer this question it needed to assume a qualitative approach (Allen et. al. 1992, Green 1988, MacDonald 2000 et.al, Milne et. al 2000, Milne 2002, Milne and Hatzidimitriadou 2002, Parker 1998).

Analysis of the Data Gathering Process

In addition to being concerned with how social theories are applied within research, methodology is also about how research is conducted. In her reflections on whether there is a feminist method, Harding (1987:2) claims that there are basically only three methods of research technique, namely observation of behaviour, interrogation of informants and examination of records. Reference to and the review of existing literature, including statistical, quantitative as well as qualitative data on care, provided the impetus and context for this study as well as the basis for questions it posed. However, its primary research technique or data gathering method was the carrying out of interviews.

The in-depth qualitative interview technique is extolled as a practical and penetrative method for gathering information about personal experiences and subjective opinions (Ackroyd and Hughes 1992, Finch 1984, Kaufman 1994, Mason 1987b, May 1993). Kaufman (1994: 125) states that in using this research technique:

the investigator learns not only what is pertinent to the individual ... but something about the identity of the individual and how she or he defines and constructs the self in relation to the subject matter at hand.

These qualities suggest that this information gathering technique would be a suitable approach to adopt to gather data from older spouses to fulfil the objectives of this research. Indeed, in reality it was the only viable option. I did not consider observation of how spouses care for each other within their own homes to be morally or ethically permissible, least not because of the issue of privacy and to establish how spouse understand and make sense of care requires discussion. In contrast to the observation of older spouses caring for each other, the delivery of home care services may have been morally acceptable but for this study it was impractical. This is because as a part-time student in full-time employment without access to a car and with an average annual leave allowance I could not realistically schedule and carry out enough observations so as to have adequate data. Thus, the primarily data gathering technique used for aspects of this study was face-to-face interviews preceded by examination of published material in order to an adequate understand from which to develop interview questions.

The Development of Interview Questions

Analysis in this study is based on Grounded Theory analysis. Ely, et al. (1991) also claim that the qualitative research process evolves; it is a cycle of doing-thinking-doing, with transcriptions and reflections. Existing knowledge of the topic provides the initial questions to begin this cycle, whilst analysis of collated data gives rise to additional questions for exploration in later interviews. Similarly, Bryman and Burgess (1994: 217) claim that data collection and analysis are not separate and discrete research phrases rather they are simultaneous, continuous and interwoven with one another.

My initial interest and knowledge in co-resident care within intra-generational most important other relationships in later life began with and grew out of my personal and professional experiences. I knew older relatives and friends of my own who cared for each other and, as a hospital social worker, I had also been aware of and involved with older patients who on discharge had returned home to be cared for by their co-resident contemporary most important other, usually by a spouse or occasionally by a sibling, friend or partner. To develop this clearly very limited and highly anecdotal understanding of spousal care in later life I turned to published data, statistical information and care literature. From my understanding of information in these materials and the questions that they left inadequately unanswered, I formulated my interview schedule. In line with the grounded approach, I refined and developed my interview schedule as fresh data emerged but put the same set of basic or key questions to all the spouses. The character of these revisions and their basis are discussed in further detail later in this chapter.

Questions from Literature

Interview Questions for Couples

Care statistics such as those compiled by Green (1988), Rowland (1998), Milne et. al (2001) and Milne and Hatzidimitriadou (2002) and the hierarchy of care derived by Qureshi and Walker (1989) show that when older people need care then their most likely source of care is someone with whom they lives, usually a spouse. These statistical studies also reveal what caring can and often does, involve within older spousal caring relationships, namely the provision of assistance with a wide range of everyday tasks including personal hygiene, mobilising, medication, finances and domestic activities, whenever it is required, for however long, usually with limited help from other sources (Green 1988, Rowland1998, Milne et. al 2001, Milne and Hatzidimitriadou 2002). To provide an insight into how the spouses in this study experienced care I had first to identify what types of care and support they needed, received and provided. I planned to approach this issue directly and indirectly. So as well as asking the spouses outright about what care they received and provided, I intended to encourage them to describe a typical day, how they managed their disabilities on a day-to-day basis and how their routines and social activities had changed as a result of their limitations. I anticipated that such a description would provide more a more comprehensive insight into the types and levels of care that the spouses received and provided than direct questions as in responding to such questions many smaller instances of care tend to get overlooked. Nevertheless, I still expected to have to ask the spouses specifically about whether they needed help and if so received assistance with activities for example gardening, DIY, transport and going out socially, that are not usually defined or identified as care but they do have a part to play in the running of a household and maintaining social relationships. Qureshi and Walker (1989) and Parker (1993) report that older people often find these activities and accessing assistance with them difficult. My personal and professional experiences also suggested that they were issues about which older couples were concerned.

I did not want to just examine what types of care the spouses received and provided but how they actually experienced and understood care within their relationships.

Qureshi and Walker (1989) suggest that the older people and their families experience or understand familial or informal care not in terms of care but family relationships. Caring for an older family member was what being family was about regardless of whether the underpinning motivation was affection or dutiful obligation. They also point out that many older people within their study valued their independence and resisted asking their families for help because they did not want to be a burden or feel beholden to them. Thus, they highlight the value that these older people placed on reciprocity. Would the spouses in this study resist asking their kin for assistance? Moreover, Qureshi and Walker (1989) focused on intergenerational caring leaving open the question as to whether spouses would have the same kinds of worries about accepting help from each other?

Finch and Mason (1990, 1993,) identified the importance of give and take in exchange of help within families. They suggest that the provision of familial help or support, rather than being governed by kinship rules, results from negotiations, in which reciprocity is an important guiding principle. However, they stress that this reciprocity tends to be less about the equality of what is exchanged than how the participants perceive or qualitatively evaluate the exchange taking into account relationship histories, fairness and morale identities. The importance of the non- practical in care evaluations is apparent in research conducted by Mason (1987a,b), Wenger (1989) and Wright (1993) in their studies of spouses and older carers. In each of these studies the participants stressed that to them caring was about much more than practical matters; it had to do with company, sharing, duty, commitment to one to another, emotions, marital vows, fulfilment of spousal and gendered roles and expectations and the expression of personal identities. Such factors may account for why Allen et. al (1992), Thornton (1989) and Wenger (1989) found that, in many later life spousal or most important other caring relationships, in which one partner was clearly the carer of the other, the partners described themselves as caring for each other.

In the light of the foregoing studies I wanted to ascertain how the spouses understood the exchange of care within marriage, why they cared and what principles and values underpinned and structured it. To access this information I planned (i) to take note of how they spoke about what they did for each other and how they used and interpreted care terms such as carer, (ii) to ask the spouses why they cared or why they felt their partner cared and how they felt about providing and / or receiving care from their spouses (iii) whether there were any ways in which they were unable to assist each other and how they felt about it and (iv) who they turned to for assistance with activities that they could not manage and why to this source?

As this last question indicates spousal caring relationships do not exist in isolation from but as a part of a network of other social relationships and was part of my exploration. The social network approach to understanding care and support has mainly been developed and applied in Britain by Wenger (1984, 1990, 1995). This approach recognises that older people tend to have a network of support made up of kith, kin and/or service providers. Wenger (1984) identifies five different types of supportive network based on availability of local close kin and involvement with family and friends and with community organisations / groups. Thus, the type of supportive network that any older person has mainly depends on whether s/he has family and whether they live nearby and their own involvement in community activities. Wenger (1984, 1990) explains that the different types of network offer different kinds and intensities of support and hence they tend to be associated with differing levels of care service use.

The network approach to understanding care prompted me to ask the couples about their kith, kin and service use. I intended to use this line of enquiry to identify what kinds of support the couple accepted from what sources, whether it is given to one or both of spouses, how the

spouses it perceived and under what kinds of circumstances it is provided as well as using it as a means of gathering information on their social lives.

Finally, Anderson and Bury (1988), Arber and Ginn (1991, 1992b), Brubaker (1985a,b), Askham et. al (1992), Briggs and Oliver (1985), Ginn and Arber (1991), Peyrot et. al (1988), Townend (1987), Ungerson (1987), Victor (1991) and Walker (1987) identify the length of marriage, diagnosis, access to and use of aids, adaptations and care services and class or socio-economic status as having an influence the experience of care. Accordingly, I prepared questions about these factors to put to the spouses.

Interview Questions for Service Providers

Older spouses make up a significant minority of home care service users but references to the provision of home care to older couples within published care literature are few (Scottish Executive 2003). Thus, I wanted to identify how much experience the service providers in this study had of supporting older couples, what challenges they found in supporting these service users, what training and support they received to help them support these service users and whether they felt they were adequately.

Warren (1990, 1994) and Twigg and Atkin (1994), in their research into home help and home care provision, identify the influence of gender and family care models on the practises and perceptions of home care service providers. I intended to focus on these same issues but to look at them in relation to home carers' practise and perceptions of older couples using this service. Thus, I planned to ask the home carers what criteria they felt that home carers needed to meet to be able to do their job, why couples used home care, what kinds of support they provided to couples, how they actually provided the support and how they described their relationships with married service users.

RECRUITMENT ISSUES

Approaches to Recruitment

In their research into recruitment, McLean and Campbell (2003) identify three methods of recruitment, via personal contacts and snowballing, via professional / institutional contacts, and advertisement in the media. At the point that I was preparing to begin to recruit interview participants I changed my job and undertook a long-distance move. A consequence of this was that I had almost no local personal or professional contacts. One way that I might have addressed the problem of my lack of contacts was to have become involved in a society, club or group for or dominated by older people. I did not do this for several reasons. Firstly, there was the question as to what kind of organisation should I become involved. If I were to become active in a group or society for or dominated by older people such as the British Legion, I might encounter few or no couples who had (or acknowledged) care needs. Alternatively, if I were to have become active in a group or society for people with a certain disabling condition then I

would only meet couples who are affected by this condition. This would create an immediate bias. Secondly, to develop contacts in this way tends to require regular and sometimes frequent involvement in the society or group. I worked irregular shifts so my spare time occurred at variable times and at this point was quite limited. Hence, I forwent this option as impractical. I also dismissed the idea of advertising in the press. Advertising in specialist publications would ensure that I would reach my target audience but such publications tend to have a nationwide coverage. I wanted to conduct face-to-face interviews and I would not be able to do this with any respondents who lived too far away. Advertising in the local press would avoid this problem but the chance of reaching suitable candidates would be reduced. Furthermore, I was generally uncomfortable with the idea of advertising in the media. This was because of the potential risks involved in broadcasting my details to a wide audience and, if my advert were successful, subsequently in going to meet previously unknown people at their choice of location. I reasoned that in the same way vulnerable older people may feel that it would be risky to respond to an advert in the press to take part in an interview with a stranger and so do so. Thus, recruitment for this study was predominately completed by approaching and seeking the support of care organisations in reaching potential interview participants. I felt that this method of contacting older people offered them and myself some small degree of protection. I would be supplying my personal contact ¹details to a formal organisation and potential participants would have the assurance that at least I was 'known' to an organisation with which they were familiar. The recruitment of interview participants via care organisations carried with a number of consequences. Firstly, it meant that older couples who were currently not users of care services would not be recruited and their experiences of caring not explored. Their absence would possibly also lead to an under-representation of older couples in receipt of high levels of non-spousal informal care and thereby the types of support networks with which this is associated. It may also skew this study's finding on older spouses' attitudes towards service use and informal care in favour of the former. Secondly, approaching organisations offering services to older people with specific disabling conditions would, as pointed out above, automatically inject a bias, towards the experiences and needs of older spouses with this condition. Thus, the focus of this study would be restricted to viewing care in marriage in later life through the lens of these specific disabling conditions. In this case, it could be expected that it would attribute too little significance to care needs, problems and issues of older couples with other conditions. However, the involvement of local authority home care in recruitment should help minimise the development of this kind of bias in this study. In spite of these limitations of recruiting via services, for the practical and safety reasons outlined above, this became the main approach to recruitment in this study. Only a very small

¹ I offered each organisation that supported me in recruiting older couples the opportunity to check the validity of my claim to be student researching older couples and caring.

minority of couples were approached via recruitment through non-care services or via other potential participants.

Which Couples to Interview

To achieve its objectives, this study needed to gather data from people aged 65 years or over about their experiences and perceptions of providing to and / or receiving care from someone of their own generation with whom they live. Since this study initially intended to analyse how different types of informal relationship influenced the experience of care it did not specify what kind of relationships the couples should have except that it should be intra-generational, co-resident and not be based within the formal economy. It was, however, expected that most of these kinds of such exchanges of care would take place within 'most important other' relationships and that marriage would represent the most common one and as discussed later the one on which this study concentrated. The couples' ethnicity, economic status, length of residence in the area, receipt of informal support and use of formal community-based care services were not considered important criteria for their participation but couples living in long-term residential care were excluded.

The couples' care needs were to result mainly from a chronic physical disability and those suffering cognitive impairment so as not to be unable to give their informed consent independently to taking part in this study were excluded. This meant that the majority of older couples whose care experiences stem from Alzheimer's disease and other dementias were not considered to be suitable candidates for interview². Finally, because I planned to carry out face-to-face interviews, the couples needed to live within a reasonable distance and travelling time of either my work or home. Ultimately, this resulted in all the couples living in North East Scotland in an area served by the two local authorities, referred to within this study as LA1 and LA2.

Ethical Issues

Volunteerism Based on Informed Consent

In its recruitment and interviewing of older couples, this study assumed volunteerism and informed consent as guiding principles. I reasoned that this would ensure that any couples who had concerns about how being interviewed might affect them or their relationship would not volunteer to take part in this study. Unfortunately, volunteering is not always the product of, what might be termed, pure voluntarism. It may reflect the so-called volunteers' desire to please or fear of whoever approached them about volunteering, the result cajoling or even miscommunication - the volunteers may think their participation is compulsory rather than

² It is recognised that there are procedures and methods of gaining informed consent or assent for individuals who are personally unable to provide it. I choose not to use these not only because they can be protracted and difficult to execute but also because I am unskilled in their application.

optional. To ascertain, as far as practically possible that the older couples volunteering to take part in this study were volunteers, I committed to explain to potential participants when I contacted them about being interviewed and again before I began to interview them what this study was about, what being interviewed was likely to involve and to emphasise being interviewed voluntarily.

Whilst such steps support voluntarism, it is likely to have little impact on the problem of one spouse cajoling or coercing his or her partner. To coerce is to exercise power over and hence it can be a facet of abuse. In such cases there exists the disturbing risk that this study may become caught up in facilitating emotional abuse. For example, a carer may coerce his / her spouse into taking part because he / she intends to use their interview to belittle, humiliate and embarrass him / her about his / her dependencies and thereby massage his / her own ego by presenting his / herself as a heroic carer. Alternatively, a care recipient may cajole his / her partner to criticise his / her best partner's care giving efforts and belittle him / her as a spousal carer. However, abuse tends to take place in private and to be kept hidden (Action on Elder Abuse 1995). Consequently, abusers are unlikely to want their partners to participate in interviews about care within marriage, as this could potentially provide them with an opportunity to disclose their abuse. Abused partners are also unlikely to coerce their partners into being interviewed against their wishes because they do not usually have the necessary influence. In spite of this, I felt that I had to be prepared to deal with a disclosure of abuse should this occur during the course of this study.

The Question of Disclosure of Abuse

Physical, sexual, psychological or financial abuse and/or severe neglect can occur and become an integral part of any relationship (Action on Elder Abuse 1995). Age Concern Scotland estimates that between 7 and 9 per cent of older people are subject to some form of abuse. The analysis of calls made between 1997 and 1999 to Action on Elder Abuse's helpline and to the Scottish Helpline for Older People since 2001 found that (i) 70 per cent of calls were about the abuse of older people in their own homes, (ii) the abusers were often family members, most commonly adult children, who lived with the abused and (iii) very few family carers were abusers (Age Concern Scotland accessed 2005, Jenkins et al. 2000). In spite of innovations like helplines, awareness raising and campaigns aimed at encouraging older people to disclose abuse, secrecy and shame continues to surround it thereby hindering its disclosure (Age Concern Scotland accessed 2005, Biggs 1996, Rose 1996). Wilson (1994) found that where social service providers identified abuse within later life caring relationships, one of their most common interventions was the separation of the individuals. Unfortunately, service providers are not always effective in identifying and dealing with the abuse and some are perpetrators of abuse (Age Concern 2003, Bright 1996, Jenkins et al. 2000, Penhale and Kingston 1995, and Wilson 1994).

On balance, the foregoing suggested that I would probably not encounter a disclosure of abuse. For the reasons outline above, I believed that spouses in abusive relationships would not present themselves to study as volunteers for interview. I also believed that service providers would be unlikely to knowingly introduce me to older spouses whose relationships they knew to be abusive but abuse is usually a hidden aspect of relationships and so they might not know of it. Nonetheless, whilst improbable a disclosure of abuse was not impossible. I decided that were a participant to disclose abuse, I would ask his/her permission to relay the information to the social work department as recommended in the Action on Elder Abuse briefing (1995). I overlooked the need to plan how I would deal with the potential impact of disclosure on myself other than to speak with my supervisors.

Qualitative Interviews and Informed Consent

In their discussions of research ethics, Larossa et al (1981) and Kayser-Jones and Koenig (1994) explain that participants in qualitative research can only be given general indicators as opposed to specific and comprehensive information about the potential risks and benefits that may be involved their participation. This is because often what actually emerges within qualitative interviews, and hence what risks and benefits of participation, first becomes apparent as they are taking place.

Arguably, the worst imaginable risk that any couple could face as a result of being interviewed as part of this study was that their caring relationship, their marriage, would break down. This outcome seemed fairly improbable. Separation tends to be an unattractive and difficult option for most long-term older couples because of their commitment and emotional investment that have made in their, usually long-term, relationships and the fact that they tend to share accommodation, finances, friends and family. Indeed, only a small percentage of couples who divorce are elderly (2001 Census via National Statistics Online). Furthermore, I assumed that due to their working relationships, service providers would have some insight the stability of their service users' marriages and would not introduce this study to couples whose relationships they knew or suspected to be fragile.

In contrast to the relative improbability of relationship breakdown was the possibility that the participants may become upset or distressed as a result of reflecting on their limitations and changed circumstances. If this occurred during the interview I planned to offer the participant(s) immediate support, to suggest possible sources of ongoing support and, in cases involving a referring service provider or co-ordinator, to seek their agreement to inform them of their distress. If it were to occur sometime after the interview I could only hope that the spouses would be supportive of one another and/or, as necessary, access appropriate support.

What benefits might older caring couples enjoy on account of participating in this study.

MacDonald (1999), in her research into support at home, found that her participants had not received comprehensive advice on how to access the range of services that they felt necessary.

This study too might uncover gaps in the participants' awareness of service provision but this seemed unlikely given the involvement of specialist service providers in their recruitment and my relatively limited knowledge of services locally for older people.

Any benefits derived from interview participation were, just like the risks, likely to be emotional or psychological.

Siddell (1995) claims that disability, caring and ageism can result in older carers and care recipients feeling very isolated. This suggests that older caring couples may enjoy and benefit from taking part in an interview where they have the opportunity to talk to someone, who is interested in and values their experiences and perspectives as may boost their morale and reinforce their sense of self-worth. Alternatively, it may be demoralising if they have repeatedly spoken about their care needs and experiences, for instance during assessments, especially if this has not produced positive results. Being interviewed may, however, overall exert a relatively neutral or ambiguous impact on the participants. Lewis and Meredith (1988: 142-146), in their study of intergenerational caring, describe how some daughters felt angry and bitter about having cared for their mothers alone but at the same time proud and satisfied that they had managed to care for them independently. This study too would probably lead spouses to touch on emotionally neutral, ambivalent or contradictory aspects of care as well as clearly positive and negative ones.

To make an informed decision as to whether to consent to taking part in this study the potential participants needed information about the possible risks and benefits that this could involve. For the reason explained above, I could not provide them with specifics. What I was able to tell them about was the aims of this study, the sorts of topics their interviews would cover and that they did not have to discuss anything that they did not wish to and if they wanted to they could halt or even terminate the interview. Furthermore, I planned to offer them the option of home-based interviews on the basis of the argument put forward by Twigg (1997, 1999) that the ideology and privacy of home imbues older people with the power that they do not enjoy in other places thereby enabling them to resist uncomfortable questions and investigation.

Qualitative Interviews with Spouses

Chronic illness, disability and care impact on close relationships as they result in modified routines, social interactions, financial status, life styles and sometimes residency (Booth and Johnson 1994, Parker 1993, Thompson and Pitts 1992, Wright 1993). However, each partner within a relationship has his / her own experiences of and feelings about these changes, which he/she may not share or make known to his/her partner. Duncombe and Marsden (1996: 153) assert, in their research into the private sphere, that 'within the couple relationship there lies a realm that is kept private from one partner by the other'. Such exclusivity and subjectivity suggest that one partner cannot possibly speak authoritatively for his/her partner. This study's relational understanding of care and feminist theoretical stance on diversity within relationships

presupposed that it should interview both husband and wife, either individually or together. Speaking about personal or sensitive issues is seldom easy and the presence of a partner can heighten embarrassment. Hobman (1995), in his study of later life partnerships, describes how when he tried to explore the issue of surviving a partner with couples, he frequently encountered a 'conspiracy of silence'. Conducting research into bathing, similarly, Twigg (2000: 89) points out how:

It proved harder to ask questions about intimate care in the presence of the other member of the couple. To do so became a violation of their own privacy and the partner, typically, put up a barrier that was not present when a disabled person was interviewed alone.

To research intimate and sensitive subjects with couples Brannen (1988), Duncombe and Marsden (1996) and Seymour, et al. (1995) advocate that researchers interview partners individually but simultaneously. They suggest that this approach reduces the participants' embarrassment about speaking about personal matter in front of each other and removes the opportunity for them to collaborate their responses between interviews. Also, in care research, interviewing carers at the same time as care recipients usually avoids the need to arrange substitute care.

A significant practical problem with carrying out simultaneous individual interviews is finding a suitable venue in which to conduct two interviews in private at the same time. This problem intensifies when the venue has to meet additional specifications, such as having a loop system, to enable to interviews with disabled participants to take place. Ultimately, it is impossible for a lone interviewer to carry out simultaneous individual interviews. The options available for this study were to interview the spouses sequentially or together. It opted to interview them together as couples.

Rejecting Individual Interviews

At the heart of the individual interview lies a promise of confidentiality. This confidentiality is credited with encouraging participants to speak freely about all manner of issues (Brannen 1988). Whilst this is advantageous to accessing data, it can engender the development of potentially problematic emotional intensity, especially in interviews that involve women on account of their close cultural association with listening and nurturing.

Ribbens (1989: 587) states:

In in-depth interviewing we (*women*) seek to empathise in order to enter another's world in a way that increases our understanding of it, and yet normally this sort of listening occurs in the context of long-term caring relationships. ... The subtle distinctions between listening with empathy and actually responding with care and concern, may be hard for the interviewee to appreciate, against her more general experience that listening implies caring. To see the interview as empathic thus may create disjunctions in expectations. At the end of the research we do walk away generally.

Such developments within this research would be undesirable because, realistically, the only support that could be offered was advice on how to access support, such as self-help groups or counselling.

Another significant problem with confidentiality is that, it cannot be guaranteed (Larossa et al. 1981 and Kayser-Jones and Keonig 1994). I doubted that this study could guarantee the participants' complete confidentiality. I planned to give all participants fictitious names but I would not be able to disguise identifying details, such as their limitations or use of services. This would not favour anonymity. Furthermore, my own experiences of working in social care within the area pointed to the fragility of confidentiality. Therefore, it seemed more ethical to interview the spouses together so that they would hear each other's comments and have a chance to put forward their own point of view.

Whilst the service providers who introduced couples to this study and I were greatly concerned about the confidentiality, the spouses themselves showed relatively limited concern about it. Many claimed that everyone already knew everyone else's business and in some cases they actually substantiated their claims with details of others' affairs. They also suggested that they found such information reassuring for it confirmed that they were not the only ones facing challenges and gave them insights and pointers on how to cope with their difficulties. Nevertheless, this did not change the respectful manner in which I treated information.

Advantages and Disadvantages of Joint Interviews

The joint interview is often criticised for generating information that reflects 'public' images rather than the 'private' realities. Nevertheless, it has considerable potential to uncover idealisations (Allan 1980, Larossa et al. 1981). The participants of joint interviews are subject to slightly different moral constraints. This means that participant A feels at greater liberty than B to speak about X whilst B feels freer than A to speak about Y. Hence, when B tries to gloss over something in respect of X, A may verbally challenge or 'correct' B or simply look puzzled thereby revealing that B's version of events was somewhat idealised. Moreover, Shotter (1993: 179), in his discussion of the conversational realities, questions the idea of a split between public and private realities. He argues:

the assumption of an already stable and well formed reality 'behind appearances', full of 'things' identifiable independent of language, must be replaced by that of a vague, only partially specified, unstable world, open to further specification as a result of human, communicative activity.

Research attention given in recent years to discourse in respect of social experiences, relationships, disability and chronic illness, as well as the growth of services, such as family therapy, that use talk to try change relationships, illustrates the power accredited to language (Billington et al. 1999, Hockey and Strawbridge 1998, Latimer 2000, Lawes 1999, Mills 1997, Prestley 1998, Shilling 1993, Williams 1999).

In addition to helping each other construct a joint account and uncover idealisations, the participants of joint interviews are able to offer each other moral, psychological and practical support (Allan 1980, Laslett and Rapport 1975, Seymour et al. 1995, Twigg 2000).

Furthermore, for interview participants who have communication difficulties, such as a lack of clarity to their speech, the presence of a partner may be essential to boost their confidence to take part and to facilitate communication.

Finally, one of the most obvious benefits of the joint interview is that it exploits the old adage 'two heads are better than one'. In a joint interview the participants are able to jog one another's memories, correct and confirm or modify and contradict each other's comments both verbally and non-verbally through changes in the volume and pitch of their voices, their nods, smiles and grimaces (Allan 1980, Kaufman 1994, Seymour et al. 1995). Thus it produces more complete and complex verbal data than those produced in individual interviews as well as a wealth of non-verbal data to support or undermine the verbal statements (Allan 1980, Seymour et al. 1995, van Dijk 1985). For instance, if a spouse, who took the lead in answering questions in a joint interview with her partner, claimed that she always dealt with DSS and other officials on behalf of them as a couple, her behaviour in the interview would be consistent with and hence supportive of her claim.

In joint interviews each participant has the chance to put forward his/her side of the story on every topic raised and the interview can encourage equitable participation. This is because the power balance favours (usually) the interviewer, hence, he / she should be able to engineer opportunities for both participants to contribute to the generation of data. Most obviously the interviewer can ask each participant for his /her comments but she / he can also encourage more reticent or quieter participants to speak. For instance, the interviewer can show a particular interest in what they say and ask them more about it. However, a range of factors can impede not only equitable but also frank discussion in joint interviews with spouses. Husbands and wives may watch what they say out of a desire to protect their partners' dignity and feelings, to shield them from additional worries and anxieties or out of embarrassment. Spouses may also modify or hold back on comments to protect and maintain the privacy of their marriage. This may be because they wish to and accordingly cooperate with each other to present a competent image to outsiders (Arber and Ginn 1992a, Ungerson 1987). Alternatively, they may want to keep any disharmony or conflict within their relationship private. Furthermore, where there is conflict in the marriage the non-dominated spouse may not openly express views that he / she expects will result in some kind of retribution.

Incompatible styles of communication present yet another factor challenge to equitable interview participation. In mixed gender conversations, one of the biggest and most common hurdles to ensuring that women and men have an equal chance to express themselves are their different conversational style and practices (Coates 1986, Giles and Coupland 1991, Sattel 1983, Seymour et al. 1995, Spender 1985, Tannen 1994, West and Garcia 1988, West and

Zimmerman 1983, 1985, 1987). When men and women talk, men typically dominate the conversation. Men tend to speak more than women, use more mutually reinforcing tactics and strategies and introduce or change to new topics more often. Women tend to interrupt less, listen more, do more work to maintain dialogue, use more hedges and tag questions and are less effective in determining conversational topic than men (Cameron 1992, Coates 1986, Fishman 1983, Sattel 1983, Spender 1985, Tannen 1994, West and Gracia 1988, West and Zimmerman 1983). Indeed, West and Gracia (1988: 586) found that men made three-quarters of all interruptions and 'initiated all of the seemingly unilateral changes' of topic in conversations involving men and women.

Saying very little or nothing can also be used to control conversations and interviews (Fisher 1983, Sattel 1983, Spender 1985, West and Gracia 1988). Sattel (1983: 122), in his work on inexpressiveness and power in conversation, suggests that men tend to adopt this type of strategy for the purpose of 'intentional manipulation of a situation when threats to the male position occur'. Seymour et al. (1995) found that more men than women refused to take part in their study into adjustment to disability. They attributed this bias to the fact that men tend to avoid speaking about matters that reveal their vulnerabilities and/or jeopardise their masculinity. Within this study one woman and one man were absent at the time of their interview appointments, but due to the small numbers involved it is unrealistic to draw any conclusion about interview participation and gender.

Care and relationships tend to be thought of as feminine issues and their discussion tends to highlight personal vulnerabilities (Seymour et. al. 1995). Consequently, this study might have expected the men to under-participate in the interviews and/or to attempt to steer them towards 'safe' topics. Although this was not obviously so, the men changed the nuance or tone of topics from fairly neutral to definite more often than women. For example, one man, having become quite exasperated with the way that his wife uncritically relayed their refusal of an offer of home care, took up the story and forcefully pointed out why they had turned down the offer. The reason was that their use of this service on a previous occasion had been fraught with unresolved problems that threatened to reoccur.

To correctly identify dominance in joint interviews is not always easy. For example, one participant may appear to dominate an interview when in reality he/she is acting, by mutual agreement, as advocate or spokesperson for his / her partner due to the latter's communication or confidence difficulties. Conversely, a participant, usually but not always a man, may dominate an interview without this being recognised because he (she) has skilfully primed, rehearsed, and possibly threatened his (her) subordinate partner about what to say. In this scenario both partners are likely to appear to make an equal contribution.

In this study several spouses were more vocal than their partners throughout their interviews and several others in respect to certain issues or subjects. Issue or subject domination appeared to relate the difference in the individual spouses' interest in the issue. For example, many of the

women spoke at greater length than their husbands about assistance with housework. In interviews where one spouse was overall more vocal than the other, this reflected either an aspect of care or how the spouses customarily conducted their business. Nevertheless, even interviews with more and less vocal spouses, the quieter ones always made some comment and most tended to reveal their support of what they former with a few affirmative words or gestures.

RECRUITMENT

False Start

I began my attempts to recruit older couples via service providers by approaching local branches of national organisations that serve older people. I was aware that this might not be a very effective or efficient approach, but luckily, the Development Officer of the local branch of a national organisation showed an immediate and encouraging interest in my research. Although she personally was unable to put me in touch with anyone to interview, she assured me that the Carers' Support Worker in a named resource centre would be able to do so. Hence, I was disappointed and alarmed when this service provider told me that she felt unable to introduce me to any older caring couples because she felt that my intended method of investigation was, at best, morally questionable. In her opinion, joint interviews represented an invitation to older spouses to talk about each other and their situation in ways that would be upsetting, damaging to their relationship and might even precipitate a crisis of care. Accordingly, she urged me to think very seriously about the potential ethical and moral consequences of my chosen method and my study generally.

Thinking More Deeply about Ethics

The Carers' Support Worker's views unleashed a wave of doubts and questions about my research and my intended information gathering techniques. How great were the risks for spouses of taking part in joint interviews about care? Would participation in such interviews really threaten to undermine marriages? Would spouses be completely unaware of how one another felt about caring or their relationship? Would they express only negative thoughts and feelings and events? Would their lifetimes of experiences have prepared and equipped them with skills to cope with harsh comments? Alternatively, would talking about how they cope or the enduring character of their relationship give the spouses a boost? After all, caring in later life is not a unidirectional or uni-dimensional process nor is it an exclusively negative experience (Hobson 1995, Kahana et al. 1994, Kahana and Young 1990, Wenger 1990a). Only the spouses could answer these questions because their answers lay in the details of their experiences, personalities and psyches and so only they could assess the degree of risk being interviewed represented to them.

Yet, in view of this the ambiguity or doubt as to the precise risks and benefits associated with participation in this study would potential participants be in position to be able to make an informed decision or assessment about their participation.

Consent to participation in research is usually agreed at the preparatory stage of the research process. This study sought the participants' consent, which they gave verbally, when setting up their interviews and again just prior to beginning them. However, Lyman (1994) suggests that this is not always adequate or appropriate when carrying out interviews with people with a disabling condition that means their ability to consent is inconsistent. In such cases she suggests that consent should not only be obtained at the preparatory stage of the research process but rather repeatedly.

In every encounter with a researcher, the person (interviewee) indicates willingness to participate without coercion or manipulation and willingness to continue as the encounter proceeds (Lyman 1994:162).

This approach to consent is arguably also highly suited to research where all the risks cannot be defined in advance.

I planned to assure and subsequently remind the participants that any topic that they did not want to discuss could be dropped and should they wish that they could stop and withdraw from interview. Moreover, I committed myself to taking remedial action, including if necessary ending an interview, should the participants become distressed and to exclude from future interviews any question(s) that repeatedly gave rise to distress or upset. Finally, I planned to guard against the trap, that Larossa et al. (1981) describe as an 'unwitting shift from interview to interrogation' in trying to gain information: I would not persistently return to any question or subject that the spouses/partner appeared to want to skirt around.

I cannot claim that the sum of my reflections that the Carers' Support worker promoted, amount to a panacea about how to manage the ethical and moral challenges of qualitative interviewing but they made me more conscious of my responsibilities as an interviewer.

Other Openings

The installation of a care data bank in the public library gave me access to the names of current contacts for local support services. The first service provider whom I identified and successfully contacted using this resource was the co-ordinator of a stroke survivors' support group. After I had introduced myself, my research and my reason for contacting her - to seek her assisting in recruiting older couples to interview, she invited me along to speak to the group at its next meeting. The timings and location of their meetings meant that due to transport problems and clashing commitments it would be several months before I could make one of their meetings. In view of this, the coordinator and I agreed that she would tell the group about my study and my request for interview participants. To equip her to do this, I provided her with details about the origins, focus, aims and purpose of my study as well as what participants could expected to be involved in taking part in interview. Approximately two

weeks later she telephoned to request written information to pass to the group. I prepared and forwarded an information sheet, which I called 'Are You Willing to Talk to Me'. Disappointingly, this did not lead to any interviews. In retrospect I believe that by not attending one of the group's meetings I missed an opportunity to find out what would encourage older couples to take part in interviews.

Problems with Terminology

To produce an information sheet, I had to resolve the problem of what terminology to use. 'Couple' was the most obvious choice to use to refer to the types of two-person relationship in which I was interested but, due to its common usage, it could be assumed to address only married or intimate heterosexual partnerships. The alternative was to use the term 'dyad' but this term is largely absent in everyday speech. Ackroyd and Hughes (1992: 105-106), in their reflections on interviewing, advise against the use of what they call 'esoteric language' because participants may not understand it and so be unable or unwilling to respond. Patton (1987: 123) points out that where interview participants do not understand what is being asked of them they feel uncomfortable, ignorant or even hostile. Thus, the use of the term 'dyad' in recruitment material could possibly have a negative effect.

Choosing a term to represent the participants' needs, activities and roles presented a further problem. Care and related terms like carer were fitting and familiar, yet, they have great potential to create misunderstanding and miscommunication. In her study of the diversity of meanings applied to welfare concepts, Seymour (1999a: 46) claims that shared terminology obscures the variety of interpretations and usage of these concepts across different academic disciplines and by welfare practitioners and lay people. In face-to-face discourse, individuals check with one another what each other what mean when use a particular term and so they usually achieve an acceptable level of communication (Ellis and McClintock 1994). Yet, misunderstandings can still occur that damage rapport and threaten data collection. For example, in this study often when couples claimed that nobody helped them, what they meant was that they were not regular service users. If, in response to this claim, I were to have asked these couples about how they felt about their families being unsupportive, I would possibly have caused considerable offence and thereby negated any rapport that I had gained with the participants. A further issue that had to be considered was that many care terms can be viewed as 'leading' because of their moral and ideological associations that in some cases are quite ambiguous (Dalley 1988, 1993, Ellis McClintock 1994, Graham 1983, Begum 1992, Lloyd 1992, Morris 1991a, Oliver 1993, Seymour 1999b, Thomas 1993, Ungerson 1983a, 1987, 1990a, Whalley-Hammell 1992). For instance, 'care' is commonly associated with and understood in terms of feminine roles, relationships and identities but also with service provision, as epitomised in the phrase 'put into care'.

Whenever I spoke to service co-ordinators about recruiting interview participants, I had no trouble conveying my interests. I described quite simply in whom and what I was interested. On this basis, I decided to use familiar terms in a descriptive context in my recruitment material³. Thus, in 'Are You Willing To Talk To Me?' I explained that I would like to interview people aged over 65 who live with and care for or are cared for by a spouse, friend, brother or sister but not a younger person such as a daughter. To further facilitate effective communication I provided potential participants with the option of contacting me for additional information. Most potential participants also had the option of seeking clarification from the service providers/co-coordinators who introduced them to this study.

Within the recruitment material the term 'carer' was used only once in respect of paid carers and the term 'care recipient' not at all but they are used throughout this thesis. This is in order to distinguish between those spouses who regularly provided more tangible care or assistance than they received within their marriages from those who received more than they provided. It must be stressed that the spouses did not necessarily refer to or think of themselves either as carers or care recipients.

Faltering Progress

Having established contact with the stroke support group, I continued to try to contact other organisations. Typically, I made several telephone calls to an organisation before I received any response, and this was usually a negative one. Most service providers/ co-ordinators did not say why they were not able to help with the recruitment but a few explained that it was because, as is common within services, their users tended to live alone or, if they lived with a partner, they tended to have severe dementia.

My optimism was rapidly fading when a local group co-ordinator of a voluntary sector organisation offered to speak to the group's members about my study and about being interviewed. To help her with this I forwarded her a copy of my information sheet, 'Are You Willing to Talk to Me?'. Three weeks later I received a list of six couples to contact. I was relieved and encouraged by this level of interest but also concerned. Whilst attempting to recruit interview participants, I had continued to develop my interview schedule and, around this time, I had begun worry that it focused too much on the kinds of assistance that the participants needed or provided and not enough on how their experiences or perceptions of care. I was faced with the dilemma of whether to use my interview guide or schedule and possibly fail to access enough suitable information or revise it and risk losing the interest and support of the newly recruited couples by postponing their interviews. I weighed up the risks. I wrote to each of the six named couples, thanking them for their interest and explaining that I would be in touch in the near future.

³ The recruitment sheet 'Are You Willing To Talk To Me?' that was passed on to older people and returned to me via service providers forms

This delay should not have happened and it was not repeated. On all other occasions when I was provided with contact details for potential interview participants, I contacted them relatively promptly, usually within fortnight, to talk about their interest in being involved in research.

Once I had revised my interview questions⁴ so as to tighten the focus of my questionnaire I re-established contact with couples. Four agreed to be interviewed but two refused. One couple gave no reason for their refusal but the other couple, pseudonymed Mr and Mrs Newman, believed that they were not sufficiently disabled to be able to provide any useful information. Mr and Mrs Newman both had diagnosed disabling conditions and limitations but they considered themselves to be independent because they were able to get out and about as they had a car. However, Mrs Newman explained that her husband and she may become more limited in the future and if so, as a married couple, they would automatically look after one another.

In his study of how people adjust to the dilemmas posed by chronic illness, Radley (1989: 232) states:

the experience of the body is subject to its use in daily life, so that the apprehension of ease or of illness arises in the context of the activities in which people engage. Those feelings to which one's constitution or one's role in society give rise often have a naturalness which discourages their interpretation as symptoms. This does not mean that remedial action will not be taken but that either the person concerned, or other people, will be unwilling to view these physical changes as indicative of illness.

Substituting disability for illness this perspective suggests that given the influence of ageism, older people are unlikely to recognise or define their limitations as disabilities or care needs unless they are very profound. This has clear negative implications for the recruitment of older caring couples.

Although Mrs Newman refused to be interviewed, she offered to help, as co-ordinator of an advisory/self-help group, to recruit 'suitable' couples. I gratefully accepted her support and she supplied with the names of two couples.

Making Contact with Interested Couples and Partners

MacPherson et al. (1988) include amongst the challenges involved in interviewing older people the issue of interviewees forgetting the times and dates of their interviews and interference from relatives worried about what their kin were getting involved in. A letter provides formality and a tangible source of information. Writing to potential interview participants would then (hopefully) forestall such problems. It would also afford them the opportunity, although they may not take it, to discuss and decide jointly as couples/partners whether or not to participate in the interview process. Communicating by letter is slow, with an inevitable delay between sending out a letter and receiving a reply, in comparison with telephone communication.

⁴ See Appendix 2

During telephone conversations questions can be put and answered and interview arrangements made all within minutes. However, this means of communication is not problem-free. For example, hearing difficulties are not uncommon among older people and the use of the telephone could risk miscommunication (Goddard and Savage 1994, Richards 1994).

Moreover, speaking to one person is arguably inconsistent with a joint or dyadic approach. Although conscious of these drawbacks, I had opted for telephoning on the grounds of speed and efficiency.

The first couple that I telephoned expressed great surprise at being phoned 'out of the blue'. I explained how I had gained their telephone number and the purpose of my call. This reminded the respondent that the local group co-ordinator had approached them about taking part in an interview. In spite of this, the respondent asked for written details about my study to read over with his wife before deciding whether they wanted to be interviewed. I sent a copy of my information sheet and a letter that stated when I planned to phone again for their response. I telephoned at the specified time and the couple agreed to be interviewed.

Sending a copy of my information sheet 'Are You Willing To Talk To Me' with an explanatory letter including the date I planned to telephone became my standard approach to contacting potential interview participants. It entailed some limited delay but it fitted well with this study's focus on couples as offered the couples/partners the chance to decide together, in their own time, whether they were agreeable to being interviewed.

DATA GATHERING AND ANALYSIS

Pre-First Interview Concerns

I was familiar with conducting interviews as an aspect of my employment but this did not imbue me with confidence as I prepared for my first research interview. Instead I was preoccupied with my doubts about my abilities to conduct successful research interviews and about the morality of asking strangers sensitive questions without this being part of a procedure leading directly to some tangible benefit for them.

My supervisors' practical comments and personal anecdotes helped to reassure me but my moral concerns lingered. Eventually, I decided that to move forward with my study, I had to personally accept the argument that researchers including their feelings are part of the research that they conduct (Finch 1984, Kleinman 1991, Hammersley 1995, Oakley 1998, Williams 1993). My feelings of disquiet were, I concluded, part of my research or interview experience that had to do with a conflict between my identities as a social care worker and a research student.

In the end my worries and anxiety about this first interview proved to be much worse than the actual, rather pleasant, experience. Consistent with how Finch (1984), Oakley (1981) and Ribbens (1989), have described their interview experiences, the participants treated me like a guest and spoke quite freely.

First Interview Experience

With the knowledge that I had gained about the couple in the process of setting up their interview, my mental preparations and equipment - a tape recorder with new batteries, a spare tape, note pad and interview guide I set off for my first research interview feeling somewhat nervous. I left home in what I thought was plenty of time but bad weather intervened and I arrived late. I worried that this would make rather a bad impression but instead it provided a natural ice-breaker. I began by explaining how the snowy weather had extended my journey and soon we were talking freely about how I reached their home. This sort of conversation became the way that majority of my interviews with spouses began. This is because it felt comfort and more importantly it lead easily onto discussion as to why I was there, namely to interview the spouses about care and to check their willingness to go ahead with the interview. I began this process of checking by reiterating what I had covered during my phone call to the couples, namely what my research was about, its aims and purposes, why I was interested in care and by assuring them that they did not need to answer that they did not want to and that information would be treated with respect and as confidential. I also reaffirmed their consent to tape record and use their information and added that they were free to question me. Only after we had talked about these matters, did I, with their agreement, switch on tape recorder and begin to interview.

This first interview resembled an unstructured interview. From the outset it jumped around from one subject to another, with the couple largely taking control over the introduction of topics of discussion. The unstructured interview is well suited to finding out how interview participants make sense of their world and hence this research but, because of its unsystematic approach to the exploration of topics, it is a very time consuming method of data collation on a given topic (Ackroyd and Hughes 1992, May 1993, Patton 1987). Therefore, it was not a practical way to collate data for this study. I had been aware during this first interview that I needed to take more control over it but seem unable to do so. Fortunately, most of the issues that I had hoped to cover had been covered but I knew that I had to be more effective in steering future interviews to ensure that I accessed the kinds of information that I needed.

In later interviews I tended to start the tape recorded interview with questions about issues that are usually relatively easy to answer or talk about such as what contact the spouses had the service provider who had acted as contact or how they obtain a piece of equipment for example a Zimmer or grab rail if such were obvious. These discussions frequently lead on to other care matters and these on to still others. However, as necessary, I steered the interviews; I asked about care issues that this progression left out, I probed carefully for further information looking out for whilst remaining sensitive to any reticence or reluctance that the participants showed towards talking about any particular topic. I also tried to keep the discussion on track and bring it back when it meandered too far. When the majority of care issues had been addressed I let participants know this and that their interview was drawing to close. As necessary, I also drew

the focus away from sensitive issues. Once the interview was over I always thanked the couple very much for their information and time - most interviews lasted between one and two hours. Then, we typically engaged in post interview chat before I left. Sometimes this included a return to points raised in the interview but very often this was when the couples tended to ask me about myself.

Post Interview Reflections

The completion of my first research interview boosted my confidence and, despite the weaknesses in my technique, I had over an hour's worth of tape-recorded information, a wealth of observational data and a myriad of issues to think about. It had also allayed my pre-interview concerns about the legitimacy of interviewing where the benefits to me were more immediate and well defined than those available to the interviewees. The couple seemed to have seen me as someone who they were able to help and I did need their help to collate information to fulfil my study objectives. Their readiness and openness to share their views and experiences and their tendency to voluntarily provide examples to illustrate their points suggested that they had willingly given their information. Finally, they seemed to have enjoyed talking to me.

Taking a Grounded Approach in Practice

A key tool in implementing a grounded approach is transcription. Shortly after each interview, I transcribed it⁵. I typed out, as far as possibly, everything the respondents and I said during the interview and noted any instances of and reasons for loss of dialogue such as where the recording was unclear. Where possible, I included details of the participants' and my own para- and non-verbal communication, in particular, errs, mms, laughter, coughs, physical indications such as pointing and nods, pauses and any changes in volume.

The process of transcribing the first interview immediately revealed three things; a loss of data due to a technical hitch, the impact of my style of communication and a significant gap in my interview schedule. Listening to the recorded interview material highlighted just how extensively I had used expressions like 'oh right' and 'mm' throughout this interview. My aims had been to signal my ongoing attention and comprehension of what was being said and to encourage the couple to talk. I had achieved this but at the cost of having little influence over the direction of the interview and this in turn contributed to missed opportunities to follow up on certain issues in order to gain a fuller picture of the couple's experience of care. For example, when the couple spoke about their move to sheltered housing, I failed to seize the

⁵ I did not seek the participants' permission to tape record their comments until after I had met them in person. This necessarily means that I have no transcripts of how the interviews were set up, of initial introductory exchanges on meeting them, or of participants giving their consent to the interview or to tape record their comments. I could possibly have explained that I would like to tape record their comments, including any telephone conversations in the letter that I sent to participants and ascertained their views on this when I telephoned them. However, approaching this issue so early and in this manner may have deterred the participation of some potential participants. I also have no transcripts of any post interview chat or subsequent interactions.

chance to explore their decision making process around their move. Thus, I became aware that to amass pertinent information in future interviews I needed to modify my linguistic style or strategy so as to purposefully but politely direct and focus the discussion. In respect of my interviews with home carers, listening to the recordings of very early interviews played a major part in ensuring that I developed techniques to keep subsequent interviews more tightly focused on supporting older couples.

The first transcription drew my attention to something that had struck me during that interview, namely, that my interview schedule did not examine whether spouses' had any previous care experiences and, if so, their influence on their current experience. Thus, consistent with Strauss and Corbin's (1990) advice that where data analysis highlights holes or gaps in the collated information these should be addressed in subsequent instances of data collection, in all subsequent interviews I asked the spouses about past experiences of care.

Transcription made me aware that during interviews I collated both verbal and observational data. Typically, I recorded the visual data, either at the end or beginning of each transcript together with any verbal information that the participants shared with me prior to starting or concluding the tape-recording of the interview. However, initially I only sought the participants' consent to gather and use their verbal data. This is because it was only after I had completed and written out three or four interviews did I realise that my observations, for example of the lay-out of couples' homes, especially whether there were steps. I fully acknowledge that this was a serious omission and that its amendment was tardy.

In preparing the spouses' interview transcripts I actively listened out for information to develop the issues raised in the published literature from which my interview questions were drawn. For example, I consciously looked for information about the spouses' social support networks, what kinds of support they received from formal and informal sources and viewed support from these different sources. As I prepared the transcripts I also became aware of themes and issues that characterised the participants' experiences and understanding of care such as the difference in the spouses' readiness to accept informal support with masculine and feminine domestic activities. Once I became conscious of a particular theme or issue, I began to look out for it in subsequent interviews and transcripts and re-examined ones that I had already completed and looked up the topic in other research. In this way I identified where data from this study supported, developed or paralleled those in published literature and where they appeared to be contradictory or to reveal fresh insights into care, for instance in the case of how home carers experience supporting couples or how men experience needing assistance with gardening and DIY. In these instances, I found differences between the couples or between the findings of this study and others I sought to give reasons for these anomalies.

Refused Interviews and Interviews with Individuals

Four⁶ couples whom I contacted in the course of this study declined to be interviewed. Two couples gave no explanation, one claimed to be too old to be interviewed, and as already discussed one couple claimed that they were insufficiently disabled to be suitable candidates. On two occasions I arrived to interviews couples to find that only one of the spouses was available, in one occasion the carer and on another the care recipient⁷. The carer was home alone because he had recently been in hospital and, because of this, his wife was temporarily in residential care whilst the care recipient was alone because her husband was away helping their son – something it emerged he did quite often, usually at short notice. Consistency of approach would demand that I should have rescheduled these interviews but instead I went ahead with them. There were practical reasons for this, namely the erratic schedule of the carer, shift work as well as problems of accessibility (I had taken almost two hours to reach the home of one of these participants) meant their rescheduling would be difficult and possibly unsuccessful. However, more important than these practicalities was the fact that the available participants did not want to postpone their interviews and may not have agreed to be interviewed on an alternative date.

Conducting these individual interviews illustrated the advantages of joint interviews when researching care in relationships. In particular, they revealed just how much information interview participants provide as they interact with one another and the extent to which they expose each other's idealisations as they add to and 'correct' each other's comments. Furthermore, contrary to expectations, these individual interviews did not yield data that were richer, more detailed about sensitive issues such as personal care or the spouses' feelings about care than those produced in joint interviews.

The lack of in-depth of discussion of these issues with the spouses in both individual and joint interviews may reflect the fact that the spouses had grown up when culturally, compared with today, the expression and discussion of feelings and sexuality were far more constrained (Gibson 1993, Hepworth 1998). Moreover, the types of feelings that the spouses acknowledged – for example, frustration, anger, depression, uselessness, guilt, stoic tolerance and acceptance – are remarkably consistent with those that older people in other care studies have expressed about dependency and care (Qureshi and Walker 1989, Aronson 1990). Examining emotions in later life, Hepworth (1998: 174) claims that whilst there is a tension between socially prescribed feelings and what individuals actually feel, some older people prefer to 'concentrate their energies on producing passable performances of the emotions they have come to believe to be socially acceptable'. Burkett (1997: 49), in his discussion of social relationships and emotions,

⁶ This does not include the sisters referred to later in this chapter.

⁷ Before restricting the focus of this study to care within the context of later life marriage I also interviewed a sister who was cared for by her brother. At this point I was finding the recruitment of non-spousal couples difficult but I was still hoping to include and hence pursuing such participants. The data gathered in this interview has been omitted from this study.

argues that the appropriate emotions for particular circumstances and the consequences of not adhering to them, such as being judged as inadequate, are instilled at a very early age. Elements of this argument were evident in the spouses' accounts. For example, one older woman⁸ elegantly explained that people of her generation had been raised to 'get on with' rather than to 'dwell on' things, and to expect disdain should they fail to maintain a 'stiff upper lip'. She also went on to stress how they had witnessed the dividends of this philosophy in wartime and the austere post war years.

Well we were brought up to be much more disciplined (*than these days*). ... I think there was a lot more backbone in folk in those days because you had to get on with things. There was no social security, (I think social services / works is meant) nae counselling people. In fact I think this counselling encourages folks to think things about themselves. ... They are encouraged to feel sorry about themselves. ... Well we had friends and we used to. I was in the ministry of works in the civil service. You would go in, in the morning, and you would not know if all your friends would be there in the morning. And there were bombs dropped around our own houses. Faer's deid ? (*who's died*). And local lads went to war and never came back. I had three cousins killed in the war. And you just accepted it. No one came running to counsel you if somebody died. All the things laid on to make people chicken hearted and soft.

In view of these factors, the couples' early emotional socialisation and life experiences might have led to a reluctance to talk about feelings and possibly emotional restraint, irrespective of whether they were being interviewed individually or as couples.

EXTENDING RECRUITMENT

In the two years following the first interview, I attempted to contact twenty-one voluntary sector organisations for older and disabled people. My efforts yielded thirteen introductions, ten interviews and much anxiety at the pace of recruitment and the need to find an alternative means of accessing older couples/partners. Many of the couples whom I had already interviewed had three things in common besides those specified as necessary to take part in this study. These were that they lived in warden controlled or sheltered accommodation, had church connections, or used domiciliary services. Thus, it was logical to approach these types of organisation for help with recruiting additional older couples. I contacted the two of the main housing organisations in the local area and three churches, each from a different denomination, with my request for their support. I had to wait several months for these organisations to reply negatively to my request. If the churches were to have become involved in the recruitment, then this may have resulted the participation of non-care service using couples and thereby a reduction in this study's bias towards this population.

Following my lack of success with local churches and housing associations, I was very concerned that domiciliary service providers might not be prepared to offer me their support.

⁸ Although this woman was introduced to me as a potential interview participant, she was in an intergenerational caring relationship. I have quoted her on the issue of 'getting on with it' because she expressed clearly what the spouses typically, but nowhere so precisely, imparted.

Home care service providers tend to carry heavy workloads and I reasoned that they would probably view my request for help with recruiting interview participants as extra yet avoidable work. For a time, I stalled and worried about how to increase the likelihood of these service providers viewing my study and request for their support in a favourable light. I was conscious that when I had approached service co-ordinators for their help with recruitment I had not consistently spelt out the usefulness of the anticipated findings of my research. This I could easily remedy. However, I had doubts about whether these anticipated findings would be adequately attractive to front-line service providers since their implications for practice were fairly indirect and implicit. An obvious way to improve the probability of securing the interest of these service providers in this study, and hence their co-operation with recruitment, was to raise its practical and social policy implications. Among the couples that I had interviewed, it was clear that home care contributed to how they understood, perceived and conceptualised care, regardless of whether they actually used this service. The logical conclusion of this observation was to increase the focus on home care. The inclusion of the views of home care service providers alongside those of spouses should reveal how the former and latter influence one another's understanding of care and service use. This would offer a more rounded and complete insight into the experience of care in later life. Furthermore, it should also yield findings with overtly practical or pragmatic applications as well as ones with implications for social policy. In turn, this increased practicality should increase the likelihood of service providers agreeing to help access potential interview participants. Thus, on these practical and theoretical grounds frontline home care providers became part of this study.

Preferred Interview Techniques for use with Home Care Service Providers

The methodological and practical advantages and disadvantages of joint interviews were discussed earlier in this chapter and many of these also characterise group interviews. Additionally, the group interview represents an effective technique of amassing significant quantities of qualitative information from several participants in a fairly short time (Flick 1998, Patten 1987, Walker and Warren 1996). Furthermore, Walker and Warren (1996: 169), in their research into service provision, identify the group interview as an effective means of interviewing support workers because they felt that being interviewed in a group gave them a relative degree of anonymity and hence confidence to talk about unofficial as well as official ways of working. Finally, Patton (1987: 135) and Warren and Walker (1996: 169) claim that most group interview participants find taking part in this form of interview enjoyable. The importance of this cannot be underestimated, especially in cases where interviews with employees are timetabled to take place during in their own time.

The success of group interviews is influenced largely by the interaction of the participants with one another. Most home carers are women and women tend to adopt a co-operative style of communication (Cameron 1992, Coates 1986, Fishman 1983, Scottish Executive 1999).

They also tend to work in relative isolation with few opportunities to talk about their work and therefore usually seize any legitimate chance to talk about it (Warren 1990). Thus, both the gender and working condition of home carers are conducive to the use of group interviews. Indeed, they suggested that group interviews could be expected to promote considerable discussion and a proficient generation of data.

Although the group interview was this study's preferred method of gathering data collection from home carers, for reasons given later in this chapter only one such interview was conducted. In this interview many of the predicted benefits, especially the adding to and illustrating of one another's comments, were observed.

Contacting Home Care

The voluntary sector service providers and coordinators whom I had contacted about and from whom I received support with the recruitment of older couples were mostly front-line workers or their direct line managers. Accordingly, I approached service providers within home care who operated at the same kind of managerial or hierarchical level. I contacted the area managers for home care services in two neighbouring local authority social work departments, LA1 and LA2. LA1 included the suburbs of a city, towns - many relatively small, villages and rural areas. LA2 served the population of two small towns and the rural hinterland between them. So that the managers did not automatically assume that I was appealing for altruistic and unreciprocated support, I took care to emphasise the expected practical application of this study's potential findings. They neither refused nor committed themselves to my request but explained that they needed to speak to their superiors about it. The home care services manager in LA1 added that I should address my request in writing to the Director of Social Work. The subsequent responses from LA1 and LA2 to my written requests were quite different but both eventually led to interviews with older couples and home care service providers. I also contacted a social work department in a third local authority, LA3, that mainly served an urban population but this did not lead to any interviews.

Response from LA 1

The Director of Social Work in LA1 responded promptly to my correspondence with a request for further information about how I intended to protect the participants' confidentiality and the predictable resource implications of my research activities. I outlined how I intended to try to preserve the participants' anonymity and confidentiality, namely by gathering, transcribing and analysing all data personally and by substituting names with pseudonyms. I stressed my familiarity with treating information as confidential, adding that I was both trained in social work and currently employed in social care. I assumed that home-based interviews with older couples/partners would carry negligible resource implications for the service but acknowledged his concerns about resource implications of interviewing service providers. I explained that I

hoped to conduct group interviews scheduled around staff meetings so as to help minimise costs and inconvenience to the service. I added that I would be willing to interview home carers in their own time but only if this was acceptable to them. The Director accepted my reassurances about confidentiality but rejected my suggestions about using group interviews to minimise the resource implications of my study as inadequate. I wrote again, reiterating my continued interest in interviewing older couples and restating that, if necessary and with their agreement, I would be prepared to interview home carers in their own time.

Three months later I received a message providing me with the name and number of a home care organiser whom I should contact but there were further delays. I had to wait from the home care organiser to return from sick leave and then I had to negotiate a protracted administrative procedure before I was supplied with the details of two couples and advised that three home carers would contact me. I only ever heard from two and my requests for the contact details of the third, so that I could contact her, were refused.

Response from LA 2

Several weeks after writing to LA2, I checked on the progress of my request. I was informed that it had been forwarded to the Head of Department. Two weeks later I received a 'research questionnaire'. This sought information about my research methods, the kinds of information to be gathered, the participant confidentiality and the purpose and value of my research to the council's social work department. A month on from its completion I was invited to meet and discuss my research with the Information and Research Officer and the Services Manager for Older People for LA2. I was encouraged yet my experience to date tempered this optimism. Fortunately, the meeting with the Information and Research Officer and the Services Manager was informative and fruitful. Firstly, I learnt that in LA2 HCAs, home carer assessors assessed the needs of service users and HCOs whilst home care organisers attended to the delivery of the service by timetabling and supervising home carers. This form of organisation was in contrast to other local authorities in the area, where the tasks of assessment of service users' needs and organisation and supervision of home carers were combined with the remit of home care organisers. Secondly, I was informed that home carers did not meet regularly for staff meetings. This meant that group interviews with home carers would be more difficult to arrange and organisationally less practical than individual interviews. Thus, the services manager argued for the latter. In order to secure opportunity to interview these service providers I agreed to carry out individual interviews rather than the group interviews as I had originally planned. Moreover, the recruitment process was further progressed as the service manager offered to set up a meeting with the local HCOs and HCAs, so that I could explain my study objectives to them and seek their support with the recruitment of older spouses /partners and home carers. In return for this support, I was asked to commit myself to compiling and submitting a report of

my findings to the Information and Research Officer. This I did and later I honoured my commitment.

Interviewing HCOs, HCAs and their Manager.

The meeting with HCOs, HCAs and their manager took place a little over a month later in the social work department home care office. It began with the home care manager, with whom I had already had telephone contact, introducing me to two local HCOs and HCAs. With these formalities completed, I outlined my study, to point out specifically why I wanted to interview home carers and older spouses/partners and asked them if they had questions. I had anticipated a flood of questions but I was asked only a few, easily answered ones. I moved on to interview the HCOs and the HCAs about their views on and experiences of home care. I worked through my list of questions⁹ in a very orderly fashion and the service providers responded, sticking to the point and mostly speaking one at a time. They seemed to listen to one another, jog one another's memories and also provide each other with a kind of reassurance that enabled or encouraged them to say things that would not be widely accepted as appropriate generally in social work. For example, after one of the participants spoke about home carers assisting users in their own time, another gave specific examples of this kind of practices, whilst another spoke of her knowledge of home carers involving their families in helping users.

In my presentation I emphasised that I was interested in couples, but, it was difficult to keep the HCAs and HCOs and their manager focused exclusively on these service users. Quite early on in the interview it became clear that the HCAs and HCOs did not know precisely how many service users were couples or partnered and they were not able to access this information easily from their computerised administration system. Moreover, they tended to talk generically about service users or people except in respect of issues that pertained only to couples and when I drew their focus back on to couples. As the interview continued, I found that now and again I too employed the more ambiguous term 'people' rather than always sticking strictly and specifically to couples or partners. The HCOs' and HCAs' choice of words and the way that I quickly assumed their terminology highlights the dominance of the understanding and perception of home care as a service for lone older people and the actual and conceptual invisibility of older couples within this service.

With the interview completed, the HCOs and HCAs agreed to put me in touch with home carers, older couples and, if they were able to identify any, partners. They knew of only one non-spousal co-resident caring relationship that received home care provision.

With respect to when and where to interview home carers, the HCOs thought it unreasonable to ask them to be interviewed in their own time since they themselves had just been interviewed in work-time. This had significant financial implications for the service but the home care manager sanctioned such interviews on the understanding that these would last no longer than

⁹ See appendix 4.

thirty minutes. I was also offered the opportunity to book the use of an interview room in the social work offices in the two towns covered by the department to carry out the interviews.

Interviews in LA2

Within a few weeks of the meeting with the HCAs and HCOs, I was sent the names of seven married couples and a sibling partnership. I contacted all the couples and interviewed five. Disappointingly, I was unable to interview the siblings. One of the sisters had been admitted to hospital and the other rejected the possibility of an interview at a later date. By this point it was clear that I would not be able to recruit adequate non-spousal participants to make realistic comparison between caring in different types of later life relationships. Therefore, from here on this study concentrated on spousal caring relationships.

Two months elapsed before I received the names of seven home carers, all of whom were interviewed. During the early interviews with home carers I was constantly aware of the thirty-minute time limit. As a result of this I took quite a structured approach and accepted short, sometimes one-word answers and seldom asked for examples.

Unfortunately, the transcriptions of the first three home carer interviews, all carried out on the same afternoon, revealed that these participants had mostly spoken about and illustrated their points with examples involving older service users who lived alone. At the beginning of these interviews I had checked that the participants had experience of working with couples or partners and explained that this was what I was interested in but I not had reiterated this point later in their interviews. In subsequent interviews, I pushed for fuller answers than I had accepted in the earlier interviews and took special care to keep the interview focused on couples. Whenever there was any ambiguity, I checked with the participants that what they said applied to couples and asked them to illustrate their points using examples involving older couples. However, I recognised the emergence of several common patterns. Firstly, home carers typically assisted or had assisted only one or two older couples. Hence, they had only limited experience and information about couples to share with me. Secondly, they seemed to prefer to answer my questions in terms of service users who lived alone rather than saying they could not answer it in terms of couples. Thirdly, the home carers firmly believed that whether a service user lived alone or with a spouse was irrelevant to their working practice and relationships: a point of view that is likely to have compounded the tendency to give information about services users in general rather than couples in particular.

After completing the interviews with older couples and home carers in LA1 and 2, I still needed to recruit more interview participants. I secured a total of four interviews in LA1 and the interval from making my initial request to carrying out my first interview had been ten months. My progress in LA2 had been much swifter and more fruitful. Thus, I sought permission to recruit more interview participants in LA2. This was granted and, after an initial delay, I

received the names of and interviewed three older couples in another area within LA2. I also met with a care manager to discuss her role in arranging home care.

THE RESULTS OF RECRUITMENT

Forty older spouses from twenty-one marriages took part in this study. Approximately two thirds of the spouses were aged between 70 and 90 years old, whilst the remaining third was made up of four spouses of over 90 years old and spouses in their 60s.

I carried out nineteen joint interviews and two individual interviews with older people in their homes. All couples lived in the area served by the local authorities LA1 and LA2 in the north-east Scotland but only twelve were recruited through home care service providers in these local authorities, two from LA1 and ten from LA2. Seven couples were recruited through voluntary sector service co-providers/providers, two of whom worked for later life rather than care organisations whilst two couples were recruited through a potential interview participant. About a quarter of the couples lived in the country but the majority lived in towns - the largest of which had population in 2001 of around 10,800 (General Register for Scotland 2001). If LA3 were to have supported this study, then the proportion of older couples living in more intensely urbanised locations would have been greater. Nine couples were owner-occupiers, five were either local authority or housing association tenants, two lived on family farms and six lived in sheltered accommodation. With the exception of one couple, all the spouses lived alone, although the majority had some family member living relatively nearby. Further details of the couples' homes and their locations are provided in chapter three where their impact of spouses' need for support with home maintenance and transport are discussed.

I carried out a nine interviews with service providers in LA2 and two in LA1 making a total of eleven. The interviews conducted in LA2 included one group interview with a resource service manager, two home care assessors and two home care organisers, one individual interview with a care manager and seven individual interviews with home carers. Both of the interviews carried out in LA1 were individual interviews with home carers. All these service providers were women and all worked in relatively small towns and in rural locations. The involvement of the third local authority would have introduced service providers working in a city to this study.

All the interview participants were white in view of the ethnic composition of local population (General Register Office for Scotland 2001).

Representativeness: Older Caring Couples¹⁰

Age and Gender

In this study thirteen wives were caring for their husbands whilst eight husbands were caring for their wives. A further six spouses appeared to practically care for each other in apparently equal measure. In 2001 in Scotland a slightly greater proportion of men than women aged 65 or over were providing care to someone, usually their wives, within their own homes (Scottish Executive 2002a). The higher incidence of women caring for men in this study than nationally can be attributed to the limited numbers involved in this research.

In 1999 almost a third of people aged over 75 living in Scotland had problems performing at least five day-to-day activities, such as climbing stairs or doing housework (Hope 2000: 126).

In their analysis of the GHS 1991 Goddard and Savage (1994: 3) claim:

the proportion of elderly people who report a longstanding illness increases markedly with age, and the older they are, the more likely they are to say that their illness limits their activities.

Consistent with this Bowling et. al (1994) observed in their longitudinal study of changes in functional ability in older people a substantial deterioration in the functional abilities of the interview participants over a two year period.

The extent of the spouses' limitations and care needs varied greatly, from those who needed almost round the clock supervision and support with the full range of everyday living activities through to those who needed support with only a few activities. Many, including those in the role of carer, spoke of the progressive deterioration of their abilities and health as they aged. However, amongst the most disabled were one of the youngest and one of the oldest spouses.

Resources

The link between poverty and ill health has long been established; as household income decreases the likelihood of the household including a person with a limiting illness, health problems or disability rises (Arber and Ginn 1992b, Black Report 1980, Bunting 1997, Drever and Whitehead 1997, Glaser and Grundy 2002, Glaser et. al 1997, Townsend 1987). Although health inequality studies seldom include or focus on older people, Victor (1991: 23) states:

there are profound age, gender and classes differences in health status in later life and these represent the continuation of inequalities observed within the non-retired population.

This study did not specifically gather data about class or income but from the spouses' comments about their previous occupations and purchasing power, it became clear that they were drawn from varied employment backgrounds and enjoyed very different economic circumstances. Whilst welfare benefits made up part of the incomes of the majority – possibly all – of the couples, some couples had no or few other financial resources but others appeared to

¹⁰ Appendix 5 provides a table of the spouses' limiting conditions and service use

have additional sources of income. The latter tending to described themselves as 'comfortable' or having 'no financial worries'.

Arber and Ginn (1992b), in their study of influence of class on caring, identified a significant difference in the timing of the onset of a need for care between the middle and working classes. Glaser and Grundy's (2002) study of class, conducted twenty years later, reported that middle class men and women tend to develop care needs on average up to twenty years later than working class older people. Furthermore, Blane et. al (2002) found that a manual employment history, lack of choice of timing of retirement and traumatic events including failing health tend to have a negative impact on the quality of life in early old age.

In this study seven men and five women including one whom had a genetic disabling condition, had developed either physical or sensory disabilities before they reached the statutory retirement age. Two of these men, one of whom had been disabled by a serious industrial accident, directly attributed their disabilities and retirement to their manual occupations. It is possible that the limitations and early retirement of a third man was also attributable, at least in part to manual employment. Another two men had retired early from their jobs as manual workers due to acute illnesses. Whilst these men received successful treatment for their illnesses, they later developed chronic conditions and their current care needs.

The noise pollution within his workplace had contributed to the sensory impairment but not the retirement of another man. Conversely, visual impairment had led to the early retirement of yet another man but this was unrelated to his non-manual working conditions. In contrast, to the aforementioned manually employed participants, two men who had pursued professional careers drew attention to the fact that they had enjoyed many years of healthy retirement before the onset of their disabilities.

Of the five women who were disabled prior to retirement, one had worked on the family farm; one on the shop floor of a factory, one had held a clerical post and one had been involved with the church, the usual occupation, if any, of the fifth was not recorded. None of these women linked the onset or worsening of their conditions to their employment.

Arber and Ginn (1992b) highlighted that not only the issue of the timing of the onset of disability, but also how different levels of resources impact on the actual experience of care. For instance, those who have the necessary financial resources can choose to carry out alterations to their homes to reduce their dependence on others or purchase assistance rather than depend on allocated public sector provision. Studies conducted by Phillips et. al (2000) and Twigg and Atkin (1995) suggest that people with a middle class background also tend to be advantaged over those of working class in securing services on account of their greater confidence in dealing with service providers and greater powers of articulation.

A minority of couples had purchased specialist services and equipment that other couples could not conceivably afford. The couples with greater financial means also appeared to be the ones who were the more articulate and better equipped to negotiate with service providers.

Moreover, the extent of the inequality in the couples' experiences would have been much greater if it were not for means-tested benefits, allowances, services and grants.

Disabling Conditions

Old age is sometimes treated as an explanation or cause of disabling conditions in later life but only 5 per cent of co-resident carers in the GHS 1995 ascribed their care recipients' needs to old age (Coupland et. al 1991, Dept. of Health 1992, Conway and Hockey 1998, Jarvis and Tinker 1999, Green 1988, Siddell 1992, 1995, Victor 1991). Jarvis and Tinker (1999: 618-619) in their research into trends in morbidity and disability claim:

people visit their doctors more frequently now, and ... doctors display more frankness towards patients than in the past. (Also) there have been steady improvements in diagnostic techniques, and consistently positive changes in lay knowledge of medical matters over the last twenty years.

Although some of the oldest spouses regarded their age to be a contextual or additional factor in the deterioration of their abilities and development of care needs, none actually attributed them exclusively to age. They accounted for them, instead, in terms of events such as falls or recognised, and usually medically diagnosed, conditions/diseases. Ten care recipients and twelve carers had muscular or skeletal conditions, eight care recipients and six carers had circulatory conditions, one carer/ care recipient three and two care recipients had neurological conditions whilst three care recipients had respiratory diseases. Amongst older people muscular skeletal and circulatory conditions are the two most common types of diseases (Dept. of Health Central Health Monitoring Unit 1992, Goddard and Savage 1994, MacDonald et al. 2000, Wood and Bain 2001).

In the general population, hearing, visual and mobility problems are the most common forms of functional disability or impairment in later life (GHS 1991, SHS 1999). These were also the most prevalent amongst the spouses. All the care recipient spouses experienced some degree of physical disability, twelve also had a sensory disability, three a cognitive disability, one brain damage and one psychological difficulties¹¹. The severity and impact of debilitating conditions on the spouses' everyday lives varied considerably. This variation, as the following chapters explain, was structured by environmental, social and cultural factors, gender and role expectation as well as the severity of their impairments. Notably, no men but nearly all the women highlighted the problems they faced in meeting their domestic needs.

¹¹ The impairments of the spouses with brain damage and psychological difficulties did not prevent them from giving their consent to participating in this study. In the case of the spouses who were cognitively impaired, which I only became aware of having arrived at their interviews, there was not indication that these spouses did not want to take part in this study. Furthermore, their partners, as spousal representatives, gave the consent to be interviewed. However, for consistency, were I to have known in advance of meeting these couples, I would not have interviewed them.

Caring and Service Use

Data from the GHS together with the Scottish Household Survey (SHS) and their secondary analyses have provided detailed insights into the practicalities of everyday caring in later life (Askham et. al 1992, Green 1988, MacDonald et. al 2000, Milne 2002, Milne and Hatzidimitriadrou 2002, Milne et. al Owen 2001, Parker 1998, Rowlands 1998). For instance, Green (1988) and Rowland/Parker (1998) claim that older spousal carers are over represented amongst carers whom the GHS describe as 'heavily involved'. These are carers who assume the main responsibility for caring for the recipients of their care and spend more than twenty hours each week carrying out a wide range of care tasks, including demanding ones such as personal care. Milne and Hatzidimitriadrou (2002) estimate in their analysis of the 1995 GHS that 32 per cent of all older carers provided personal care and 26 per cent practical or physical help. Around 45 per cent of co-resident older carers care for 50 or more hours every week but only 25 per cent receive regular support from health or social work services. Whilst the majority of co-resident carers do not typically receive regular formal support, over half of older carers have a long-standing disability or illness that in two thirds of these cases restricts their activities (Milne and Hatzidimitriadrou 2002).

In this study the types and levels of care that the spouses provided for their partners varied according to their own and partners' abilities and their level of service use. Some orientated their whole day around caring whilst others provided more moderate levels of care. However, this study was primarily concerned with how the spouses' qualitative rather than quantitative experience of care, how experienced and made sense of their needs and care rather how much care they received. Furthermore, in spite of there being some variation between the couples most were what the GHS terms 'heavily involved' in caring. The spouses' high instance of service use can be attributed to the recruitment methods used in this study¹². All the couples were known to and received some level of support from care service providers. Over 54 per cent of the participants, or twelve couples, regularly received home care support and a further three couples had received it in the past. The GHS 1995 found that 8 per cent of co-resident caring relationships regularly received home care (Rowlands 1998). The spouses' incidence of service use clearly sets them apart from the majority older caring couples. In this respect they were not typical or representative of older caring couples but, in other ways, especially regarding their disabilities, attitudes and approaches caring, they were not unusual.

Representativeness: Home Care Service Providers

All the service providers were women, the majority worked part time and most had no or very limited formal training. This gender bias, qualification level and employment arrangement is fairly representative within this service in Scotland (Scottish Executive Statistical Bulletins for Social Work Services 1999 and 2004a).

Although the service providers, like those who took part in research into domiciliary and community care conducted by Warren (1990, 1994) and Warren and Walker (1996), had few formal qualifications, they were, nonetheless, on account of their domestic roles and their employment histories, experienced carers. However, they had limited experience of supporting older couples. Each home carer regularly assisted at least one couple but none assisted more than three. In 2001, over three-quarters of home care service users in Scotland lived alone (Scottish Executive 2003). This suggests that home carers generally will be much less familiar with supporting couples than individuals. Thus, the home carers in this study can be considered to be fairly typical of this service provider population.

SOCIAL CHARACTERISTICS AND INTERVIEWING

What emerges within an interview is the product not only of what is asked but also what the participants choose to say and how they choose to say it. These choices are strongly influenced by how researchers and participants interact as people. Whilst respect and genuine interest play a part in shaping such interactions, social characteristics do too (Gill and MacLean 2002, Padfield and Proctor 1996, Ribbens 1989, Song and Parker 1995, Shaffir 1991, Stanley and Wise 1998). Moreover, the impact of social characteristics on data generation is complex, not least because both researchers and participants take one another's social characteristics into account, sometimes more or less subconsciously (Gill and MacLean 2002, Padfield and Proctor 1996, Song and Parker 1995, Stanley and Wise 1998, Wax 1979). Reflecting on her experiences as an ethnographical researcher, Wax (1979: 509) claims:

age, gender, temperament and ethnicity become, if anything, magnified in the process of developing interactions with strangers.In fieldwork these basic aspects of personal identity become salient; they drastically affect the process of field research.

The experiences of Gill and MacLean (2002) support this claim. They found that, throughout their fieldwork people viewed and reacted to them primarily as women. Consequently, although gender was not one of the original foci of either of their studies, it became an increasingly salient factor within both. Padfield and Proctor (1996), in their study of the effects of an interviewer's gender on the generation of data, found their research participants claimed that they were ambivalent to the gender of interviewer. The contents of their interview supported their claim with one exception, namely:

What the woman volunteered herself, without being asked, about a sensitive subject..... the women added their own experiences when responding to Mo (woman), confining themselves to the question when interviewed by Ian. Neither (of the women) made a big issue of 'confiding' in a woman, indeed both assumed that they had told Ian (Padfield and Proctor 1996: 361).

The pertinence and influence of different social variables or characteristics depends on the individuals involved, their social characteristics and the discussion topic. Ribbens (1989: 579) proposes that:

much of what is said about gender can equally apply wherever the researcher has different ascribed social characteristics from the people being researched. Such social differences have major implications for how people talk to each other and what they say to each other as a result.

Merton (1972: 22) points out that:

(Assuming) human beings in socially differentiated societies can be sufficiently located in terms of single social status, category, or group affiliation – black or white, men or women, under thirty or older – ... neglects the crucial fact of social structure that individuals have not a single status but a status set: a complement of interrelated statuses which interact to affect both their behaviour and perspectives.

Furthermore, Williams (1993: 585) highlights the diversity and complexity of people's lives and argues for a 'loosening of hard and fast sociological categories'. Within this research, the spouses and I exhibited many different social characteristics but the following focuses on gender, age and accent because these emerged as the most influential and prominent social variables.

Interviews and Gender

Song and Parker (1995: 251) define gender as a perceived and 'incontrovertible reality' that erects and maintains barriers in cross gender interviews and enables disclosures of personal information in same gender ones. Early feminist researchers, including Finch (1984) and Oakley (1981), stressed how willing women interviewees were to talk to them. They attributed this willingness to a combination of factors. These included the women's familiarity with talking about their lives as result of their encounters with doctors, social workers and other officials, the informal atmosphere created by use of home-based interviews and most importantly the fact that the women identified, related, and trusted them – the interviewers – as women. A further issue that is likely to have facilitated rapport between women and these researchers is the kind of topics that they were interested in, namely 'women's issues' like child-care. The researchers' gender together with their knowledge and interest in these kinds of issues is likely to have led the women to the assumption that the former had much in common with them; a condition suited to sharing.

The foregoing arguments, conversely, imply that rapport must be difficult to establish in cross-gender interviews involving men. McKee and O'Brien's (1983) analysis of their experiences of interviewing parents appears to support such an assumption: their interviews with fathers were shorter in duration and less conversational in style than those with mothers. They also found that some men, in particular lone fathers, 'seemed to want a woman to talk to' to 'offload', to gain advice or simply to spend time in female company rather than to help them meet their study objectives.

Common ground on the basis of gender alone, and thereby rapport, cannot be assumed. Women are a socially stratified population. What it means to be a woman is different for a black woman

as compared to a white woman, as compared to a disabled woman (Lloyd 1992, Morris 1991a,b, 1993 and 1995 Williams 1989).

The omnipresence of gender was undeniable within this study. Phrases like 'you know what men are like?' and my agreement revealed and made me very aware that the participants related to me as another woman. Nevertheless, gender was not a unique social variable that overrode and negated the importance of others. For instance, on other occasions the home carers, spousal carers and I perceived and related to each other as (formal) carers.

H/C: I think all nurses and Home Helps have saire (*local term for sore, painful, or aching*) backs. I am sure of it.
A: I work in residential care so I know what you mean
H/C: Well you will know then. We all have saire backs.

In the same way that relating woman-to-woman aided the development of rapport, the shared experience of being a carer as well as other areas of commonality also fostered the sharing of information.

Accent and Dialect

Lack of familiarity with an accent, especially in combination with dialect and localised phrasing, can create difficulties with comprehension and make communication laborious (Barnes 1999, MacPherson et. al 1988). Within the interview context such difficulties can impede effective communication and the development of rapport (Giles and Coupland 1991, Honey 1991, MacPherson et. al 1988). To ask for a comment to be repeated, especially more than once, is uncomfortable and tedious but when the subject matter is of a sensitive nature repetition can be embarrassing and even, in some instances, unacceptable. Moreover, compounding such difficulties is the tendency to omit key words or to use highly localised euphemisms when discussing sensitive issues, such as personal care and increasing physical impairment (Gubrium 1991, Gubrium and Holstein 1994, Gubrium and Holstein 1999). For example, from personal experience, I knew that different euphemisms were used to refer to the personal care tasks in the different local authority-run facilities in the same town. Thus, with regard to this aspect of language, an interviewer who shares the same accent and dialect as his/her interview participants may fare no better than one who does not.

Whilst several different accents were heard in the course of this study, comprehension did not emerge as a significant problem. Occasionally, the participants checked the meaning of what I said and I had to verify with them the meaning of one or two dialect words, usually ones specific to agriculture or farming: such as 'grieve'- a farm overseer. However, I heard less dialect and accent when conducting interviews than in day-to-day interactions with friends and colleagues. Whilst this was concurrent with the relative formality of the interview situation and the use of orthodox types of speech, it also suggested that the participants were aware of and responding to my own accent.

Accent and dialect are powerful markers of social identity that readily distinguish between speakers, define individuals as insiders or outsiders and can form the basis of value-laden judgements (Barnes 1999, Ellis and McClintock 1994, Giles and Coupland 1991, Honey 1991, Montgomery 1995). Within the interview situation, comprehension aside, it is difficult to predict the impact of a difference in accents. Song and Parker (1995: 251) claimed that some of their interview participants seemed to derive confidence to disclose sensitive information from cultural commonality with their interviewer whilst other participants seemed to be 'emboldened in speaking about themselves' where there was a cultural difference.

Within this study many couples stated or inferred that they felt their accent was part of their identity. Indeed, one couple pointed out that they had retained the accent of where they were raised even though it was almost sixty years since they had left there. My northern English accent was not the same as any of the spouses' or service providers' accents and they defined it accent varyingly, some according to national boundaries and others according to regional or county boundaries. This occasionally made me a relative insider but mostly an outsider. I do not know what characteristics the spouses and home carers associated with my accent and hence whether these encouraged or discouraged them to trust me. Any lack of trust was not obvious. My accent appeared to prompt a few of the home carers and many of the older couples to ask me accent-related questions such as – where exactly was my accent from, have I still got family there, when and why did I move. I answered all such questions not only to help facilitate a rapport with the participants but also to show a kind of equity about being questioned.

Age

Different generations exhibit different patterns of communication and hold different beliefs and values about talk (Coupland et. al 1991, Eckert 1997, Giles and Coupland (1991). Giles and Coupland (1991: 159-161) claim that younger people tend to value the outcome of talk whilst older people tend to appreciate talk as 'a valued commodity in itself' and to prize 'getting on well'. These values or views bode well for positive information-filled interviews with older people. However, Giles and Coupland (1991: 163-5) point out that when older people take part in group discussions they tend to move forward their discussions according to 'local coherence' of topics rather than in an orderly manner adhering to an underlying main theme. They go on to graphically describe how, in spite of their attempts to keep the discussion focused, a comment about talking to pets sparked off comments about company, the use of day services, friendship, pen-pals, letter writing and, ultimately, Scotland. Such a practice – local coherence – has great potential to undermine effective interviewing. The interviews with older couples tended to be quite conversational and only through steering was their tendency to drift curtailed. For instance, in one interview a discussion of health and dietary needs that began with a comment about 'low fat' biscuits became so wide ranging that it included the subject of boxing before it was returned to the original theme.

In contrast, the interviews with home carers tended to remain much more sharply focused. Whilst these differences are consistent with age-related patterns of speech, the influence of the different settings and time restrictions on the interviews cannot be discounted. Richards (1994) points out that when interviewing older people sensory problems can be a 'real barrier to effective communication' but preconceived ideas about older people who have such disabilities can compound and enhance the impact of these problems. She explains how, in the interview situation, this can potentially lead to the loss of data in cases where interviewers ignore or belittle such people by using communication tactics such as extreme linguistic simplification that over-accommodate their difficulties. This study attempted to treat the participants, regardless of their disabilities, equitably and with respect. On occasions, when spouses appeared to have difficulty responding to open questions, closed questions substituted. The intention was not to demean but to support the spouses' involvement in the interviews. The responses gained through this somewhat crude tactic suggested that I avoided causing offence. Giles and Coupland (1991) outline a further form of 'intergenerational over-accommodation' whereby older people disclose their troubles seemingly unprompted or, when elicited, speak about them willingly. Appropriately managed responses to such disclosures can be a boon to data collection and research. Alternatively, Coupland et al. (1991) warn that, if an older person (mis)construes or senses an interviewer's response to such a disclosure is insincere, he/she is likely to permanently change the conversational topic or terminate the discussion. Although the spouses spoke about their painful, bad and sad experiences of living with care and disability, they did not seem to 'disclose' these experiences but rather to refer to them as they imparted their experiential knowledge and wisdom, about care, disability and relationships.

SUMMARY

This chapter has examined the methodology of this study and methods it used to collate its data. It has also detailed how the process of recruitment of interview participants resulted in changes to its intended interview techniques and its original aims. It has also reflected on the extent to which the participants and, by inference, their data can be considered representative of older caring couples and home carers in general. Finally it reflected on how the participants' and my own social characteristics may have influenced the generation and type of data collated. This study now turns from how it gathered its data to their analysis in the following chapters.

CHAPTER 3: CARE AND THE GENDERED DIVISION OF TASKS WITHIN THE HOME

INTRODUCTION

This chapter examines the impact of care on how the couples divided up their domestic activities and responsibilities and, in particular, how they experienced and understood needing, receiving and providing assistance with these activities. The spouses tended to construct and understand domestic activities and responsibilities in gendered terms. They viewed certain activities, including housework, laundry, cooking and shopping as women's work and other activities such as home maintenance, gardening and driving as men's work. Accordingly, this chapter refers to these activities as feminine and masculine domestic activities and divides up its exploration of how the spouses managed their domestic needs along these same gendered lines. It sequentially examines how the spouses managed their feminine and masculine domestic activities and also their financial transactions in the context of these needs following the onset of their disabilities. It identifies how the spouses addressed and felt about their need for assistance with these gendered activities, the kinds of assistance that they were prepared to accept from their informal and formal care sources and how they understood assistance from these different sources. As it reflects on these issues, the significance of the principles of reciprocity and fairness in how the couples made sense of and practiced care emerge. Hence, this chapter begins by outlining the theory of social exchange and forms of reciprocity found in caring relationships.

RECIPROCITY AND EQUITY

Social Exchange Theory

Social exchange theory suggests that, to fulfil needs that they are unable to meet independently, individuals engage in social interactions or exchanges with others and thereby enter into relationships (Dowd 1980, Zafirovski 2003). Whilst ever those involved in a relationship continue to benefit from the exchanges that take place within it, the relationship will continue but, where this is not the case, exchanges will cease and the relationship will be discontinued. In other words the survival of a relationship depends on mutual contingent benefits (Gouldner 1960). An exception to this may occur where there is a significant power imbalance. For example, B may be able to force A to support to him / her despite a lack of reciprocity but this relationship is likely to be relatively unstable. Although exactly equal exchanges tend to be quite rare, exchanges should, at least in the long run, be viewed as being more or less equivalent either in form or value. The latter being relative as it depends on the circumstance of those involved in the exchange.

However, Gouldner (1960) claims that reciprocity, as well as describing or explaining an exchange process, reflects a moral norm or obligation: the belief that people should help those

who have helped them. Gouldner (1960) distinguishes this reciprocal based moral obligation from moral obligations that specific roles impose but, in practice, these different kinds of obligation are frequently tightly bound up together so as to be inseparable. For example, spouses are obligated to care for each other on the basis of their marital status but most are also reciprocally obligated to care for each on account of their exchanges of care throughout their married lives.

Spousal Care and Reciprocity

Studies of the domestic division of labour and caring within heterosexual relationships have repeatedly identified and stressed the importance of notions of fairness and equity to spouses' satisfaction with their marriages and even to the survival of such relationships (Curtis 1986, Delphy and Leonard 1992, Lennon and Rosenfield 1994, Morris 1990, Risman and Johnson-Sumerford 1998, Ward 1993). In their study of the impact of disability and care on marriage, Thompson and Pitt (1992: 118) hypothesised that:

in the case of chronic illness, where the spouse of the ill partner takes on more burdens because of the illness and at the same time receives fewer rewards from the partner, ... both spouses would be distressed as the result of inequities in the benefits and costs that each incur in the relationship. The well spouse may be vulnerable to feelings of anger, resentment, and lessened commitment to the relationship. The ill partner may experience guilt, fears of being a burden and worries about being deserted.

Their empirical data partially supported their hypothesis but the impact of the increased relational inequality was not as strong as they had predicted. Keith and Schafer (1985) and, more recently, Kulik (2002) found that when equity is disturbed in intimate relationships the intimates try to restore it. The results of Thompson and Pitt's research implied that the spouses in that study somehow, either actually or psychologically, managed to restore equity in their marriages. Similarly, in this study, when the men began to provide domestic care and the when women added other forms of care to their existing provision of domestic care it disturbed the balance of their relationships. Nonetheless, the couples seemed to (re-)evaluate their relationships in ways that enabled them to regain (or retain) their sense of equity.

Nolan et. al (1996) point out that care research has repeatedly found that the rewards of caring are bound up with relationships. Hirshfield (1983), in her research into family caring and senility, claims that in cases where the care recipient matters and is important as a person to the carer then the latter is likely to find satisfaction in caring and attribute meaning to the caring relationship; a practise, she refers to as, 'developing mutuality'. In their study of male carers, Neufeld and Harrison (1998) identified three variations of reciprocity in addition to a balance of 'give and take'. These were waived, generalized and constructed. Waived reciprocity occurred when, on account of the care recipient's disability or condition, there was no expectation of reciprocity in the present or future and care was provided because it was needed. Carers who waived reciprocity had had a positive relationship with the recipients and still valued reciprocity

as a principle. Generalised reciprocity was concerned with altruistic values and the greater good and the provider derived a sense of satisfaction from engaging in care as an altruistic act. Moreover, the provider recognised the contribution that his/her care recipient had made to the welfare of others and felt that his/her caring offered those younger than him/herself a good role model. In contrast to waived and generalised reciprocity, constructed reciprocity emerges in relationships where carers actively interpret their care recipients' non-verbal behaviours and communications as responsive interactions, in other words in reciprocal terms. Neufeld and Harrison (1998) found that such reciprocity usually occurred in long-term and highly valued relationships and tended to support mainly positive feelings about caring and the care recipients. Thompson and Pitt (1992) proposed a number of ways in which their participants may have restored equity in their marriages. These include taking into account the disabled partners' earlier contributions to their relationships, evaluating their current contribution in accordance to their abilities and considering what they would do in other circumstances. Call et. al (1999) suggest that family relationships – including marriage – can be seen as 'a long history of reciprocal exchanges' that balance over time but are not necessarily in balance at any one time. Within this framework, care for a sick partner represents one instance within an ongoing series of exchanges.

Similarly, Pickard et. al (2000) and Pickard and Glenndinning (2002) emphasise that caring within later life is often about the continuation of the relationship in which it is provided. This does not necessarily mean that caring is easy but the difficulties and demands of caring within such relationships are counterbalanced by love and earlier experiences. Many of the spouses in this study included amongst their reasons for caring that the partners had previously looked after them and or that they had always looked after each other throughout their marriages. Only Mr and Mrs Hendry completely reversed their caring roles. Mr Hendry, who now received extensive assistance from his wife, had in his younger years enjoyed much better health than his wife whom he had cared for alongside her mother. Amongst the spouses a mutual exchange of support was more common than a reversal of care roles. Mrs Beattie described how her husband and she supported one another:

As a couple we have always worked into each other's hands both when the children were small and all through life. ... We have been 59 years married this year. Yes, we have had a lot of practice and I think it is what you are prepared for in a marriage. You know that the marriage must go on and we have always helped each other.

Presumably because of their ages and the progressive nature of many of their conditions none of the spouses predicted a future time when their caring roles would be reversed. However, many of the caring spouses unequivocally asserted, with a confidence borne out of their long-term marriages, that if they were to have needed care then their partners would have supplied it. In only three relationships was it not possible to distinguish objectively between the main carer and care recipient, yet most of the spouses perceived themselves as looking after one another. For example, Mr and Mrs Kerr spoke equitably of keeping an eye on each other even though

there was a significant difference in the assistance they received and provided. Mr Kerr helped his wife remember things, made her laugh, encouraged her to go out (take respite), co-operated with her care-giving activities and tried, usually unsuccessfully, to help her carry out practical tasks around their house and garden. Mrs Kerr assisted her husband with his personal hygiene, communication, mobility, medication, domestic chores, home maintenance and transport needs, and managed their finances. This suggests that the spouses evaluated one another's contributions in the context of what they believed they could fairly do. In some couples the difference between the spouses' individual contributions was less and in others greater and in these cases, claims to look after each other may have reflected, constructed reciprocity, as described by Neufeld and Harrison (1998). The other forms of reciprocity, waived and generalised reciprocity that Neufeld and Harrison (1998) identified were not apparent in this study.

Very few spouses felt that their partners did less than they were actually able to but those who did, felt that their partners exploited or took advantage of them in respect to certain aspects of their care giving. For example, one spouse complained that her husband actively made the task of assisting him with his medication difficult and trying. She explained that when she gave her husband his tablets he often claimed to take them when actually he had left them lying around somewhere or other. This meant she had to be extra vigilant to ensure not only that her husband received his medication correctly but also that any tablets that he discarded were disposed of safely. Another spouse claimed that, unlike when a home carer assisted her husband with his shower, when she assisting him he 'took a loan of' her by being uncooperative.

Appreciation

Reciprocity has repeatedly been identified as significantly influencing the physical and mental well-being and feelings of burden of both carers and care recipients (Craft and Grasser 1998, Dwyer 1994, Nolan et. al 1996, Grasser and Craft 2000, Neufeld and Harrison 1998, Pruchno et. al 1997, Stoller 1985, Vaananen et. al 2005). Stoller (1985) and Pruchno et. al (1997) in their studies of morale and sense of well-being of care recipients emphasised the importance to the recipients of care of being able to contribute to the well-being of their carers. Many care recipients are physically limited in what they can do but in the absence of cognitive impairment, their ability to either express appreciation and/or comply with caring practices is seldom completely eroded. The latter sometimes serves as a facet of appreciation.

Appreciation is an important benefit or satisfaction available to carers (Nolan 1993, Nolan et. al 1996, 2002, 2004). Lewis and Meredith (1988), in their study of intergenerational caring, found that appreciation reassured carers that to care was worthwhile and hence eased their sense of burden. Nolan et. al (1996: 86) argue:

A carer who experiences satisfactions (*with caring*) is likely to provide better care, so in satisfying caring relationships the cared-for person must similarly always gain. This merely highlights the inherently reciprocal nature of good caring

relationships... Therefore in this broader sense all the satisfactions of caring provide some reciprocity.

Indeed, Nolan et. al (2002) suggest that the provision of high quality is related to the extent that carers feel valued and appreciated. The exchange of appreciation can play a significant part in securing and maintaining equity of caring relationships. However, Begum (1990) claims that care recipients can feel subject to 'the burden of gratitude'. In her study of women in receipt of care, she explains that her participants felt that they were *expected to* appreciate the care that they received but this was not how they always felt. Appreciation of care tends to show a gender bias (Begum 1992, Morris 1995, Rose and Bruce 1995 and Ungerson 1987). When women care they are seen as normatively expressing their identities and fulfilling their roles. Thus, their activities do not always command appreciation. In contrast, when men care they are seen as doing something extraordinary, as something different and mostly extra to what they usually do. Therefore, it and they are noticed and appreciated, especially when they provide care for women, the conventional providers of care.

The spouses' responses to care supported and challenged this gender bias. Both the men and women expressed, openly or by inference, their appreciation¹. The men tended to commend their wives' caring skills and competences. For instance Mr Oliver described himself as being 'in safe hands'. In contrast, the women clearly and unambiguously exalted their husbands as 'marvellous' or 'wonderful' because they cared. In their research into emotional work and sentimental activity, Duncombe and Marsden (1993, 1995 a,b, 1998), James (1989, 1992) and Mason (1996) claim that women tend to be more skilled than men in recognising and responding to the emotional needs and sensibilities of others because of their greater experience of servicing others. Having compared the findings of their research into women and men caring for cognitively impaired care recipients and pre-mature infants, Neufeld and Harrison (1998) conclude that the men in their studies were less skilled in decoding non- verbal communication of their care recipients and accordingly less likely to establish effective constructed reciprocity. All this suggests that women are more likely than men to understand the importance of appreciation in caring relationships, hence, they are more likely to express it more readily and unambiguously than men. It also implies that they are also more likely than men to be more skilled at 'detecting' how their care recipients feel about the care that they receive. Whilst the women in this study appeared to take pride in their husbands' commendations of their skills, they appeared to receive them as confirmation of 'what they already knew' rather than a fresh insight into their husbands' feelings or views.

¹ This study focused its participants' attention on caring at every stage from recruitment onwards. If the care recipients' expressions of appreciation are considered to be a form of positive self-presentation, then they may be viewed as artefacts of this study's care focus. However, some of carers claimed that they actually felt appreciated. This suggests that the care recipients' expressions of care are likely to have been about more than image. .

Reciprocity is important in relationships but helpful exchanges are bound up with the exercise and distribution of power and the expression of personal and social identities. Thus, in trying to understand how exchanges of assistance within families, Finch and Mason (1993: 58) warn against:

focusing too narrowly on the material value of the goods, labour or time which is being exchanged. On many occasions the negotiations seem to be less about balancing out the value of exchanges on objectively identifiable criteria and more concerned with establishing how the nature of the exchange is to be understood and treated by the key participants

This points to the importance of understanding caring exchanges within context of relationships. For the couples, caring involved reciprocity but it was also about their marriages, their roles, their relationships, their moral identities and about doing the right thing as spouses, men, women and married couples. They cared because they were spouses, because they valued, cared about and loved their marriage partners and their needs mattered. Thus, they derived satisfaction and achievement from seeing their spouses cared for and comfortable.

FEMININE DOMESTIC ACTIVITIES

The Spouses' Division of Domestic Labour

The traditional gendered division of domestic labour has repeatedly been found to play an important part in the defining and the performance of the roles, relationships and identities of spouses (Allan 1985, Ahlander and Bahr 1995, Arber and Ginn 1992a, Delphy and Leonard 1992, Keith and Brubaker 1979, Keith and Wacker 1990, Mason 1987a,b, Morris 1990, Sullivan 2000, Szinovacz 2000). In general, prior to the onset of disability within their relationships, the women in this study had assumed responsibility for and as far as they were able continued to undertake the cooking, cleaning, shopping, washing and ironing, and any other feminine domestic chores whilst the men assumed responsibility for and either arranged for or personally carried out the maintenance of their homes and gardens and driving. They adhered to this traditional division of labour not only on grounds of convention but also because they felt it was fair and hence contributed to marital stability. Mr Fyfe explained:

I did the decorating. I did the DIY stuff and (*names his wife*) ran the house and did the cooking. ... It was, if one says, the typical, not necessarily male chauvinism, but you know I did one end of it and (*names his wife*) did the other.

Most husbands also helped their wives to some degree with their household activities and conversely some wives helped their husbands with their masculine domestic activities.

Szinovacz (2000) concluded from his analysis of changes in patterns of housework at retirement that although husbands 'help' their wives, women remain responsible for and do the bulk of domestic chores in retirement. Nevertheless, he acknowledged that:

among aging couples, health also becomes important,.....wives' health limitations encourage husbands to help more ... husbands' health has little effect on wives' housework. (Szinovacz 2000: 99).

This more or less summarises how care and disability revised the couples' domestic practices. Whilst continuing to divide responsibility for their domestic needs along traditionally gendered lines, just over half of the couples were unable to practise a traditional division of domestic labour. This was because the women's limitations impinged on their abilities to do 'their' housework. In these relationships the men no longer had a choice about doing domestic chores; they had to do them.

Irrespective of the gender of its provider, the spouses recognised domestic care as care. For instance, Mr Jarvis claimed:

Mr Jarvis: My wife looks after me and does everything for me. I wash the dishes and sometimes dry them. But nothing much.

A: When people say that it's very difficult to know exactly what they mean as for some people it means taking them to the toilet, getting them dressed in a morning and

Mr & Mrs Jarvis: No, no.

Mrs Jarvis: He dresses himself, he toilets himself, he showers himself, I'm there just in case he needs me. He's very independent. But as for the house that's me.

This was somewhat surprising since activities such as housework are generally seen as being what women normally do. One possible explanation for this was that the couples' exposure to needs assessments and care services in which domestic activities are defined as care had influenced their views on what is care. Whilst political messages help shape people's views, their influence tends to be tempered and mediated by personal beliefs and tradition. For example, in their study of care policy and practices, Twigg and Atkin (1994) found that service providers' expectations about caring and service provision were structured not only by policy but also by their gender, age and personal values. Since social policies and anti-sexist ideas tend to be more familiar to service providers than users, it might be assumed that political messages and the spouses' use of services were unlikely to fully account for why they recognised the performance of feminine domestic activities by women as well as men as care. When the men in this study became disabled and their wives became their carers, the couples' the domestic arrangements changed little but other aspects their lives changed considerably. This was because, in addition to domestic care, most of these men needed assistance with a wide range of other activities and their wives undertook to provide them with such support. This overall increase in their wives' activities is likely to have disturbed the balance of these relationships and such a disturbance, for the reasons discussed above, can be expected to have led the spouses to look again at how they evaluate their contributions to their relationships. This process may have led the spouses to appreciate and redefine the carrying out of domestic activities by women as well as men as care.

Half of husbands in this study were significantly involved in the provision of domestic care. Seven men, three with input from services, carried out more or less all of the domestic chores within their relationships whilst two men were equally involved as their wives in carrying out feminine domestic activities. In a further four relationships the extent to which the individual

spouses were involved in provision of domestic care was in flux. The women's hands-on domestic contributions were declining because of their increasing limitations whilst their husbands' were increasing. In some couples these changes were accompanied by an increase in use of services. Mr and Mrs Ferguson described the changes within their domestic arrangements:

- Mrs Ferguson: I mean you (*looks at her husband*) do a lot but more toward the cooking and things like that rather than the house. The home help comes in on a Wednesday.
- A: So your housework is more shared then
- Mrs Ferguson: Yes. Yes isn't it? (*directed towards her husband*). More fifty/fifty.
- Mr Ferguson: Well I do a lot more than I use to.
- Mrs Ferguson: Well you can put it that way, yes, because I would have never seen anybody in my way before. I never asked anybody to do. I was up and down ladders putting up curtains, doing windows. He just did his (paid) work and that was it. Well up to a few months ago I used to do all the ironing as well but I just got that this shoulder and wouldn't (*breaks off but it was clear implication was her shoulder could not cope with the demands of ironing*). It's just a case of you do what you can and shout when you can't but at least you try to do what you can. (*Pauses seemingly thoughtful*).I would have been on the go from morning to night before. It depresses me really. I can't even hang out clothes because I can't reach the rope. It means that you have got to be dependent all the time on somebody for something. Maybe it's a little thing but it is still taking away their time. There has to be someone there. ... I mean there is no use having a washing machine to do the washing and no one there to hang it out so (*names her husband*) has to be there until such times as the washing is finished. He has got to plan his time out as well as everything else.

As Mrs Ferguson's actions typically illustrate, almost all the women (and, as discussed later, many of the men) tried as hard as possible to struggle on with their domestic responsibilities in spite of restrictive and often painful, energy sapping chronic conditions. To call on others for help was their last resort. Needing assistance to fulfil what they regarded as their domestic responsibilities frustrated, angered and depressed them. These emotions were compounded by the distress and guilt that they felt, at least initially, about accepting such help from their partners or others.

Feminine domestic activities (had) played an important part in how the women related to their husbands (and others) and how they expressed their personal identities and reputations. They were good and caring wives and they evidence this in the way that they kept house and home for their husbands and families. This was illustrated in Mrs Jarvis' phrase quoted earlier 'as for the housework that is me' and in Mrs Addison's reflections on her activities as a farmer's wife:

I was accustomed originally with having a few hens and I made butter and made cheese. I was a true farmer's wife. Really I had a busy life. I was a bit lost (*when we moved*) to begin with. *Pause...* but I realised that very soon (*breaks off*). It was a move because I wasn't fit. I had given up all that extras (*butter making etc.*) and was just quite content that I could hope to look after husband.

In his discussion of the emotional significance of dependence, Scrutton (1999:154-155) explains that, regardless of how well meant, care diminishes its recipient's sense of self because it underlines that he/she is failing in his/her efforts to remain independent. Thus, he suggests that care can demoralise and hurt the pride of people even those who appear to accept care with good grace. To the women in this study to need and accept assistance with their domestic activities threaten to impinge on, contract and undermine their identities as 'good housewives' and their usual means of relating to others. Furthermore, as Mrs Ferguson's concerns about the demands on her husband and his time reveal, they were very conscious that their partners' provision of care threatened the balance and equity of their relationships because, when these men became carers, they did not always cut back on their own domestic activities. It would be wrong to think that the foregoing emotions and concerns were limited to women. Men also had them but they were less pronounced, partly because as carers women did not become heavily involved in their husbands' domestic responsibilities but also, as is discussed in more detail later, because of the different social expectation on men and women.

Practical Solutions for Dealing with Feminine Domestic Activities

When women had to 'shout' for help with their activities, in the first instance, they tended to call on their husbands. Dovetailing their skills and abilities with assistance from their husbands they continued to accomplish as many of their domestic tasks as possible. This approach reduced the couples' reliance on outside sources of assistance and thereby helped maintain their autonomy. All the couples adopted this co-operative approach but two couples - in which distinguishing a main carer was impossible - applied particular skill and resourcefulness. This was exemplified by how they shopped and cooked. Mr May, who had mobility and visual problems and his wife, who had osteoporosis, had figured out that they needed to shop in a morning because this was when their energy levels were at their optimum. When shopping Mr May pushed the trolley - this served as a sort of wheeled Zimmer frame - while his wife selected the items and wrote cheques to pay for them. In respect of cooking, Mrs May prepared and oversaw the cooking of their meals and utilised her husband's strength to lift and strain pans. Mrs and Mrs McAllister's limitations, again visual and physical, similarly structured their approach to cooking:

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| Mrs McAllister: | He makes most of the meals. I make most of the soup. You cannae. You've never made soup on your own have you. |
| Mr McAllister: | No, no. I have to do all the vegetables you see. |
| Mrs McAllister: | Oh aye, I canna see. He does the tatties and cuts up onions and carrots and leeks and such like. .. We donna starve. We like our food. ... I loved cooking and baking. I still bake scones and pancakes yet. Och I've. But (<i>names her husband</i>) weighs out. He weighs out for me. |
| Mr McAllister: | A combined effort. |
| Mrs McAllister: | It is a combined effort. Yes that is right. |

Mr McAllister: I does (*sic*) the vegetables for the dinner. She sees that everything is cooking. She looks after the cooking bit hersel' more or less.... She usually asks me to look into the oven

Mrs McAllister: Oh aye that's right.

Mr McAllister: The same with if she is doing a roast in a pan or anything like that I always look in just to see how it is doing.

Mrs McAllister: I used to object to him looking at my cooking but nae now you see. No.

A: Why did you object?

Mrs McAllister: Well because it. It was him that was doing. ...(*Mrs McAllister did not elaborate any further*)

This dovetailing approach helped the spouses complete their domestic activities, and, with its emphasis on ability, it also helped maintain their morale. Moreover, reducing their dependence on assistance from outwith their marriages, it fostered their independence and autonomy as couples. However, in spite of the sharing involved in the dovetailing approach, responsibility for domestic activities did not shift with their performance between the spouses: women continued to be responsible for feminine ones and men for masculine ones.

Discourse, Meaning and Men's Attitudes to Caring

Ungerson (1987) claims that men transfer and apply the principles and language of paid employment to caring at home and in doing so turn it into their job of work. In their study of older men and caring, Kaye and Applegate (1994: 228) observed that the older caring husbands imported organisational skills and 'tough-it-out' attitudes from their workplace into their care experiences. Similarly in this study, caring husbands transferred work practices and drew many analogies between caring and paid employment. Mr Reid declared caring to be a 'full time job'. Mr Geddes referred to himself as a 'home help'. Mr Taylor carried out as many caring activities as possible according to a rigid timetable. Mr Green longed to streamline the arrangements for the use of the laundry in their sheltered accommodation complex. Furthermore, these men claimed that their paid employment and or military experiences had provided them with useful practical skills and the necessary aptitudes and attitudes to cope with caring. Mr Reid explained:

Well you see I was in the army. I was a territorial in 1937 and then called up before war started, August '39 was demobbed in December 1945. So that was six and a half years in the army and you learn to do things for yourself in the army. That was the training (*for life and caring*)

Taylor (1993) and Gollins (2001), in their studies of care and gender, also found that their male participants identified their military experiences as helping them to be effective carers. In contrast, Fisher (1994) advises against the overenthusiastic application of the occupational model to men's care on the basis that it can result in the qualitative similarities in care provided by husbands and wives being overlooked or denied.

The men and women in this study used occupational similes and analogues freely to describe the formers' approach to and carrying out of care tasks. However, these men were morally and emotionally motivated to care for their wives and to them their caring activity was about

reciprocity, fairness, being good husband and doing the right thing. This emotional, moral and practical combination was exemplified in Mr Green's explanation for caring.

Mr Green: I am a carer.I care for her. That is my job. That is what I do because I love her. I have always looked after her. As I pointed out to her recently when I was at work, very busy, she looked after me and now it is my turn. I was very busy with (*names his employer*) I was promoted to executive engineer for this area. We had an interesting life...

In spite of having been instilled with a coping attitude by their war time experiences and military training, the inconsistency between the men's belief in the propriety of a conventional gendered division domestic labour and their involvement in feminine domestic activities, may have been expected to have caused them some kind of emotional discomfort or upset. This did not seem to be the case.

Contrary to her expectation, Parker (1993:120-121) also found that, for older spouses, assisting their partners with activities that had once been part of their domestic role was not a problem. She reasoned that the commonality of chronic limiting conditions in later life eased older men's acceptance of such changes because it meant that they sometimes 'shared the experience of their spouse's failing health or increasing impairment with at least some of their contemporaries'. Some spouses in this study shared the experience of becoming increasingly limited and/or becoming carers with their marriage partners or other contemporaries. Whilst this may have helped facilitate the men's acceptance of domestic caring, it did not appear to ease the women's emotional acceptance of assistance, at least in the initial stages, as the theory implies it should. In her discussion of how gender is conceptualised in marriage, Thompson (1993), criticises the idea of the catchall sex role:

Women and men do not simply conform to structural conditions and confirm cultural images .. Instead, both partners collaborate to create strategies that reconcile personal and relationship concerns with the realities of life (Thompson 1993: 565).

Risman and Johnson-Sumerford (1998) likewise point out that in marriages, where the spouses are guided by fairness and sharing, gender is not deterministic in their division of household labour. Recent research into marriage and kinship also emphasises the influence of the principles, moral values and reasoning on how families deal with change (Mason 2000b, Neale 2000, Williams 20001). Neale (2000) argues that responsibilities are not determined by status and duty but are contingent: people work out what they think is the right thing to do in a particular set of circumstances through moral reasoning and 'relational' thinking. Williams (2001) likewise claims that when dealing with change, families tend to treat their more vulnerable members according to their needs and capacities. In other words they act fairly. All the husbands in this study who were caring for their wives felt that – morally as well as dutifully – they should look after their wives; some also stated that they wanted to care for them. [The same applied to wives caring for their husbands.] As they frequently pointed out,

they had vowed to care and had enjoyed the benefits of their enduring marriages and so as 'good husbands' they felt that it was only right to care for their wives.

Mr Reid: I feel that err fortunately I have got a bit of health left and I am able to do it (*care*). Why not? I am quite what shall we say dedicated. Yes that is the word.

Mr Geddes: Well we have had a good married life. Well I think so anyway. And understanding... I do what I do. It doesn't bother me. I don't moan about having to do it. Or anything like that you know. Part and parcel of life. (*Mr and Mrs Geddes speaking this phrase together*).

Gollins (2001: 17) suggests:

male carers experience caring in quite different ways to women, although many of their caring activities are the same. Male carers see it as an activity, and not as part of their identity. Male carers do not 'see' themselves as carers.

There were many similarities in how the men and women in this study experienced providing domestic and other kinds of care. Some men and some women declared that they were house-proud and that they enjoyed cooking and caring for their spouses. Just as some men took business-like approaches and attitudes towards domestic activities, so did some of the women. For instance, Mrs Lawrence repeatedly stressed that she was constantly on the look out for easier ways of tackling chores. In spite of such similarities, there were undeniably differences in how they felt about, experienced and understood domestic care. Firstly, carrying out domestic care activities was routine for the women but largely novel for men. It offered them opportunity to develop and improve their domestic skills, to feel a sense achievement and, not infrequently, to hear praise. Typically Mrs Beattie claimed that her husband 'found himself having to cope with quite a lot of things and has done admirably well'. Arber and Gilbert (1989), Rose and Bruce (1995) and Ungerson (1987) have also shown that older men usually get a sense of achievement and praise when they cook, clean or shop but older women do not. Secondly, regardless of how many domestic care tasks men undertook and however competently, they retained the designation of their wives' 'helper'. The latter remained ultimately responsible for these types of activities, unless they had a severe cognitive disability. Consequently, caring husbands, even when heavily involved in the provision of domestic care, were not subject to the stress of being responsible for it. Moreover, in relationships where the women chose to use domestic services, their husbands also received domestic care. These two issues are considered further in respect of the couples' service use.

This study does not ultimately support but challenges Gollins' assertion that male carers do not see caring as part of their identity. Domestic care was and had always been integral to the roles and identities of the women as wives and housewives and when men became spousal carers it became part of their role and identity. To the couples caring was an integral part of being a good husband as well as wife.

The Significance of Relationship in the Provision of Assistance

Dominelli and Gollins (1997: 396/403-404) claim:

power is a complex phenomenon, which is constantly negotiated and renegotiated between social actors. ... At an interactional level, relatively powerless people can influence that interaction between them and more powerful others.

Relating this to caring relationships, they suggest that such relationships:

allow the care recipient room to assert their own agenda. (*and where*) bonds are established between them (*carer and care recipient*), which focus on their mutual dependency, ... the person cared for can generate power of their own.

Yet, the power available to a care recipient, through negotiation and action, is limited. It depends on the carer's willingness to let the care recipient assert his/her wishes and the latter's ability and confidence to do so.

Before they became disabled, the domestic power of the women in this study had been absolute; they could clean when and what they liked to their own standards, but once they had to accept help from others they could no longer do these things. Their domestic power and influence were necessarily reduced but within their spousal caring relationships the women were able to retain and exercise more influence over domestic activities than in their formal caring relationships with home carers and cleaners. This was not only because the men needed instruction on how to do various tasks but also because, regardless of their proficiency, they were ready to negotiate and to respect their wives' domestic wishes.

- A: You (*Mrs Fyfe*) said that previously you cooked and shopped and all the rest of it, do you still have any input in to it now?
Mrs Fyfe: No I don't I don't really want to.
A: What about decisions about
Mr and Mrs Fyfe: Oh Yes
Mrs Fyfe: Finding new menus and recipes.
Mr Fyfe: We are not too mince and potatoes all the time.
Mrs Fyfe: No, we like to try different things. The only time we have rows is in the kitchen. He will do it his way and I want it done my way.
Mr Fyfe: I think that is understandable. You know my invading a province, which was exclusively the lady of the house's. But we still shop together. (*names his wife*) can walk with a shopping trolley as long as she has got something to hold on to. So what we do is make a list and (*names his wife*) does certain things and I go round and get things so we are still very much involved in that. As far as the meals are concerned it is very much a discussion. We try. We have the cookery books out and we try this, that or the other.

Caring husbands became involved in and infringed on their wives' domestic 'provinces' or domains but they did not take them over. Nowhere was this more evident than in respect to shopping and cooking. Although men as carers cooked and shopped, their wives were always the decision-makers in these matters. Cooking and shopping are closely associated with femininity and the production of gender identities, relationships and roles (Bowlby 1988, Campbell 1997, Charles and Kerr 1986, 1987, Murcott 1983, Sidenvall et al. 2001). Bowlby

(1988) and Campbell (1997) in their studies of shopping highlight the link between shopping, the provision of meals and the women's nurturing domestic role. Campbell (1997: 167) argues that:

shopping is basically part and parcel of the activities, which help define the female role, and especially that sub-roles of housewife, which is in turn seen as associated the more general status complex of wife and mother.

In their classic studies of gender and food, Murcott (1983) and Charles and Kerr (1986, 1987) insist that women feel responsible for trying to provide their nuclear families with 'proper' meals; that is meals they consider to be nutritional. Kemmer (2000), and Valentine (1999) challenge the continued applicability of the findings of the aforementioned studies on the grounds that since their publication, gender ideology, household structures and eating patterns and practises have changed. However, in their study of cooking and shopping in later life households Sidenvall et. al (2001) found that older women remain traditional in their choice of ingredients; dishes and approaches to meal preparation unless they were ill, lacked strength, energy, dexterity and/or had poor vision. In these circumstances, they purchased 'prepared products' and or 'ready-to-eat' foods with simplified cooking procedures so they did not have to depend on others.

In the absence of cognitive disability the women in this study determined what food was bought, what was cooked, when and how it was cooked. Indeed, wherever possible they actually cooked it. They compiled shopping lists, selected and ordered pre-prepared meals and chose foods when out shopping. These activities revealed both their continued domestic influence and their strong sense of responsibility for their husbands' physical health through their diets. Moreover, through these activities, the women protected their husbands from the stress of unrelenting and often taxing culinary domestic decisions. Allan (1985: 90 – 91) points out, in his study of family life, that when only activity is taken in to account, the degree to which women are involved in maintaining the home and family is underestimated because all their organising and planning is overlooked. Allan (1985) chooses childcare to illustrate his point but he could have easily chosen menu planning. Apparently relaxing in front of the television, women are often quietly figuring out what to cook over the next days so as to avoid waste of any fresh foods they have in store, what foods need to be bought, whether to buy fresh or frozen, what kind of foods are now recommended as part of a 'healthy diet', how to encourage their husbands to eat such foods and how much will the next food bill amount to. In these ways women continued to care and exercise domestic control.

The couples did not construct or make sense of the exchange of domestic assistance within their marriages in terms of a power struggle. Wilson (1995: 107) in her study of gender relations in advanced old age found that 'in close marriages, issues of power had faded as issues of daily survival became increasingly important'. Using case studies she illustrates how one of the main concerns of older caring spouses is how to assist their partners rather than take control from them and so increase their personal power. Similarly, in his study of very long-term marriages,

Brubaker (1985a) found that such marriages tend to be characterised by sharing and 'give and take' rather than one partner attempting to dominate the other.

In this study, when a wife was no longer able to shop, cook or clean, for the spouses, the key issue was how they could overcome this obstacle. It was about helping and caring for each other and coping as a couple.

Mrs Beattie: I would have probably needed more help (*services*) but I have been able to be at home because he (*Mr Beattie*) has been so helpful. ... we have always helped each other. So naturally when I have not been able to do things he has just fallen in.
.... I would not like to think what might have been had he (*not be able to help*). That is another blessing that we have been spared to each other. Many person my age is on her own or the other way round on his own. So we have that to be thankful for.

Mrs Ferguson: Well, up until a few months ago I used to do the ironing as well but I just got that this shoulder and that wouldn't...

Mr Ferguson: And the home help did it for a few weeks but by the time she does all the ironing it's most of her two hours gone.

Mrs Ferguson: It was cost too much. Well we have to pay for the home help and I felt it was better for her to do the house through once a week. ...He said 'I'll cope with the ironing'. Now and again I've done a shirt...a dressy one. It doesn't matter about your ordinary ones but a dressy one. But we always manage to cope between us.

Helping one another and working together to overcome difficulties and cope, was, in the eyes of the couples, what their marriages were all about.

Non-spousal Assistance with Feminine Domestic Activities

Sources of Assistance

Whilst the couples valued their independence and strove to limit their dependence on outside help, the women were concerned that they should not overburden their husbands with their domestic needs. Hence they looked beyond their marriages for domestic assistance but not to their families. They did not want and did not consider it right to rely on their children for such assistance, in spite of often emotionally and physically close relationships with them. Instead they looked to services for domestic assistance.

Mrs Ellis: We see her (*daughter*) nearly every day but we don't ask her to do anything for us you know. ...

Mr Ellis: Pride

Mrs Ellis: If I was desperate or took the flu and she would come over and do but she is at uni. ... and she has her house so you can't expect her to everything for us you know. ... She would do things in the house but part of me.

Mrs Geddes: Well, I would definitely need someone in to Hoover (*if her husband did not do it*). I like to see things (*tidy?*). I would hate to see the house going down. No doubt my daughter would do it but ... You can't depend on the family all the time you know.

She is working and the daughter-in-law works full-time. There is no doubt that if I said I would like the house hoovered there would be no problem. If I was ever left on my own I think I would like to be independent and have somebody come in once a week.

Mrs Hay: We don't want anything that would prevent them (*their adult children*) from carrying on their own lives.I want them to do as little as possible. I want to interfere with their lives as little as possible.

The couples' preference for formal care defies the political dogma that insists that older people's families should be their primary source of care and so challenges social policies based on the familial ideal for formal assistance. The possibility that this finding is a reflection of this study's methods of recruitment is undeniable. Nevertheless, it is consistent not only with the value that the spouses placed on reciprocity within relationships and their fear of becoming beholden but also with the research findings of Finch and Mason (1990, 1993), Qureshi and Walker (1989) and Tanner (2001).

Gender and Domestic Care Services

Ten couples used domestic care services: five used their local authority home care service and five employed part-time cleaners. With the exception of Mr Green, and possibly Mr Reid, where the couples had been active in arranging their use of such services, the women had undertaken the task of finding and organising them². Phrases such as 'her own (cleaning) lady' and 'she does what I can't do', nonetheless, reflected and typified how the majority of the spouses perceived such services; namely services provided by women for women to help them with their work.

Just how important the gender of these service providers was to the couples and their perceptions of such domestic care services could not be firmly established. The couples had little time for 'what if' questions and only one couple, Mr and Mrs McAllister, had received such support from a man. This had been an isolated occasion arising from the need for relief cover but the couple had been dissatisfied with his performance. In their opinion he had not got on with work promptly, had not cleaned thoroughly and had spent too much time speaking. They did not ascribe these inadequacies directly to his gender but their comparisons of his performance with that of other home carers, all of whom were women, suggested that they believed this was a factor.

Mrs McAllister: I could have done without (*the home care service*) one week. ... Well he came in here and he sat down where you (A) are sitting. And I have the hoover and that ready sitting out in the kitchen. And he never attempted to get up you see. And I said 'The hoover is sitting in the kitchen'. 'Right' he said 'I better

² As discussed in chapter 5, in instances where the couples had begun using services as result of a crisis either in their health or existing informal care arrangements, they had not always actively sought services themselves rather they had been allocated them.

get going'. So he started in the kitchen never moved a chair out below the table. He never moved anything. He did that and he wasna three minutes there. He went through there (*points to hallway*). I said 'Never mind the front bedroom because that is a spare room'. Well he never went into our bedroom, the back one. He opened the bathroom door and hoovered the floor. He never did anything to the toilet or anything like that. I donna know whether he opened the inner door there to the front (*porch*) or no. He came through here and he never moved the seats or the table or anything he just went round about with the hoover. He went through to the kitchen and left the hoover. He never took it out or anything. He came through and sat down there. And (*names her husband*) was coming in for his fly cup (*a drink*) well it must have been about coming on for three o'clock and so I gave him (*the home carer*) a fly (*a drink*) and then he sat for ages and started telling us about his life story. ... Well what he did I do everyday you know what I mean - and do a better job myself.

A: So your normal
Mr McAllister: She just comes in and knows what to do.

The use of domestic care services benefited the spouses as couples and as individuals. As couples, they benefited from their homes being cleaned, their laundry washed and their larders filled and, as individuals, they were beneficiaries of relief from various household chores. Furthermore, the use of services offered women a means of providing their husbands with domestic care; that is of looking after them in a traditional manner. Thereby, these services enabled women to fulfil their domestic responsibilities and express their identities and reputations as good (house)wives. In this respect domestic care services were the women's services.

Power Issues and the Use of Domestic Care Services

Whilst the women in this study benefited from using such services, most did so at the cost of the loss of their domestic autonomy and erosion of domestic power. For a service to function in the ways that the users wish, the users must control it. They must relay their personal requirements in such a way that providers of the service know precisely what to do, what not to do, how and when to do it and to what standards.

Baldock and Hadlow (2002), Clark et. al (1998), Harding, (1999) and Tanner (2001) claim that older women often have quite low expectations of home care services. In particular, they believe that local authority home carers / home helps are not allowed to do the type of tasks that they most want and need help with, like cleaning windows and changing curtains. Clark et. al (1998), also highlight the discordance between the fluidity of the older women's subjective needs and the inflexibility of rule-bound statutory provision.

Around a quarter of women in this study dismissed local authority home care as a possible source of this assistance. This was because they believed or knew from experience that it was hedged round with regulations that offered limited opportunity for service user control and so

could not provide the kind of assistance they wanted. They were also very aware of the financial implications of service-use and they wanted value for money.

Mrs McKenzie: Home helps don't do any cleaning. They go and do shopping and they will come back and maybe make a cup of tea and they will sit and speak. ... The main purpose of the home help now is in a social sense just to give company for the people they call on. No I won't have a home help I would rather get a lady in private. I'll pay them. I have always been pretty particular about my house. I would expect them to do it properly to do it the way I would so. Not this year but maybe another I will.

Mrs Ellis: Now days home help don't do bugger all. It is no their fault, they are only allowed to do certain things. They are no allowed to hang up curtains for you or do this or that. What are they there for? You ken what I mean? Actually I would not have a home help if I was stuck I would advertise for a woman to come say two or three hours a week and I would pay her myself. Not a home help, just a woman who was wanting a cleaning job because that way there would be no. I'm no wanting her to kill herself but you are no wanting someone in that just goes your shopping for you are you? You are wanting someone to do your ironing, or clean the bathroom. Jobs you are not able to do. But I would not have a home help. If I had a home help I would get sent somebody whereas if I am doing it myself I can pick who I want for my house.

Twigg (1993) and Walker and Warren (1996: 19), in their research into care services, argue that is a wrong to assume that direct payment for services confers power on the service-user. To function effectively in the care market a consumer requires information, financial resources and consumerist attitudes and values. Tanner (2001), in her study of how older people address their needs, observed that most of her study participants were ill-equipped to access and use private sector services. Some were financially excluded. Illness, frailty, lack of information or availability of suitable provision thwarted others and inadequately consumerist attitudes and values still others. Such factors also impeded the couples.

Once users have accessed a service, they need to take control of its delivery if it is to meet their needs. This is especially crucial in the initial stages when work patterns are laid down. In times of crisis self-confidence, self-esteem and physical and mental reserves tend to fall to a very low ebb. In their research into links between identity, self-esteem and service use, Baldock and Hadlow (2002) identified a sharp drop in older people's self-esteem and confidence when they develop limitations that result in their becoming housebound. Some of the spouses had sought help from services when they realised that soon they would no longer be able to manage their domestic activities but most had first begun to use services at the point of the onset or sudden worsening of their disabling condition; in a time of crisis. Predictably, they had then considerable problems asserting their wishes to their newly allocated home carers. Mrs Beattie outlined how she floundered when faced with directing her home carers:

But in the early stages (*of her disablement*) I was (*breaks off*). At some points of it I would get this. I don't know. It wasn't exactly panic but it was just a feeling that came over me and I felt. I would say will you (*names her husband*) be back soon and that sort of thing. I think part of it was there was just one thing after another. In the end I, you think dear me what next. But in the early stages when they (*home carers*) came in I said 'I don't know what to tell you to do'. But they said, 'You are suppose to tell us what to do'. I said 'Well, you just do what you see. The work you are supposed to do. Well maybe if you did something in the bathroom'. There was that sort of thing.

Mrs Beattie's comments imply that she became markedly more assertive as time and her crisis passed but she did not appear to do so. Like most of the women, she characteristically 'made allowances' for inadequacies in many aspects of service delivery rather than demand an improvement.

Mrs Addison's approach and reasoning over her predicament with her cleaner was typical.

Mrs Addison: The help from the lady who does my housework is just not all it would be if I was doing it myself. Having a weekly clean I accept that it is done.
A: You don't feel you could say anything to her about it?
Mrs Addison: I don't want to start anything.

Hence, she uncomplainingly tolerated an unsatisfactory cleaning service because she feared that the provider would withdraw her essential services. In this instance, Mrs Addison's dependence on this service was further compounded by the relative isolation of her home which meant finding another cleaner would be difficult. Only when a situation became absolutely dire did the spouses, usually the men in their capacity of their wives' protectors and masters of their homes, lodge an official complaint or, more often, terminate the service.

The care service user/provider relationship is an unequal power relationship. The user needs and depends on the provision. Therefore, power rests with the provider regardless of whether or not there is financial exchange between the user and provider. Women in this study, including those like Mrs Addison who purchased domestic assistance, tolerated inadequacies in services because they depended on and felt powerless to change the provision. Moreover, most also lacked the necessary skills and aptitudes.

Logically, domestic experience might be assumed to aid service users explain their domestic requirements but Sidenvall et al. (2001: 164) found:

when asking our informants about how they did their cooking, that they had difficulties in explaining what they wanted and how they cooked their food. They had recipes in their mind (*sic*) and cooked instinctively according to familiar routines.

This study did not ask the women to give details about how they approached their domestic tasks but, as the chapter on methods showed, they tended to assume that women have a degree of shared knowledge about feminine issues, including how to cook and clean. Thus, they might possibly have experienced the same kind of difficulties as the women in the aforementioned study.

In a longitudinal study of home care receipt in Canada Aronson (2002: 405) describes three ways in which the participating older women engaged, responded to and used this service. Some took charge or control of the service; some restrained their expectations and resigned themselves to what it provided and some felt overwhelmed by it and gave control to its providers. In her explanation of these different responses, Aronson (2002) acknowledges the influence of the women's different experiences of disability and illness, financial means, social and personal identities but she specifically draws attention to their different levels of ability to negotiate successfully with service providers. Those service users who took control of the service were those who interacted assertively with service providers.

In Britain, home care service, at least theoretically, pursues a policy of user empowerment and the provision of user-led services (Myers and MacDonald 1996, Richards 2000). This is enacted at a very basic level when home carers ask users what they want them to do. A minority of the spouses had the confidence and abilities to communicate their needs and so take control of their use of domestic services. Mr Green was relatively inexperienced domestically but, with a wealth of experience in management and communication, he was able to successfully instruct their home carer as to his wife's and his needs. [Mr Green was the only man to predominately organise the delivery of domestic services. He undertook this tasks because his wife was cognitively impaired and was reluctant (or unable) to speak.] Mrs Ferguson, Mrs Patterson and Mrs Hay were also able to effectively influence the delivery of their domestic service. Each of these women had had opportunities to develop and practise their skills of assertion. Mrs Hay had trained and worked as a nurse before accruing extensive experience of employing domestic assistance, especially au pairs. Mrs Patterson had taught and Mrs Ferguson had always dealt with officialdom because her husband refused to do so. These women were the exceptions. The majority of the women lacked the necessary skills, confidence or mindset / belief system to negotiate with service providers so as to influence service delivery. They found asking for assistance difficult because they believed strongly in 'not bothering' people and, if provided with assistance, being grateful. To ask for assistance, at best, bordered on being bothersome; to ask for assistance to be provided in a certain way was then, unacceptable; it was more or less unthinkable. Moreover, making such demands would put the positive self-images and reputations of these women as pleasant, grateful and appreciative at risk of unfavourable redefinition. One woman exclaimed that there was no point in approaching services 'with saire face (*pathetic / miserable expression*) and girnin' (*moaning/whinging*) you will never get anywhere'. They did not want to be thought of as moaning, demanding and embittered old 'wifies'.

Such a finding may be considered predictable. Studies involving older women have repeatedly shown how the omnipresence and interplay of sexism, disablism and ageism within services and throughout society mean that their demands and requests tend to be heard not as assertions of their rights but rather as groundless moans, groans and whinges (Biggs 1993, Bytheway 1995,

Campling 1981, Charmaz 1995, Featherstone and Hepworth 1993, McDonald and Rich 1983, McFarlane 1994, Minichiello et al. 2000, Morris 1995, Robertson 1997, Sontag 1978, Thompson 1992). Consequently, older women tend not to speak out about what they really want but remain oppressively lulled into quiet grateful acceptance and tolerance; silence. In short, the use of services domestic care services presented the women in this study with a way to fulfil their domestic responsibilities and roles, and thereby care for their husbands and express their identities. For these reasons the women valued these services but only those with confidence, effective communication and negotiating skills were able to use such services without surrendering their domestic influence and control.

MASCULINE DOMESTIC ACTIVITIES AND CARE

Masculine Ways Of Caring

The masculine domestic activities – gardening, home maintenance and driving – are traditionally and stereotypically associated with men through the role of husband. These activities together with financial management are integral to the autonomous and independent functioning of any household but in spite of this, community care has, until very recently, largely overlooked or marginalized these important needs and activities at every level from policy making to front line provision³. Harrison and Heywood (2000a: 2) point out in their research into planning in health and housing that

Most community care plans contained little about housing issues⁴. ... What there was, (*was*) mostly included in scattered references; very few plans had distinct sections addressing housing issues for older community care clients.

They highlight various institutional reasons for this, including the fact that no one profession is obliged to collate information on all of these issues, but alongside these reasons the influence of normative understandings of care must also be acknowledged.

Caring is 'given' to women: it becomes the defining characteristic of their self-identity and their life's work. At the same time, caring is taken away from men: not caring becomes a defining characteristic of manhood. Men are marked out as separate to and different from women because they are not involved in caring for ... others (Graham 1983a: 18).⁵

Thompson (1993: 559) argues that this feminine image of care fails to recognise the different way that men convey care, namely by doing practical things, providing for and spending time with others. Christian-based marital vows encumber husbands and wives with the duty to care

³ This study was carried out before the publication of the Government Green Paper Independence, Well-Being and Choice: Our Vision for the Future of Social Care for Adults in England (Department of Health 2005).

⁴ Harrison and Heywood (2000a,b) include repairs, gardening, heating, transport, and housework as well as issues such as overcrowding and lack of facilities within their definition of housing issues.

⁵ Research, for example by Figes (1994), Fisher (1994), Hearn et. al (1998), Parker and Seymour (1998), Risman and Johnson-Sumerford (1998) and Sullivan (2000) has shown an overall but limited increase men's involvement in domestic care activities and that gender divisions of labour within marriage, are not clear cut. Thus, it is recognised that there has been changes since Graham made the above claim but not to the extent that it invalidates it.

which conventionally, men have fulfilled in terms of material provision, protection and the promotion of welfare. In their research into later life marriages Mason (1987b: 205) and Hobman (1995) found that men were committed to providing their wives and families with financial security and protection in the sense of four walls and a sound roof over their heads. The husbands in this study also cared in these kinds of ways. They assumed responsibility for and either undertook or arranged for the upkeep of their homes, gardens and meeting their households' transport needs and in the past they had been breadwinners. Mrs Kerr was an exception. She was the only woman to drive, assume responsibility for and carry out home and garden maintenance. This is likely to be attributable to the uniqueness within this study of the onset this couple's care experience. Unlike the other carers, Mrs Kerr became a spousal carer as a young woman after her husband was involved in a serious industrial accident that left him brain damaged and physically disabled. Thus, the couple's circumstances, including their financial ones, may have left Mrs Kerr few options but to undertake and be responsible for their masculine domestic activities

The couples did not describe home and garden maintenance or driving as care. Nonetheless, they recognised and understood the men's responsibility for and execution of these activities as ways in which they took care of their wives, marriages and homes. Indeed, some men applied their 'masculine' skills directly to caring for wives in respect of helping them manage their disabilities. For instance, Mrs Ferguson explained:

Everything that I had my husband had worked out for me even down to the tap turners. He made a piece of wood with a round head with a stalk for the handle and three nails put so they fitted over (*the head of the tap*) and that was 20 years ago he made that. ... We had the old fashioned knobs on the doors when I first took it (*become disabled with arthritis*), the round ones. (*names her husband*) changed all that and put handles on them, the lever handles. And as I say he made that thing (*for the taps*) and just whatever he could think of to ease it for me.

Thus, this study interprets masculine domestic activities as representing masculine forms of care or ways of caring.

Gender Differences in Sources of Assistance

Brubaker (1985b), in his study of golden wedding anniversary couples, found that women's involvement in 'masculine tasks' did not increase in later life in the same way that men's involvement in 'feminine tasks' increased. Mason (1987b: 204) similarly found that there was no obligation on women to help their spouses carry out home repairs after retirement, although some chose to help with decorating. In her study of disability and marriage, Parker (1993) identifies how her participants – especially wives – were hindered in their efforts to address their home maintenance needs by a lack of strength, energy, relevant know-how and skills. As carers, the women in this study did not do more but less DIY, gardening and driving. Most, like the women in Parker's (1993) research, lacked the necessary skills and abilities but more significant was the fact that they prioritised meeting their spouses' everyday basic care needs.

Therefore, they tended to reserve their time and energy for coping with these more immediate care tasks. Instead of trying to meet their home maintenance, gardening and travel needs from within their marriages, the couples tended to seek to assistance either from within their informal social support network or from tradespersons or services. Although the spouses tended to be able to largely meet their masculine domestic care need through these sources, they felt that such needs should be included in needs assessments and, as necessary, guidance given on where and / or how to access to suitable public, voluntary or private sector provision. The spouses involved in Parker's (1993) and Seymour's (1994) studies of caring within marriage similarly felt that the lack of formal help with such tasks was one of the shortcomings within community care provision.

Gender Differences and Similarities in Accepting Assistance

At any age the use of services represents an acceptable way of carrying out home maintenance activities or travelling long distances and with increasing age it increases on account of social expectations about the giving-up of physically and sensory demanding activities, like DIY and driving. Such age-related expectations were reflected in how the spouses felt about giving up these activities. The oldest men- those beyond their mid eighties- together with the most physically limited men welcomed and expressed the greatest relief at not having to carry out home and garden maintenance activities. The men who were slightly younger, in their late 70s to early 80s, and who continued to be responsible for masculine domestic activities within their relationships, tended to ruefully accept and construct their need for assistance with the upkeep of their properties as an inevitable part of their ageing and physical decline. The youngest men, those aged up to their mid 70s, who needed such assistance, especially those who had been keen and or skilled in DIY, gardening or driving were markedly disappointed or bitter about needing help with such activities and found accepting such assistance demeaning and depressing. It reinforced their awareness of their changed circumstances and eroded abilities and in doing so seemed to threatened their self-esteem and identity. For example, Mr Oliver said:

- Mr Olivier: Well I just plead poverty and an invalid and get somebody in. You say 'Could you go up there and get that out for me?' ... So just with pleading.
- A: You get round it. So how do you feel about someone doing things?
- Mr Oliver: It doesn't really bother me. I feel as though I want to go and do it myself sometimes. And you see I am one of the type that thinks it is not done right unless I have done it myself.

The edginess in Mr Oliver's tone, his caustic and satirical jokes and his concluding statement of dissatisfaction with the end product of assistance undermined his claims of indifference about receiving help and suggested quite the opposite.

The foregoing findings highlight the superficiality or inadequacy of simple gendered assumptions about acceptance of assistance. Men are more accustomed to receiving domestic care or services than women and are more likely to readily accept help with feminine domestic

activities. On this basis, the receipt of care or assistance tends to be presented or assumed to be less emotionally traumatic for men than for women (Arber et. al 1988, Qureshi and Walker 1989, Twigg, Atkin 1994, 1995). However, older people tend to try particularly hard to continue to carry out activities that are closely bound up with their personal identity (Arber and Ginn 1992, Tanner 2001). Thus, how men feel about accepting domestic care and assistance with home and garden maintenance and transport is likely to be quite different.

The majority of the men in this study had driven, gardened and carried out some DIY. Some had given up these activities instantly because of the sudden onset disability, such as a stroke but more had cut back on them gradually as their disabilities or the demands of caring made their completion increasing difficult. A significant minority, the men who regarded themselves as having been 'handy', keen gardeners and or car/driving enthusiasts and whose employment had involved these kinds of activities, had struggled particularly hard to continue to garden, drive or carry out DIY. Indeed, their efforts characterised how women tried to continue to carry out their domestic responsibilities.

This overlap or duplication between the paid employment their favoured domestic responsibility of these men, whether gardening, DIY or driving, suggests that these activities played a large part in their lives and as a result seems to have become tightly bound up with their identities. Hence, they experienced their inability to garden, drive or carry DIY as a significant loss that was difficult to deal with. For example, cars and driving were integral to Mr McKenzie's professional and personal roles and identities. He had been a chauffeur and his cars had been his 'pride and joy'. His retirement ended his role and identity as a professional driver but he had continued to drive his own car. When disability forced him to give up driving, he was robbed completely of the activity and thereby also of his domestic driver role and identity. Mrs McKenzie pointed that when their GP had advised her husband to give up driving he was 'not very happy' indeed he was 'really wild'. Similarly, Mr Hendry, Mr McAllister and Mr Inch had been keen gardeners and had worked on the land. Mr Hendry had been a groundsman while Mr Inch and Mr McAllister had worked on farms. Retirement stopped these men working the land professionally, whilst disability stopped them as gardeners, leaving a huge gap in their lives.

- Mr Inch: It (*the garden*) was mine. Always. Aye I liked it.
Mrs Inch: I mean he did like his garden. He had a'ways something to do in the garden. ... He misses his garden.
- Mrs McAllister: He loved his garden. ... I wouldnae have interfered (*in the garden*) you see. What I would have done wouldnae have been right so.
- A: What do you do in place of gardening?
Mr McAllister: Very little, very little (*said softly*).
A: What do you feel about somebody else having to do your garden?
Mr McAllister: Hellish Terrible, terrible.

The tones and expressions that the men adopted to impart these thoughts helped clearly convey the message that gardening was something more than a hobby or spousal duty to them. They did not simply garden, they were good gardeners. In the same way that Mr McKenzie did not just drive he was a driver. Not being able to garden or drive meant a loss of part of what or who they were. Regrettably, data were not collated on whether these men thought that their employment history had impacted on how they felt about cutting back on or giving up their domestic activities but a correlation seems possible.

The impact on the couples' division of domestic labour was less pronounced when men had to curtail their involvement in masculine domestic activities than when women had to cut back on theirs. Nevertheless, the men's need for and acceptance of assistance with these activities was not insignificant or unimportant. It changed how they contributed to their marriages, demanded that they find alternative ways of addressing these needs and, for some men it, impinged on how they expressed their spousal identities and related to their wives and others.

Home Maintenance⁶

Home Maintenance Responsibilities

Nationally the most common forms of housing tenure in later life are owner-occupation – 46 per cent of older people own their homes outright – and social renting (MacDonald et. al 2000).

The majority of couples in this study were owner-occupiers but a significant minority were housing association or local authority sheltered accommodation tenants. The tenancy status of the couples who lived in cottages on their children's farms was unclear.

In their study of home ownership, Askham et. al (1999) found that whilst home owners tend to reject the idea of moving into any other form of tenure, some older home owners, in particular those with disabilities and poor health, had considered moving into serviced/maintained accommodation. This was because they felt burdened by the responsibility for the maintenance of their properties. The couples' homes ranged from large houses with gardens that required considerable maintenance to serviced one-bedroom flats designed for people with special needs. Wilson et. al (1995), in their research into housing satisfaction, identified that, in later life, ease of access to and within bathrooms and kitchens increases in significance. Seven couples had carried out alterations or adaptations to make their long-term homes more accessible. These included changing the use of downstairs rooms, putting up grab rails and, the most common major alteration, the installation of level access shower in an existing bathroom. Eleven couples had moved house because of access difficulties. Six of these couples had moved into sheltered

⁶ 'Home maintenance' is used in this study as an umbrella term to cover needs and practical activities, concerned with structurally and aesthetically repairing and maintaining the various aspects of the couples' accommodation and contents; the building, its fixtures, fittings and household equipment. Thus, it includes all kinds of tasks from the large and/or technical such as plumbing to small and basic such as changing fuses and bulbs. The home maintenance is considered very apt phrase since a home is more than accommodation and home maintenance, especially achieved though DIY, tends to be about more than the simply keeping property and its contents in good repair.

accommodation and five into other forms of accessible and usually serviced accommodation. Access and support, in particular difficulties in climbing steps, having unsuitable bathroom facilities and the need for and security of having easily accessible support were the primary factors in the spouses decisions to move but the freedom from responsibility for home maintenance also emerged as influential. Around half of couples in serviced accommodation drew attention to how even the smallest of their maintenance needs was taken care of for them.

Mrs Beattie: They (*one of the wardens*) will come in and put a bulb up for you. I didn't ask them but she (*the warden*) was in and she said 'One of your lights (*has blown*)' and I said, 'Yes. We have got the bulb but it was just someone to put it up. One of the grandsons would do that or a friend'. She says 'Where is it?' and she was up on the chair and put it up and she has done the second one.

Only those couples who lived in serviced accommodation, were not responsible for their own home and garden maintenance.

DIY and Assistance with Home Maintenance

Consistent with the traditional gendered division of labour, with the exception of Mrs Kerr, the men had assumed responsibility for their home maintenance needs. A financially secure minority had always employed tradespersons to meet all but the most basic of their home maintenance needs but the majority had met such needs through DIY except for tasks that they found too big, technically complex or dangerous to attempt. However, disability and care had limited the kinds of tasks that the men not only had the energy and time but also felt able to do with the result that only three men continued to carry out any DIY other than very basic tasks. Most couples had been advised about how to make their accommodation more suited to their needs and how to apply for financial assistance for large and more technical adaptations. Many had also been supplied with grab rails and some with level access showers but how to address small everyday household repairs and home maintenance activities remained a challenge.

A: What about DIY jobs? How do you manage those?
Mr McAllister: Oh with difficulty. ... Well like changing a bulb here now. I gets, well, I can manage myself (*the tone used suggested that this would be a significant and risky struggle*), but I gets (*names neighbour*) to come in and change it. Anything.....Aye we usually get somebody (*tradesperson*) to come in

Parker (1993) records that many of her participants who depended on the services of tradespersons were concerned about their reliability and the cost. She goes on to highlight how one woman identified the need for and lack of a service equivalent to local authority home care to help with home maintenance. Askham et al. (1999) also suggested that their participants worried about the cost, trustworthiness and reliability of tradespersons. Harrison and Heywood (2000a,b) claim the importance of 'good housing services' to the health, well-being and independence of older people has been known for many years but this knowledge has not been acted on sufficiently within community care planning or practice. Thus, they point out that

whilst in some areas 'good housing service provision' can be accessed, care service providers are often poorly informed about 'hands-on housing services' that operate across all tenures. 'Care and Repair' operated in the areas where this study was conducted, yet neither the couples nor home care service providers made any reference to this service or any other service of this kind (Scottish Executive 2001b).

Perceived lack of reliability and trustworthiness of tradespersons did not emerge as key concerns for those couples but for some expense was an issue.

Mrs Ellis: We cannae do it (*decorate*) and we can't afford a painter and decorator....Before he (*looks towards her husband*) would have done it. I wouldnae. He decorated. I cleaned up the mess. I was never a painter. That was no my department.

Thus, as far possible they tried to limit their use of such services, either by supplementing it with DIY or more commonly by accepting help from their friends, family or neighbours.

Mrs Kerr: I can do that (*paint*) I can paper walls as well but I have not done that for an awful lot of years. I had the painter in to do this but this has been done a lot of years too.

Mrs Lawrence: You always did the decorating. We always did the decorating but you did the most of it.

A: How do you manage that now?

Mrs Lawrence: No. We just got somebody in. This was all to be done. We were in here. When we came first. As I often say it is difficult. It was difficult because we really had just this room (living room), the bedroom and the bathroom. The kitchen wasn't done. The kitchen wasnae. Everything was just awkward to work with. It was no like the straightforward like it is now.

Mrs Oliver: (*names son-in-law*) is quite good about that. The son in law. ... If we are needing anything. He is quite good.

Mr Oliver: (*names grandson*) he is on (*names place*) he is pretty good as well. He has helped me out with a few things.

A third of the couples made reference to receiving help from family, friends or neighbours with their home maintenance needs. Their acceptance of such assistance from these informal sources contrasted starkly with their fervent reluctance to accept their assistance with feminine domestic activities and gardening. Moreover, they understood the exchange of help with home maintenance activities to be part of what being a family, good neighbour or friends was about. The lack of a known financially accessible alternative source of help with home maintenance provides a simply and rational economic explanation for their ready acceptance of informal support these activities. Yet, Duncan (2000), in his research into rational behaviour, warns economic rational explanations of behaviour are invariably incomplete as social and moral processes, expectations and contexts distort and complicate them. Finch and Mason (1993) claim an important principle in social intergenerational exchanges is balance; 'one party should not become too dependent upon the other'. Home maintenance needs, especially large ones, tend to occur quite infrequently. This infrequency reduces the risk that the providers of such

assistance will feel burdened, especially as the provision of such assistance often involves performing activities that they enjoy and receive praise for.

In spite of this, the spouses considered themselves fortunate or lucky to have such help. For example, Mrs Ellis declared 'We are lucky because our son in law and our daughter's pal get together and do it (*decorating*) for us'. Not all the couples were so fortunate. For example, before their last move Mr and Mrs Beattie had been worried about how they would cope because of their lack of easily available family support.

Mrs Beattie: Now I didn't have (*names son*) any longer and I didn't have (*names son-in-law*) any longer. (*names second son*) would and did help when he could but he is the father of (*names granddaughter who has a profound learning disability*) so that was it. But in this situation was this move. While we wanted it, how are we going to manage?

Home maintenance is a necessary part of community living and the provision of services to help with activities is therefore vital to foster and support older couples' independence. It is totally unacceptable that older couples have to rely on providence or chance as a source of support to meet such important needs.

Gardening

In contrast to DIY, Mason (1987b: 205) claimed that between husbands and wives:

Responsibility for gardening appeared more diffuse than in other areas: this is probably because it was mainly seen as a pleasure and a hobby, and also encompassed ideal 'male' and 'female' aspects, for example heavy and dirty work versus 'making it look nice'.

Whilst this study did not examine whether there were (or had been any differences) between what aspects of gardening the men and women undertook, it too found that the women gardened in greater numbers and extent than in respect of any other masculine domestic activity.

Nevertheless, fewer women than men gardened and fewer still assumed any responsibility for this activity. Also all women, who gardened, chose to do so because they enjoyed it, with the exception of Mrs Hendry. Some of the men were keen gardeners but, regardless of their level of interest, the upkeep of their gardens was their responsibility and activity, unless their spouses chose to garden.

With the exception of Mr and Mrs Hay who had always employed a part-time gardener, the couples had tended their own gardens. However most couples, in spite of their attempts to minimise heavier tasks such as digging by the introduction of paving or perennial ground-covering plants, now found the upkeep of their gardens, a physical and, in some cases, an emotional challenge. Seven couples continued to maintain their gardens without outside assistance. Within two of these relationships, care had led to a change of gardener. Mrs Hendry had taken on gardening as carers but, unlike her husband, she did not like it and found it stressful and physically very hard work.

Mrs Hendry: That is something else I have had to take on the ropes of, the garden. When he (*her husband*) was younger I would not have looked at the garden because he was so good. He isn't able now so we just make the best of it. ...I find it very tiring gardening I really do. People say they enjoy it but I don't. No. It is an awful thing. ...We don't get on in the garden. ...It is the one place we just can not agree. We don't get on in the garden at all. No way.

Mr and Mrs Hendry did not explain why they disagreed but it may have had to do with the strength of their antithetical feelings as these seemed to prevent them from appreciating how each other felt. Consequently, they seemed unable to help each other deal with their emotions on the matter and so dissipate the tension in their relationship.

Five couples found it impossible to maintain their gardens without outside help. Three of these received assistance from their neighbours as part of a non-monetary exchange and four paid someone to tidy their gardens. Mr and Mrs McAllister and Mr and Mrs Patterson received support with gardening from both informal and formal sources. Mirroring the way that women identified and organised services and assistance with feminine domestic activities, men mainly organised gardening assistance but finding such assistance appeared to be largely providential.

Mr Oliver: Oh we get somebody to do that (*the garden*) because I canna bend and weed and dig and that sort of thing. It just happened that I knew a man who liked doing a bit of gardening and he said no problem. I'll come and fix it for you. So he lives in (*names town*) but he comes down here every second week to do it.

Mr McAllister: I'm not fit to do my garden as much as I was. So I hired a chap to dig the garden but I work away with this and that. It is a bit of a struggle.

A: How did you find him?

Mr McAllister: He was ok.

A: Was he someone you knew?

Mr McAllister: No it was through the milkman I got in touch with him.

Mrs Ellis: We had a gardener and he used to do all the front but we still have the gardener because I need the back (*lawn*) cut and he will weed all the front for me and do the things I cannae do.

A: How did you decide on the gardener?

Mr Ellis: It was just

Mrs Ellis: When you live in a place like (*names village*) you know everybody. Everybody tells you

Mr Ellis: Just speaking kenn

Mrs Ellis: Speaking to somebody like going up the road 'I am needing a gardener' and 'so and so does gardens'. So you go and you find them out. You get it word of mouth you know. You give then a phone, or you see them you ask them.

Home care providers who took part in this study were conscious of the gardening problems and concerns of their users but could do little about them. The home carers spoke to service users about the subject and at least one home carer planted bulbs and seeds in pots with them but they

were not allowed to tend their gardens. Home care assessors, organisers and their managers had no resources to provide help with gardening but they explained:

HCA: If it is a small garden and it is covered in weeds and someone who is on their own we will arrange something through the community service, who will come round twice a year and basically kill all the weeds and give it dig. They are not gardeners per se but at least they will cut the grass and keep it tidy.

M: In my experience is that some people don't want it because it is people with community service orders and it is not, you know, universally popular.

Appleton (2002) suggests that older people view their inability to maintain their gardens as a sign of the slipping away of their independence and standards. Thus, they value help with their maintenance. Whether ex-gardeners would view 'the hit squad' approach as 'gardening' or as clearance service is open to question. Furthermore, it is an approach that takes no account of the pride and emotional attachment that some older men have to their gardens and gardening. Hence it is inadequate, insensitive and inappropriate. It simply attacks the practical problem of excess weeds, overgrown lawns and offers a temporarily tidy garden. It does nothing to address the felt needs of ex-gardeners. The physical and emotional need for a sensitive gardening service is clearly recognisable from what the couples said but, as yet, the market or service niche remains empty. None of the couples reported having been offered the hit squad 'service'.

Transport Needs.

The Importance of Transport

The Scottish Executive's report 'Older People in Scotland' states in respect of transport:

for most people access to transport is essential for sustaining daily life and social activities. This is particularly true for older people who are more likely than younger people to be limited in the distance they can walk (MacDonald et. al 2000: 37).

Bowling et. al (2002) and Gilhooly et. al (2003) identify access to private cars and or good and affordable public transport as significantly contributing to 'quality of life' in later life. Ironically, as in the wider population, as the spouses' physical need for a car and to be able to drive increased, their car and driving licence ownership declined (MacDonald et. al 2000). Most of the couples had had access to a car but less than half currently owned a car and held a driving licence and some of these anticipated that within the near future they too would have to give up driving either due to their age or encroaching impairments: a step these couples realistically assumed would restrict their activities and independence. In their investigation into the use of home care services Stoddart et. al (2002) found that car ownership was associated with a lower use of home care services than non-car ownership. They suggest that whilst this may reflect a difference in health status of these groups, car ownership facilitates mobility and thereby independence and access to support. To the couples their car represented convenience, independence, and a means of coping with their everyday care routines.

- Mrs Taylor: We have a van and as well as a car because we need transport. ...He (*Mr Taylor*) has to go for some errands into the village. It only takes about half an hour. ...The longest I am on my own is forty-five minutes.
- A: What would you do if you need to be out for longer?
- Mrs Taylor: We would have to make some other arrangement
- Mr McAllister: I still drive
- Mrs McAllister: Just shopping ..
- Mr McAllister: That is as far as we go. As long as we get our shopping done.

In addition to using their cars for essential journeys – attending medical appointments, church services and community facilities such as banks, post offices and shops, the couples also used them to visit friends and family and trips out. In this way, their cars helped them preserve their social lives, personal relationships and thereby quality of life. Mr and Mrs Geddes explained:

- Mrs Geddes We are lucky having the car. ... We always say the car is a necessary luxury. It is necessary....
- Mr Geddes: We don't go long distances. (But) it is very essential. Otherwise
- Mrs Geddes: We wouldn't get out very much. This is where the car is an asset in getting from A to B. We have quite a few friends
- Mr Geddes: And we have got relations out at (*names place approx. 30 miles*) and my brother (*names place approx. 15 miles*) and we go to (*names place*) to see my sister-in-law and you know

Gender and Transport

In the general population only a quarter of older women but over two-thirds of older men hold a driving licence (MacDonald et. al 2000). With few exceptions, the couples had been both one-car and one-driver relationships and the licensed spouse had usually been the husband. This had significant gendered implications for their care experiences. Only five of the women in this study - the same proportion of women as in the general later life population - had ever held a driving licence and only Mrs Kerr still drove regularly. Mrs Addison and Mrs Fyfe had given up driving permanently and Mrs May temporarily because of their disabling conditions. Mrs Hay had given it up mainly because of the demands of caring. None of the men gave up driving because of their caring responsibilities. When Mrs Addison and Mrs Fyfe surrendered their driving licences, their newly created transport needs were easily resolved: their husbands provided them with lifts. The eight men who gave up driving because of their disabling conditions could not depend on their wives for lifts because they had no licence. Thus, these couples depended on public transport, community transport, service user/patient transport and lifts from their friends and family to meet their needs.

A minority of men who were the main care recipients within their marriages continued to drive and to provide their wives with lifts. This practice was one of clearest examples of carer – care recipient role reversal – yet because it was such a normative practice, the couples did not define it in terms of care. It was what they had always done; it was a very ordinary, self-evident way to manage their transport needs.

Gilhooly et al. (2003) suggest that reluctance to give up car ownership and driving is associated not only with the loss of an easy way of getting about but also with the loss of 'intangible benefits such as status', especially for men. The end of car ownership and driving generally created considerable practical and social difficulties for the couples. However, as discussed above, for Mr McKenzie, Mr Ellis and Mr Hendry, who were car enthusiasts as well as drivers, it also resulted in distress and a sense of loss. That one of the few comments Mr Hendry made was 'I miss my car' reveals just how significant the giving up his car and driving licence was to this man.

Transport and Location

Eighteen per cent of the older population live in rural areas and thirty-seven per cent in cities⁷ (MacDonald et. al 2000). Four of the couples lived what could be referred to as commuter settlements on the outskirts of a city, eight lived in towns with populations in 2001 of between approximately 10,800 and 9,500, five in towns with populations of less than 8,000, three couples lived in hamlets - a settlements made up of hand full of houses and two lived on farms. (Aberdeenshire Council 2006, Angus Community Planning Partnership 2000, General Register Office for Scotland 2001). Two of the couples living in the largest of the towns had moved there from the surrounding countryside because of their need for accommodation that suited their disability. None of the couples lived in remote areas, that is to say in settlements of under 3,000 people and more than thirty minutes drive away from a town or in what may be described as undesirable urban sink estates (SHS 1999).

A range of health and social work service facilities including GP practises, dentists, sheltered accommodation, day care services, short and long term residential and respite provision as well as community facilities such as banks, pharmacies, shops, post offices and hairdressers were available in the city and the largest towns. Only the city provided tertiary and more specialised health service provision as well as a wide choice of commercial and leisure facilities. In contrast, the small settlements had few, if any community facilities. Irrespective of where they lived because of their care needs and / or responsibilities the spouses needed transport to access facilities - whether basic or specialist - as well as to socialise.

In respect of public transport the report 'Older People in Scotland' claims that the majority of older people who depend on public transport have reasonable access to it but some 16,000 live in rural areas where it is more limited (MacDonald et. al 2000). There was considerable variation in the level of public transport services across the area where this study was conducted. The city boasted an international airport, intercity train services, long distance coach services, regional and local bus services as well as taxi services including ones that offered wheelchair accessible vehicles. Three of the towns had a rail link but the frequency of stops at these locations varied.

⁷ The SHS (1999:225) defines a city as a settlement with 125,00 or more people.

The main mode of local public transport, where this study was undertaken, was buses. Some of the places were relatively well connected by local bus services to local towns whilst still other places were served by very infrequent bus services. The level service also differed between weekdays and weekend and according to time of day. Moreover, no public transport services operated within at least a mile of Mr and Mrs May's and Mr and Mrs Addison's homes whilst the nearest service to Mr and Mrs McAllister's home was impractical.

- Mr McAllister: There is no buses here. No buses that you can depend on. Well if you go somewhere you cannae get back.
- Mrs McAllister: But you wouldnae manage anyway on a bus. Neither would I
- Mr McAllister: If you get a bus to (*names nearest village*) you have either five minutes to do your shopping. Well that is no use or you cannae get back for four or five hours.

Thus, for these couples cars, lifts and specialised transport services were vital to their continued independence. Without them they could not reach any community facility. Hence, they recognised and valued help with travel as essential forms of care.

- Mr May: It is a bit isolating (*the location of their cottage*).
- Mrs May: Facilities, we are away from.
- Mr May: I can't drive so I am completely dependent. .. She (*Mrs May*) has to do the driving but this time she has been ill since early December. She stopped driving the first week in December. She wasn't fit to drive. .. And she has now this last week (*late May*) been out twice in the car all the way to (*names village*).
- Mrs May: Yes, well I haven't got permission yet (*to drive*) but I did get the car out and drove up to the village. I thought I would go berserk you know (*from staying in*). I can go for little walks around here otherwise I can't unless somebody fetches me. But once I have got to use the car again. He (*Mr May*) has been doing the shopping while I have been ill this last six months. He has been out with the community car and helper.
- Mr May: Yesterday they came up here from (*names place*) took (*names wife*) and I. ... They dropped my wife at the health centre and then the driver went with me to (*names shop*) They took me back to the health centre, picked up (*names wife*) and came back here.
- Mrs May: Five weeks they have been taking me in and out (*to appointments*). I pay each time but I am going to send a cheque to say how grateful I am.

In spite of the clear need for good transport services in the countryside to access essential services and facilities more transport services, including supported travel schemes, operated in the urban areas than in the rural ones in which this study was conducted.

Although the combination of a lack of local facilities and the inadequacies of rural transport services magnified and intensified the need for transport and help with travel for the couples who lived in the countryside, these issues were not exclusive them. Spouses in more urban areas repeatedly outlined difficulties in accessing suitable parking in front of their homes and in town/city centres due to the misuse of 'disabled' car parking spaces and problems with obtaining 'orange badges' and authorisation to designate areas close to their homes as disabled

parking spaces. Mrs Patterson detailed the difficulties that she and her husband had encountered.

Mrs Patterson: Well, we have unsuccessfully tried to get a (*disabled*) parking place in front of the house because the bus (*patient transport*) invariably can't get parked. ... It is dreadful and they refused it (*a parking bay*). 'Oh it doesn't fit the criteria' ... We sold the car. If we had a car in the garage, now he would not be driving it and I don't drive, so I don't see any point in that, any old car would have done, then we would have got a parking place. Now can you see sense in that?... And he informed me that this was not a busy road. And I said when were you last in this road.

A: I imagine at nine in morning... (*there is a school just along from the couple's house*).

Mrs Patterson: And quarter to twelve to quarter past twelve it is always busy. And then the actual service bus comes along here as well.

Nevertheless, there were more services and supported travel schemes in the urban areas than in rural areas where this study was conducted to facilitate older and disabled people with their transport needs.

Getting Around Without A Car.

In the areas where this study was carried out older and disabled people's use of public transport was financially and practically supported by local authorities and some public transport service providers. The local authorities provided travel passes that entitled the holder and, as necessary according to the holder's need, a 'companion' to concessionary fares. The main public transport operators were in the process of introducing tilting and low-floored buses with spaces for wheelchairs but such vehicles were, even at the conclusion of this study, still relatively few in number and mainly confined to city runs. In spite of such measures few of the spouses were able to use buses, due to their disabling conditions, and even those who could felt that they were a less than perfect solution to their transport needs. In addition to the physical inaccessibility of some vehicles, they pointed out that the buses did not run when and where they wanted to travel to, or at suitable times. There were also other practical problems. For example, Mrs Oliver explained that she was able to go by bus to the shop but she could not manage the return journey with heavy shopping on the bus. The participants in Gilhooly et. al (2003), most of whom claimed to be relatively fit, also identified access and 'carrying heavy loads' as difficulties when using public transport.

The use of taxis offers a solution to some of the aforementioned problems but this form of transports tends to be expensive. In the areas where this study was conducted the local authorities supported a taxi card scheme entitling older and disabled people who were unable to use other forms of public transport reduced fares with certain taxi-firms. Only Mr and Mrs Beattie appeared to have such a concessionary travel pass that covered taxi-use and so for most of the spouses travel by taxi was prohibitively expensive except for the shortest of essential

journeys. Moreover, the only firms to operate taxis that did not require the wheelchair users to transfer out of their wheelchairs mainly operated within the city. Thus, taxi travel was not a realistic option for most of the wheelchair using spouses.

To attend day services, clinic or hospital appointments the couples were able to access patient/service user transport. Where such transport was linked to social work provision, such as day care or lunch club, it usually took the form of some kind of mini-bus with places and equipment to secure wheelchairs and either shallow steps or a tail-lift, as well as an onboard assistant. Such transport tended to be provided on an ongoing as part of the service. In contrast, patient transport to medical appointments had to be booked on an appointment-by-appointment basis. Over a third of the couples used and were satisfied with patient / service transport. Mr and Mrs Patterson were a typical example.

Mrs Patterson: He goes to stroke club on a Monday. They have their bus round to collect him so that is fine. And when he goes to hospital on a Wednesday morning the bus comes and collects him for that. But apart from that because there are no taxis here that will take wheelchairs. They are wonderful, all of them. They are very cheery. All these people, who are picking him up, we know their first names.

Mr and Mrs Taylor were an exception. Their experience of using this service prompted and confirmed their decision to buy a wheelchair accessible vehicle.

Mrs Taylor: We bought a van, which takes the wheelchair. ... We had the hospital transport come before and it was terrible because you were all around the town taking you there and all around the town before you got home again.

Just three couples were aware of and regularly used specialised and community transport schemes. Each couple used a different service but all of the services were quite limited in respect of times and areas of operation. Mr and Mrs Geddes used a shop mobility service that ran one day a week whilst the services that Mr and Mrs May and Mrs Hendry used operated within the specified area boundaries. In spite of these restrictions, these spouses were positive about these services. For instance, a 'marvellous thing' was how Mrs Geddes commended the shop mobility provision - an accessible minibus providing transport from the users door direct to the 'disabled entrance' of the shopping centre where shopping scooters were available. When the couples were unable to meet their needs through public or specialised transport services, they accepted lifts from friends and family. Finch and Mason (1993: 33), in their research into the negotiation of family responsibilities, pointed out that their participants considered lifts to be a sufficiently important type of assistance to mention, even though the commitment and inconvenience to the provider is minimal. Furthermore, Gilhooly et al. (2003) found that unless lifts formed part of a reciprocal arrangement their participants were reluctant to ask for them, even for essential journeys. This was very much mirrored in couples' attitudes. Although the couples did not tend to ask for but to be offered lifts, they restricted their acceptance to important journeys, such as medical appointments, hospital visiting and bringing

home a 'big shop'. Lifts to social events were acceptable only when the provider was going to the same function; in such cases lifts tended to be constructed as an organisational aspect of socialising.

Mrs Addison: I have a very good friend who when she is away up to the (*names a society*) she stops by and takes me there and back. So that night is catered for. I don't have to depend on my husband.

The couples' attitudes towards asking for accepting lifts show that they valued this form of assistance but were concerned about its possible effect on the reciprocal balance of their relationships with kith and kin – an issue considered in detail in the next two chapters. Indeed, their tendency to restrict their requests for and acceptance of lifts suggests that they were careful not to use up the 'goodwill' of their friends and family on frivolous journeys but rather tried hard to preserve it for essential ones. Ultimately, the couples did not want but often had to depend on their informal relationships to meet their transport needs.

Longer journeys of several hours or more were of much lesser concern to the couples than short everyday ones. However, periodically some couples needed to take such journeys either for specialist appointments or to visit or holiday with family or friends who lived at some distance. In making such journeys they were faced with additional problems to those they encountered when making local everyday journeys. In particular, they tended to involve discomfort and pain due to sitting for long periods, coping with a lack of suitable toilet facilities and anxiety about how to quickly cover long distances such as those between check-in and boarding points. Breaking journeys into short sections or flying rather than using their cars or trains were some of the measures that the couples took to limit these problems but these options often increased the cost of the journey.

The inadequacies in public transport and specialised transport services, especially in rural areas, compromise the independence of older couples. These services, especially supported transport schemes, need to be developed and expanded so as to reflect and meet the needs of older people with mobility problems or other physical disabilities.

HOUSEHOLD FINANCES

Challenges in Gathering Household Financial Data

Research conducted by Pahl (1983) and Vogler and Pahl (1994) into household finances showed the gender division of responsibility for and management of household finances to be varied, complex and cross-cut by household type and level of income. In some of the households in their study the partners pooled their income and shared its management, in others they managed their own separate incomes, in others men managed and controlled the household finances whilst in still others men controlled their finances but women assumed responsibility for them. Disability, care and retirement further complicate household financial responsibility and management practices as they bring about changes to household income and expenditure and the individual householders' abilities to handle their financial affairs (Alzheimer Scotland

Action on Dementia 1997, Argyle 2002, Ginn and Arber 1991, MacDonald et. al 2000, Tinker et. al 1992, Ungerson 1987, Walker 1980, 1982). The consequences of such changes can reach beyond financial ones. For example, Ungerson (1987) describes how, as spousal carers, some of the women in her study enjoyed the challenge of assuming full responsibility for their household finances whilst others felt overwhelmed. Neither of these effects was apparent in this study.

In spite of the reassurances given about confidentiality of information provided to this study, the couples provided only few, vague and generalised data about their household finances. Their overall reticence to talk about financial matters was understandable and not unexpected. Delphy and Leonard (1992) drew attention to how notions of privacy and cultural avoidance of the public discussion of money tend to militate against the discussion of this subject. Furthermore, the spouses may not have felt entirely sure that their information would not somehow come to be used for unscrupulous purposes. Hence, in view of this study's adopted principle of volunteerism, it seemed unacceptable to push for more detailed data on what the couples saw as a highly private and sensitive matter. Consequently, this left many questions about the impact of care on the spouses' financial practises unanswered.

What did emerged very clearly was that how the spouses managed their finances was closely bound up with being and functioning as a couple. Unless, help was needed with form filling to access benefits, the spouses dealt with their finances autonomously as couples. They did not seek help from outside their relationships but from one another. Spouses with visual and physical impairment engaged their partners to write cheques and handle cash for them whilst the spouses with cognitively impairing conditions relied on their partners to manage their money. With the exception of cognitive impairment, disability did not always prevent them assuming responsibility for their financial dealings. For instance, Mrs Ferguson, who was almost unable to write, continued to manage their financial affairs.

Mrs Ferguson: He (*Mr Ferguson*) never fills them in (*official forms such as tax returns*).He would have the tax man and everyone after him. ...Until we retired 2 years ago he didn't even know how to make out a cheque, didn't know what he had in the bank. Nothing. ... The only time was one of the times when I went into hospital ... and even then (*said with emphasis*) I had to make out most of it. ... Many a time I've felt like saying you take over for a while but no. But it isn't very good for the partner that has all the responsibility.

Mrs Ferguson's feelings echoed Vogler and Pahl's (1994: 266) finding that money management can be 'a chore', especially in relatively low income households. Mr and Mrs Ferguson's employment histories and reliance on welfare benefits suggests that they probably represented such a household.

The Couples' Perception, Use and Management of Their Household Finances

The couples provided most of their information about their finances and their use in their discussions of welfare benefits that related to care such as attendance allowance. Although the spouses were entitled to such benefits, they had mixed feelings about receiving income from this source. On the one hand they felt that they had a right to welfare benefits since they had paid their taxes and contributed to the system but on the other hand they were reluctant to claim non-universal ones. Walker (1987), Pudney et. al (n/d) and Costigan et. al (1999), in their research into welfare benefits, acknowledge that there is a stigma derived from notions of fecklessness and questionable deservedness attached to the receipt of benefits, especially means tested ones. The couples keenly emphasised the legitimacy of their claims and their judicious use of their benefits. They stressed that they had worked, often until their disability had rendered employment untenable, and that they used their benefits to help meet their care needs.

Mrs Ferguson: I worked for years with the arthritis. Then the last job I was in I was made redundant. ...I knew there was no way that I could get another job. It's alright working for a place you've worked for years they know that you can do it. ... it was maybe hard to get there (*to work*) but once you were there and got your self going it helped. But No one else would take you on... And I'd been in hospital to have this hand done and that ankle and the doctor said 'No. I think you have stuck at it long enough'. So he just signed me off. I went on to the invalidity after that until I retired but it wasn't far to 60. I must have worked for about 15 years (*with arthritis*).

Mrs Beattie: I get my attendance allowance and I am very willing to pay for it (*assistance*). I know a lot of them (*older people*) have drawn out of it (*home care for domestic tasks following introduction of charges*). But why if you get attendance allowance? Well what is the attendance allowance for? To put in the bank or what? I couldn't be paying them off what our pension would be but we have these helps.

With such comments the spouses sought to negate beyond any shadow of a doubt that they were feckless or 'benefit scroungers' but honest, respectable and deserving and, in the case of Mr and Mrs Beattie, faith-filled Christians. Thereby, they protected their reputations and identities as upright citizens.

The spouses' financial discourse defined them not only as moral beings but also as couples. Irrespective of whether of the level or form of income and whether it was paid to, managed and/or administered by one or both spouses, it belonged not to one or other spouse but to the couple – It was their income that paid their bills and afforded them treats and luxuries such as meals out or extra television channels.

The privacy of their financial affairs and the sharing of their income and expenses bound the spouses together as couples. However, Pahl (1983: 239) and Vogler and Pahl (1994: 270/271) advise, in their research into the domestic management of finances within marriage, that such apparent equality might reflect an 'ideological commitment to sharing and equality' as much as

a reality. This study cannot confirm whether equality was what the spouses practised or merely believed that they practised. Nonetheless, it would claim that their shared management of their common funds was one of the ways that the spouses defined being a couple.

CONCLUSION

This chapter has explored how the couples managed the disruption that disability and care brought to their traditionally gendered division of domestic labour, whereby women had carried out feminine domestic activities, such as housework, laundry, cooking, and shopping and men masculine ones, such as house maintenance, driving and gardening. It has shown and explained how this gendered division of labour was bound up with how the spouses expressed their personal and spousal identities as well as how they cared for and related to one another and others. However, it found that, in the context of care, the spouses attributed greater priority to feminine rather than masculine forms of domestic care. In fact these activities appeared to become incorporated through caring into men's spousal role and identity as caring husbands. Thus, it appears that for the couples who took part in this study, working together to meet their domestic care needs was what their marriages and being a good husband or wife was all about. In this way this chapter has highlighted how alongside gender, notions of being a couple, reciprocity, fairness and 'doing the right thing' are important in the practise and understanding of care in later life marriage.

The chapter also highlighted the significant contribution that masculine domestic activities made to the maintenance of the couples' independence and autonomy. Unfortunately, it also showed that this is not reflected in community care policies and provision. To foster the independence of older couples community care policies and service development need to assume a more comprehensive definition of domestic care to includes masculine as well as feminine activities.

Regrettably, this chapter was not able to explore in detail how disability and care impacted on the spouses' financial practices but it was able to reveal that their autonomy in dealing with their finances and the privacy of this issue served as an important aspect of being a couple. The next chapter revisits the issues of transport, gender and the notions of fairness and reciprocity as it explores how the spouses as individuals and as couples experienced care in the more public arena of their social lives.

CHAPTER 4: CARE AND THE COUPLES' SOCIAL LIVES

INTRODUCTION

Participation in social activities offers respite from routine, psychological refreshment and an opportunity to reaffirm social relationships. Thus, it helps carers and care recipients to cope with the daily grind of care and in this way it helps support caring relationships. From this perspective the couples' social lives represent an important aspect of their care experience. This chapter explores how disability and care impacted on the spouses' social activities and how they experienced their social lives. It identifies the different types of social activity the spouses enjoyed and took part in, the support that they received and provided and reflects on how they conceptualised this support. One type of assistance required by some of the couples and discussed in this chapter was personal care. The discussion of this aspect of care may seem to be misplaced in this chapter since it is about the couples' social lives but it is actually not completely misplaced. This is because personal care was not only a form of support that some of the spouses needed to 'get ready' to go out but also a factor that influenced where some of these spouses were able to socialise and how they felt about socialising. Nevertheless, it may have been expected that this study would have devoted a chapter specifically to this important and sensitive aspect of care. This was simply not possible because the spouses provided so few data. Indeed, so few data were gathered that the analysis of the spouses' experiences of personal care mainly focuses not on how they dealt with these needs but on how they spoke and avoided speaking about this subject and what this reveals about how they managed and coped with this aspect of care.

The chapter also outlines and considers whether functionalist theories of ageing can explain the changes that the spouses made to their social lives as well as reflecting on how, in addition to their actual limitations, gender and age-based social expectations impinged on the spouses' participation in physical and non-physical social activities. Finally, the chapter looks at how changes within the spouses' social lives affected their access to social support and how this in turn influenced their commitment to continuing to participate in their social activities.

TYPES OF SOCIAL ACTIVITY

Before the onset of their care needs, the spouses' individual and joint social lives had been made up of a wide range of different kinds of social and leisure activities that reflected their differing standards of living, life styles and values. Some had gone out almost everyday, others relatively infrequently. Some had been sports enthusiasts; others had enjoyed being members of societies, clubs or guilds and some had simply liked to meet and chat with their friends. The remainder of this chapter divides social activities into these two main types; those based on physical social activities such as sports and outdoor activities like walking and non-physical social activities typically centred around conversation. Participation in the 'arts' – visits to theatres and art

galleries – arguably represents a third form of leisure activity but it is grouped with and treated as a non-physical social activity. This is because the spouses' enjoyment of this kind of activity appeared to derive in large part from sharing their interest with likeminded others. For example, Mrs Geddes preferred to go to the ballet with her daughter rather than her husband because she shared her interest in it.

The distinction between physical and non-physical social activities is an artificial one made on grounds of analytical clarity. Thus, the issues explored in relation to non-physical social activities were not exclusive to them, merely more pronounced than in relation to physical ones, and visa versa. For instance, social interaction with their friends was the 'raison d'être' for the spouses' involvement in organisations such as women's guilds but it was also one of their reasons for taking part in sports and other physical activities, especially in the case of the women. Typically Mrs Patterson and Mrs Jarvis highlighted the social aspect of going bowling and to dance classes:

Mrs Patterson: We both played (*bowls*) .. He played in competitions, I didn't. But we both went on a Wednesday afternoon and we had this game with four ladies and four men, you know, playing against each other. It was just a social game. [*names husband*] played competitions, he played another two days a week.

Mrs Jarvis: I line-dance at the [*name of local club*] on a Monday ... There is few of my friends from round here go and it's eight 'til nine so it's only an hour. And I joined (*names another club*). The voluntary services runs it on a Thursday afternoon, an over 50s club. And my friends and I go there and we do gentle exercise, Greek dancing and Russian dancing.

Socialising with relatives, particularly children and grandchildren, was universally popular and accounted for almost the whole of some couples' social lives. It is not included in this chapter but in the next one because the spouses mainly perceived and constructed family visits and events in terms of kinship relationships rather than in terms of socialising.

THEORIES OF AGEING

Theories of ageing such as disengagement theory, originally forwarded by Cumming and Hendry (1961), and activity theory, aim to explain how behaviour changes with age. These functionalist theories and their criticisms provided a useful analytical framework for exploring and understanding the couples' social lives, especially the changes they made to them. The disengagement theory proposes that older people (gradually) withdraw from their social interactions and this withdrawal benefits both them and society. Society benefits from it because the roles and activities that were occupied by older people become available to its younger members thereby allowing for an orderly continuation whilst older people benefit from it because it means they are no longer subject to the pressures of their earlier social roles, commitments and interactions. Thus, they can concentrate on themselves and prepare for their final social disengagement, their death. This theory can be criticised for being overly simplistic.

It overlooks how factors such as physical or cognitive limitations, social and cultural expectations and social policy also contribute to and help account for disengagement in later life.

Another difficulty is the assumption that, at the individual level, the desire for disengagement encounters no competition from desires which seek to prolong engagement. This seems to be very improbable given the complex nature of human behaviour (Victor 1987:36).

The inverse of disengagement theory is activity theory. The basic tenants of this theory suggest that successful ageing depends on maintaining established activities, roles and relationships for as long as possible and finding substitutes for any that are lost or have to be surrendered. The weaknesses of this theory lie in its failure to address the issue of power and intra-age group differences on the basis of health, gender, race and economic resources (Powell and Powell 2001).

The different approaches the couples took to manage the impact of care and disability on their social lives and activities mirror and illustrate different aspects of these early functionalist theories on ageing. At first sight many appeared to have disengaged in so far as they had cut down on or withdrawn from some of their social activities. Around a fifth of the spouses withdrew to a significant degree from their social lives and concentrated on their immediate needs. However, their reasons for and feelings about withdrawing from their social activities included physical, network and psychological factors and hence were not so simplistic or straightforward as the disengagement theory implies. Indeed, disengagement was seldom the spouses' desired or the preferred option, they missed taking part in social activities. Furthermore, the majority of spouses did not become totally disengaged from their social lives. Whilst they gave up and lost interest in some of their social activities, they continued to participate in some others and even took up new ones in place of long-term interest that they could no longer take part in. Thus, the couples' social lives were characterised by a mixture of withdrawal and continuation and hence neither disengagement nor activity theory adequately explains or accounts for this mixture. A closer reflection and description of the couples' approaches and attitudes towards their social lives and activities is provided by continuity theory. This theory suggests that older people adapt and how they adapt is influenced by their preferences and past. They try to preserve and continue to engage in the aspects of their lifestyles that they value and disregard those they do not consider important. The spouses' decisions about what social activities to continue or to give up and their implementation of these decisions, as the following shows, were influenced by their personal and moral histories and identities and also by their financial and social resources, their physical limitations and service provision. Thus, to explain and understand the spouses' choice of social activities, it is necessary to take into account the influence of social and cultural

expectations, social policies and service provision as well as their own personal and social resources and values.

PHYSICAL SOCIAL ACTIVITIES

Participation in Sports and Other Forms of Physical Social Activities

Sports participation was the biggest social casualty of the couples' care experiences. Over half of the men and slightly smaller proportion of the women had regularly enjoyed taking part in various sports and other physical activities but only six spouses continued to take part in such activities. Each of these pursued an activity that not only provided them with a change of scene and exercise but also a link to their pre-care social lives and interests. Baldock and Hadlow (2002: 2) claim:

old age is a time of 'identity work' in which people search for ways to sustain their self-images and to link their present existences to their previous lives. There is a need to be seen, and to see themselves... as whole persons with lives of value and achievement.

Whilst this claim was made in respect of housework, the pattern of the spouses' interest and involvement in sports suggests that it has a wider applicability. Mrs Jarvis, who had always enjoyed dancing, went to dancing and gentle exercise classes; Mrs Kerr, who had swum in her youth, went swimming; and Mr and Mrs Lawrence and Mr and Mrs Oliver, who had always enjoyed the outdoors, went out daily for a walk. Mr and Mrs Oliver had also been keen bowlers and they were planning and preparing to start playing bowls again.

- Mr Oliver: I am hoping maybe to get back (*to bowling*) by the time it is closed this season. ... I just have to take things a little bit at a time. I can walk a wee bit but I canna walk far. This stepping off the mat and balancing on one leg sort of thing I might go a bity (*sic*) off balance. And then you have to walk up and down and I use one stick for walking so I will have to see how I get on with that sort of thing. I will try it in the house first, two or three times and then I maybe have a go at the bowling. ...But I think it will be another month or two yet. It will be at least that.
- Mrs Oliver: I'm starting on Sunday and (*names husband*) is coming up as well. He is just going to have company and a change of four walls.
- Mr Oliver: So it will be treat to get back to the bowling.

Mr and Mrs Oliver were the only spouses within this study not to assume that when they gave up a physical activity as result of disability that it was irretrievably consigned to the past. However, to adopt a goal and to work towards it or to look forward to something were not uncommon coping strategies. They helped motivate and gave the spouses reason to persist with specific tasks such as rehabilitative exercises and to carry on in general. Going bowling represented Mr and Mrs Oliver's motivating goal.

Mr and Mrs Lawrence's and Mr Mrs Oliver's accounts of their daily walks highlighted another important issue within care in marriage, namely that spouses have needs as couples as well as individuals; a point that is often overlooked (or dismissed) within care practice and policy.

Mr Oliver: It is fine to get out but as I said (*to the GP*) this is the person has all the work. He says 'I realise that'. I says 'life would be an awful lot easier if I had a power chair'. I says 'Not for me I'm just sitting there it doesna mean anything to me'. I says 'For the Mrs'. Oh he says 'I quite see your point just leave it to me'. So we got an indication to go to (*names hospital*)

Mrs Lawrence: All he got was out there (*points out of the window and tracing direction of the route that they took before her husband obtained an electric wheelchair*) and round to there, round there and round there and back. Just a wee bit. Just to give him a wee bit fresh air. ... (*Since getting the electric wheelchair*) we go up town, we go shopping, we go I like out as well. I like out. I'm not a person that likes in very much. He goes out I go out. So we go up the road for our paper. The paper shop is up at the top of the road. But we go along and down and along and along the back and up the side and come round here. We are about three quarters of an hour. We come back and...then we go out again after that say like to town.

Giving Up Sports: A Lack of Alternatives, an Absence of Assistance, and Guilt

Care recipients

Physical and sensory impairments and lack of strength, stamina and energy made participation in sports for the majority of the care recipient spouses either impossible or difficult. Some sports can be modified to suit for people with disabilities but, in this study, only Mr Patterson played a 'modified' version of one of his earlier sporting interests. Mr Patterson had been a keen bowls player and now played carpet bowls at a day care centre with other users. Carpet bowls is an indoor bowling game played on a relatively long and narrow felt carpet, with 4 inch bowls as opposed to the much larger ones used in lawn, crown and flat green bowls. Carpet bowls, unlike other games of bowls, also makes 'due allowance' for disabled players for example in respect of stepping onto the mat or dropping the bowl (Bowls Canada Boulingrin 2006). These differences meant that Mr Patterson could play carpet bowl but he showed no enthusiasm for playing it. Mr Patterson provided no explanation for his lack of enthusiasm but it is likely that he derived less pleasure from playing it than he had from playing the kind of bowls that he had played with his wife and friends. Moreover, the differences in the company and circumstances in which Mr Patterson played carpet bowls compared to when he had played before the onset of his disability are also likely to have led him to attribute less value and meaning to the game.

None of the caring spouses offered their partners any help with sports and, as discussed later, few carers continued their own participation. The challenges involved in providing such assistance is acknowledged but this does not adequately account for why they did not offer any such assistance nor why they did not try to obtain it from physically fit service providers.

Sports can physically and psychologically benefit people of all age groups but they are often physically demanding and carry some risk of injury (Department of Health 1998, Grant 2001, Health Promotions England 2001). Grant (2001: 777) maintains that:

much is to be gained by regularly partaking in deliberate physical activity during later life, although this is not always as easy as it sounds. At a personal level, changes in functional capacity and dealing with an ailing body can serve as a deterrent. ... (and) the stigma associated with being older also poses a significant physical, sociological and psychological challenge.

Culturally, older people are assumed to be frail (Biggs 1993). Hence, it might be assumed that they are socially expected not to take part in sports and those who do so are seen as behaving in an inappropriate, even foolhardy manner. This ageist attitude towards physical activity in later life carries particular consequences within the context of care. Firstly, it suggests that older carers who do take part in sports are irresponsible and selfish because they may be injured and so be unable to fulfil their caring responsibilities. Secondly, the possibility of injury means that to assist someone to take part in a sport increases his/her risk of harm. This is inconsistent with normative understandings of care, namely the provision of protection, security and comfort. Whilst the couples' cessation of sports was closely linked to their practical and physical limitations, their disabling conditions and care commitments, phrases such as 'at our age' revealed their agreement with and internalisation of ageist social expectations.

Carers

Many of the spouses who were carers were physically fit but most gave up sports or played them less frequently. This had to do with more than ageist assumptions; it had to do with caring as a physical, moral and emotional experience. Long and Mancini (1990: 39) claim that the social lives of caring couples can be marred by feelings of guilt. Active spouses feel guilty about leaving their partners behind when they go out to enjoy themselves and the latter feel guilty about hindering the formers' social lives. Parker (1993) and Thornton (1989), in their research into care within marriage, found that their care giver participants no longer derived the same enjoyment from taking part in social activities that they had previously shared with their spouses. Hence, they tended to give them up. They attributed this to feelings of guilt and to the fact that taking part in these activities without their partners didn't have the meaning that taking part in them with them did. Furthermore, Strain et. al (2002) highlight how, within a range of constraints, older people make conscious choices about the activities in which they want to invest their energies.

All the spouses in this study placed a very high value on caring. For reasons of time, energy and guilt, the effort involved in arranging alternative care for their partners and probably diminished enjoyment of their sporting activities, they chose to severely reduce or give up such activities. It was part of the process and meaning of becoming and being a spousal carer.

- Mrs Geddes: (*names her husband*) would do more of his bowling I think.
Well, he hasn't exactly given up but it has stopped him playing
as much bowls as when.... So I imagine if we had no physical
worries
- Mr Geddes: I'd be away
- Mrs Geddes: You would be away everyday I would think.

Mr Reid: We were members of (*names place*) golf course. We used to golf two or three days a week. We used to leave in the morning about eight o'clock and on the first tee about half past eight and play a round and that is how we went on until she had a stroke. ... I have given up golf now. This (*caring for his wife*) is a full time job. By the time it comes to eight o'clock at night I am pretty tired. And I sit down in front of the telly. I don't worry about it but I read the paper and just relax.'

Mr Fyfe: I used to golf. That has stopped because I could not afford to be away four hours, five hours a week. I never was a great golfer. I was not chasing the low handicaps. It doesn't really make much difference. It was very sociable. I miss the sociability of it but that is it. We don't have separate contacts now as such. I had the men down the golf course but that has just had to go. It is as simple as that.

Another barrier that men who are carers can face in trying to continue their social lives is 'alienation from conventional male friendships, activities and interests' (McKee and O'Brien 1983: 155). McKee and O'Brien (1983) found that, whilst caring provided the men in their study with material that was suited to engaging in domestic-focused conversation, it also meant that they tended to have nothing conversationally in common with other men. Hence, when they were in the company of men, to avoid creating an embarrassing situation, they had to take care not to talk about their domestic concerns. From the spouses' interviews it was clear that caring was not only their daily occupation but also their source of things to talk about. For example, Mr Fyfe said:

Housework is housework. I used to feel there was a mystique about it but there isn't and when I listen as I do, because women agonise about the washings (*sic*) and you want to say in the name of goodness what are you on about. And in this day and age. I don't know if it is age. Well I do a lot of shopping and the pharmacy down the road is absolutely magnificent. The pharmacist himself knows us by first name and the girls are so attentive and there is one lady here who has a big problem with the drying of her clothes. Is it going to rain and things like this. I listen to it and think very good and then one day I must have had a look on my face and she said 'I know Mr (*names self*) the answer is buy a tumble drier' and I said 'that is it!'

It seems unlikely that Mr Fyfe or any of the other men would consider this kind of domestic topic appropriate to talk about with golfing or other sporting friends. Caring may thus have discouraged the men from continuing to meet with their friends to play sport.

Gender

Dixey (1988) suggests that considerable gender differences exist between the leisure practices and interests of men and women. The men in this study tended to play more sports and attribute greater value and meaning to such activities than women. Some men also identified themselves as sportsmen. For instance, Mr Jarvis defined himself as having been a mountaineer and an athlete. By comparison the women mostly took part in and enjoyed sports for the social interaction that they provided. These differences suggest that giving up their favoured sports

would have a significant impact on the men but it was much less than might be anticipated. For example, Mr Jarvis reflected on how he felt:

I don't feel that I'm that curtailed you know. I can sit here and watch the telly. I'm a great believer in wild life and we've got a channel here, National Geographical and it is all wild life. I don't complain about being ill because I feel that I'm not particularly ill compared to some. I am disabled to the fact that I was a mountaineer as I told you. I'm disabled there and I can't dance. I could probably go half way round the floor.

The influence of their physical limitations and social expectations on these men's acceptance and attitudes towards their loss of their sporting prowess cannot be ignored but the significance of their wives' support should not be underestimated. The ways in which these women helped their husbands make the transition from being active to inactive sportsmen resonated with the kind of transitional support that Mason (1987b) found women provide to their spouses to help them through the transition from work to retirement. She explained that the women 'knew' how important work was to their husbands and how on retirement their husbands would slip into social and physical inertia unless they undertook to structure their time and activities. Thus, they kept them company and seized opportunities to boost their self-esteem. Whilst the provision of this support, for some of the women, was at the cost of changing their own routines, Mason (1987b) claims that they felt that to do anything less was to fail as wife. The women in this study acknowledged their husbands' earlier sporting achievements but they also drew attention to their interest in and knowledge of other activities and interests. For instance, Mrs Patterson highlighted her husband's knowledge of current affairs, his interest in televised sports and other informative programmes and his involvement in non-physical social activities. The women also identified and encouraged their spouses' participation in alternative activities, such as social events in sheltered housing, and modified their shared social lives to facilitate their partners' continued participation. Thus, they practically fostered their partners' sociability and emotionally and sentimentally nurtured their morale and self-esteem. The provision of this support tended to either create extra work for the women or to restrict their social activities. For example, whenever her husband went out Mrs Patterson had to check on wheelchair access, arrange for suitable transport and, as discussed below, negotiate with service providers whilst Mrs Jarvis forewent the opportunity for a dance to protect her husband's enjoyment of their evenings out:

Mrs Patterson: I mean you don't think of it before but as soon as you are thinking of going out for a meal you think how I can get in there? And now we know quite a lot of the places that have access. But I phoned them.

Mrs Jarvis: We go out every Wednesday and Sunday together.

Mr Jarvis: We go down to the (*names association/club*).

Mrs Jarvis: Our friends are there and we have a social night. We have a game of bingo and have a news (*chat*). (*names husband*) used to dance a lot when he was able and he gets frustrated because he is not able to dance. So we play the bingo, have a news and

come home and our friends stay and have a dance. He'll say to me 'just stay and have a dance' but *I know* [my emphasis] how he is feeling.

In spite of the restrictions and extra effort involved in going out, it continued to provide the couples with pleasure and enjoyment. It is also likely that going out benefited their relationships. Duck (1988) suggests that when spouses socialise with others, they see attractive qualities in one another that their domestic routines and tensions tend to veil. Thus, jointly participating in social activities contributes to the affective 'glue' of marriages. Arber and Ginn (1992a) identify presenting as competent adults to external audiences as one way in which older people seek to preserve their personal identities and their public image. This suggests that whenever the spouses went out socially and enjoyed themselves, they expressed and re-affirmed their identities as individuals and married couples. In the context of care, this assumes an additional significance. Oliver (1983) claims that care within marriage tends to result in the spouses and their relationships being seen and treated as carers, care recipients and caring relationships. Morris (1991a,b 1993) similarly asserts that marriages involving care are not infrequently seen as being somehow not normal. Thus, through their social lives the spouses sought to resist the redefinition and reduction of their spousal roles and relationships to ones concerned only with care.

Physical difficulties and internalised social expectations about what activities are appropriate for older people appeared to effectively militate against the spouses' desire and commitment to continue to participate in sports and other physical social activities. Unsurprisingly, then, socialising activities dominate the couples' social lives.

NON-PHYSICAL SOCIAL ACTIVITIES

Assistance and Support

Disability and care did not impact on the spouses' participation in non-physical social activities to the same degree that they did on their participation in sports. Nevertheless, they did cause the spouses to reduce their level of participation and to need assistance. In contrast, to the near absence of assistance to take part in sport, such assistance to take part in non-physical social activities was available. Indeed, the spouses tended to underestimate the extent of support and assistance that they received and provided with these activities. This was because they viewed and defined certain forms of such support, for example, the provision of lifts, company or checking about disabled access when making bookings, as ordinary aspects of socialising. The failure to identify such support as care can be accounted for, in part, by the overlap and similarities between what is involved in having a social life and assistance and support.

However, going out socially is about escaping or suspending the daily routine, the grind, which for the spouses includes the demands of care. Thus, they may have chosen to construct support to socialise in non-care terms in an attempt to try to keep care out of their social lives, and possibly thereby protect the meaningfulness of their social lives.

This exclusion of care appeared to be particularly important in respect of personal care. Personal care is very pervasive; it interrupts and precedes almost all social interactions, from those that form part of daily living, through regular social events to special occasions. The care needs of some of the spouses meant that they had to receive or provide personal care to get ready to go out and or to use changing or toilet facilities whilst out participating in their social activities. In spite of this, few of these spouses mentioned personal care in relation to their social lives and none gave detailed information.

Personal Care

Twigg (2000: vii) argues that ‘much of daily life turns around the maintenance and care of our bodies’: A statement that within spousal caring relationships needs to be extended to include the bodies of their partners too. The provision and receipt of personal care was a significant aspect of some of the spouses’ care experiences but accessing information, especially detailed information about it, with regard to getting ready to go out or any other context, was difficult. The respondents simply did not want to talk about it, at least not in any depth. Whenever the discussion turned to personal care, they either changed the subject or diverted attention away from its more sensitive elements. Mr and Mrs Geddes handled the subject typically.

- Mrs Geddes: I don’t like the bathing part of it. I still like the privacy of my own bathroom, being able to close the door, which I can’t do
- Mr Geddes: Well it was a bit embarrassing to help you when It wasn’t so much embarrassing. That’s the wrong word. It was... (*pause*)
- Mrs Geddes We’re married. We shouldn’t be embarrassed with each other. (*Mr Geddes indicated that he seconded his wife’s opinion*). But you get annoyed with yourself that is when you get frustrated. You want to be able to get your clothes on and you can’t do it. You are so dependent on someone. I wore a brace you see I couldn’t get it on myself. I had to have help to get it on. It had so many buckles you had to tighten them all up. I needed help with that. Ever so frustrating. It was frustrating having to wear it. But I knew I had to
- Mr Geddes Still got it. (*Mr Geddes disappeared out of the room at this point. He returned with the brace and the discussion turned away from feelings to how to fit the brace.*)

Moreover, the couples tended to adopt matter-of-fact manner of speaking about it that created the impression that there really was nothing more to say about it. This tended to inhibit further exploration of the subject. Consequently, this study was only able to gather limited data about personal care and most of these concerned accessing bathing equipment or services and becoming accustomed to the receipt of personal care. For example, Mrs May enthusiastically recounted accessing a bath-seat and Mrs Ellis provided details of how she was eventually able to access a bathing service for her husband.

- Mrs May: I said ‘Have you got anything so I can have a bath. I cannot get in and out’. So she (*OT*) took me down (*to the department*) and oh I saw this beautiful seat with rubber feet that go inside the bath. She said ‘I don’t know if you will get one of those’. I said ‘let me try it’. She

got me into the bath and the seat was up so I got in and sat there for a minute and she pressed a button and down I went. 'Oh' I said 'this is heaven'. 'I don't think you will get one. There are other alternatives'. She showed me a little thing and I said 'That is no good I couldn't lever myself'. She said 'I'll speak to someone and see what I can do for you'. I had only been home a couple of days and the local area (*social worker*) rang me and she said that they had something for me. And they arrived with a brand new seat, brand new (*said very excitedly and with emphasis*). They showed me how to charge the battery about once month. It is an absolute joy. I don't know what I would do without it.

Mrs Ellis: We don't have a bath; we have a walk-in shower and we have a chair for him. We've no bought this house. This is a council house so we got all that done for us.It benefits me too because I just walk in an have a shower and if my health was to detoriate it is there for me. We have just got someone to shower him because the last time he was really ill he couldnae move. I couldnae cope with him because as I say I have had a heart by pass. I could not lift him. All I could do was get him to the side of the bed and give him a sponge but he likes to be clean. So I thought I cannna carry on like this I will have to have help. So now he gets a girl in twice a week who showers him for me. (*when the discussion moved onto service use and accessing services Mrs Ellis added*)

I phoned up the social work the first time I got in touch with them and I said I wanted someone to shower my husband twice a week and it had to be for an hour because I did not like him having to get rushed. So the boy¹ comes back. Tuesdays and Thursdays for half an hour at 5 o'clock. That is hell close together and 5 o'clock. I said 'Hold it. I don't want it'. 'What's wrong?' 'What's wrong you've not given me a thing I have asked for'. (*Mrs Ellis's was getting louder and louder as she relayed this information*). 'Tuesdays and Thursdays is not spread out and 5 o'clock is teatime. ... We would not rush him, they were telling me and I told them ... no.I thought that was terrible. But then this time (*names a HCA*) saw about it but the social (*work department*) had no-one spare so it is a girl² from (*names voluntary organisation*) but she is nice girl.

As a result, this study accessed almost no data about the more intimate or sensitive aspects of personal care. To find the accessing of information about personal care difficult was not unexpected. It is an embarrassing and difficult topic to talk about and the presence of a partner possibly enhances the embarrassment and difficulties. In view of this, it may be that the use of joint interviews as the method of data collection for this study reduced its chances of successfully encouraging the spouses to speak about how they experienced and felt about personal care. However, as discussed in chapter two, the spouses who were interviewed individually did not discuss personal care or any other sensitive topic any more freely than those interviewed as couples. This suggests that problems of accessing information about personal care cannot be attributed entirely to this method.

1 and 2 It is not unusual in this area to use the terms boy and girl for man and woman when speaking about service providers.

Personal care is generally recognised as a difficult subject to talk about and to research (Twigg 1997, 2000, Ungerson 1983b). The reasons for this include (i) it involves various degrees of nakedness and culturally, nakedness is closely associated with privacy and intimacy, usually of a sexual kind and (ii) to need such care reveals a lack of basic competence that threatens adult status and invites infantilisation (Twigg 2000: 45). Twigg (2000) claims that these problems have to be addressed or avoided when speaking about personal care. She goes on to suggest that one way in which this is achieved is to speak about the nakedness involved in personal care in such a manner as to present it as non-erotic. The back is often used metaphorically to represent the body for this purpose because it is viewed as a non-sensual and non-sexual part of the body. Hence phrases about back washing provide acceptable and non-embarrassing ways of talking about help with bathing (Twigg 2000: 59). Several spouses used back-washing phrases, sometimes in conjunction with innocent childhood models of bathing, to talk about assistance with their personal care needs. For instance, Mrs Nichol explained that meeting her personal care needs was a case of ‘back to childhood days – a good wash and your husband washes your back’.

When the couples likened their experiences of bathing assistance to their childhood bathing times, they rendered the receipt of help with bathing ordinary and acceptable. Indeed, Mrs Beattie takes this a step further highlighting the innocent fun that can be had with water:

- Mrs Beattie: Well, I can't go in a bath. There is a shower next door but I've not been use to showers and we were trying out the shower. ...Anyway we have been having (*names personal carer*) now. It is really hilarious. There is a thing I have to hold on in case I fall (*in the shower*) but I can hardly hold on
- A: The grab rail
- Mrs Beattie: And then it is a high shower ... and poor (*names personal carer*). I said ‘I think you are wetter than I am’. ‘Don't worry about me. I'm waterproof.’ We get much fun. We have not done it the same way twice running. There must be a way. We manage after a fashion.

Whilst the spouses' childhood models were quite nostalgic, taking the form of stereotypical characterizations of (long-ago) childhood innocence, they offered the spouses an acceptable way to think, speak and possibly cope emotionally with their current bathing experiences.

Another way in which the spouses coped with problems of nakedness and incompetence associated with personal care was to redefine it. Several spouses who needed someone either to be within calling distance ‘just in case’ or to give them ‘a hand in and out the bath’, constructed such support as supervision and mobility rather than personal care. However, not least because it involves an asymmetrical nakedness – fully clothed carers and undressed care recipients – with the all power implications, and norm violation that this encompasses, assistance to get in and out of the bath is more stigmatised and embarrassing than assistance to get about generally. Hence, assistance with mobility in the context of personal care is different from assistance with mobility in other situations and the spouses' enthusiasm for bathing aids that enabled them to

bath independently reveals that they were very conscious of these differences. This is clearly illustrated in the example given earlier involving Mrs May.

To lend acceptability to their experiences of receiving assistance from service providers the spouses tended to employ nursing imagery or models even though all the spouses who used community-based services to help them with their personal care needs received this input from home carers not nurses. However, traditionally, help to bath has been thought of as belonging to and until recent years has actually fallen within the remit of community-based nurses. Mrs Ellis had been strongly of the opinion that this should still be the case, although experience was beginning to modify her views.

Mrs Ellis: I objected because I thought we would get a nurse to shower him. I did not think it was bad a nurse (*bathing him*) but when I think they are just taking some one off the street and sending them in I did not like that because it could have been someone I knew.

Twigg (2000:111) points out that the care of the body, including the provision of personal care, as well as being regarded as a nursing activity, is also a caring activity associated with women. The dominance of women in nursing and home care is likely to support the transfer and application of ideas about what is acceptable for nurses from this profession to home carers. All the home carers who provided the couples with personal care were women and this emerged as a key factor in their acceptance of this service. Several women used services because they preferred same-sex assistance whilst one of the men insisted that he would not like a receive personal care from a man because this would make him feel vulnerable.

Another tactic that some of participants in Twigg's study employed to cope with receiving personal care was what she terms as psychologically distancing. Some of participants who hated receiving such assistance repeatedly told themselves that they were getting clean so it did not matter that someone was seeing them naked in the bath. The couples, too, were pragmatic and stoical about personal care; it was a fact of their caring lives. They accommodated and dealt with these needs practically but cognitively they somehow seemed to distance or keep them isolated from other aspects of their lives, especially their social lives and relationships. In this way they ensured that their personal care needs did not encroach on or at least did not dominate and diminish their lives. For example, Mr Patterson needed and received assistance with his night-time routine from service providers, but rather than viewing this as a problem or barrier to going out in the evening, Mrs Patterson negotiated with service providers to re-arrange the timing of service. Thus, the couple were able to accept evening invitations to special events like celebratory parties and meals out. Similarly, Mr Kerr did not allow the fact that he could only use toilets with wheelchair access to prevent him from enjoying going out with his wife and their friends to listen to traditional music. As far as possible the couple visited venues with suitable toilet facilities but they were not deterred from going to events that were staged in venues without such facilities. In such instances, Mr Kerr accepted assistance either from a

trusted friend or his wife and drew the proprietors' attention to the inadequacies of their premises. However, a minority of spouses seemed unable to prevent having to deal practically their personal care needs from overshadowing and spoiling their social lives.

Mrs Hendry: And he used to go to (*names centre*) day centre but he doesn't go there any more on a Wednesday because I find that that is too much of a stress for me. Two early mornings...because I would need to get up tomorrow at six o'clock to get him ready. And that is even worse tomorrow because I have to get myself ready to go out with my caring lady, who takes me my messages (*local word for shopping / groceries*), which puts on me a double stress.

Mrs Taylor: We used to always go out Sunday. Saturday was shopping but Sunday was a drive somewhere, picnics and...but we have not done much of that. I like to keep down the hassle as much as possible for my husband.

For these couples the demands of personal care overshadowed and outweighed the benefits of their participation in social activities with the result that they gave them up. To enjoy and benefit from the social activities the spouses had to cognitively disassociate and distance personal care from their social lives. This suggests that personal care had both a perceptual and practical impact on the spouses' social lives. It not only determined where they could go and hence what they could do because of the practical constraints involved but also whether they felt that they want and were able to continue to go out socially.

Care Services and Social Activities

Day care services, lunch clubs, support groups and formally organised social activities within sheltered accommodation, such as bingo sessions, concerts, fellowship groups, and seasonal events like Christmas celebrations, contributed to the social lives of over half of the couples. However a minority of couples, who because of physical limitations or caring were unable to join in community-based activities, built almost their whole social lives around these social activities provided by care services. Regardless of their level of use of such services the spouses tended to adopt a non-care perspective and understanding of them. An exception to this was when caring spouses spoke about how they benefited from their partners' use of care services such as day care. In this instance, these spouses highlighted the care element and how this meant that they were able to have respite from their caring responsibilities. Nevertheless, even these spouses spoke in terms of these services providing their partners with an opportunity to go out and meet other people.

The lack of difference between the activities offered by care services and the leisure industry - after all, bingo is bingo whether it is played in a bingo hall or in a community room in a sheltered housing complex - is also likely to have contributed to and reinforced the spouses' tendency to construct social events and activities provided by care services as 'ordinary' social events and activities. However, it also reflected and was consistent with their apparent

commitment to separating and excluding care from their social lives, in much the same way as they tended to view the support that received to pursue their social interests in social rather than care terms.

However, in spite of the spouses' tendency to overlook the care aspect of social activities and provision provided by care services, for some the care factor was what enabled them to participate. For example, as a result of their physical limitations, Mrs Nichol, Mr Jarvis and Mrs Beattie who were all restricted in their level of participation in social activities in their local communities were still able to comfortably join in social activities and events within their sheltered accommodation complexes because of the easy access and support available in these facilities.

Giving Up Non- Physical Social Activities

Almost a quarter of the couples had more or less completely withdrawn from all forms of social life beyond their homes because the overall physical effort and emotional discomfort involved in going out outweighed its potential benefits. Mrs Taylor and Mrs Ellis explained how environmental issues and people's reactions had expunged their enjoyment of going out.

- Mr Taylor: What we find when we go shopping is people standing in the passageways talking and with her in the wheelchair you can't get past.
- Mrs Taylor: It gets on his nerves. It annoys him.
- Mrs Ellis: We have no social life. Not that I am complaining because he cannae help having (*states disabling condition*)but with him having that there is nowhere we could go, like. He cannae go out for a meal or nothing. We cannae do nothing together. ...
- Mr Ellis: Have you ever seen a fish in a bowl? Well, you feel like that fish.
- Mrs Ellis: Yes but no bugger is noticing him but he has got it in his head. Plus with the medication he has he shakes a lot ... so he is not very good at eating. ... We have no social life. And some days he just donnae feel, well, you know. And some days he cannae breathe right, you know. And if he gets an infection. ... You get right bad infections in the lungs and he is at death's door.

These spouses rationalised the loss of their social lives and tried to take a positive outlook but they still felt upset, annoyed, angry, disappointed and cheated:

- Mrs Ellis: I feel a wee bit bitter because ill health just hit us as when we were sixty. You see retired people enjoying themselves but we are not. But there are plenty worse off. Some have been ill all their life. We have had good health.

In contrast, Mr and Mrs Reid, who took part in very, very few social activities and Mr and Mrs Hay, who had no social life outside of their home, did not seem to feel significantly upset or distressed about it. Zimmer et al. (1997) and Strain et al. (2002) identified that participation in leisure activities in later life tends to fall not only with decreasing functional ability but also increasing age. Mr and Mrs Reid, and Mr and Mrs Hay were much older than the

aforementioned spouses. Pratt and Norris (1992) suggest that older people who withdraw socially do so for all kinds of reasons including to cope with frailty or to preserve their time and energy to carry out selected and rewarding activities. Mrs Hay and Mr Reid were dedicated carers but they were exhausted from trying to meet their partners' extensive care needs. For these spouses, to get ready to go out or to take part in any form of social activity represented extra work, stress and difficulty. Mrs Hay declared:

I don't go anywhere. It doesn't matter. We have almost reached the stage where we don't even enjoy the garden because it is so difficult to get him in and out. We have got ramps to take the wheelchair out and to get him. I have to get him down on the lift with the help of someone else.

Furthermore, many of the benefits derived from engaging in social activities come from interacting with friends and both of these couples revealed that their social circles were somewhat contracted. Mrs Hay pointed out:

They (*friends*) are getting fewer and fewer and fewer. Well, our friends are all gone (*died*). Our age group, they are almost all gone. We don't have any older people coming here. I could count them on my hands (*the ones left*).

Caring is also likely to have further reduced their social circles as the demands of care frequently erode relationships, like friendships, that are underpinned and maintained by reciprocity (Roseneil 2000). The contraction of Mr and Mrs Reid's social circle may have been further compounded by the fact that they had undertaken a long distance house move after their retirement. Wenger (1984: 17) points out that 'length of residence in a community has a significant effect on the strength of affectual bonds and recent incomers may find themselves less well supported than long term residents'. Mr and Mrs Reid had lived in the area around ten years but had been resident only relatively few years before Mrs Reid began to require care. This may have resulted in the couple failing to establish robust friendships. Indeed, in spite of having been active church members and living in sheltered accommodation, Mr and Mrs Reid seemed to have only limited social interaction with others in their community except for their daughter and her family.

Whilst their limitation and practical difficulties encouraged the spouses to limit or withdraw from social activities, age-based social expectations provided the context for their partial or complete withdrawal. Mrs Ellis felt too young to have to curtail her social activities whilst by comparison Mrs Hay and Mr Reid felt that to withdraw from social activities was quite normal for people of their age. Wilson (1995: 104), in her study of gender roles in advanced old age, reports that her participants frequently articulated:

the need to withdraw from social life. ... It was not clear how far men felt that they had to give up activities, or offices that they had held in clubs and societies, because of socially held perceptions that they were 'too old', and how far they acted because they felt 'too old'. ... Given an ageist society, the distinction is almost impossible to make objectively, but in terms of personal perceptions it could be important.

Irrespective of age, withdrawal from social activities carries risks, including increased vulnerability to loneliness, isolation and boredom (Zimmer, et al. 1997). The internalisation of

ageist social expectations about social activity in advanced later life appeared to make it easier for the oldest spouses in this study to accept the loss of their social lives but it did not protect them from all the negative consequences of taking such a step. Mrs Hay, who apparently accepted the demise of her social life, emphasised how very simple and monotonous her life had become and how important contact with family in limiting her feelings of isolation and depression.

Social Activities as a Source of Social Support

In their research into the outcomes of social care, Qureshi et. al (1998), identify participation in social and recreational activities as a source of 'distraction from other worries and difficulties' that helps prevent boredom and depression in older individuals. Coleman et. al (1993) found that leisure activities – hobbies, interests, outings and social interactions – all promote and sustain self-esteem in later life. More recently, Bowling et. al (2002) have suggested that participation in social activities contributes to a good quality of life in old age. Furthermore, participation in social activities boosts the health of relationships (Duck 1988, Siddell 1995). Siddell (1995: 65) claims:

Social isolation is a recurrent theme in the literature on chronic illness and although those living with a supporter do at least have some interaction with another person, couples can be equally isolated. Withdrawal from social life because of immobility, lack of energy, embarrassment or pre-occupation with illness.... invariably involves the supporters ... putting a great strain on the relationship.

Although participation in social activities does not coincide with or necessarily result directly in social support, it promotes contact with others and this can provide access to social and emotional support. Measuring social and emotional support is problematic and debate persists as to how social support enhances well-being but that it actually does is widely agreed (Duck 1988, Cicirelli 1990, Hansson and Carpenter 1994, Jerrome 1992, Siddell 1995, Zimmer, et al. 1997). Social contact and support also play a significant part in establishing the norms of behaviour including ways of coping, especially in relation to infirmities in later life (Jerrome 1992, Phillips, et. al 2000). Duck (1988: 97-98) claims that in everyday conversations, where trivial and mundane concerns are aired, individuals verify their experiences and find new or better ways of addressing issues. Somewhat more specifically, Jerrome (1992: 93-98), in her anthology of older people's clubs and societies, argues:

Issues of health and ill health tend to dominate the lives of organisation members. They influence the content of meetings and informal communications in the club ... contemporaries commiserate with one another and also compare the roles they play in relation to sick family members: spouses and siblings. In some cases the object of assistance is present during the discussion. ... The spirit of optimism and determination not to let physical illness get one down, ... inspires elderly participants in club and fellowship (sic). But the presence of sickness and concerns for its consequences are acknowledged. ... People with health problems are expected to be sensible and avoid taking risks, though exceptions can be made. ... Equally, disapproval is expressed towards people who give in too easily to their symptoms, who moan and complain, who rely too much on other people, who

should 'buck up'. ... The talk is of responses to symptoms rather than the symptoms themselves, and value judgements are invariably attached to observations. ... The outcome is a set of norms of behaviour in sickness and in health.

Few spouses were in any doubt as to the benefits of taking part in social activities. It gave them something to look forward to, provided a change of scenery, company, enjoyment and a temporary escape from their routines and worries. It acted as a refreshing breath of fresh air and a boost their morale. Mr and Mrs Kerr explained how they felt about going out:

- Mr Kerr: If you say on the Wednesday. I'm nae going (*to the social club*). It's saire ... (*his hip - Mr Kerr had hurt this in a fall earlier that week*) but when you are there it helps you.
- Mrs Kerr: It takes your mind off it and to speak to other people as well instead of moaning to me.
- Mr Kerr: It is better to get out.
- Mrs Kerr: You have to. You have got to get on with your life.

As will be discussed in more detail in the next chapter, many of spouses belonged to and were supported by, what Wenger (1984) terms, 'locally integrated' support networks. These networks are associated with contact with friends and neighbours and this by implication supports the sharing of information. Going out and interacting with other people provided the spouses with a chance to access and share advice and information and this often gave them reassurance that that they were not alone in coping with disability and ageing; others also shared in these experiences. Thus, in these ways socialising offered them social support and to some degree emotional support because they felt that others understood them. Moreover, social interactions often helped the spouses gain useful insights into their lives and circumstances that supplied them with a relative perspective on their own later life and caring experiences. For example, Mr and Mrs Kerr and Mrs and Mr Jarvis became aware of care experiences of other spouses through conversations at their social clubs. Frequently voiced adages like 'there is always someone worse off' suggest that such insights or knowledge of others' circumstances helped the couples cope with their own and possibly even take a more positive view of their own situations.

The spouses' awareness of the benefits of socialising meant that most care recipients cooperated with substitute care arrangements to enable their partners to go out socially and, in some cases, actually even encouraged their partners to develop and pursue their own social interests / activities. This presented them with a way to care for their carers and contribute to their relationships, thereby maintaining equity independent of their disabilities. Nevertheless, most spouses found it difficult or impossible to go out without their partners.

Gender, Social Activities and Support

Older women have a proportionally higher incidence of participation in social activities than older men (Arber et. al 2003, Jerrome 1992, Wilson 1995). In this study too women tended to take part in more social activities and derive a greater benefit from their social activities than men. The women also seemed to have a clearer understanding of the supportive value of

socialising. Hence, they tended to assume greater responsibility for sustaining their own and their partners' social lives. They sought out alternative social activities and reconstructed everyday functional outings as social ones in response to care-driven changes to their social lives. For example, Mrs Ellis, who had a restricted social life, presented the task of going to draw her pension as a social outing.

Mrs Ellis: Oh, I go out every Tuesday morning. I go out with my next-door neighbour and my other friend and we go and get our pension and we have a coffee.

The women's greater commitment to having some form of social life and their deeper understanding of the supportive function of social interaction can be traced and attributed to the central role that friends played within women's social lives and the character of women's friendships. Friendship is a voluntary relationship; individuals choose to be friends hence this relationship provides the individuals with assurance of their worth and so boosts their self-esteem (Jerrome, 1992,1993 a,b). Furthermore, women's friendships tend to be intimate, characterised by emotional intensity and self-disclosure. Indeed, one of the main activities of women's friendships is conversation (Jerrome 1993b: 251). In his study of gossip in sheltered housing, Percival (2000: 314-315) defines gossip as:

an integral and positive aspect of interaction between women, when socialising in groups. ... A form of communication, which allows women to share interpretations, as well as information, and reach a common appreciation of the world around them.

Positive statements about their friends and their company littered the women's accounts of their social lives:

Mrs Addison: I have a very good friend who ... when she is away up to the (*names a women's organisation*) stops by and takes me there and back.

Mrs May: I like friends coming over.

Contact with their friends emerged as integral both to the women's motivation to take part in social activities and to their enjoyment of them. Whenever and wherever women went out socially, they met and 'blethered', 'news-ed', gossiped, spoke and talked to their friends and in doing so appeared to provide and receive social and emotional support.

Mrs McKenzie: But every Thursday morning my next door neighbour she and I we are quite friendly. ...so (*names a neighbour*) takes me down to (*names village*) every Thursday and I get my big shop then ... she and I go and have a cup of coffee and cake. And I really enjoy that. ... I really enjoy the Thursday having a blether (*natter*) and (*names a neighbour*) enjoys it too.

Mrs Kerr: I meet my friends there (*at the pool*) so of course there is a bit of talk and then we go for our coffee and then home for lunch.

By comparison to women's friendships men's friendships tend to be sociable rather than intimate and to focus on doing rather than talking (Jerrome 1993 a,b.). The men in this study had what might be termed 'mates', with whom they did (or used to do) things such as playing

snooker or golf. They talked but their talk was felt to be different from the women's talk. It was conversation, discussion or comment rather than 'blether' or chat. Mrs Fyfe observed: 'I know (*names husband*) loves a gossip. Not a gossip like a woman would but conversation'. The men's relationships appeared to withstand care and disability less well than the women's friendships, possibly due to the active character of the relationships and, as pointed out earlier, the gendered character of care.

Mrs Patterson: I feel sometimes that he (*names her husband*) could do with more men coming in. Somebody did suggest to let me go out that we have (*names a sitting organisation*) but again they are all women. And well there is no point really in that, having more women coming. ... We have one very good friend, our son-in-law's father, who is eighty and he comes fairly regularly and in the fine weather takes him out in the wheelchair. They go for long walks. He is a great walker. So that is very good.

Whilst the women were the direct recipients of their friends' social, and possibly also emotional support, this support ultimately benefited the couples because it helped to cope with the demands of care within their marriages. This meant that the women's friendships were an important, if indirect, source of social support to the men.

The difference in the character of men's and women's friendships meant that the women derived considerable social and some emotional support and benefit from their social activities. This implies that the cessation of their social activities would hit the women particularly hard. Mrs Hay, Mrs Ellis, Mrs Reid and Mrs Taylor, who were dealing with severe and ongoing reduction of social lives and contacts, found this depressing. However, by focusing on the positive aspects of their lives including having a caring family they seemed to be able to 'contain' or manage the problem of social isolation and erosion of morale.

CONCLUSIONS

This chapter has drawn attention to how the spouses' social lives were on the one hand, constrained by, but on the other hand, kept separate from their caring responsibilities. It has highlighted how participation in social activities provided them with respite and a way of accessing social support and expressing their identity as married couples. It has also identified and analysed what kinds of support and assistance the couples actually received and provided in order to take part in different types of social activities. This included a discussion of how the spouses coped with personal care in the context of their social lives.

The chapter also identified gender patterns in the spouses' social activities and access to social support. In particular, it highlighted women's interest in and commitment to non-physical activities that centre around conversation and the sharing of information with their friends and how their participation in these social activities provided them with direct access to advice, guidance and social and emotional support which they subsequently used to benefit their caring relationships.

In its examination of the couples' social lives, this chapter has revealed how the spouses' friends and family were involved in their care experiences. The support and assistance that the spouses' received from within these relationships and from service providers forms the focus of the next chapter.

CHAPTER 5: ASSISTANCE AND SUPPORT FROM KITH, KIN AND SERVICES

INTRODUCTION

This chapter focuses on how the spouses experienced care in the context of their social networks. It begins by trying to identify the couples' supportive network types and discussing the impact of their home locations and distance from their adult children and their families on their care experiences. It then moves on to identify what support the couples were prepared to accept from their friends, neighbours, family and service providers, and what meaning they attributed to the support that these different sources provided. To explain the couples' care preferences, it analyses the influence of social care expectations as well as the spouses' own expectations and concerns about informal care. The last part of this chapter examines the couples' perceptions of care services and how these influenced their approach to and experience of accessing and using service provision.

SUPPORT NETWORKS

Network Types

Wenger (1984, 1990b, 1994) identifies five different types of later life social support networks based on three key factors, namely the availability of local kin, level of interaction between an older individual and his/her kith, kin and neighbours and his / her level of involvement with community groups. Whilst personality is a mediating factor, the actions of others - for example whether adult children marry, have children, move or remain in the area - strongly influence the type of social network that an individual has. The names of the five networks, local family dependent, locally integrated, local self-contained, wider community focused and private restricted, reflect the different kinds of relationship that the older people have with those in their social network. The local family dependent support network is associated with closeness of kinship relationships and residence. Older people with this type of network tend to have limited involvement with friends, neighbours and community groups and to rely on their adult children for support. The locally integrated support network is similarly associated with close relationships with local kin but also with friends and neighbours. This type of network is also associated with long-term residency and involvement in local societies and community groups. The local self-contained support network is associated with low-key relationships with local family and limited involvement in community groups. Older people with this type of social network tend to focus on their own households and to assume that their 'neighbours are there if they need them'. Unlike the aforementioned types of social network, in which local kin are available, wider community focused and private restricted networks are typically associated with a lack of local kin and migration, especially in middle age or later life. Older people with a wider community focused network tend to be involved in community groups and to have active

relationships with family and friends who live at some distance. In contrast, older people with a private restricted network tend to lack local relationships and are not usually involved in local community groups.

Wenger (1995) also explains that network type tends to correlate with four categories of social and demographic variables. These are (i) personal attributes including gender, age, marital status and household composition, (ii) socio-economic factors, (iii) migration factors including place of birth, duration of residence and age of settling and (iv) cultural factors including ethnicity and religious affiliation¹. In respect of age, she points out that with increasing age, shifts in network type increase and smaller and more restricted networks become more common. The most common shifts being from locally integrated and wider community focused to local family dependent and private restricted respectively with the result that these network types become ever more common with increasing age.

Network type can be assessed on the basis of eight specific questions about distance to and interaction with family, friends and neighbours and involvement in social and faith groups or by interview (Wenger 1995). In this study the couples' network types were identified on the basis of information that they provided in general about their informal relationships and interactions. Based on this information three couples appeared to have local family dependent support networks, six locally integrated networks, four local self-contained networks, one a wider community focused network and two private restricted networks. The couples with local family dependent networks were amongst the oldest participants in this study but the couples with private restricted networks were not - one of these couples, Mr and Mrs Taylor, was actually one of the youngest. Both of the couples with private restricted networks had few kin, had been dealing with disability for a long time and lived in quiet residential areas where most people went out to work. Combined, these factors may have reduced their opportunities to develop or sustain social relationships.

The network type of five couples was ambiguous, contradictory or in flux. Mr and Mrs Oliver appeared to have had a locally integrated support network but, because of the restrictive impact of Mr Oliver's disability on the couple's social interactions, it was no longer clear whether this was the case. It was also unclear as to whether any change in their network type would be temporary or permanent as the couple hoped and planned to resume, at least some of their social activities in the future.

Mr and Mrs May's network had been almost been a text-book example of a wider community focused network. They had moved to their current home location long after their retirement and

¹ Due to the types of data available to this study, it considers only the influence of age and migration on the couples' network types. All spouses who took part in this study were white British. This means that it is unable to make comparison between the network types of older married and non-married people or between those living in different household compositions or different ethnic backgrounds. Also, it collected only limited data about the spouses' religious affiliations and, as discussed in chapter two, socio-economic status.

had become actively involved in a range of community groups where they had made friends whilst remaining in contact with a wide circle of friends and relatives who lived hundreds of miles with the exception of their daughter who was their nearest neighbour. However, Mrs May's ill-health and inability to drive had severely curtailed the couple's attendance at community groups and societies and contact with local friends over the last few months. When Mr and Mrs May were interviewed it was unclear whether this would become a permanent situation as it depended on whether Mrs May's health would improve enough for her to resume driving. Mr and Mrs Beattie's network type was also in flux due to significant changes in the composition of their family and changes in their own limitations. Mr and Mrs Beattie, like Mr and Mrs May, were amongst the oldest spouses taking part in this study and whilst their future network was likely to be small, it was difficult to predict what type it would be.

Mr and Mrs McAllister's and Mr and Mrs Addison's networks, whilst apparently stable, did not conform well to any single one of the described types. Mr and Mrs McAllister had quite a small local social network, no local kin and did not appear to be particularly involved in any local community group; factors suggesting a private restricted network. However, the saliency of their relationships and the frequency of contact with their neighbours, especially their immediate neighbours, who were also friends, seemed to be inconsistent with this type of network. Mr and Mrs McAllister lived in a rural settlement made up of a hand full of houses, where there were almost no community facilities and public transport services were poor. In spite of this, Mrs McAllister was unable to drive and Mr McAllister felt able to drive only relatively short essential journeys such as shopping and appointments. Hence, it seems likely that their social network reflected the physical and service environment of their home location. Mr and Mrs Addison's network type was particularly complex. The overall size of their network was small but, as with the aforementioned couple, this may be attributed, at least in part, to where they lived, on a farm. The couple had lived in the area all their lives and their son and wife also lived on the same farm but not in the same house. Whilst Mr and Mrs Addison's son and family were not involved on a regular basis in meeting Mrs Addison's care needs, Mr Addison often undertook farming tasks alongside his son and Mrs Addison had frequent visits from her grandchildren - which served to boost her morale. Mrs Addison also had a close relationship and frequent contact with a friend and neighbour who assisted her with a range of activities. The couple were also involved in local societies, community groups and church. This combination of local relationships and interactions did not point clearly to any one type of network.

Location and Distance

Comparing the distribution of support network types in urban Liverpool and rural North Wales, Wenger (1995) found that the locally integrated network was the modal network type in both

areas, making up 45 per cent of the Welsh and 46 per cent of the Liverpool networks. Accounting for the network type of at least a third and possibly up to approximately 45² per cent of the couples, the locally integrate network was the most common network type in this study. All the couples whose network type was identified as locally integrated lived in towns or commuter settlements.

Local self-contained networks made up a greater proportion in this study than in they did in either Liverpool or Wales in Wenger's (1995) study. The proportion of wider community focused networks (about 5 per cent) and private restricted networks (about ten per cent) was quite similar to the proportion of such networks that Wenger (1995) found in Liverpool whilst the proportion of local family dependent networks (about 14 percent) was closer to what Wenger found in Wales. One couple with a local family dependent network lived in the country whilst the couples with private restricted networks lived in towns. The interpretation of these differences is difficult and their significance doubtful on grounds of the limited numbers involved in this study and the ambiguity as to the network type of around a quarter of the couples. If these could have been clearly identified, then the relative proportions of the different networks, and hence the comparisons with Wenger's (1995) findings, may have been quite different. Finally, nowhere in this study had a population that was anywhere near the size and density of that of Liverpool.

Although this study was unable to establish any definite association between the couples' network types and where they lived, where they lived undeniably influenced their experiences and perceptions of formal and informal care. On a practical level, again as discussed in chapter three, living in the countryside heightened the couples' need for assistance with transport and the value that they placed on it. Living in the countryside also increased the spouses' chance of needing to move area to find suitably accessible accommodation. For example, both Mr and Mrs Lawrence and Mr and Mrs Nichol had to move out of the countryside into town to find accommodation that met their needs. In spite of these shortcomings in the availability of provision in the countryside several couples seemed to prefer and to believe that services arranged from small town or rural bases were superior to those provided from city bases³. Mrs Beattie specifically pointed out that:

It (*home care service provision*) did not work too well there (*in the city*) in that it was not working as it should. But it was just the problem of the organisation. I think there are four different organisers in that area. Even when I came here the organiser was excellent. She says her girls are mostly from the country and are all excellent workers. They are so used to looking after older people.

² The higher percentage includes Mr and Mrs Beattie's and Mr and Mrs Oliver's networks within this classification.

³ This study is unable to vouch for any difference in the quality of rural and urban services. Indeed, with the exception of accessible transport, accommodation, and certain voluntary sector services, the availability of service provision appeared to be comparable across all of the couples' home locations.

In her research into the interaction of gender, class and locality, Callaghan (1998) identified that local practices reflected local expectations. She explains how her participants accounted for the levels of social interaction in their different neighbourhoods in terms of local culture. It was what was done in that place. For example, in financially poorer areas where levels of social interaction were high this was paraded as one of the benefits or an asset of that locality.

Similarly, as discussed in chapter three, several spouses attributed being able to find someone to assist them with their gardens to where they lived because in those places everyone knew one another hence their skills and availability.

Another facet of locality or place interwoven into the couples' experiences and perceptions of care was that of distance, in particular distance to relatives. Just over half of the couples had an adult child living in their neighbourhoods and around a third of the remainder had such a relative within an hour's drive of their homes. However, over half of the couples⁴ had at least one adult child and his / her family who lived a long distance away, indeed, a third lived abroad. One couple had no children.

Thompson (1992) suggests that the geographical separation of generations has been counterbalanced by 'greater mobility, easier communication and more spare resources' than in previous times. Also such separation means that child-parent visits become 'more of a special occasion' and hence something to look forward to. Telephone calls, letters, periodic visits and prayers defied the adage 'out of sight out of mind' and reassured the spouses that others were interested in them. These forms of contact also gave them something to look forward to and back on with pleasure and so helped maintain their morale. Mrs May recounted how:

We look forward to going out with friends ... and we go on holiday. We had a gorgeous holiday last year. They (*one of their sons and his partner*) gave us a wonderful time in (*lists several historical European cities*) and the countryside in (*names a well-known area*). They live there in (*names area*).... Another thing we love is in the summertime when friends or family ring up and say 'we are coming up; can we come and have a day with you?' And they come and I rustle up some food and we have a lovely day. And my children; when (*names son*) comes up, he comes for a week at a time and we go off out in the car visit the north coast. There is usually something to look forward to.

Nevertheless, some spouses felt that the physical distance between where their children lived and where they lived meant that they missed out, especially on seeing their grandchildren growing up.

Mrs McKenzie: He (*their son*) settled there (*in another part of UK from the couple*).... He would come up one year and we would go down the next year. We saw them only once a year and we missed an awful lot when the children were growing up. They keep in touch by phone but it is nice to see them.

Distance limited the amount practical care that some of the couples' children and other family members and friends were able to offer them but, as will be discussed later it did not result in the spouses feeling that they did not cared.

⁴ The majority of these couples also had at least one adult child who lived relatively nearby.

Support Preferences

Older people's family members, friends and neighbours represent the sum of their potential sources of informal support and assistance but, when they require support, rarely do all sections of their networks become actively involved in its provision (Finch and Mason 1993, Phillips et. al. 2000, Qureshi and Walker 1989). This can have to do with distance but different types of relationship tend to offer different types and levels of support.

Friends and neighbours tended to be thought of and have generally been found to provide social and emotional support but only relatively low levels of practical assistance (Coleman et. al 1993, Jerrome 1992, 1993a,b, Qureshi and Walker 1989). As discussed in the previous chapter, Jerrome (1993a), in her research focused on women's friendships, emphasises the social and emotional supportive importance of friendships. She explains that friends act as confidantes and companions and because they are chosen, serve to confirm each other's sense of self-worth and boost self-esteem in ways that relatives cannot. Moreover, she suggests that friends play a vital role in times of uncertainty and change by conversationally helping each other put events into perspective and providing moral and practical support.

Interaction between friends is primarily expressive: it involves emotional support, mutual visiting, shared social activities and small reciprocal acts of assistance which are mutually enjoyable (Jerrome 1992:72).

Similarly, Phillips et. al (2000) identified, in their research into older people's networks, friends as someone in whom older people, especially in the absence of a spouse, confide and talk to about things, in particular things related to health. They also found that whilst older people tend to turn to their immediate families rather than their friends for help with tasks such as domestic chores and transport, friends did represent an alternative or complementary source of instrumental support. Qureshi and Walker (1989) also identified friends and neighbours as being active in supporting or backing up older people's principle source(s) of support by helping out with shopping, housework, cooking and gardening. Concentrating on practical assistance Qureshi and Walker (1989) found that, of the older people within their research who received informal care, the vast majority of them received it from one or more of their family members. In cases where they had a spouse or another co-resident relative, he or she was the preferred carer but where they had not, daughters and daughter-in-law were usually the preferred helpers unless there were extenuating circumstances to prevent them from becoming carers such as illness, other commitments or distance. The amount and types of help that these family members provided varied but the activities with which they helped included all kinds of housework, shopping, cooking, laundry, personal care, gardening and decorating. Nevertheless, in their study of non-kin carers, Nocon and Pearson (2000) found that friends and neighbours who assume the role of principle carer are involved in provision of all kinds of support and assistance, including ongoing domestic and personal care.

FRIENDS AND NEIGHBOURS

Friends or Neighbours

Friends and neighbours are frequently grouped together colloquially and in social research (Bott 1971, Green 1988, Nocon and Pearson 2000, Phillips et. al 2000, Qureshi and Walker 1989, Rowlands 1998. Townsend 1963, Wenger 1984, 1994, 1995). For example, the 1995 GHS identified friends and neighbours as the second most common informal source of non-residential care making up 20 per cent of non-co resident carer population. This practice of grouping these relationships together makes comparisons between them difficult. However, in her research into social support networks Wenger (1984, 1994) suggests that older people with 'wider community focused support networks' tended to distinguish between friends and neighbours whereas those with 'locally integrated support networks' did not because their friends were often also their neighbours. Approximately half of the couples had friends and family living within the immediate neighbourhood and a third clearly identified their neighbours as friends. In contrast, five couples consistently distinguished between their neighbours and their friends. None of these couples were identified as currently having a wider community focused network but four of these couples had arrived in their current communities late in their working lives or after they had retired. They also seemed to have few friends living nearby. The fifth couple, although long-term occupants of their current home, had pursued a different and more affluent lifestyle than their neighbours with whom, possibly because of this, they had not sought to develop a relationship. With the exception of these five couples, the spouses generally treated the boundary and designation of friend / neighbour as 'fuzzy', permeable, inconsistent or non-existent. In spite of this, the couples spoke of and constructed some aspects of assistance from these sources as neighbourliness and others as friendship. For example, Mrs McKenzie constructed her neighbour's provision of a weekly lift to shops as neighbourliness but the pleasurable social interaction that they enjoyed over coffee at the end of their shopping trips as friendliness. For reasons of clarity the following considers the support that the couples exchanged with friends and neighbours separately. However, it recognises the fluidity of these groupings.

Neighbourliness and Assistance from Neighbours

The ever-increasing use of technology to communicate, ever-greater mobility and the growth of individualism have cast doubt on the function of the spatial neighbourhood as a source of support and friends (Crow, Allan, Summers 2000, Wellman 2000). However, care studies continue to show that neighbourhoods spawn and sustain friendships (Bott 1971, Green 1988, Nocon and Pearson 2000, Phillips et. al 2000, Qureshi and Walker 1989, Rowlands 1998. Townsend 1963, Wenger 1984, 1994, 1995). Within this study about a fifth of the couples regularly received practical assistance from their neighbours and the proportion may have been even higher if it were not for their commitment to reciprocity, concern for their reputations and the fact that around a third of the couples lived special accommodation. Six of the couples not

in receipt of assistance from their neighbours lived in sheltered accommodation and another three in residential schemes designed to suit older people with physical disabilities. In 1994, the Department of Environment reported that 28 per cent of sheltered housing tenants had high levels of dependency. Unsurprisingly, then several of the aforementioned couples pointed out that their neighbours, although sociable and willing to help out, were limited in what they were able to do. These findings, arguably, challenge ideas about the demise of community relations based on spatial neighbourhoods (Wellman 2000).

In their research into neighbourly relations, Crow et al. (2000: 138) point out that their study populations were keenly aware that 'the rules of reciprocity apply in neighbourly relations'. The couples in this research were very conscious of and committed to maintaining a social balance within their relationships with their neighbours. Two of the couples who received practical assistance from their neighbours on a regular basis accepted it as part of a direct reciprocal social exchange. In return for helping them keep their boundary hedge tidy, Mr and Mrs Patterson gave their neighbour the use of their garden power tools. Mr and Mrs Inch's neighbour maintained their garden and for this he had use of their garden to grow what he wanted and to take it away. This direct and clear reciprocation guarded against the problem of indebtedness and protected the couples' moral identities and reputations as 'good neighbours'. In contrast, how Mr and Mrs McAllister and Mr and Mrs McKenzie reciprocated their neighbours' assistance was not immediately clear but their apparent lack of a sense of 'indebtedness' strongly suggested that they had or did.

As discussed in chapter three, reciprocity can be realised in many different ways; over short and long time intervals and in accordance to local and personal circumstances (Crow et al. 2000, Finch and Mason 1990, 1993, Phillips et al. 2000, Qureshi and Simons 1987, Stoller 1985). Furthermore, perceptions of assistance vary. What a provider considers very little or insignificant, a recipient may view as very significant. Hence some years later the former is less likely than the latter to recall it. Positive relationships and enjoyment of each other's company can further obscure the fact that certain activities are acts of support and assistance both at the time of their provision and subsequently. Nocon and Pearson (2000: 353) found that, whilst some carers in their research had received help in the past from their care recipients, they did not identify this as a reason for caring for them now. Mr and Mrs McKenzie and Mr and Mrs McAllister had lived beside and enjoyed a good relationship with their neighbours for many years, in the case of the latter for almost fifty years. In view of this, it seems reasonable to assume that at sometime in the course of these relationships the couples would have helped their neighbours even though neither identified any such instances. It also seems likely that these couples had engaged in the long- term and ongoing practice of neighbourliness.

Crow, et al. (2000: 139) argue that the moral identity and behaviour of a good neighbour tends primarily to be achieved and expressed through rather non-specific and undemanding, yet highly valued supportive exchanges or activities, summarised in phrases such as 'keeping an

eye out for each other' and 'there if needed'. Mr and Mrs McAllister and Mr and Mrs McKenzie were familiar with a good quality of neighbourliness. Mrs McAllister asserted 'We couldnae get better neighbours than we have. They are an awful nice couple. They would just do anything for you' whilst Mrs McKenzie explained:

You do need people or neighbours as you get older. I mean we are lucky you (*we*) know the neighbours. The neighbours are all very friendly. We don't run out and in each other's houses or anything like that but if we need anything or anyone they are there.

The majority of couples were confident that, if needed, their neighbours would assist them in an emergency and many evidenced this by recruiting them as key holders or contact persons in respect of their community alarm systems. Most couples had never had to call on their neighbours for help but the few who had had seen their confidence justified. Mrs Kerr described their neighbour's response when she called for help after her husband fell:

I had to get a neighbour to help me. ... Well, the one that I went for happens to be on the first on the list for the community alarm. I didn't use the alarm I just went across. So he came and helped me lift him. Then he hung on to him while I came into the house for a chair.

Neighbourliness, having or being a good neighbour, was one of the most valued and valuable forms of support that neighbours made to the couples' care experiences. It gave them a sense of security that fostered their confidence about coping with their care needs as couples within the community. Yet they did not think of or understand this very valuable contribution to their care experience in terms of care but in terms of relationships. It was about neighbourliness. Thus, they acclaimed those who offered them assistance and engaged in neighbourliness as 'good neighbours' and, wherever possible, they reciprocated their support in some way.

Practical Assistance from Friends and Friendship⁵

The provision of assistance is accepted as a mark of being a friend, yet friendships seldom tolerate gross imbalance within the exchange of support and assistance. Hence the demands of care and disability threaten this reciprocally based relationship, when the support that it offers is possibly most needed. Most couples claimed to have good friends whom they could count on for support and assistance, but they were able to provide few examples of such provision. Indeed, they consciously limited the amount of assistance or help that they accepted from their friends for fear of becoming beholden to them and when they did accept assistance they worried about being indebted to them. For instance, Mrs Patterson had accepted lifts to visit her husband in hospital from her friends but now she was concerned about how to return their assistance and so redress the balance within these relationships:

Well, I was very indebted to all my friends. They were very good about. And a lot of other people err I knew well enough but not personal friends... but they came and offered to take me in because (*names hospital*) is not the easiest place (*to get to*).

⁵ Since the exchange of social and emotional support between the spouses and their friends was considered in chapter four the current chapter concentrates on practical assistance.

Other spouses felt or knew from experience that disability created needs that were either physically or otherwise too difficult for their friends to cope with. For example, Mr Oliver told how a friend had offered to push his wheelchair and then had almost tipped him out of it. He no longer accepted such offers of help. Exceptionally, Mrs Addison accepted considerable, seemingly unreciprocated, practical assistance as well as social and emotional support from one of her friends. This imbalance suggests that Mrs Addison's friendship with this woman should have been highly strained and on the point of collapse but Mrs Addison gave no hint that this was the case. Her friend's views were not available. Several factors emerged that may have helped this relationship withstand this apparent imbalance of give and take. Firstly, the friendship was a longstanding one. Mrs Addison did not refer to any past exchange of assistance between her friend and herself but this is a possibility. Secondly, the rewards or benefits of care are not necessarily exclusive to the care recipients. Nolan et. al (1996) point out that carers often find satisfaction and rewards in caring and in the interpersonal dynamic of the caring relationship. Mrs Addison implied that her friend enjoyed and therefore presumably benefited from visiting and helping her. Thirdly, Mrs Addison's friend was a woman, a retired nurse and a widow. With no patients and no husband to care for in her retirement this woman may possibly have found in assisting Ms Addison, largely with feminine activities, a means to continue to express her caring feminine identity and thereby preserve her sense of worth. Fourth, the contribution that gender and culture made to the acceptability of assistance should not be underestimated. Mrs Addison had very definite ideas about what constituted the roles of men and women. Domestic servicing and caring were in her opinion and experience unquestionably 'women's work'. Accordingly, her friend's assistance, especially with domestic and feminine activities like baking, fitted her views on gender. Consequently, Mrs Addison may have found it easier to accept help from her friend than from her husband with such tasks. Also, accepting this assistance enabled her to fulfil some of her spousal responsibilities and to express her feminine and caring identity in familiar ways. In particular, it helped her to care for her husband and his dietary preference for homemade cakes. Nonetheless, the provision and receipt of this level of instrumental help found in Mrs Addison's friendship really was exceptional in this study. Typically, the spouses accepted only limited assistance from their friends although, as revealed in the previous chapter, they provided significant social and emotional support.

FAMILY

Over half of the couples enjoyed or had enjoyed supportive contact with their siblings and several highlighted ways in which their grandchildren, nieces and nephews assisted or had assisted them. Whilst the couples valued and appreciated this support, the following focuses on the spouses' adult children and their input since this is who the spouses usually meant when

they referred to their families with regard to the provision of care. One couple had no adult children.

Finch and Mason (1993) concluded from their research into family responsibilities that there is no consensus in Britain about providing help to kin but there are certain circumstances in which it is widely accepted that the family will help. One such set of circumstances is that parents and adult children should help one another but then again only up to a certain limit. In their studies of care in later life, Qureshi and Walker (1989), Aronson (1990), Minichiello et. al (2000), McEwen (1992), Phillips, et al. (2000) and Twigg and Atkin (1995) found that older people value and try hard to maintain their independence. They do not want to depend on their children for care and so become a burden and beholden to them. Furthermore, Taylor (1999: 77) found that some older people even 'protected their adult children' from the knowledge about the pressures that caring put them under. Outside of their marriages their adult children were the spouses' most common and versatile source of informal care and support. In spite of this, the majority were proud of how little assistance they actually accepted from them and some were even concerned about how little they were able to do to help their children meet their responsibilities and commitments. The level of importance that the couples typically attached to not becoming a burden or beholden to their children, is illustrated in Mr and Mrs May's and Mrs Hay's reflections on their family's help:

Mrs May: She (*the daughter*) is much too busy (*to provide regular care*). Her husband is a businessman in (*names city*) and she has a large number of acres and very valuable horses. She works terrible hard. And we don't want to be a burden to anyone. She will help out occasionally if necessary.

Mr May: One thing we did insist when we were discussing coming was that we were to be independent of each other (*we = daughter and parents*). We did not want help from them and we weren't in any fit state to give them any.

Mrs Hay: We don't want anything that would prevent them (*their adult children*) from carrying on their own lives.I want them to do as little as possible (*for us*). I want to interfere with their lives as little as possible.

Moreover, this attitude towards familial assistance was independent of network type.

Although the couples did not want to burden their children with meeting their basic practical care needs, they expected them to care. They sought and valued what has become known as 'intimacy at a distance' (Rosenmayr and Kockeis 1963). Colwell and Culkin (1995), in their survey of older people's usage of and attitudes towards services, found that many of their respondents felt lonely and resentful that their families visited them infrequently and mainly out of a sense of duty. In contrast, most of the couples in this study felt that their children cared about them and were willing to assist them. Only a small minority believed that their child or children provided them with less support than justified by circumstances. In these cases, this

resulted in distress, strained relationships and derision of the child or children for their transgression of social, or at least their own family, filial caring norms.

Whilst a lack of care was the exception, the types and degree of care that couples received from their adult children differed considerably between and within families. Many different social, material, moral and emotional factors and principles have been successively identified to explain why certain family members become more actively involved than others in caring (Dalley 1988, Finch and Mason 1990, 1993) Graham, 1983a, Mason 2000a,b, Nolan, et al.1996, Qureshi and Walker 1989, Ungerson 1983a). To explain why women rather than men tend to care Rimmer (1983) and Walker (1983) draw attention to the interplay of the labour market and gender whilst Dalley (1988) Graham (1983a) and Ungerson (1983a) highlight the strong ideological and emotional influences on women to care. In their study of family caring relationships, Qureshi and Walker (1989) claim that who becomes a carer within a family tends to conform to a hierarchy of normative preferences, including closeness of the kinship relationship, unless the expected or potentially preferred carer has a legitimate reason or reasons not to care. Such reasons include poor health or conflicting commitments. Many couples highlighted social and practical reasons, in particular health, distance and their work and family commitments to explain and present as inevitable the differences between the levels and kinds of care that their individual children provided. Whether the couples' children shared these views is unknown, but it seems likely on the basis of Finch and Mason's (1993) findings that suggest caring responsibilities tend to represent the outcomes of negotiations. Finch and Mason (1993) recognise within family care two kinds of negotiations: explicit ones involving open discussions aimed at solution of specific problems and implicit ones. The adult children of at least six but possibly up to eight couples had been directly involved either by invitation or otherwise, in their parents' major decisions about care. For example, Mr May and Mr Geddes revealed the involvement of their families in their decisions to move to accommodation more suited to their care needs:

Mr May: I was in hospital for six months with that (*a problem with his leg*) and I came out and (*names wife*) promptly went sick so the first Christmas after that we were both ill couldn't do anything. ... We have got three children. The eldest boy was in (*names place*). The youngest was commuting between -shire and (*names a European country*) and the girl was married and living in (*names place*).

A: So there was none of them on hand at all?

Mr May: ... They had a family conference and they just told us that there was no point in us going on living in (*names place*) because it was a long weekend otherwise they can't see us. There was no popping round to see us. ... Anyway she (*their daughter*) had this cottage which was semi-derelict and she said that she wasn't going to repair it this year but if you like we will get it repaired and you can come up there.

Mr Geddes: Well actually we both decided you know. And family decided. And there were rumours afoot that no more sheltered housing

was going to be built and we thought well... and when we saw this we liked what we saw and we just agreed to take it.

The balance of power between the couples and their children in these kinds of decision-making processes was difficult to assess because of the spouses' need to present themselves in a positive light as autonomous and competent adults and because of the type of decision being taken.

Home-owners are often reluctant to move from their long-term homes but the use of services, facilities and other forms of provision including sheltered accommodation, serves to minimise older people's reliance on their families for care (Askham et. al 1999). Moreover, such services tend to be accessed through gate-keeping service providers such as care managers, who should be committed to listening to and promoting the views of older people. An HCO in this study pointed out:

Sometimes we do nothing more than the protection of the system. In so much as, often, occasionally we get requests from families 'my mother does not want you go in her bedroom but it is a mess and I want you go in there anyway' or 'I know Mum does not want to go into a residential home but the whole family would feel more happy if she was safe and was getting fed'. And quite likely she is not what we would deem safe but unless someone is sectioned as not capable of making that decision. We can, do, say there is nothing, we will offer all we can but that is it. So it does. I think that bit is good. It stops. Some people would end in places they do not want to go.

Hence, should the couple's opinions have differed from that of their children, their involvement with service providers should have helped protect them from family manipulation and ensured that their wishes rather than those of the latter were realised.

Irrespective of how great or small their children's influence, the couples projected their involvement in their care decisions as being their right because they were family and they cared. In contrast to explicit negotiations, which are easy to identify and describe, implicit negotiations are much more difficult to describe since there is no definite focused discussion. Implicit negotiations are about the different ways that people have:

of communicating with each other about what kinds of responsibilities they regard as reasonable for themselves and for other people. Such communication is likely to take place over a period of time so that sets of commitments develop gradually.As a consequence when a specific need arises it seems obvious who will help (Finch and Mason 1993: 61).

Thus, such negotiations can be very powerful in the development of commitments. There were strong indications that the majority of couples engaged in implicit negotiations with their children. For example, in accounting for why they met particular care needs in this or that way they frequently made references to things that their children had previously said, knew about or had done. Mrs Ferguson explained that her son had drawn up plans for them to make their home more suited to their needs because, on account of his work, he had the necessary knowledge. In respect of their decision to move Mrs Beattie referred to a conversation she had with her daughter about her husband's employment.

Mrs Beattie: My daughter is married to a minister and my husband is a retired minister. (*names daughter*) was married to a minister.

She said 'Mum we will be likely to be like you and move around places and if we move away from (*names city*) and there is a chance that we will be moving this year'. They were just seconded to a church, doing the work there. She said 'Once we move you will be left in (*names city*) yourselves'. Well we have relatives somewhere near but it wouldn't be same as family. So it would be a good idea (*to move*). So we went ahead as we thought that (*the daughter moving away*) would happen.

Regardless of its development, type and degree, the couples constructed and valued the care that their children provided in terms of being part of a family. It was what being or belonging to a family was about. It was the right and proper thing to do. Yet, what types of care fell in within this definition or understanding varied between couples but, with few exceptions, they felt that to depend on adult children for care to meet ongoing basic personal and domestic care needs transcended their understanding of what family is about. Hence they were not prepared to ask for or accept such assistance from their children except in short term emergency situations. The possible impact of the recruitment method and material, in particularly the wording in respect of intergenerational carers, on the generation of these findings about as to family and practical care cannot be ignored. Nevertheless, the main reason that the couples were reluctant to turn to their families for care, namely they were concerned about becoming a burden and beholden to them - is not unique to the participants of this study.

Regular Hands-on Care

Mr and Mrs Reid and Mr and Mrs Inch regularly accepted everyday hands-on assistance from one of their adult children. Mr Reid immediately identified his daughter as a carer whilst Mrs Inch gradually revealed their son's involvement in caring for her husband during the course of their interview. Initially, Mrs Inch made a passing reference to their son assisting her with her husband's bedtime routine when he was there. Later she commented on him helping her lift her husband when he fell and how he arranged the payment of household bills. Towards the end of the interview it became apparent that their son lived with them and could only be described as extensively involved in caring. Qureshi and Walker (1989: 126) suggest that living in the same household as, or in close proximity to, an older relative in need of care increases a person's likelihood of becoming a carer. Mr and Mrs Inch had four adult children; one lived with them, two lived nearby and the fourth, the couple claimed, lived "'awa'" out in the country'. Only their co-resident son provided hands on care on a regular basis. Similarly, Mr and Mrs Reid had a son as well as a daughter but only the latter regularly provided care. Mr and Mrs Reid's son lived more than two hours drive away but their daughter lived close by and it was to be near her that Mr and Mrs Reid had moved to the area.

Mr Reid: My daughter is local and that is why we are here. We would have never have come to (*names town*) because we are west coast and would have preferred to (*have*) retired to the west. Our family (*their daughter and her husband and children*)

moved up here and when the children were young my daughter began teaching and she required help looking after the children so we moved up to help out.We came to nurse them. Now they are helping us.

A: Have you had to do any other caring in addition to your grandchildren?

Mr Reid: I cared for my mother-in-law. She stayed with us until she was taken into hospital. We looked after her, my wife and I. That was the fashion way back in the old days before they had carers. It was the family did the caring but now, it is changed and the families are all working. So you need to have professional carers.

A: How do you feel about that sort of change?

Mr Reid: I think it is a bad thing. I think it is bad thing that there are too many wives out working.

Thus, proximity along with Mr Reid's traditional beliefs about caring, gender and family were clearly important factors in explaining this couple's acceptance of their daughter's and grandchildren's assistance.

Periodic Assistance in Emergency and Everyday Situations

Help to lift a partner after a fall was the type of emergency help that the couples most frequently needed. Whilst local adult children were key sources of such help, the nearness of others, in particular neighbours, meant that they sometimes called on them first. Mrs Hendry explained why her daughter, although living locally, was not first on the list of contacts for their emergency alarm call:

She (*their daughter*) works full time so she comes number three. The people who will get keys have got to be neighbours who are nearby if we are in trouble. So it goes to friends round the door and then she comes third on the list.

In other kinds of emergency their adult children were the couples' preferred carers. They did their parents' laundry after their washing machines broke down, took them to appointments and assumed the responsibilities of caring spouses when they were ill, hospitalised or recuperating.

Mr May: Well, I went and stopped next door (*with daughter when his wife was in hospital*).

Mrs May: That was best. We closed the house down and he stayed there.

Mr May: I could have managed but the place may have been untidy.

Mrs Ellis: I got my bypass and... He (*her husband*) wasnae as bad as he is now. He was able to do a hell of a lot more for his self. He was able to do the dishes and help me. And my daughter came in and helped both of us you know what I mean.

Such care was confidentially expected because helping and caring for each other in times of difficulty was what the couples believed being part of a family was all about but they still appreciated it. Furthermore, they were keen to reassert their independence. Mrs Ferguson described her stance when her husband was admitted to hospital:

I mean fair enough my son is there if I need him cause when (*names husband*) took his heart attack I went on the phone to tell him and he wanted to be just right in his car and away. I said no because that was nine o'clock at night when I came back

from the hospital. And I said no way because I knew he would be upset and I said 'you are no going to drive'. Nothing he could do anyway – better get a nights sleep. But he takes turns of this ME ... so he has to watch for stress and that.... (*names son*) came down on the Friday and he stayed till Saturday. ...Him and (*names grandson*) went home on Saturday night. I said 'you are better going home now (*names son*) because Dad seems to be on the mend'. Once you got the tubes out. On the Saturday afternoon he took me to the shops and I got microwave meals and I cooked like that or boiled an egg and had cereal and coped like that.

The couples also accepted practical assistance from their adult children in less critical times, usually with large or more physically challenging domestic tasks, such as changing curtains, putting up shelves, repairing fences and moving house but also with small and fiddly ones such as wiring or installing of new electrical items. The couples tended to need help with such tasks either as a one-off or infrequently. Usually there was no immediacy about these tasks so children who lived some distance away as well as ones who lived nearby, were able to be involved in the provision of such assistance. Mrs Beattie described how following their house move their daughter travelled over 100 miles on her days off to help them unpack. She also revealed how one of their sons who lived several hundreds of miles away seized incidental opportunities to help them with a range of practical tasks during his occasional visits. Whether he visited with the intention to carry out such tasks or whether they arose incidentally is unknown.

Many periodic tasks can be, at least temporarily, left undone without serious consequence, and so assistance to complete them made only a small and strictly speaking non-essential contribution to meeting the couples' care needs. In spite of this, the couples drew particular attention to their children's help with such tasks. As discussed in chapter three, the lack of alternative sources of help with certain activities such as small DIY tasks may have led the couples to emphasise their children's involvement in such provision but this is unlikely to be the full explanation.

Siddell (1995: 63) asserts that the discrediting and discounting of chronically ill individuals and their views pose a bigger threat to their sense of self, well-being, self-confidence and self-esteem than physical restrictions on their activities. In her study of older people's attitudes, McEwen (1992) suggests that social policy and care services lack an historical perspective on older people's attitudes and hence they do not take account of how these shape their needs. For example, cut backs in the domestic aspects of home care fails to recognise that older people 'do mind' that they cannot care for and clean their homes. Clark et. al (1998: 3), in their arguments for local authority home care provision to help older people with their housework, pointed out that their interviewees felt that the presentation of their homes – the cleanliness, tidiness and orderliness - reflected to the outside world their personal values and their competence as adults and householders.

Seeing dust pile up or no longer being able to reach the top shelf was a constant reminder of what they (their interviewees) could no longer do. This could have a negative impact on both mental health and motivation to managing. Many older

women were concerned and often distressed about the appearance of their net curtains and the difficulties they experienced in changing them. Having clean 'nets' was an outward sign of respectability, having 'mucky nets' was evidence of not having 'troubled to wash them' (Clark et al. 1998: 3).

From this perspective 'mucky nets' signal that no one can be 'troubled to help older people to maintain their standards' or maybe even to listen to what they think is important. Conversely, the receipt of support with 'what matters' helps maintain and boost their self-esteem. When the couples' children assisted them with periodic tasks such as changing curtains, they showed that they were aware of and respected the spouses' standards and hence that they cared about them. The provision of such assistance highlights just how closely intertwined practical care can be with other forms of care. Thus, it illustrates the argument Graham (1983a) made twenty years ago, that to fragment care into practical and non-practical provides only a reified picture from which distinctive and compelling qualities are lost.

Help with periodic tasks also brought together apparently conflicting and incompatible needs; namely the couples' need to know and feel that their adult children cared with their need to avoid becoming dependent on them for care and hence beholden to them.

Periodic tasks tend to be relatively undemanding and to be carried out infrequently. They usually involve limited effort, time and unpleasantness. Their execution sometimes involves the use of skills that are pursued as hobbies, and their completion tends to result in praise. Taken together, these factors suggest that the couples could accept such help without feeling that they were burdening their children. Similarly, they suggest that their children could offer this kind of help without assuming a burdensome commitment to meeting their parents' needs.

Furthermore, as stated above, when adult children offered such assistance they revealed not only their respect for their parents' values but also that they cared. Conversely, acceptance of such assistance, on those rare occasions when it was not physically needed was the 'right' response: to refuse their assistance would be to shun their care.

Social and Emotional Support

Hobson (1995) concluded from his research into later life partnerships that family is a common theme in the lives of many couples. Family orientated people enjoy being with their relatives and derive a sense of security from these relationships. The couples valued highly their relationships with their adult children and the social and emotional support that these encompassed. In these relationships the couples found a practical safety net of care and emotional security. Their children's willingness to care, their provision of help in times of crisis and with specific periodic activities demonstratively affirmed the couples' confidence that they cared about and for them. Similarly, their families' commitment to keep in touch regardless of distance and to involve them in their lives, through 'ordinary family interactions' – family celebrations, events and casual visiting and by turning to them for emotional support assured the spouses that their families were interested in and valued them. This also helped maintain their

sense of self-worth because they were invited to attend weddings and coming of age parties, to child-mind in their capacity as grandparents and were approached for advice and support as loving and supportive parents. Mrs Beattie described how they had supported their son on one very difficult occasion:

Mrs Beattie: And they (*their son and daughter-in-law*) phoned us up, he had been given three months to live. And they phoned us up: could we go down. The children and themselves wanted us to be there to talk it over what it would maybe mean. So we went down for three months. Not for three months for a couple of days you know to talk over things.

In these ways the couples were able to help balance their relationships with their children, fulfil socially valued family roles and so preserve their self-esteem and moral identities. It was what being a family was all about.

Whether adult children provided the couples with practical assistance or social emotional support, the spouses always experienced and understood their provision as an enjoyable facet of being part of a caring hence functioning family. It was their reward for or return on their long-term and still ongoing investment in their family relationships.

SERVICES

Perceptions of Services

The couples tended to divide services into two types, namely those that reduced their dependence on their informal sources of care such as home care and those that provided specialised assistance or input – such as physiotherapy, day care, occupational therapy and care management. Since the couples tended to define care narrowly as practical assistance with domestic and personal care activities, they recognised and identified the former as providing care but not the latter. Thus, when the couples were asked about what assistance they received with caring, they tended to overlook the input of specialised services. For example, Mrs Geddes insisted that her husband and she did not receive ‘any outside help at all’ adding ‘we don’t get any home help or carers’. Yet the couple lived in a warden controlled sheltered housing scheme, and regularly used the services of a chiropodist, mobile hairdresser and shop mobility. Mrs Hendry also claimed that no-one helped her care for her husband but her coping strategies depended on regular input from their GP, OT, Care Manager, volunteer carer as well as day care, chiropody and specialist transport services. The identification of the couples’ level of service use was further complicated by their lack of clarity about the job titles and the roles of certain service providers, particularly those concerned with care management, assessment and service allocation.

Typically the couples were very positive about ‘non-care’ services. In part this was bound up with their deferential respect for these practitioners on account of their qualifications, specialised knowledge, training and experience. However, it also had to do with the fact that these services did not substitute for self-care or informal care. This meant that their use was

free from the shame, stigma and guilt that the spouses, especially the women, tended to feel about being unable to meet their own and their partners' basic domestic and personal care needs. Another very important point was that the advice, techniques, aids and adaptations that these services supplied, enhanced the spouses' independence and alleviated the impact of their limitations. Over half of the couples (had) benefited from aids and equipment provided by occupational therapists and several spouses had regained some use of their limbs through rehabilitative physiotherapy after their strokes. This association with progress, either by moving things forward or halting regression, supported the couples' strong desire for autonomy and independence. Hence, these services were arguably good for their morale. In contrast, the couples associated their use of care services such as home care with growing dependence, loss of autonomy and declining capabilities.

Gubrium and Holstein (1999: 521) describe how nursing homes are used as 'a discursive mechanism for cataloguing, elaborating and evaluating bodily characteristics' of their users both before and in the course of their use. Discursively home care served the couples in much the same kind of way in that the need for and use of this service functioned as a reference point of when they spoke about impairment, disability and dependence. Women, in particular, spoke of home care in a way that suggested they equated the use of this service with a particular degree of severity of disability or impairment and as an indicator of growing dependence:

Mrs Hendry: Well err... I'm quite good (*as in fit and able*). Well I like to do things. ... I mean you have to carry on. What can you do? I'm not at the stage that I need a home help.

Mrs McKenzie: I sit to iron. I never used to before but these last few years I sit on a stool and do my ironing. ... Eventually I might have to get someone in. Dr (*names doctor*) has spoken a lot this last few years. ... He said 'why don't you let me send in a home help?'. ... Not this year but maybe another I will. I'll get someone to come in to do heavy cleaning.

To these women to begin to use home care signalled that their impairments had become so severe or limiting that they were no longer competent, they could no longer cope as (house)wives. They were failing. Thus the use of home care services was to be avoided or delayed as long as possible and always kept to a minimum.

Baldock and Hadlow (2002) suggest that older people's reluctance and refusal to use care services, at least in part, reflects the conflict between the need to use care services and the need to preserve and sustain their self-image in later life. It was the start of a slippery slope of increasing dependency.

Agreeing to service was for most of our sample was incompatible with their personal project to fight, delay and even deny disability. ... To use a service was an admission of a weakness of spirit and resolve (Baldock and Hadlow 2002: 2-3) .

Furthermore, in her contribution to the 1999 Royal Commission on Long-Term Care, Harding (1999: 43) points out how pressures on local authorities to make public resources stretch as far as possible and to target 'those in greatest need' has resulted in provision that 'may well have

become less inclusive and more segregated (and hence more stigmatising) as the range of people who 'qualify' has narrowed'. The couples' spoke about their use of home care in ways that explained and justified their use of this service. Whilst this had to do with their personal values and social expectations relating to adulthood, femininity and marriage as discussed above, it was also bound up with concerns about their reputations and notions of fairness. Their use of services, they stressed, was necessary and measured. It was not ill founded and definitely not more than they were entitled to and needed. One participant summed this up when she said 'we've worked all our lives, you (*her husband*) from fourteen and me from fifteen so we are only getting back what we've (*put in*)'. They were only taking and using their fair share of public provision, to which they had in years past contributed through their taxes and insurances. The concordance between the political or media presentation of care services as a scarce resource that should not be squandered and the couples' views and attitudes towards the use of services supports the assumption that the former helped inform the latter and may even have influenced how the couples perceived their needs and even themselves.

Although the couples resisted and had negative feelings about using care services, paradoxically they also cherished them because they then maintain their household form without relying on and so risking becoming beholden to their informal sources of care.

Network Type and Care Service Use

Wenger (1994) explains that, due to the differences in their access to local sources of informal support, older people with certain network types tend to make heavier demands than others on domiciliary community care services. In her study older people with private restricted networks tended to make the heaviest service demands, those with the more robust network types, local family dependent and locally integrated networks, tended to make rather less demands on community care services whilst those with community focused networks and the necessary resources tended to buy in services. With regard to local self-contained network Wenger (1994) found that older people aged below 80 with this type of network tended to resist or refuse service input.

All the couples in this study were service users but their level of service use varied from relatively low to high. For example, the service use of some couples extended no further than being linked to a community alarm system or living in sheltered accommodation whilst others made regular and frequent use of day care, home care for assistance with personal and domestic assistance and respite services.

Three couples with locally integrated networks - either living in sheltered accommodation with access to a warden or being linked to a community alarm system - had quite low levels of service use and three had amongst the highest levels of service use in this study. As well as being linked to a community alarm system or living in sheltered accommodation, each of these couples used home care for personal care - one couple receiving this service twice daily, one

also used this service for domestic assistance, two used day care services and supported transport, two used residential respite care and one used a sitting service. Two couples with local family dependent networks also had very high levels of service use accessing assistance from home care with personal care at least daily, domestic support as well as being linked to a community alarm system or a warden within a sheltered accommodation scheme. One of these couples also made periodic use of a local residential respite facility. The third couple with this network type only received a limited amount of daily home care input.

The two couples with private restricted networks, Mr and Mrs Fyfe and Mr and Mrs Taylor, had quite low levels of service use - both couples were linked to a community alarm system and Mrs Taylor also received thirty minutes of personal care from home care support daily. Mrs Fyfe had also twice received personal care from home care on a short-term basis after she had been discharged from hospital following treatment. Whilst the service use of these couples was low, if their circumstances were to change, in particular if either Mr Fyfe or Mr Taylor could no longer provide care, their need for services would rise significantly.

The couple with the wider community focused network was linked to a community alarm system and was in receipt of one and a half days of day care and a few hours assistance with shopping. The four couples with local self-contained networks had a low level of service use. All had access to a community alarm system and one additionally received two hours of domestic assistance a week. Four of the couples whose network type was ambiguous or in flux had a low level of service use. In contrast, the fifth couple lived in sheltered housing with round the clock access to a warden and received personal care support from home care from Monday through to Friday as well as domestic assistance.

The foregoing findings about the couples' service-use show some similarities with Wenger's findings (1994) but also some marked differences. The significance of these differences must be considered as questionable. This is not only because of the limited numbers involved in this study but also because of the bias created by the recruitment methods and materials used. Moreover, these factors are also likely to account for why the spouses' network types did not appear to strongly influence the couples' experiences or attitudes towards services and their use.

Accessing and Using Services⁶

In their study of service user choice and participation, Allen et. al (1992) found that only 10 per cent of their participants had personally asked for home help initially and around 10 per cent did not know or could not remember who had requested it for them. The majority of this 10 per cent believed that their family, medical or social service providers had requested it. Myers and MacDonald (1996) similarly reported that although their participants knew that they had come in contact with social care services because of a negative change in their circumstances such as

⁶ This section focuses on accessing and using public sector services. Finding out about the availability of private sector domestic care services was considered in the chapter three.

a fall, almost half of them were unsure about who originally had referred them to these services. Moreover, they felt that the decisions about their use of services had been taken by professionals, sometimes in conjunction with their informal carers but without any or with very little input from them.

A small minority of the spouses had actively sought information about or referral to care services but most had not. Furthermore, their commitment to trying to manage meant that many, regardless of network type, had initially only come to the attention of service providers on the heels of a major health or care crisis, and even then, not always.

Mrs Ferguson: Years we coped with different things not knowing what help was available. They are giving you more help now. When I was first in hospital that four or five months I never got offered anything but I have since. ... When I was in the hospital (*subsequently*) they took me to occupational therapy to see what I needed. ... There was one girl in (*hospital*) with me and she had been diagnosed three month before ... and I've never seen so much. They changed the handles on the doors, they gave her a stair thing; they gave her one of these bath ability things. Well I never had one at that time. She went home with practically a shop. So I said to myself wait a minute what have I been doing for twenty years trying to cope and no one even saying 'what have you got'?

Mrs Beattie: Having the polio and taking the steroids I was taking this and the next thing (*illnesses*) and I had various X rays to find out what was wrong. And none of these X-rays showed this (*fractured hip*) up but they weren't looking for that at the time. ... Nevertheless, you would have thought it would have shown up something. ... It was over four months later I was due to go to the clinic at (*names hospital*). They deal with the orthopaedics there. (*names consultant*) went though the thing with me and wanted to do an X ray. ... So he took one as well and discovered it. And he said, 'How have you managed?' I said 'I've crawled around in terrible pain but I managed one way or another with it'. ... That was the next thing, the hip operation. I had the hip operation and there you know they give you advice and I had physiotherapy and in the hospital there was a lady came round and she said you could have Home Care. I was told it would be a good help for me. I refused it at first.

A: So what made you feel think that you should refuse it?
Mrs Beattie: First of all the very reason that quite a lot of us older people feel and not only old but people. Well, in the days when they were called home helps. People would say would you not like a home help to help you with some of the heavy work in the manse? 'I manage and anyway I would be up I would have to see that everything was in order. I can't have someone coming in to do my work'. So I was just as well carrying on myself. So when I got to this stage I knew that I was not managing. It wasn't really fair for me to keep holding out when I could have someone in.

Although most of the couples were aware of who had referred them to home care and other services and why, their own active involvement in the process was quite limited and passive.

Mr Green described how his wife and he became service users:

Mr Green: Well, they laid them (*home care services*) on I think from the hospital, the original help I had when I was in (*names place were they used to live*). I think they must have done because the wife was in the (*names hospital*) and she was there for some weeks before she could come out. So when she came home err. I don't know who made arrangements but somebody. The GP may have put something in. I think probably he did but I never knew for certain.

Other participants appeared to have been slightly more involved in the assessment or procedures – they engaged, in a sort of Hobson's choice manner, in the process. They were offered services that they either accepted or rejected. Only when the spouses had no alternative, such as when essential services did not materialise, did the couples tend to become (re)actively involved in accessing services. In such circumstances the spouses tended to feel unsupported and uncared for rather than empowered and concerned about what saw as practitioner incompetence.

Mr McAllister: I tried to get something for to get mysel' into the bath and lift mysel' out but never nobody came back and that is about, I would say, three or four year ago. Never seen the social worker since. ... The last thing I got somebody. She was in enquiring about the bath. She came from (*names small town about 12 miles away*). And she said she would come back again but she could be dead she could be by the time she come back.

A: How do you feel about that?

Mr McAllister: Well I just think that they are not. (*Pause*)

Mrs McAllister: Kind of neglected

The value and commitment that the couples displayed towards their independence and autonomy, presupposes that outrage, anger or, at the very least, annoyance would characterise their responses or reactions to way that services were more or less imposed on or prescribed for them. Their response, on the contrary, was to commend the service providers as efficient and caring. This was because the spouses perceived assessment, allocation and securing of services as belonging to the role and responsibilities of service providers who they trusted and expected to employ their professional knowledge and skills to arrange adequate and appropriate services for them; in other words to care for them. Indeed, the majority of those who were not regular service users assumed, even expected, that if necessary they would be allocated services without actively drawing attention to their needs. In spite of initiatives such as check-ups for people aged over seventy-five, the couples' experiences seldom supported their assumption.

The spouses' 'unexpected' response to service providers' exercise of power also mirrored their contradictory and complex perceptions of welfare provision. They viewed access to services on the one hand as a right, anchored in governmental community care policy, but on the other hand as a privilege. They considered the receipt of satisfactory or good services to be a matter of good luck or fortune, but then attributed poor standards of services to faults or glitches in the

'system'. They believed that there should be enough good quality services and facilities for disabled (and) older people but refused to take them for granted. In attempting to understand the couples' contradictory perceptions of services their experiences of pre- as well as post-welfare provision, attitudes and ideologies have to be acknowledged and, alongside these, the rights / privilege paradoxes that characterise present day welfare policies, procedures and services. Twigg (1993: 160) states:

Rights within social policy has (sic) tended to be confined to areas like social security where allocation is made on a quasi-legal basis according to principles of entitlement. Services, by contrast, have traditionally been allocated on a different basis, one of discretion exercised in relation to individual cases by professionals.

Finally, health and care crises tend to create feelings of vulnerability, even a desire to be looked after. Siddell (1992:190) draws attention to the influence of circumstance on behaviour, perception and feelings:

We might feel strongly about the patronising nature of the patient-doctor relationship when we are well but when we are sick we might prefer the doctor to be omnipotent and to take over.

Likewise, Twigg (1993), in her critique of the consumerist model of social care, highlights how personal frailty and vulnerability, together with the complications arising from the complexities of caring relationships, can impair confidence, knowledge and clarity of judgement. This implies that professional support and guidance can have an important part to play in helping people to make informed decisions about care. Robertson (1995: 16) reports that consultation with older people shows that they actually want care managers to be powerful as well as caring so as to 'compensate for their own powerlessness' and to ensure prompt and effective service delivery. Myers and MacDonald (1996: 109) go further, suggesting that 'the ceding of power to a professional may itself be a positive choice' rather like engaging a powerful advocate in the time of crisis.

'Such a shock', 'traumatic' 'the biggest wallop' were just some of ways that the couples described the onset or unexpected sudden worsening of their disabling conditions. They felt that their lives were turned upside down, and they were unsure of how to approach the future. One spouse claimed that she had dreaded her husband's discharge from hospital because she did not know how she would cope with everything. She felt that it was all so daunting. In these kinds of situation to hand over decisions and receive sensitive yet knowledgeable input from social and medical practitioners brought the spouses relief and reassurance that things would be properly taken care of:

Mrs Lawrence: It just seemed to fit in because we had the district nurse, and (*names member of hospital team*) and then we had the lady from the social and they just all seem to tell you. They knew the things that there was, what you could do and what you could get and what you could ask for (*my emphasis*). And then when I was in (*names hospital*) and there was little meetings here and there and you could go and listen and see what is going on. And I did.

Mrs Patterson: I mean the girls came in the first night.
 A: How did you learn of them?
 Mrs Patterson: Well (*names hospital*) got in touch with the supervisor here.
 A: Did you have to request that or?
 Mrs Patterson: They requested it. They had asked me whether I would be wanting that sort of thing. And I said, well, yes I would. So they got in touch with the supervisor but she got in touch with the people here. And the supervisor for here came to see me to see what sort of hours I wanted them so that was all set. That was alright.

An exception to their otherwise minimal involvement in assessment and pre-allocation procedures was the couples' active participation and expression of choice in occupational therapy assessments. Occupational therapy assessments tend to be more 'active' than other care service assessments, as they usually involve seeing and trying out pieces of equipment, sometimes during home visits as well as discussion. Several spouses told of how, as hospital inpatients, occupational therapists had asked them what they needed help with at home and invited them to look at and try out equipment. For example, Mrs May explained:

When I was in hospital they said 'is there anything we can do to help you at home. What troubles you most?' ...I said that 'In the house the thing that is a source of great trouble is I can't bath properly anymore'. ...The occupational therapy department they came and said 'Would you like to come and see the model kitchen and model bathroom to help to see if there is anything that would interest you?'

This active element is not only likely to have given the spouses a stronger sense of being involved but also to have helped facilitate its recollection.

Although occupational therapy aims to promote independence, it did not necessarily completely erase the spouses' need for assistance. Unfortunately, the caring spouses were not always adequately involved in occupational therapy assessments. Mrs Oliver complained:

When it was the home visit I was very disappointed because the lady came in here with (*names husband*). 'Now this is just a rush visit...because there is somebody phoned in sick and I've got to cover'. Now I wasn't there. She went up the stair she came down the stair. Everything was...I was just completely ignored. And it was supposed to be at least half an hour, to see if he could make a cup of tea and... But they weren't in half an hour.

This failure to involve carers sometimes resulted in the provision of equipment that enhanced the independence of one spouse at a cost to the other. This illustrates again how the 'couple' aspect of care tends to be overlooked within care practise.

The couples' perceptions and understanding of care and the roles of service providers raise questions about the key community care policy aim and theme of user involvement, at least in times of crisis. Yet, Siddell (1992) and Stimson and Webb (1993) point out that a patient's deference in the consulting room does not always result in his/her compliance with treatment decisions once he/she is feeling physically and mentally stronger and away from the surgery. With their crises abated, a minority of men in this study became proactive in seeking additional or alternative services and assertive about how they wanted them to be delivered. The structure of reviews may have played a part in this but increased familiarity with service provision too

seemed to encourage the couples to be more proactive in drawing attention to their service needs. Nonetheless, it must be stressed that in general the majority 'managed' with the services that they were offered. They tolerated and made allowances for inadequacies in service delivery or were more often negatively rather than positively assertive; for example they gave up physiotherapy routines, cancelled services, and left pieces of equipment languishing.

Using and Receiving Services

Twigg (1989) put forward a three-part model as to how care agencies conceptualise their relationship with carers that suggests these agencies see their clients either as resources, co-workers or co-clients. In respect of spousal carers, she also claims that possibly due to their age and in some cases disability, older spouses tend to be defined as a form of co-client whilst their younger, fitter counterparts tend to be perceived as resources or 'co-workers' (Twigg 1989: 60). Later, Twigg and Akin (1994) added the concept of superseded carers to the model. The difference between co-clients and superseded carers lies in the objectives that services seek to meet. The aim of services provided to co-clients is to relieve the strain on these carers so that they can go on caring whilst services provided to superseded carers seek to supersede them. The couples' views on their relationships with services, and how they fit into their care experiences should reveal how they conceptualised their relationships to service providers: the other side of coin. There was considerable fit between the couples' perceptions and Twigg's model. Mrs Kerr and Mr Taylor felt that they were treated as resources. Mr and Mrs Nichol spoke of their home carer and Mr Reid implied that he felt that he was part of a caring team but also partially superseded.

Mrs Taylor: Well, let's put it this way if he (*her husband*) was not willing (*to care*) I would be in a home.

Mrs Kerr: (*I have*) saved the health board thousands and thousands and thousands over the years.

Mr Reid: I found it pretty heavy work doing twenty four hours nursing and we decided to bring in the carers on the mornings, five mornings a week, to dress her (*Mrs Reid*). They come in at eleven o'clock and they dress her. During the week one gives her a shower.The situation is we still have the carers coming in five days a week – five mornings a week – and one of these, Wednesday, she gets a shower on that day. She gets another shower at weekends with my daughter. And that is the situation. In the meantime I am doing the cooking, the shopping, looking after her all the time apart from the carers in the morning, who dress her. That is the situation.

Mr Nichol: We have a Home Help that comes in twice a week. That helps you see.

There were, however, significant differences between how the couples and the agencies constructed and understood the notion of co-client. Twigg and Atkin's (1994) co-client model

sees the co-clients as separate individuals with exclusive and possibly conflicting interests. This overlooks or at least glosses over the fact that spousal co-clients (and possibly other co-clients) often have shared or conjoined needs and interests. In contrast to this individualist co-client model, the spouses constructed themselves as co-clients because their service use helped them meet their needs as couples. For example, Mr and Mrs May used a community transport service to meet some of their travel / transport needs and, as discussed in chapter four, the use of an electric wheelchair enabled Mr and Mrs Lawrence to go out together.

The spouses also had needs that emanated from their caring relationships but which often appeared like individual needs. When couples used services to meet these kinds of needs the service usually, but not always, helped the individual spouses in different ways, often with one spouse emerging as the primary or direct service recipient. For example, Mr and Mrs Green saw themselves as using a day care service. Mrs Green went to the day care centre, took part in the activities, interacted with other users and providers and enjoyed the change of scene. Mr Green did not go to the centre but the same service gave him respite from his caring responsibilities.

Similarly Mr and Mrs Ellis used a bathing service. The service provided Mr Ellis with assistance to bath and his wife help to fulfil her role as a spousal carer:

Mrs Ellis: The last time he was really ill he couldnae move. I couldnae cope with him because as I say I have had a heart bypass. I could not lift him. All I could do was get him to the side of the bed and give him a sponge but he likes to be clean. So I thought I canna carry on like this I will have to have help. So now he gets a girl in twice a week who showers him for me.

Identification with the tradition role of housewife led some care-recipient wives to perceive and speak of domestic care services as helping them to fulfil their domestic responsibilities rather than or at least as much as helping their partners to fulfil their caring roles. In this way domestic care services helped the couples maintain their spousal identities and their traditional domestic arrangements which as chapter three highlights they valued greatly. With this (partial) exception, the couples used services as couples. They were service-using couples: a perspective that challenges the dichotomy of separate and individual carer/care recipient needs and interests.

CONCLUSIONS

This chapter attempted to identify the couples' support network types before it moved on to examine how the spouses experienced and understood support that they received from their friends, neighbours, family members and service providers. It found that whilst the amounts and types of support that the spouses accessed from within their informal relationships varied, they consistently viewed its provision in relational terms. It was either about being a good neighbour, friend or part of a family, hence its acceptance was underpinned by principles of reciprocity and fairness. However, although the couples' kith and kin served as an important source of social and emotional support, they were rarely involved in or recognised as their

preferred source of basic care. Where the spouses were unable to fulfil these care needs from within their spousal relationships they turned to services for help. This may, at least in part, reflect the role that services played within the recruitment of spouses in this study. Nonetheless, these findings are consistent with and appear to support the claims made by Finch and Mason (1993:178-179) that social policy and, by implication, service provision is out of step with the realities of how family responsibilities are practised and understood:

Social policies in Britain have long operated with a view of responsibilities, which sees them as a 'natural' property of relationships between spouses, between parents and children, and possibly beyond that...(but) responsibilities between kin grow out of, and are dependent upon, the history of particular relationships. It makes little sense therefore to build public policies, which assume that certain assistance will be given more or less automatically. Support may well be offered – but its availability will vary from one family to another and from one individual to another. ...Another strong message from our data: people do not want to have to rely on their relatives for extensive help. We have found evidence of active avoidance of, sometimes resistance to, accepting help from a relative. ... Policies, which are designed to make people more dependent on their relatives, breach a principle which many people hold dear.

Having examined how the couples understood their use of services, the next chapter considers how home care service providers perceived and experienced home care service to older couples.

CHAPTER 6: HOME CARE PROVISION

INTRODUCTION

Local authority home care played a significant part in how the couples in this study experienced and understood care and care services. It was their main formal source of assistance with domestic and personal care and its use served as a discursive reference point. It represented, on the one hand, the end of the spouses' autonomous coping but, on the other hand, a means of sustaining their independence from their families. In contrast to previous chapters, this chapter examines care in later life marriages from an external perspective, namely that of home care service providers and in particular home carers. It begins by looking at how the composition of the home care service user population impacted on the generation of data. It then moves on to its main objective, to analyse how the service providers' perceptions of home care and its use informed and structured their approach to practise and their relationships with service users.

It identifies the range of care activities that the home carers undertook and how these were not equally available to all service users. In particular, it highlights how couples and men were at a disadvantage in respect of accessing sensitive caring and 'added extras'. Finally, the chapter considers the service providers' responses to older spouses in terms of Twigg's four-part model of idealised service responses to carers (Twigg 1989, Twigg and Atkin 1994) and the challenges that these service users presented to the home care service.

THE SERVICE USER POPULATION

The Scottish Executive (2002a) estimated that in 2001 approximately three quarters of the home care service user population in Scotland lived alone. Correspondingly, the service providers in this study overwhelmingly assisted service users who lived alone. Neither the precise number of older couples using home care nor the percentage of the service population that they represented was readily accessible because the computerised recording system used in LAs recognised individuals rather than couples. Hence, such data could only be accessed manually by sifting through electronic or paper files searching for such service users. The HCOs and HCAs in LA2 stated unanimously that couples made up only a minority of service users in that area and offered various estimates as to what proportion of users were partnered or married. One HCO estimated that a third of the service users were couples but her colleagues strongly decried this as a significant overestimate. The care manager further highlighted that older couples who were not dealing with dementia or other forms of cognitive impairment represented a minority within this minority. Consequently, all the home carers had only very limited experience of assisting older couples, usually just one or two

older couples or partners on a regular basis and possibly a few others through their weekend or relief duties.

The service providers' limited experience of supporting older couples had a significant impact on their responses. Firstly, it meant that they had very little experiential information to share during their interviews. Secondly, it appeared to foster anxiety about the risk to client confidentiality. The home carers seemed to assume that because couples were so few giving details about individuals would endanger their anonymity. Thirdly, the home carers claimed that the marital status of service users was irrelevant to how they interacted and related to them. Hence, they did not always clearly distinguish between couples and service users who lived alone. Attempts were made to focus the service providers on their work with older couples but these were largely unsuccessful. The service providers in this study were able to provide only limited information about couples because they had limited experience of supporting such services users. However, their difficulties in focusing on spousal service users and their assumptions about the applicability of a uniform approach to all service users strongly suggested that within this service couples and their needs are nearly invisible. Hence this service is more likely to provide older couples than individuals with inadequate or inappropriate support.

Until the question was posed during their interviews most of the service providers had never questioned why relatively few older couples use home care. Their explanations centred on the demography of the older population and the assumption of a link between coping and marital status. Living alone, especially after the death of a partner, was associated with vulnerability and helplessness, whilst living with a spouse was presumed to confer both ability to manage and resistance to outside help. In particular, they envisaged that, in honour of their marital vows, older spouses pooled their resources to (to try manage to) care for one another. The high value that the couples in this study placed on their independence and autonomy and their approaches to managing their care needs provide some support for these assumptions. However, many of the spouses had care needs that outstripped their resources as couples and, whilst these were now typically met, some couples had struggled on for quite some time before accessing and accepting home care. Furthermore, many were ill-informed and misinformed about home care and in some cases this had contributed in part to their delay in seeking services. The service providers revealed that they too found some new service users to be confused and misinformed about the service, especially the domestic aspects of it. They pointed out that many such users believed that they were not prepared or not allowed to do a wide range of domestic activities that in fact they actually do.¹

¹ This study did not ascertain which domestic tasks home carers were forbidden to carry out. Policy and procedure material was not accessed and the information that service providers provided was highly inconsistent in respect of this matter.

The supervising and managerial service providers were aware of leaflets that described the service but they were doubtful not only as to their current availability but also their usefulness. In spite of this lack of accurate and up-to-date information, ignorance and misconceptions were not mentioned as possible factors deterring older couples from approaching and using the service.

THE INFLUENCE OF THE MODEL OF FAMILY CARE

Being Caring as a Person Specification

Warren (1990) found that an individual's suitability and ability to work as a home help was considered to reside in her character, personality and experience of providing domestic support and care rather than training and formal qualifications. Three themes, everyday life, domesticity, and caring, particularly within the context of the family, emerged within this study not only as the qualifying criteria to work within home care but as the key principles in how the participants understood and practised home care. The managerial and supervising participants pointed out that, because of the diversity of the service, a wide range of personalities and skills are required within home care but all those involved in the service must care.

- M: Horses for courses. You need the big tough ones (*home carers*) who are able to go out and clean a gent's house who only wants a certain amount of cleaning done and no more.
- HCO: And you need people that are couthie (*local word for sociable or affable usually applied to women*)
- M: Yes people that are couthie and homely and are prepared to and people that are prepared to take it when they treated as a servant. It is really hard to say.
- HCO: People with strong stomachs
- M: We had one who used to cope with the swearers because she swore back.
- HCO: Unless we had somebody who did not care half of the time I think most things. Of course there are rules and statutory regulations but I think that outside that the only time would be if someone didn't care (*would they be unsuitable*).

The home carers agreed with their supervisors that their job was varied and challenging and, to able to do it, it was essential to have a caring nature. They pointed out that home carers required patience, compassion, understanding, trustworthiness, friendliness, kindness, a liking of older people and an ability to get on with them. They also pointed out that, practically, home carers needed to have good domestic and care skills, which they believed most women had on account of their experiences of running their own homes, of being wives and mothers and in some cases of working in caring or domestic jobs. The service providers revealed that these kinds of care and domestic experiences underpinned their 'working relationships' with service users as well as their care practise.

HCO: If you care about providing the service. The admin is one thing but...I actually think of home helps as an extension, I know it sounds corny but if you care about the people you care for you obviously you care for the carers who care for them. They become like an extended family, that's how I look at it. That is how I see it. Obviously you want the best for your family; you want your workers to have the same respect and care. I want them to feel compassionate as I do about the work.

H/C: It (*the home carer-user relationship*) is just like being friends.

H/C: Tender loving care I think, you know. It is just how you would treat your own grandparents you know.

Walmsley (1993), in her research into caring roles and relationships, draws attention to how the domestic environment and the overlap between care tasks performed by informal and formal carers encourage the adoption of models of family care in domiciliary care services.

Warren (1990: 78) found that the home helps 'constructed models and rationales of their caring relationships based on the ideology of good housewife and caring relative'. Sinclair et al. (2000) also found that service providers drew on such models. Nonetheless, the service provider-user relationship is a working relationship but the home carers in this study sought to build a 'working relationship' with service users only as a last resort when they were unable to develop a more informal one. Thus, their 'working relationships' tended to be restricted to service users whom they found difficult to interact with and support.

Levin, et al. (1985) recorded older people as describing home carers as friends or female relatives, most commonly as daughters. More recently, Sinclair et al. (2000) found that the significance of the home carer-client relationship to individual clients varied considerably. Some clients were very attached to particular workers whilst others appreciated them as service providers. The older couples in this study did not liken their relationships with their home carers to kith or kin relationships instead they described and made sense of them in terms of purposeful yet pleasant relationships focused on helping. As discussed in previous chapters, the couples did not want their kith and kin to provide them with basic hands-on care on a regular basis and made strenuous efforts to avoid this happening. Therefore, to understand and describe their relationships with home in these terms would have been surprising and contradictory.

The discrepancy in how the couples and the home carers described and understood the provider-user relationship must also be attributed, at least partially, to the home carers' tendency to speak about service users generally rather than specifically about couples. The home carers did not suggest that their relationships with service users differed according to their marital status. However, three-person relationships tend to be less intimate than two

person relationships. Therefore, it might be expected that home carers would develop less close and less intimate relationships with couples than with single service users, especially women.

Nolan et. al (2002 and 2004), in their research into the educational preparation of nurses to work with older people, emphasise the importance of relationships to high quality care service provision. They state

there was a reciprocal relationship between the delivery of high quality care and the extent to which both professional and family carers felt valued and appreciated (Nolan et. al 2002:2).

They go on to acknowledge that their observation is consistent with what Tresolini et. al (1994) had previously identified and termed 'relationship centred care'. This is an approach to care that recognises that interactions and relationships not only between service providers and users but also between providers and users' families and providers of different care services are significant to how care is experienced and perceived. Moreover, Nolan et. al (2002) go on to claim that in positive caring relationships, all the participants - the service user, the user's family / informal carer(s) and the different service providers - felt a sense of security, belonging, continuity, achievement, purpose and significance. Whilst this study did not set out to gather data specifically about these senses, as this chapter later reveals those that emerged strongly suggest that the service providers experienced and fostered such senses within their working relationships with service users, their colleges and their supervisions.

Qualifications, Training and Blindspots

The home carers' extensive use of family care models was not unexpected, although just how heavily the HCAs and HCOs employed such models was unanticipated. Perceiving home care as a matter of everyday family life and care, a significant minority of the service providers regarded training as largely unnecessary. Life provided all the training required. Nevertheless, training in some practical and technical techniques were deemed advantageous. For instance, the HCOs, HCAs acknowledged the usefulness of training in office administration and computer literacy, and over half the home carers acknowledged the value of training in first aid, moving and handling and awareness of specific disabling conditions, such as Alzheimer's Disease.

In their study of home help, Hedley and Norman (1982) described the role of home helps as 'developing and changing' and the range of duties that home help organisers undertook as 'awe-inspiring'. It included carrying out assessments, supervision, administration, financial investigations and, in some cases, also being responsible for laundry, 'meals-on-wheels' and incontinence services. In spite of this most local authorities did not require home help organisers to be formally qualified. Twigg (1992:69) likewise found that HCOs had little

training, a narrow approach to assessment and were equipped to recognise only practical care needs. She goes on to argue that this matters because home care tends to be the main or only service with which older people have contact. Hence, the different types of care needs that service users may have are unlikely to be formally recognised and accordingly appropriate provision is unlikely to be made available. Furthermore, Twigg and Atkin (1994: 59) point out that HCOs responses to the needs of service users tended to be not only routinized but also underpinned by traditional assumptions about family duties, gender and care.

Consequently, when they made decisions about the allocation of service provision they sometimes overlooked or failed to recognise the importance of some non-practical care issues such as the restrictedness of caring. To illustrate their point, Twigg and Atkin (1994:60) give the practice example of how a HCO (mis)interpreted a carer's practice of going out on a regular basis as neglect and uncaring and consequently allocated the couple a very limited service. A subsequent assessment showed that going out actually provided the carer with a 'safety valve' that enabled the carer to cope with the restrictions of caring.

Almost twenty years on from Hedley and Norman's (1982) study, Sinclair et al (2000: 23) claimed that 'since the days of home help service' the roles of home carer and home care organiser have become 'more stressful' and 'more skilful'. They also pointed out that in the three counties making up their study area, the majority of homecare organisers had a relevant formal qualification for the job as well as on the job experience. The profile and practise of the HCOs and HCAs who took part in this study were not unlike those who took part in the research carried out by Hedley and Norman (1982) and Twigg and Atkin (1994). They were characteristically married women who lacked professional training and qualifications and their approaches and practices were, as already stressed, mainly premised on family care ideals.

HCA: I have recently cut somebody's service back for housework against their wishes. And the reason for that was that she gets help to get up and dressed in the morning and she gets meals on wheels and she gets her family come down. She has seven daughters and they come every afternoon and stay with her for the evening and I felt that there was nothing stopping them hoovering. So basically I just said to her. It was cut; it wasn't stopped.

HCO: It was as (*names manager*) was saying it was wanted rather than needed.

HCA: She felt that she needed it because she felt that wasn't what family was there for. She was quite happy to pay for the service but she felt that she could not give her family money to do the hoovering. She didn't feel that she had to pay them for coming and sitting with her because she felt that was her right but for them to actually do anything she felt obliged to give them something and she wasn't happy with it.

H/C: Families are not very good at helping the old folk. Not in my experience. I find that they seem to think the responsibility is ours. But that is not always the case. There are those who come in and want to help their families but not as a rule. I have heard people saying they don't even (?) their parents because it is our responsibility. They won't feed them or anything like that.

These examples reveal that these service providers understood the older people's need for and use of home care in terms of a malfunction or a lack of care in their kinship relationships. In short, a need for home care was the result of kin not behaving as they should, or more exactly, as the family model of care and these service providers believed that they should. This represents a fairly negative reproof of any kin but particularly damning indictment of a spouse since social and cultural expectations about care are much stronger in respect of marriage than in other types of kinship relationships. Indeed, unlike other kinship relationships marriage formally obligates spouses to care for each other (Finch and Mason 1993). Hence, this makes marriage, at least theoretically, a relationship that is based on and is about care. Thus, to define a husband or wife as uncaring (or not caring enough) not only accuses him / her of not behaving as he / she should and of failing to carry out his / her spousal duties but also implies that his / her marriage is dysfunctional and failing, even that it is no longer a proper marriage. As previous chapters in this study and the research findings of Qureshi and Walker (1989) and Finch and Mason (1993) have shown, older people including couples usually did not use services because their families were uncaring and uninterested in their welfare. They used them because they preferred to use services for assistance with their basic everyday care needs. However, the foregoing examples show that, at least in some instances, the application of family models care within services, especially the idea that kin should care and as necessary, be encouraged to care by the withholding of services, are likely to inhibit the delivery the kinds of services that older people want. A commitment to the ideals of family care may even get in the way or hinder providers in hearing or understanding their wishes. Again this has a particular poignancy for older couples seeking services. This is because the withdrawal or withholding of support could ultimately result in the spouses having to separate.

Home care assists its users to meet their essential care needs and so cope within their own homes within their communities. In respect of older couples the support of this service, as this study has shown, helps older spouses to continue to care. Without an adequate level of such support some users and their partners would face a crisis of care that probably would ultimately lead to their use of residential care facilities. Although proportionally fewer older spouses than older people living alone enter residential care, this has specific implications for older caring couples. The number of places for older couples within residential care remains

limited and so admission to such facilities usually means splitting up, one spouse becomes a user of residential care and one spouse continues to live in at home. To assume spouses should care for their partners and to refuse or cut back on such support to married service users would undermine the capacity to care. It would also lack economic prudence and be unsupportive of marriage, a most important informal caring relationship.

A failure to recognise the need for home care services to help prevent admission to residential care is most unlikely. However, an assessment of need based on the family model of care is likely to misinterpret or overlook care needs that are bound up or rooted in being a couple and accordingly to deny them services to meet these needs. For example, as discussed in chapter three and chapter five in respect of Mrs Addison, assistance with feminine domestic activities was not just about the practical meeting of domestic needs but also about her role and identity as a wife and how she related to her husband. To withhold or withdraw services to older women, who like Mrs Addison believe in a traditional division of domestic labour would be to deny them support to meet their needs as wives as well as women.

Whilst the service providers in this study were strongly influenced by family models of care, the restrictive influence of economic factors on their practice should not be overlooked. The HCAs explained that whilst they wanted and tried to provide services that met with service users' preferences, in reality they could only offer services that met with the operational restrictions and resources.

HCO: I think what a lot of them don't understand [*is*] the size of staff group we have. Everybody wants 9 o'clock bedtime or tea at 5 o'clock and it is my fault if they get their tea at 4 o'clock. I remember on one occasion I explained that I have 20 staff and this chap thought I had 130. And up until that point he had give staff quite a hard time because his tea was late. But after I had been and visited him and explained that there are 160 clients and 20 staff, he was fine. It really was a failure to understand but it had never been explained how it worked. After I had explained how it worked he was fine. I suppose, a lot of them are really quite selfish but all the same I suppose to a lot of them it is important.

The restrictive impact of having limited resources was not unique to these practitioners. Allen, et al. (1992), in their survey of older people's participation in community care services, found that resource issues confounded social workers and domiciliary care organisers in their attempts to facilitate the participation of elderly people in decisions about their services and more recently, Challis (1999), Harding (1999) and Myers and MacDonald (1996) drew attention to how budgetary constraints tended to put a squeeze on service user choice and involvement.

PERCEPTIONS OF SERVICE USE

Richards (2000) in her research study of the procedure of needs assessments identified a significant discrepancy between how service providers tended to perceive potential older service users, namely passive and helpless with an 'inability to cope' and how the latter presented themselves as determined, resourceful in their own assessments.

Despite their assumptions and claims about the relatively superior coping resources of couples, the home carers in this study tended to construct their service use in terms of their failure to cope. Their role as home carers was to 'rescue':

- H/C: (*Older couples need home care*) because the husband had a stroke and the wife can't cope.
- H/C: Well it just depends just what crops up. Sometimes one of the partners has had a stroke you know you are brought in.
- H/C: Most of the time they (*couples*) seem to be able to care for one another...when they are together without needing the home care. ... Well, the couple that I went to for quite a while ... he was the one that was caring for her and had done for while some time. Well, for many years in fact. But she was just getting worse but then he was getting that he wasn't so fit either. And then he had to go in for a neck operation. And after that he just wasn't able to cope with the housework and looking after her as well. ...So that was why I went out there and did what had to be done.

For married service users this failure perspective infers that they were failing as spouses and couples and, by implication that their caring relationships, their marriages, were inadequate. The way that the couples came to use home care, namely following on from a care or health crisis, offers some justification for this 'failure and rescue' perception but it contrasted with how the couples in this study understood their use of services in the longer term. It was a means of managing their care needs, part of their coping strategies or mechanisms.

Nevertheless, as discussed in chapter three, most of the women did not feel that they, but rather their home carers, were in charge of their service. Siddell (1992) reports, in her study of relationships between elderly women and their doctors, that some of her participants claimed that their GPs gave them the feeling that they were a burden to them and the service, whilst others felt that their GPs made them feel that they were interested in them. It is not known whether the home care services providers consciously or actively imparted to service users in their discourse and interactions that they felt that they needed to take care of them and hence to take control of the service but their approaches to practice suggests that this is possibility. Any such assumption of control, especially over domestic care activities, may, in view of the significance of such activities within traditional marriages, be expected to impinge on and disrupt the balance of power between spouses.

APPROACHES TO PRACTICE

Askham (1989: 115) suggests that it is:

Often accepted unthinkingly ... that services provided for elderly people tend to be demand led; that is the service agencies rarely seek their customers, clients, or patients, they wait for them to come. This should mean that the services respond to the elderly people's perceptions of their needs. But whereas the identification of need may be left up to elderly people, it is usually the service provider who ... defines or redefines that need, and decides how it should be met and treated.

In her study of assessment procedures, Richards (2000) similarly claims that from the point of referral needs assessment procedures serve to effectively sideline or subordinate service users' views of their needs to those of service providers. She points out how in her study the needs of older people were mostly brought to the attention of home care through involvement of intermediaries, such as medical practitioners, who tended to impart their own, usually influential, understanding of the referee's need for help, which was often accepted in preference to how the latter viewed their needs. She also highlights how assessors often structured interviews with potential service users around pre-determined areas of specified need and as a result they did not take full account of the complexity of the latter's situations or their concerns. Furthermore, the decisions based on such assessments tended to leave the assessed powerless to redefine their situation (Richards 2000: 42-43).

The service providers in this study agreed with the principle of service user participation and choice in theory but they pursued procedures and practices that contradictorily promoted and restricted their actual realisation. The HCAs emphasised that they talked to potential service users about what they considered to be their needs but they applied home care criteria that defined what qualified as a care need and hence what was eligible for an allocation of service provision. They also claimed to see assessment as a joint venture but they did not supply the assessed with a copy of the completed assessment so that they might challenge it.

HCA: A home care assessor; they are meant to go out and do a holistic assessment of needs. ... I usually don't try and explain my role I just try and introduce myself and try and get some kind of level of trust and understanding there. ... And then I tend to let them set the pace a bit with the discussion from then on. We talk about their needs, their meals, their bathing, their chiropodist, their hearing, their sight, their benefits. Quite often gardening problems are brought up for some reason. Err housing needs, family problems. ... We don't try and force standards on people. Then once we have decided between us... It is a two-way thing. It is as much what the client tells us as much as we assess them. And once we have come to some kind of agreement on that, you would then come back here with the paperwork ... Obviously there has to be a certain standard because home helps have to have a certain standard to be working in but...also at the other end of the scale is the people who think it is necessary to iron everything from socks and

underpants to sheets and pillowcases and to Hoover everyday and we have to explain to them that we can't provide that level within. And that they need to make other arrangements if that is what they felt they needed. Sometimes it can be a bit of controversy between want and need. To them that is a need but to us it would be a want.

The home carers also advocated service user participation and choice. They pointed out how, especially during their initial visits, they asked service users, if there were things that they wanted them to do. Nevertheless, they also acknowledged that few service users took up these opportunities to take control of how they delivered the service. Therefore, they tended to impose their own regimes such as cleaning bathrooms one day and kitchens another day with the result that any extra or requested jobs had to be fitted in. One home carer outlined her approach:

H/C: I will have a set day for doing the bathroom and a set day for doing the kitchen floor things like that. ...Like the lady I went to this morning, today now this is her washing day. I got her washing done and took it and got it dried. Wednesday it's her bathroom floor, kitchen floor the ironing and the dusting.

Moreover, the home carers seemed quite proud to report that the majority of service users 'just leave you to get on with it' or that they had a 'free hand' in how they provided assistance. To be given a 'free hand', they assumed signified that service users trusted them and had confidence in their abilities.

H/C: A free hand. I suppose maybe because they trust you and feel I am capable I would imagine. I have worked with old people for so long they knew the way I was doing it was probably an easier way than what they would be doing it.

As the previous chapters record, most couples found the standard of home care service that they received to be satisfactory or better. Whilst this supports the home carers' assumptions, to focus on competence obscures the power issues implicated within this practice. A minority of couples encountered incompetence and other inadequacies in service delivery, but instead of complaining, most 'made allowances' for what they perceived as 'glitches' in the service or a problem of the service being overstretched. This suggests that allowing 'a free hand' may not always be an endorsement of competence or evidence of satisfaction but a sign of resignation or of the difficulty that some service users have in asserting their wishes. Some service users whom the home carers supported told them exactly what and how they wanted things done.

H/C: The men just let you get on with it and do it your own way. Err a couple of my ladies one will say 'no you don't Hoover the living room', so you do it once a month because she has got a big rug and it spoils the rug. They will tell you when they want you to use polish and that you know. After a

- time it just sticks and in a couple of weeks you know. You tend to know what you are doing in everyone's house.
- A: So they are more particular about your method. How do you feel about that?
- H/C: Oh it doesn't bother me you know because everyone is different.

Whilst the home carers claimed that they did not mind being asked to do this or that and tried to comply with any such requests, they tended to regard service users who gave them such directions as fussy or difficult.

- H/C: Most of them (*service users*) err just let you get on with the work that you are doing. Other ones that are, you know, really, really fussy, they like to have the sitting room and the kitchen done one day and the windows and something else done another day.

This raises the questions as to whether the home carers understood the instructions that these service users' gave in terms of a rebuff of their skills.

HOME CARE ACTIVITY

When asked what they did, the home carers said that they cared for service users and then went on to list the types of practical assistance that they provided:

- H/C: I look after disabled people, personal care, housework, shopping some cooking just everything a disabled person needs really.
- H/C: Bathing, showering, shopping and mostly housework.
- H/C: You are just going in and looking after them, making sure they are all fine and everything is shipshape.

The home carers employed within LA1 tended to provide relatively more personal care than those in LA2 but, in respect of couples, the home carers in both LAs tended to provide more domestic than personal care. Whether this was representative or spurious is unknown. However, the service providers in LA1 and LA2 also acknowledged that in general the service was providing an ever-increasing volume of personal care and this was at the cost of a decline in the provision of domestic care. Clark, et al. (1998) and Harding (1999) have criticised this kind of shift within community care service provision on the grounds that it ignores or dismisses the value that older people, especially older women, place on housework and domestic standards. The home carers and their immediate supervisors, if not those more removed from the site of service delivery, were very conscious of just how significant these matters were to the users of the service.

- H/C: Hoover err do dishes, see to their washing, do windows, just about everything. All household chores, do the bathroom, do the kitchen. ...I just like to see other people's places nice knowing that they can't do it themselves and knowing that

for years they have tried to keep it nice now they are needing a bit of help. ...some of them if their house is not nice it gets to them a bit you know.

H/C: Well I think.... It used to be helping them with their house work and things like that but I believe according to our bosses, that the higher up ones, I believe that it is talking to them.

In this respect the views of the frontline workers coincided with the reasons that the couples gave as to why they used services.

Sinclair et al. (2000) found that, in spite of rules, regulations, time restrictions and prescriptive care plans that should have strategically limited their activities to key home care tasks, home carers tended take a holistic view of their jobs. They paid attention to detail, incorporated 'nice touches' into how they carried out their activities and kept a caring eye on service users so that small but important changes did not go unnoticed and unchecked. They provided what Sinclair et al. (2000) called the 'added value' of sensitive caring – an aspect of the service that neither home care employers nor service users could demand or expect – yet its provision was something that home carers wanted to provide and derived satisfaction from doing so.

Hands-on care activities formed the cornerstone of home care service in LA1 and LA2 but the home carers were involved in the provision of many other forms of care, including ones that were vital in realising the care aspect of the service. In addition to personal and domestic care, they also provided service users and their spouses with information, social and emotional support and facilitated short-term respite. They identified and monitored changes in the service users' needs and coping skills and communicated these to their supervisors to initiate prompt remedial action. They paid attention to detail and provided 'added extras' or 'delinquent' care – assistance that was not specified in service users' care plans but that mattered to them. [This is discussed in more detail later.] Thus, they alternated polishing and dusting, gave their opinions on outfits for special occasions and home decor, shared their knowledge of home remedies for 'women's complaints', indulged the service users with post-bathing pampering, and engaged in 'women's talk':

H/C: You go through to the bedroom to see if this top goes with this you know. Just your normal things you know.

H/C: I just give her, her breakfast in bed and then I bath her and put her back to bed and I just pamper her, put on her face cream, put on her make up and she goes back to bed and she gets up later on.

H/C: They are quite happy to hear about what you have been doing. I go to the (*names a women's organisation*) and I have quite a lot of people that have come from the country

and some of them in fact used to be in the (*names a women's organisation*). And they are quite interested to hear about that.

H/C: She (*an older married service user*) will often say it is nice to talk women's talk when her husband is not there.

The home carer were in no doubt that their duties included informal conversation 'yapping', 'blethering', 'chatting' and 'newsing' – but they did not seem to accept this social duty as equitable with their practical ones. It was essential but somehow it was more of an added extra than nice touches like pampering and had to be combined with domestic chores and personal care:

H/C: Well they need the work done but an awful lot of them are just so glad to see somebody. ... A lot of them feel that part of the thing should be that. You should be able to give them a wee bit of news. And they just like to have five ten minutes of a news (*natter*) with you, just keep them up to date with things and be friendly with them. A lot of them really value that very much.

H/C: A lot of it is talking to them. ... I talk to them but there is not an awful lot of time for that. You see you have to... They want the housework done and... The old people sometimes don't mind. I go to one or two and they say 'sit down and talk to me'. I went to a woman years ago. She is dead now and she would hardly let me do any housework. She wanted to talk all the time because her family didn't visit her. Then when she became really ill the family didn't want me around and said of me, (*states her given name*) doesn't do enough housework. Well, I probably didn't because she wanted to talk and talk all the time. But I'm always willing to do (*it*) because I am paid well enough for it. So I'm saying I'll go and do this. I'll get into your bathroom. It was dirty but she would not let me. No, no just sit down for a minute I'm just glad of the company. ...I used to go to another old woman now and again. Her house was manket (*filthy*) and I am trying to clean it up but she is wanting me to talk. She is over ninety, about ninety-six and that is all she wants to do is talk. ...I'm always willing to do (*housework*) because I am paid well enough for it. ... So you are torn both ways.

In their study of the importance older people assigned to various aspects of home services in Sweden, Edebalk et. al (1995) found that whilst their participants wanted service providers to be of a pleasant and friendly disposition, they rated professional competence more highly. The women especially wanted them to be skilled in providing housework. Their study also revealed that variables such as gender, age and degree of service use influenced how service users evaluated different aspects of the service. Sinclair et al. (2000: 42) also highlight the variation in the priorities of service users:

For some clients what was important above all was the standard of domestic work....For others, however, what was important above all was the relationship with the worker, and so they waited at the window for her to arrive with the kettle ready to go on.

The couples in this study sought assistance from home care to help them meet their basic domestic and personal care needs. They wanted these service providers to be competent in providing such assistance. Many also spoke positively of personal qualities and of enjoying their company and conversation but pleasant social interaction, in suitable measure, was always an added extra or bonus. Too much conversation combined with too little practical care, just as too little conversation (especially if it was judged to be the result of a lack of interest), were both sources of complaint. In view of the time pressures on the home carers and their assumption that couples provided their own company, it might be expected that they would be less committed to making conversation with married service users than those on their own. There was little clear evidence that this was the case yet married services users did appear to be slightly conversationally disadvantaged. Home carers just did not have enough time to ensure that they spoke to both spouses or to always effectively develop three-way rather than two-way conversations.

H/C: You try and speak to both, although you sometimes feel that one wants to say more than the other but you don't want to leave the other out, especially the elderly who could be lonely. They have such a lot to say and maybe one is a bit more over powering the other and you feel the other one wants to speak too but then you find that in all walks of life. Whereas if you are working with just one person it is one to one....you just try to include both of them in the conversation. There is one couple in particular that I was thinking about (*breaks off*). Err you just try to include both in the conversation ask them their views and try to bring them into the conversation. Maybe when you go home you think I should have done this or I should have done that but, as I say, when you are busy and you have a lot to do and speaking as well it is difficult to say right who do I talk to next and what about.

Talking and the types of activities that made up sensitive caring could be dismissed as trivial but the home carers were convinced of their importance. They knew that they affected how service users felt and this in turn impinged on their morale. Plus, these aspects were important to the home carers. In supporting service users in ways that enhanced the users' quality of life the home carers found job satisfaction. This was closely bound up with their personal identity, self-image and sense of self-worth as caring women. This supports Mulrooney's (1997) proposal that those with a predisposition to caring are more likely to offer high quality care than those without.

How the service providers in this study experienced home care suggests that they generally felt confident about their ability to provide good and well-targeted care, to improve service users' quality of life and to access insightful supervisory support or guidance. It also suggests that they felt that they did their best for service users and what they did was worthwhile and was usually appreciated. These feelings are consistent with the kinds of senses that Nolan et al (2004) identify, in their Senses Framework, as promoting good caring relationships and thereby quality service provision. However, the extent to which the home carers appeared to experienced these feelings, in particular their confidence about providing adequate and appropriate support appeared to be greatest in relation to their support of individuals, especially older women and as will be become clear later in this chapter somewhat less in relation to older men and couples.

Gender and Sensitive Caring

Home care is not exclusively used by older women, but almost all the examples that the home carers gave of sensitive caring involved women and their accounts of why they were able to provide such care, focused on their own feminine experiences. Thus, although this study has no direct hard evidence, it seems unlikely that older men received sensitive caring in equal measure to older women. Indeed, the example of the gardening 'hit squad' outlined in chapter three strongly suggests that they did not. Older men also emerged as relatively disadvantaged conversationally due to the dominance of women within home care.

Many home carers recognised that men and women enjoy talking about different topics. Some tried to engineer their conversations to include topics of interest to the men as well as women. In spite of this, 'women's talk' tended to dominate their conversations:

H/C: She (*the service user's partner*) was very motherly towards her husband, which he enjoyed. All men do. But I sometimes think he wanted to hear something about the outside world. He wanted to chat about something else other than what do you want for your dinner, look what I have bought you look what I have made for you sort of thing. I think he just wanted to hear what was going on.

H/C: I go in and just talk about things that maybe happened on television. They usually watch television or if they can't see they listen to the radio. And they like to keep in touch with the outside, with what is going on round about, with the outside world – particularly locally, if they are not able to read the papers and what not. Going in and talking generally or what I have done the day before if I have been in the garden or...emm a lot of them like gardening or did like gardening and aren't able now, so talk about flowers, plants, what seeds I've sown. ...Just talk about everyday things whether it is what I am doing... Obviously they are not doing

a lot, but if they have had visitors in or some are able to go out, if they have been out that day.

- H/C: Err who they maybe saw down at their coffee morning, what was happening with someone who was ill, you know, some of their friends who are ill, if they have gone into hospital, they like to know if they have gone in. Well just know it is sort of Christmas things, what will we buy for this present what will be buy for that. Wrapping Christmas presents up that is what I have been doing this morning.
- A: Are there any differences in the men and the women in their topics of conversation?
- H/C: No. Well, there is one gentleman he is quite keen on sport. And he will say what is on telly today. Like today now it is bowling in the afternoon. He said the snooker is finished it is bowling. Things like that.
- A: And is that also the same with the couple?
- H/C: Yes, oh yes. They like to hear about your family and what you have been doing at the weekend or your days off things like that.

These examples highlight the influence of context and thereby challenge, or at least add a further dimension to, the arguments considered in chapter two about men's dominance in mixed gender conversations.

The conversational bias within home care towards 'women's talk' has particular implications for caring couples. Firstly, unlike women, who looked forward to and enjoyed 'women's talk', housebound care recipient men could not claim that they look forward to 'men's talk' as part of the home care service. Secondly, such men may be conversationally sidelined during the delivery of home care if their spouses seize the opportunity to meet their need for 'women's talk'. Thirdly, 'women's talk' between home carers and women receiving care may make caring husbands feel uncomfortable. The home carers provided several examples of caring husbands going out during their visits. In some instances, this was a case of seizing a chance to go out for respite whilst in others it was a case of avoiding having to listen to their wives and home carers talking women's talk. It is difficult to predict whether and how effectively an increase in men within the service would address these conversational issues. Older men may welcome and benefit from the opportunity to have a 'man-to-man' conversation as they receive the service but they may find it difficult to relate to men who carry out a job that is made up of activities that are traditionally thought of as 'women's work'. Also, older women may feel that they should support men who work as home carers by sharing their domestic knowledge with them.

THE ESSENCE OF CARE: 'DELINQUENCY' AND ADDED EXTRAS

It has been repeatedly shown that home helps, home carers and support workers do not limit their caring to activities that they are officially engaged to do (Qureshi 1990, Sinclair et al.

2000, Walker and Warren 1996, Warren 1990, 1994). Researching the boundary between informal and formal care within the Kent Community Care Project Qureshi (1990: 62) discovered that paid helpers developed relationships with clients that led them to 'perform tasks in addition to those within their contracts and to assume a sense of personal responsibility for their welfare'. Warren (1990 and 1994) found that for selected service users, home helps and support workers carried out what they called 'favour'. These were often performed in their own time. She defined these activities as ones that are 'generally considered non-essential but of importance to the individuals'. Sinclair et al. (2000) similarly found that sensitive caring, referred to earlier, usually required home carers to bend the rules. They juggled their hours to make time to carry out forbidden cleaning tasks, stayed longer than allocated and went shopping, did service users' laundry and visited them 'out of hours'. Sinclair et al (2000) also pointed out that whilst the service does not and cannot officially acknowledge such rule bending or 'delinquency', it actually relies on it to please the clients. Delinquent caring, in various forms both during and after the home carers' hours of work, appeared to be rife in this study.

H/C: Her washing machine broke down and I took her washing home and did it in my washing machine. And I take her into (*names nearest city*), if she wants to go into (*names nearest city*). I haven't done that for a while. I have done it. I have even taken her husband in for appointments in (*names nearest city*). That is all outwith my work.

H/C: I mean, we are not supposed to clean windows. Well someone who is not able to clean windows, they are paying us. I clean windows.

H/C: I like my old folk. I do. I am fond of them. In the past I have done an awful, awful lot extra for them, you know, outwith hours.Oh I do things for (*names a service user by her given name*). I bring her a fish supper at night sometimes or I take her up to (*names place*) to see if she can get, she is very, very big, clothes for her. Things like that (*I do*). A few things like that.

H/C: I do shopping in my own time. I don't mind if I do it because I want to do it but unfortunately sometimes ...some clients feel well that is your duty. If you have done it once or twice then you should always do it. Whether they mean it or whether it is just because you have started it. It is difficult to stop it.

H/C: Yes, I think you tend, you begin to get attached to them and you worry about them. I know I do. I am terrible. I like to know that they are alright and sometimes if some of them have been a bit off I'll go back in the afternoon but I shouldn't.

The HCAs, HCOs and their managers knew about and interpreted such deviance as proof that their staff were committed and conscientious carers:

M: I think sometimes we ourselves are not aware of how much is being done. I mind (*remember*) at the time of the charging policy came in and I had a meeting with the Home Helps and was talking to them and one said 'but you can't charge somebody for writing their Christmas cards'. You know, and where in a care plan does it say.... Yet that client needed her Christmas cards (*written*). She couldn't write any longer you know. You know but nowhere is there.... And parcel up the Christmas parcels and put nice ribbon them and actually go out and buy it to make sure that when the great grand children get something really nice for their Christmas. We don't even appreciate half of what is going on. A lot of it is done in the home helps' own time. You know but that is the kind of workers you've got.

HCO: Sometimes I think we spend a lot of time protecting them from themselves because of the nature of the beast. Someone who works in this profession, most of the time anyway, they won't say no. They won't say no to someone asking them to stay on an extra ten minutes or to do something in their own time or use a piece of dodgy equipment. So a lot of time is spent reinforcing with them that there are only certain things that they can do and if there is dodgy equipment you.

Access to delinquent support, added extras or favours was something of a lottery. Only some of the home carers provided delinquent support and those who choose to provide it provided only to those service users whom they choose to offer it. They tended to choose service users with whom they had a good relationship, were able to empathise with and, most importantly, towards whom they felt a sense of moral responsibility to provide additional support. Typically, they developed a sense of morale responsibility for service users who they believed had no alternative source of support. If they did not do whatever it was that was needed then nobody would.

H/C: You do get... you almost feel like a friend to them after. ... You are maybe get closer to them and you do more than you should. ...I'll maybe... I have two clients in wheelchairs. One is just on her own and blind and really likes to go but nobody will take her. I often go with her on a shopping trip.

The influence of the 'nobody else' factor in the provision of favours is likely to discriminate against married service users. Only one home carer spoke about supporting a couple beyond her working duties.

Spouses are not always able to meet or even understand each other's needs, especially subtle ones that are related to gender as can occur within activities such as shopping, baking and gardening. For example, Campbell (1997: 169) in his study of gender and shopping proposes that:

Men (*are*) inclined to see shopping as a purely purchase-driven activity related to the satisfaction of need, whilst women are more likely to view it as pleasure-seeking activity related to the gratification of wants and desires. (*And*) to see the activity as possessing value in itself, independently of whether goods are purchased or not.

These gender differences in styles of shopping also support differences in men's and women's attitudes towards browsing. Consequently, women can find their shopping experience quite changed when they have to depend on their spouses for support with this activity. This was illustrated in Mrs Fyfe's rueful reflections on her altered and reduced experience of shopping with the support of her spouse:

Mrs Fyfe: Shopping. ...No that is one thing I miss. If you go out you are going for one thing and that is it. You can't say 'oh this is rather nice' and go look. Oh we haven't time for that.
A: So no browsing?
Mrs Fyfe: The browsing has gone
Mr Fyfe: That is a fair comment.
Mrs Fyfe: Something I enjoyed.
A: You (*looking towards Mr Fyfe*) are not a dedicated shopper?
Mr Fyfe: No, I am not. If I am going for something it is in and out and that is it.

Even if Mr Fyfe, or any other husband, were to recognise and respond positively to his wife's need to browse he could not offer her that, so often all-important, second feminine opinion as a prelude to purchase. This example suggests that spouses are just as likely as those living alone to welcome and benefit from 'delinquent' home care for certain activities.

TAKING CONTROL IN CARE

In his postmodern perspective on care Fox (1995: 107) debates the paradox of care, namely that care is both a vigil and a gift:

It is a technology of surveillance, which, ...constitutes a vigil. But although this technology is one of control and supplies the authority for professional care, it is also possible to recognise an alternative caring, which is about love, generosity, and a celebration of otherness. This gift of care seeks to enable the cared for person, and resist the discourses of the vigil.

The home carers, HCAs and HCOs veiled the issue of control within home care by presenting it as caring. It was in the best interests of the service users to take control of things so as to take care of them. Furthermore, when it was in a service user's best interests to take control of things, it was not just acceptable and justifiable, it was the right thing to do. It was caring. There was no clearer example of this than in respect of the service providers' assessing and monitoring activities. Home care services are allocated to service users on the basis of an assessment of needs but care needs change. Whilst review procedures seek to detect such changes the home carers in this study were actively involved in ensuring a good and continuing match between service provision and the needs of service users. Without thinking

about it, they quietly kept an eye on service users as they delivered the service and so were able to spot even small changes in their needs and inform their supervisors. Since service users tended to trust and respect their home carer's or carers' opinions, where further provision or re-assessment was advisable they were usually prepared to for this to be arranged.

H/C: If you feel that you are really worried about any clients or you want to change the times to suit in with you and your clients you just come down (*to the office*) and you can see them (*HCOs*) at any time. ... Well err one of ladies I thought last week.... I was needing more time with her so I just phoned up and asked if I could change my time to make.... To give her more time. ... It is going to be an ongoing thing because I can help her to get her washing done. She is getting more frail so she can't sort of wander back and forth to get her washing out of the machine and put it in the drier so I am taking extra time to do that with her now...because she is becoming more frail. ...I think really if you think they are needing something more such as someone at night 'tuck-ins', we call them. Well you just come down, I would just come down and see and say to (*names HCOs*) do you think they could get some more help. ... I don't know about other towns but I have never found that anything that I have asked for help I have never had a problem at all.

A: And how do people (*service users*) respond to this?

H/C: Fine as long as there is not too many different people coming in. Well some of them will say to you 'I am getting tired'. The lady where I have said I will do an hour and a half instead of an hour one day and half the next day err I could notice that she was becoming more frail and when I said to (*her*) I will come and do this instead of you going back and forward. 'And oh that would be fine'.

Home carers were also called on to deliberately monitor service users who were felt to be particularly vulnerable. Whilst convinced of the ultimate necessity of these activities, the service providers, especially the HCAs and HCOS, were aware of the moral and ethical issues and dilemmas that surround such practices. In particular they considered the observation and monitoring of service users with the intention of sharing information about them, especially with other agencies, to be very intrusive. Hence, this had to be done, they pointed out, very sensitively:

HCO: There are usually specific reasons... as I say it is more often with clients who have dementia of some kind who are not able to express or remember what they want to tell us as far as giving us information; it helps keep them as safe as we can between us. It is a good watching system. You do occasionally get... Mrs So-and-so had four gins on Friday night watch out for this becoming a trend and you have to ask yourself how many gins you had yourself on Friday night. (*said with a laugh*)

HCO: I think because it is done really professionally. If it wasn't done that way it would feel like 'Big Brother', you know. There is nothing you can do that we don't know about!

Where the object of monitoring or assessment was a spouse or a couple rather than an individual the HCOs and HCAs felt that these processes were somehow even more intrusive and more uncomfortable to conduct. In other words, marriage added a further ethical and moral complication to monitoring:

HCA: It (*assessment*) is such a tremendous intrusion into anyone's life ... especially when a couple needs help. When I go in with all these forms and things, especially if it happens to that they are possible entitled to a orange badge or attendance allowance and you have got all these other forms and the principle as well.

Twigg (2000: 89) acknowledges that the privacy of marriage makes care workers feel awkward about intruding on such privacy but suggests that it also means that spouses are better placed to guard their privacy against the intruding eyes and judgements of workers and professionals. Nevertheless, in the devolution of the medical gaze into the community through networks of surveillance, Heaton (1999: 773) draws attention to how:

The caring relationship between the cared-for person and the caregiver in the community became the object of the medical gaze, ... informal carers' relationships with, on the one hand, patients, and on the other, formal service providers, exemplify contemporary disciplinary practises using relays: the informal carer is the supervisor of the person they care for, in turn supervised by the statutory health and social care services.

This suggests that assessment, monitoring and the care / medical gaze that focus on caring relationships for spousal service users are also focused on their marriages and their behaviour as spouses. Thus, care assessments and monitoring become judgements about not only how well they care for their partners but also their marriages. In other words whether they are caring spouses.

The couples were subject to monitoring by service providers. Some appeared more aware of this than others but regardless of their awareness they tended to accept such intervention as mostly necessary and to their advantage. They viewed it as caring or helpfulness rather interference or attempted control. For instance, Mrs Hendry, appeared to feel that her care manager met with her simply to see how she was getting on, and to keep her up to date as to the availability of equipment. In contrast, Mrs Lawrence, who recognised that how her husband and she were coping was being monitored, actually found great reassurance in her regular contact with the district nursing service:

Mrs Lawrence: As I always say it is a circle; one (*service provider*) does that and then the next does that and next and it goes... The district nurses were very good. When he came home (*from hospital*) first they use to often pop in and she would often

pop in like on a Tuesday, that was the day they come but I've seen her pop in the first few weeks she would have popped in on a Friday just, you know. She always used to say I was just passing. But I don't think so. She just maybe fitted me in. Just passing. I liked that because if there was anything we talked it over. It was just some strength at the back.

Nevertheless, the spouses did not always agree with the service providers' assessment of their needs or how to meet them. In such instances they tended to refuse or terminate the undesired provision and to draw more heavily on their united resources as couples. If this had not been the case, they may have been more conscious of and concerned about the control aspect of monitoring and networking between service provider (the gaze).

MODEL RESPONSES TO OLDER COUPLES

The four-part model put forward by Twigg and Atkin (1994) as to how care service agencies respond to carers was introduced in the previous chapter. Applying this model to the practice responses of home care organisers Twigg and Atkin (1994: 56) found:

Home organisers did not incorporate carers overtly into their practice. However, because they so often dealt with older couples, they tended to focus at the level of the household, with little distinction being made between the carer and the disabled person. Help was provided to the household in general, and the situation was not seen in terms of supporting carers. Carers were thus incorporated, but as joint clients. Beyond this, the predominant response was one of regarding the carer as a form of resource.

Pickard and Glendinning (2002) argue that carers continue to be viewed and treated as resources, in spite of legislation and policies aimed at supporting them and giving them choices. Moreover, Parker (1998) suggests that changes in service provision appear to have led to informal carers doing ever more complex care tasks.

Within this study, the assessing and supervisory service providers appeared to regard the younger members of older service users' families as resources but not their older spouses. Occasionally they constructed older spouses as co-workers but mostly as co-clients or superseded carers. However, their perceptions also tended to be dynamic. They perceived older spouses as changing from co-workers, to co-clients and then to superseded carers. The co-client/joint approach, especially in respect of domestic assistance, was also much in evidence in the perceptions and practices of home carers. One home carer explained:

If it just an ordinary couple...you just have the one (*timesheet*). It would be for Mr and Mrs type of thing. ...Well I do the housework for them (*the couple*), ironing and things like that so it is helping both of them.

Although the HCAs and HCOs said that spouses were 'looked at together', they were hampered in adopting a joint approach in their practice by policies and administrative procedures orientated towards the assessment and meeting of individual needs.

As stated earlier, the computerised administrative system in the participating LAs did not recognise couples and, because of this, services could not be allocated to them. They could only be allocated to individuals. This had given rise to an approach whereby both spouses in a couple routinely became defined as service users, or more precisely, recipients. The HCAs and HCOs explained that the service needs of and provision of services to older couples tend to grow as their individual care needs increase and their joint capacity to care declines. This characteristic pattern was particularly clear in one of the home carers' accounts of her experiences of supporting couples:

H/C: Well, the couple that I went to for quite a while, just out the other side of (*names town*). Err she was... He was doing most of the caring for her because she was very, very disabled with arthritis. I mean I never knew that people could have arthritis as bad as that. And he was the one that was caring for her and had done for...some time. Well, for many years in fact. But she was just getting worse but then he was getting that he wasn't so fit either. And then he had to go in for a neck operation. And after that he just wasn't able to cope with the housework and looking after her as well. So that was why I went out there. ...And another couple that I just lost about three weeks ago because they went into the very sheltered housing again she was the one that over a few years has been deteriorating. She is now in the early stages of dementia and he is having to do an awful lot of caring for her. He has practically to be there all the time. Really the only time he can get away from her is if someone is there to care for her.

Without an administrative option to allocate services to couples, HCAs and HCOs reasoned that that the most economical, efficient and comprehensive approach to service provision was to define and record both husband and wife as individual service users as it catered for 'what if' eventualities:

HCA: What I tend to do is I do a joint review, photocopy it and put one copy in one file and the original in the other file. It used to be the old style that it was always in the wife's name.

M: One of the reasons why that doesn't work is because if the wife goes into hospital there is no way we can put services in because the person is in hospital.

HCO: If somebody goes into hospital.... say I have a Mrs Smith and she goes in hospital, it is such a big job to change it, if it is just short-term we will leave the service in.

Thus, this approach provided the service providers with a mechanism by which they could respond quickly to a care crisis within spousal relationships.

The reference to the 'old-style' not only highlights the domestic care roots of home care but also reveals that traditional assumptions about the gendered divisions of domestic labour still underpin and permeate this service. Whilst this may be viewed as the persistence of sexism within the service, it may alternatively be viewed as evidence that home care service

providers understand and are responding appropriately to the gendered division of tasks within the homes and lives of older couples using the service. Nevertheless, the well-intended and experienced-based practice of making older husbands and wives service users is ageist. It is premised on the ageist assumption that older spousal carers, because of their age, do not have robust personal resources and coping mechanisms. They will, therefore, become increasingly vulnerable and frail and need ever more services until they eventually, but inevitably, become superseded carers. Such negative assumptions have considerable potential to disempower, demoralise and undermine the confidence of older people and so be self-fulfilling. Minichiello et. al (2000:260) argue that older people make sense of oldness not chronologically but in terms of loss and a negative 'state of being' that is about 'being unimportant and irrelevant'. Accordingly, as older individuals encounter age discrimination, which is rife within society and services, they begin to define themselves as old and so experience ageing negatively (Grant 1996, Minichiello et. al 2000). Grant (1996), in her examination of ageism in the practices of health service providers, claims that ageism affects the choices with which people are presented, the decisions they make about those choices and thereby their behaviour and health outcomes.

If people believe that some of the 'inevitable deterioration' of ageing is preventable, they are more likely to be more active in their own self-care. ... (but because ageism can be quite subtle, service providers need to continually examine their own attitudes towards ageing and older people. Health care professionals need to move away from using the term 'age' as an explanatory variable and the assumption that after enough time certain 'things' will happen to people (Grant 1996: 9/13).

Accelerated and reinforced by the introduction of carer legislation, the development of assessments and services for carers have actually made carers service users in their own right. This increased recognition and support of carers has then supported and furthered the tendency to see and treat every older couple as two service-users. Nevertheless:

M: Every carer is offered an assessment. You know...but if there is two in a house we assess the one and then there is a carer's assessment offered but they don't always accept it.

Ironically, spouses who used carer services were usually seen as co-workers rather than co-clients.

The service providers' co-client construct and, by implication, joint approach to provision was not inconsistent with how the older couples understood their use of home care but the emphasis and understanding of the issue of use and receipt of the former and later were quite different. The spouses perceived themselves as service using couples. The service helped them as a couple to cope with the demands of care regardless of whether only one or both spouse within a marriage directly received the service. In contrast, but in accordance to their rescuer / failure perceptions, the service providers tended view to both spouses as recipients.

For instance, the home carers tended to speak of 'doing house housework' for the spouses; they did it on behalf of the wives, who alongside their husbands were the beneficiaries of the end product, a clean home. In this construct the service provider emerges as being in control and spouses as relatively passive and powerless recipients, indeed dependents. This again highlights the persistence of traditional assumptions within home care.

THE CHALLENGES OF SUPPORTING OLDER COUPLES

In her research into disability, caring and marriage, Seymour (1994: 10) claims that identifying how to respond appropriately to service users who are trying to cope with the demands of chronic illness within the context of their marriage is a considerable challenge to service providers. The HCAs, HCOs and, in particular, the care manager were conscious of differences between their experiences of assessing and allocating services to older couples and people living alone. As discussed earlier, the HCAs felt that assessing married users was more intrusive than users who lived alone. They also highlighted how during assessment interviews they 'picked up' a lot of information about the needs of users from their spouses. In contrast the care manager found that long-term spouses tended to function as a team or unit and this unity tended to obscure the spouses' individual needs and so complicated assessment. Hence, she found that gaining clarity and so making a realistic assessment of to the individuals' care needs and abilities was sometimes very difficult. The HCOs and care manager also stressed the importance of allocating services sensitively so that caring spouses do not feel undermined, left out or demoralised. Consequently, they sometimes introduced services more gradually than the service users' need would suggest was ideal. The care manager emphasised that, in spite of such measures, and often their desperate practical need for services, caring spouses, especially wives, could still find accepting care services extremely difficult. She believed that spouses have such difficulties because of their unwavering acceptance of caring for one another as their spousal duty and as what they understood their marriages to be about. That these difficulties were greater for women she attributed to the gender bias to the close association between care and femininity and female roles.

Twigg and Atkin (1994: 50) argue that social workers have a potentially important role in supporting carers to address the issues that caring raises but usually their input is short-term and centred on assessment and the allocation of services. The care manager in this study tried to support older caring wives with emotional challenges that service use presented in terms of changes and losses within their role, identity and ways of relating to their husbands. However, the support she could offer was limited because input was typically short-term and primarily focused on assessment. She felt that this was inadequate for some couples. Her awareness of this gap in provision cannot be disassociated from her concern about the lack of training on

relationships provided to home carers. She felt that these service providers were expected to deal with what she termed 'complex situations' without adequate training and guidance to help them. Thus they were at risk of suffering from stress and service users were likely to receive inadequate support. Although the care manager did not define 'complex situations', her examples focused on relationship dynamics and issues including the social and emotional impact of disability and service use on roles, identities and interdependencies within long-term marriages and relationships.

The home carers insisted that they found no difference in supporting service users on the basis of their marital status. However their accounts revealed that supporting married service users and service users who live alone presented them with different kinds of challenges. For instance, when working with couples they had to balance their interactions so as to avoid showing favour to either partner; to respect the privacy of the marital relationship, to provide support when (changes in) a spouse's condition distressed or upset the other partner, to deliver the service in spite of the tense atmosphere of strained relationships and occasionally play the role of peacekeeper:

H/C: She still likes to bake but she is not able to do a lot so the husband helps and he will measure things wrongly or do wrong and that causes aggro. (*said increasingly quietly*) There is a lot of emm (*pause*) belittling one another in front.... In so much as you are not doing that properly and they feel inadequate. So you have got to, as they go out of the room, maybe quite sort of stropy, side with them as well. Just give them a bit of praise.

H/C: You try and speak to both (*spouses*) although you sometimes feel that one wants to say more than the other but you don't want to leave the other out. Especially the elderly who could be lonely. They have such a lot to say and maybe one is a bit more over powering the other and you feel the other one wants to speak too. But then you find that in all walks of life. Whereas if you are working with just one person it is one to one. ... as I say when you are busy and you have a lot to do and speaking as well it is difficult to say right who do I talk to next and what about.

H/C: So sometimes she will just say 'Oh I wish (*states partner's name*) wasn't like that' and things like that. So I can see that she is worried.

The home carers empathised with the worried, unhappy and depressed service users and offered them a confidential listening ear. A valuable service, but sometimes more specialised support and help is required. In spite of this they gave few examples of bringing these emotional needs to the attention of their supervisors for their advice, guidance or referral to other sources of support. This omission could possibly deny or delay the offer of helpful services or intervention to address service users' distress.

In contrast to upset and misery the home carers were neither confident nor comfortable about supporting service users whose relationships were strained, especially where the tension was between spouses. When faced with tension between service users and non-co-resident family members, they tended to turn any questions that the service users posed back around. In this way they avoided being drawn into disputes. This technique is commended in social work circles because it leads service users to resolve the problems thereby empowering them. In cases where the dispute or tension was between spouses, the home carers usually tried to make light of the situation and encouraged reconciliation. Making light of a dispute is an approach frequently adopted to deal with arguments between children. Although apparently well-intentioned, the home carers could be criticised for adopting an approach that tends towards infantilisation, being patronising and negative stereotyping of older people as less than competent adults. Thus this approach could potentially undermine the self-image of the service users as competent rational adults with valued relationships. Furthermore, Conway and Hockey (1998:482), in their research into beliefs about health in later life, note that 'as well as perpetuating powerful negative stereotypes, it (infantilisation) annoys older people and fuels resentment and hostility'. The home carers gave no indication that this is how service users felt.

Without implying that there was anything more to the home carers' examples of disputes and tensions in the users' relationships than minor irritation; it cannot be assumed that this will always be so. To trivialise or avoid an argument or disagreement is not always a suitable approach. Home carers were not trained to become involved in and address relationship tensions but again they did not appear to alert their supervisors to this issue. This could deny or delay the offer of services or intervention to halt or defuse increasingly stressful, and even potentially or actually exploitative or abusive, situations.

A minority of spouses in this study found caring stressful and felt a little exploited.

Fortunately, the use of services helped these participants remedy or at least contain their difficulties. However, there are grounds, including the incidence of depression in later life and the hidden and probably underestimated problem of elder abuse, to suggest that this is not the case in all later life caring relationships (Age Concern 2005, Biggs 1996, NHS Scotland ISD (2001), Penhale and Kingston 1995, Wilson 1994).

CONCLUSIONS

This chapter has examined how home care service providers understood and experienced assisting older couples but the necessary data proved difficult to access. The service providers supported few older couples hence they had little information to offer. Compounding this to 'make up for' their lack of data on couples the service providers tended to supply information about their home care experiences in general. This generality was not always immediately

obvious with the result that information about couples with more generalised information sometimes became intertwined. In spite of these shortcomings their data were useful. Home care emerged as a very 'feminine' service that is associated with older women who live alone. As providers and users women dominated the service with the result that it was delivered with 'women's touch' and 'women's talk'. Older men and their gender-specific needs, such as the need or desire to engage in 'men's talk', were poorly catered for and more or less overlooked.

Couples also had a low profile and were a relatively low priority. Individual centred assessment, allocation and administration procedures hindered the HCAs, HCOs and care manager in adopting a couple-centred approach to practice. Nevertheless, they revealed awareness of the privacy of marriage and the spousal duty of care and sensitivity as they tried to carry out assessments and allocate services in ways that minimised the negative impact on married service users' spousal relationships, roles and identities.

The home carers took a co-client approach in the delivery of assistance to couples but, rather than perceiving them as service-using couples, they tended to see and treat the spouses as relatively passive service recipients. They perceived the older couples' use of home care in terms of their failure to cope with their care needs and so they took care of them. This suggests a need for training to raise the home carers' awareness of the principles of service user participation, empowerment and service use as opposed to receipt. Home carers may also benefit from training and a greater level of support to deal with relational issues within care, particularly within marriage. Whilst home carers provided the same kinds of assistance to service users who lived as couples and those who lived alone, the experience of its provision was different due to relational issues. In terms of training and support they were ill-equipped to deal with these issues but they drew on their skills, (personal) experiences and 'knowledge' to empathise and support such users to the best of their ability. This points to a clear need for training. Training, policy implications and related issues raised in the chapter form the core of the final chapter.

CHAPTER 7: CONCLUSIONS

INTRODUCTION

This final chapter reviews the main findings and presents the overall conclusions of this study. It begins with a critical review of the methods it adopted, highlighting how and where the involvement of service providers in the recruitment of older couples is likely to have impacted on the data that emerged and how the process of data collection could have been improved. It moves on to recap on the collated data for each of the key study objectives and to discuss their implications for care policy and practice. Lastly, it points to a number of issues that require further investigation.

METHODOLOGICAL REFLECTIONS

The completion of this study depended on the recruitment and participation in interview of older couples and home carers. Before recruitment and interviews could begin suitable terminology had to be chosen. Familiar and everyday terms were selected on the assumption that they would be easily understood and so reduce the risk of miscommunication or alienation. However, the language of care, in spite of its familiarity, is ambiguous and, during the course of this study, there were instances, such as the case of Mrs Newman as discussed in chapter two, where the chosen terms were misunderstood with the result of the loss of potential interview participants. Interaction with older people at a pre-recruitment stage might have provided useful information about the kinds of terms that older people use to speak about care. This might have been achieved through participation, possibly as a volunteer, in organisations or groups directed towards this section of the population or by seeking and taking opportunities to speak about my study at meetings of such groups. Either of these measures might also have provided a gateway to potential interview participants and a reduction in the bias towards care service users. Qualitative research findings and conclusions are influenced not only by data collection techniques but also by who becomes involved in the research and, in turn, this is determined by recruitment methods, materials and procedures. This study's prime method of recruitment was through service providers and co-ordinators in North East Scotland. This meant that, in contrast to the majority of older spouses, the participants in this study were service users. Hence, the spouses' views on care services and their use, especially in respect of home care, cannot be assumed to reflect or be consistent with those of all older people. Furthermore, approaching only the public and voluntary sectors, necessarily excluded older couples who rely exclusively on each other and / or informal sources to meet their care needs and those who use only private sector provision or directly employ assistants, possibly with the help of direct payments. These exclusions may be expected to have had impacted on the findings of this study. For example, the low incidence of and attitudes towards familial care may to be attributable, at least in part, to the involvement of service providers in the recruitment of participants. Another contributory

factor is likely to be the wording of the recruitment material, in particular the phrase 'giving and receiving help, support and care from someone that they live with who is of a similar age but not someone younger such as a son or daughter'. This was not intended to mean that the spouses should not receive any familial care but rather that intergenerational care should not be their only source of care. In retrospect a more precise or exact wording of this intention would have reduced the risk of misinterpretation. Recruitment via service providers may have also contributed to the finding that the majority of spouses held largely favourable views on and had overall had positive experiences of care service use. However, Sinclair et. al (2000) likewise found that most users of home care services were satisfied with the service that they received. As discussed in chapter two in relation to ethics it was assumed that the involvement of service providers in recruitment was likely to limit the possibility of this study meeting with spouses whose relationships were fragile, abusive or characterised by high levels of conflict. It appears that this assumption was realised. Whilst thankfully this meant that this study avoided the problems and dilemmas that engaging with such couples may have presented, it also meant that it was unable to gather data from such couples. Thus, the findings of this study and hence its conclusion may present an overly rosy or positive and cooperative picture of caring in later life marriages. Hence, the suggestions it puts forward as policy and practice implications that promote coupledness and recommend a couple-focus, in some cases, may be inappropriate and, in extreme ones could even increase the vulnerability of individual spouses.

Finally, the services that this study approached combined with the demography of the area meant that none of the participants lived in remote locations, city centres or urban sink estates and none were not white British and English speakers. Indeed, it must be recognised that the participants were drawn from a very specific and relatively narrow sector of the older spousal caring population. Although the spouses do not and, for practical reasons were not intended to represent a cross section of older caring population, published data on a range of care issues including care tasks, reciprocity and family care, commitment to independence, significance of gender within care, marriage and other social relationships, social support and morality within care suggest that their data and by implication their experiences were not atypical (Arber and Ginn 1992a, Finch and Mason 1993, Josefowitz Siegel 1990, Mason 1987, 1996, Milne et al 2001, Milne and Hatzidimitriadrou 2002, Parker 1993, Qureshi et.al 1998, Qureshi and Walker 1989, Rose and Bruce 1995, Rowlands 1998, Taylor 1999).

The process of recruitment of interview participants proved to be a continual and steep learning curve and many lessons were learnt. The keys ones were the importance of persistence and making clear the practical application of this research when trying to secure the co-operation of care practitioners. These lessons were learnt the hard way. There were lengthy intervals between requests being made to service providers for their support in identifying potential interview participants and their responses being received. Some of these intervals, although

punctuated by attempts to 'chase up' a response, were characterised by passive waiting, others by exchanges of information and negotiations.

The practice and policy implications of this study were initially under-emphasised during contact with service practitioners. Only later, in an attempt to address the problem of how to access greater numbers of interview participants, was the practical focus sharpened and its practical value more clearly propounded. This was followed by an increase in service providers' readiness to identify suitable couples. Compromise and flexibility also played an important part in achieving a desirable outcome from negotiations with service providers.

On practical and methodological grounds it was planned to conduct group interviews with the home care service providers, possibly using staff meetings as a forum. However, when permission to interview home carers depended on the substitution of this type of interview with time limited individual interviews, this study agreed to this change. The thirty-minute time restriction initially raised concerns about how much data could be collated in such a short interval, but ultimately it helped to keep the interviews focused. Obviously, it is not possible to reflect on the experience and fruitfulness of group interviews with home carers but the interview with the HCOs and HCAs suggest that they would have fulfilled their expectations.

The couples were contacted first by letter and then by telephone about being interviewed. This technique gave potential interview participants the chance to decide together as couples whether to be interviewed and also provided a means of being able to have their queries about this study answered without too much delay. Interviewing spouses together as couples provided an opportunity to observe how they created their accounts of their care experiences whilst collating their verbal data. In particular, it proved highly effective in exposing and correcting positive or negative idealisations. The spouses often corrected their partners for example when they overestimated their abilities or put themselves down. Hence, as well as being informative this practice prevented the interview from focusing exclusively on the negative and thereby helped reduce the risk of distress. On the other hand, it might have limited the spouses' expression of their more negative feelings.

Joint interviews provided a useful method for researching how the spouses experienced care as couples but the spouses also experienced care as individuals. A combination of joint and individual interviews is then likely to have yielded a fuller and richer insight into care within marriage. The use of individual interviews might have been more suited to accessing data on the spouses' emotions. However, the individual interviews that were conducted did not yield data about such issues that was any richer than those accessed in joint interviews. This suggests that cultural factors may have contributed to or accounted for why the spouses said so little about their feelings.

Although each of the aforementioned measures could have had profitable results, there is no certainty that this would have been so or that their application would be practically possible. Finally, they do not devalue the methods that were used or the data that were collated.

UNDERSTANDING CARE IN LATER LIFE MARRIAGES

The revised aim of this study was to gain an insight into care within later life marriages. This was made up of five interlinked objectives; namely to emphasise and reflect on the breadth of care within later life marriages, to explore how gender structures older spouses' perceptions and experiences of care, to consider the influence of interdependency on spousal caring relationships, to examine what kinds of support spouses received from the different elements of their social support networks and, finally, to analyse how home carers experience and perceive older married couples' use of home care.

To explore these objectives this study recruited and interviewed forty older spouses and fourteen home care service providers and a care manager. The spouses, who ranged in age from mid sixties to early nineties, were living in their own homes and dealing with care needs mainly arising from physical disabilities. All the participants lived and or worked in two local authorities in the North East of Scotland.

The Breadth of the Couples' Care Experiences

Care tends to be thought of in terms of the provision of a fairly limited range of supportive activities; in particular, social and emotional support and practical assistance with domestic and personal care to an individual or individuals. This study revealed that this kind of narrow conventional definition of care, as so often adopted in research, policies and provision, failed to capture the complexity and breadth of the care experiences of the spouses who took part in this study.

Looking after each other; tending to each other's physical needs and general well-being was central to the spouses' care experiences but disability impinged not only on the spouses as individuals but also on their marriages, their life styles and quality of life and their social lives. Thus, care involved looking after all these different aspects of their lives and relationships. So alongside the provision of emotional, sentient, practical, social and spiritual support, the spouses undertook activities aimed at maintaining their homes, their status and identity as married couples and their social contacts and roles.

Masculine domestic care activities – home and garden maintenance and driving – and socialising played a crucial part in helping the couples to continue to live independent and socially valued lives within their communities. Hence, when they were unable to carry out these activities, they had to find assistance with such activities and in this respect they were unquestionably part of the couples' care experiences. Nevertheless, the couples received almost no statutory help to meet their home and gardening maintenance needs not to even to help them find suitable assistance. Officially, home care service providers had neither the remit to assess service users' needs for help with such activities nor access to appropriate practical resources to offer them. Furthermore, they seemed surprised at the importance that the spouses, especially

the men, attached to such activities. This contrasted starkly with the empathy that they expressed towards women who wanted support to help them meet their domestic standards. To address their need for assistance with travel and home and garden maintenance the couples looked to either private sector services or their social support networks. The former were often expensive and finding suitable ones was frequently difficult. The availability of assistance from the latter was variable, varied and restricted by the couples' moral values. Thus, accessing assistance with masculine domestic activities was more or less a matter of luck. This study argues that reliance on fate to access assistance with activities that help maintain independence is unacceptable.

Care infused and impinged not only on the domestic and practical aspects of the spouses' lives but also on their social activities and relationships, making these an integral part of their care experiences. The couples' social activities showed great variation but going out socially offered the spouses, individually and as couples, respite from their caring routines, social and emotional support and the opportunity to present themselves to external audiences and thereby express and (re-)affirm their spousal identities. In these ways socialising served the spouses as an invaluable coping strategy, a means of maintaining their quality of life and of preserving their spousal identities.

Many of the foregoing points as the importance and function of masculine domestic activities and socialising are applicable to care experiences of older individuals as well as couples. However, how these activities contribute to and are part of domesticity within later life marriages and how older husbands and wives understand and fulfil their spousal roles mean that they have an extra dimension within the later life spousal caring relationships.

Duality of Care: Gendered Individuals and Spousal Interdependency

Although nationally a greater proportion of men than women beyond the age of 65 are carers, care is traditionally associated with women and is often explained or understood in terms of gender (Scottish Executive 2002a). Gender, in particular femininity, provided a useful but partial understanding of care within the spouses' marriages. In many ways how the spouses experienced and understood care appeared to confirm gendered care norms, expectations and assumptions but it also challenged, confounded, defied and contradicted them. Within the spouses' marriages, care was a 'women's issue', but, in practice, it was also a men's and relationship issue. This was because there was a duality to spouses' perceptions and experiences of care: they made sense of and exchanged care not just as gendered individuals but also as couples. Thus, spousal interdependency as well as gender structured their experiences and conceptualisations of care. The duality of the spouses' care experiences was clearest in the domestic sphere but it was evident in their social lives, service use and personal relationships. Consistent with gender expectations, the spouses believed in, had and, where possible, still adhered to the propriety of a traditional division of domestic labour. The women assumed

responsibility for and, as far as they were able, carried out 'feminine' activities such as cooking, cleaning, laundry and shopping within their relationships while the men assumed responsibility for masculine domestic activities – home and garden maintenance and driving. This suggests that the spouses would identify the carrying out of feminine domestic activities as care only when men performed them but they identified the provision of domestic care as care regardless of the gender of the provider.

Disability disturbs the equity or balance within relationships and those involved must seek to re-establish it for the relationship to continue. In the process of re-establishing the social balance in their relationships the spouses appeared to redefine and to appreciate the women's provision of domestic care.

Although most of the men had driven and, to some degree, had personally maintained their homes and gardens, few continued to carry out the latter kinds of activities but rather accepted formal or informal assistance. The fact that, in general, the men struggled less tenaciously than the women to remain autonomous in their domestic activities, was consistent with traditional gendered as well as ageist expectations. Nevertheless, most of men spoke of having tried to continue and some were quite distressed and uncomfortable about giving up and accepting help with these activities. This was especially case, where these activities had formed part of the men's professional roles and identities. In spite of this, possibly because of assumptions about men's ease of acceptance of assistance based on their receipt of help with feminine domestic activities, service providers did not appear to appreciate the distress that such loss brought. These findings then call for a greater recognition of the importance of masculine domestic activities to men, their significance within marriage and the challenge that accepting assistance with them represents.

The importance of masculine domestic activities to the independence of older couples should not be underestimated, but, as carers, both the men and women prioritised feminine domestic activities over masculine ones. This was because the former included more basic forms of care and nurturing than the latter and so they were more fundamental within the care context. At the most basic, the spouses had to eat and this meant they had to prepare meals and carry out, at least, a minimal level of cleaning such as washing up. Furthermore, failure to carry out such tasks tends not only to result in an unpleasant home environment that may potentially be harmful to health but it can also lead assumptions being made about coping and vulnerability and need for services. Where family or caring agents such as GPs and district nurses make and act on such assumptions, this can, ultimately, end in intervention that for spouses may threaten or undermine their self-esteem, spousal autonomy and even household form. However, one of the main reasons why the men in this study undertook feminine domestic activities was that it was perceived, morally, as 'the right thing to do' in their circumstances. The provision of care, including domestic care, was about being a good caring spouse. It was about who and what they were and what their marriages were all about. Thus, caring became incorporated into the

spousal roles and identities of the men as well as women. This seemed to defy spouses' own beliefs about gender roles as well as gendered care expectations in general. Yet, it actually exemplified the realisation of spouses' values and understanding of marriage and the influence of interdependency and affection on their experience and understanding of care. This interweaving of care into men's identities represents the strongest challenge to gendered care assumptions and expectations identified within this study.

Care, Social Relationships and Services

The spouses' social networks were made up of their friends, neighbours, families and service providers.

The support network types of three-quarters of the couples were identified. Of these the most common was the locally integrated, followed by local self-contained, local family dependent, private restricted and wider community focused. The network type of five couples could not unambiguously be identified. The identification of the couples' network types was based on information that they provided about their families, social circles and contacts generally rather than in responses to questions aimed specifically at identifying their network type. Thus, this may have contributed to the difficulty in identifying their network types. However, changes in their health status and composition of their families and social circles alongside environmental factors, in particular, living in low populated rural settlements with poor public transport provision also fostered a lack of certainty or clarity as to these couples' network types.

Wenger (1994) found that, in accordance with availability of informal support and dependence, different network types tended to be related to different patterns and levels of contact with service providers. In this study there was no clearly discernable relationship or association between the network type and service use. Whilst the limited number spouses involved may have attributed to this, that the majority was recruited through either voluntary sector or public sector care services and all were users of care services provide the main reasons for it.

Regardless of their network type, the couples constructed their formal and informal caring relationships quite differently and the support that they accepted from within these relationships tended to compliment and supplement rather than serve as a substitute for one another. An exception to this was the spouses' acceptance of help from home care with personal and domestic care needs that they were unable to provide but would otherwise have done.

The types and amounts of care that the couples accepted within their social relationships reflected their morality; they accepted what they felt or judged was appropriate or right to any particular relationship. Hence, care was acceptable only when it did not transgress the principles of reciprocity or notions of fairness in context of friendship, neighbourliness or being family. This principled approach to the acceptance of informal care served to protect the spouses' relationships from the strain and corrosive effects of a uni-directional flow of care and so preserved them as social relationships. This meant that when couples interacted with their

kith and kin they did so in the socially valued roles of friends, neighbours and relatives. Such interaction assured them of their self-worth and identity.

The couples conceptually divided service provision in two distinct forms of support; namely specialist/specialised help, such as physiotherapy, and care. They viewed the former as helping them to address their incapacities and to maintain their independence but the latter as confirming the growth of their failings and dependence. In spite of this, and their dismay at their need for care services, the couples actually valued this sort of provision highly because it offered them the means to meet their needs and still observe their moral principles. The use of formal care services like home care offered the spouses an acceptable way to address their practical care needs that protected their informal caring relationships from inequity and prevented their identities and reputations from becoming spoiled. Consequently, service use was the spouses' preferred option, to meet their everyday practical care needs. Yet, the possibility cannot be denied that these findings and conclusions about the spouses' care preferences may have been influenced by this study's recruitment materials and the spouses' service user status.

Unlike their personal relationships their relationships with service providers were rooted in the formal economy and existed because of care. The spouses paid for the care that they received or had paid for it over the years through taxation. They were entitled to it.

Although the couples made sense of care services in terms of the formal economy, they did not adopt a consumerist approach or attitude towards accessing such provision. They did not expect nor want to find and access services at times of crisis, uncertainty or heightened vulnerability, such as a change in their health. At such times, they channelled their energies into emotionally supporting each other, adjusting and responding to their crises and what they meant for them as individuals, as spouses, and their marriages. Hence, they not only wanted and but also needed and expected service providers to arrange services for them; they viewed it as their responsibility. Where this did not happen, the couples considered it to be a dereliction of duty and felt uncared for. This view stands in stark contrast to the positive view of consumerism, as empowering and increasing choice, found in service policy and practice. In respect of this issue, this study suggests that there are times, such as crises of care, when older people need want and need service providers to act in their best interests and when they do so they feel supported and cared for. In this way, such action helps them through their crises. However, it should be recognised that this is not an argument in favour of ongoing paternalism that sees and treats older couples as passive recipients. Service provision must always seek, encourage and creatively enable its users to express their opinions and be ready to respond.

Irrespective of whether assistance was informal or formal, the spouses constructed it as helping them as individuals and as couples. It helped the spouses who actually received it with their care needs, it helped their partners fulfil their caring responsibilities and it helped them as couples to manage the demands of care. Similarly socialising with friends, either as individuals

or as couples, provided the spouses with support and respite that boosted their self-esteem and helped them face the challenges of care. This duality starkly contrasted with the individual-centred procedures, policies, and administration systems operated by home care services.

Home Care and Married Older Service Users

The final objective was to explore and analyse how frontline home care service providers made sense of and addressed the service needs of older couples. Information on this was difficult to access. The social work departments in this study were able to supply neither the number nor the proportion of older service users who were married because their administration systems did not recognise couples. Access to information on couples was made even more difficult by the service providers' tendency to speak about service users generally rather than specifically about older couples. They attributed this to their much greater experience of supporting service users who live alone but there were at least two other factors; namely the dominance of 'individual-centred' policies and procedures and what might be termed a 'relationship-blind' approach. The service providers, especially the home carers, insisted that they treated everyone alike regardless of their marital status. This finds a resonance with the colour-blind approach, which Dominelli (1988: 36) argues not only ignores race but also dismisses it as insignificant and unimportant. By implication a 'relationship-blind' approach overlooks or, at best, undervalues the significance to service users of their marriages (or other most important other relationships) and their influence on their experience of care. The danger of this is that it dismisses what, possibly, matters most to these services users and its significant influence on their experience of care. On the basis of this research, training and awareness raising about the weaknesses and potential risks of these 'the same approaches' can only be recommended.

In spite of their apparent 'relationship-blind' approach, the service providers were actually conscious of the fact that marriage impinged on the experience of supporting service users. Assessing providers felt that carrying out assessments on married service users was more intrusive and challenging than on service users who live alone. In particular, they felt hampered in their efforts to carry out individual needs assessments by the interdependency of long-term married service users and the ideology of marriage. They faced a further challenge in how to introduce services to couples so that their needs were met but caring spouses did not feel sidelined. At the root of these difficulties was the incompatibility between the duality of the couples' experience and understanding of care and individual-focused approaches and methods available to these services providers to assess and allocate service provision. As the couples' experiences show, the assessment of individual needs alone sometimes can result not only in inadequate assessments but also the allocation of inappropriate or unsatisfactory services. This suggests that the individual needs assessment could be replaced by joint assessment. However, this could result in some loss of the benefits and advantages of individual assessments, in particular the identification of and attention to individual needs. In relationships characterised

by exploitation, abuse and or conflict and in cases where the spouses' individual needs are incompatible this could have significant and serious consequences. Indeed, it may even facilitate of abuse. Hence, an appropriate and comprehensive assessment of the needs of older long-term married spouses is likely to be achieved not by substituting but by complimenting and combining individual need assessments with a method of assessment that focuses on their needs as members of couples.

One of the professionally qualified assessing service providers drew particular attention to how the close relationships between care, marriage and femininity can make the acceptance of home care services particularly difficult and distressing for older women who are trying to look after their husbands. She pointed out that although she tried to offer such women support, what she could do was limited and in general the 'service' does not acknowledge older women's need for support to adapt to the impact of care on their role and identity.

The home carers were also aware of the distress that care could cause older couples. They had to battle with the emotional demands of providing support to spouses who were upset and whose marriages were strained. With limited training and guidance on such matters they drew on their own personal experiences and assumptive worlds to try to support the service users as best as they could and to cope personally with the demands of this work. This study is not in a position to ascertain whether the approaches that the home carers applied, namely adopting a neutral stance, playing down arguments or offering a listening ear and a shoulder to cry on, were adequate or suitable to the situations that they were dealing with. However, it is convinced that to expect frontline service providers to cope with complex situations that challenge them emotionally or physically without formal training, adequate guidance and focused support and supervision, is unacceptable and unsatisfactory. It is also incompatible with the provision of a high quality or best value service. Training in relationship issues and awareness raising about exploitation and abuse in later life are likely to assist the service providers identify the adequacy of their input and focused supervision should help them to manage the stresses of their job and recognise the limits of their role.

The pressure to provide 'added extras' was a further source of stress that the home carers had to manage. Consistent with key pieces of research into local authority home care / help carried out by Warren (1988) and Sinclair et al. (2000) this study also found that frontline service providers did not just provide a formal service, they cared and so they supported and assisted service users in ways that were beyond their remit. During their working hours they bent rules, in particular health and safety ones, to carry out activities that matter to the service users but which they were not contracted to do and provided the assistance voluntarily in their own time. They chose to offer such support for their own satisfaction of doing a good job but they also undertook them so as not to feel guilty by not doing them and in response to direct requests or manipulation. Nevertheless, they did not provide such assistance uniformly. Typically, they offered it to service users with whom they had a good relationship, with whom they were able to empathise

and whom they assessed as having no alternative source of support. The subjectivity of these selection criteria injects an unacceptable element of discrimination or 'lottery' in the meeting of care needs. Moreover, this study suggests that this 'lottery' is likely to be weighted against older men and couples having their needs met. Typically the home carers were less able to empathise with men than women and they viewed spouses as having each other. Yet, as examples within this study showed, older spouses are sometimes unable or ill-equipped to meet each others needs, especially those, that relate to the expression of their gender like baking, browsing and shopping for gifts and outfits.

Helping service users to meet their care needs by bending the rules and providing care voluntarily could have, theoretically, resulted in the home carers facing disciplinary action. There were no examples of this and the possibility of this happening seemed unlikely. The service providers in supervisory positions were aware that their supervisees supported service users in these unofficial ways. Indeed, they referred to such input to illustrate their arguments as to the calibre of this work force and the quality of the service that they gave. This study does not dispute these quality issues but suggests that other conclusions can be drawn about this extra care.

Firstly, it shows that to meet the needs of service users the service relies on and exploits the goodwill of its workforce. This is likely to increase the stress of these service providers, which is likely to rebound on their personal performance and commitment to the service. This may ultimately increase staff turnover and this would impinge in the longer-term on the level and quality of service provided to users.

Secondly, it shows that those caring at the formal/informal care interface are under considerable pressure to assume informal caring responsibilities. This highlights the need for clear guidelines and effective support and supervision to manage these stresses and to understand the boundaries of their role.

Thirdly, this well-meant support serves to hinder the official recognition of and response to these needs for it helps keep them hidden. In this way the home carers' deviant and extra support hampers the development of a needs-led service that is sensitive to and respectful of the values and standards of older people.

Fourthly, it emphasises the failure of community care policies and service provision to understand and respect the values and standards as well as the physical needs of older spouses. To many older women, both within this study and in the wider community, housework matters. The home carers recognised this with the result that much of their rule-bending resulted from carrying out various forms of housework. Services that purport to support older people should be built around what matters to older men and women as spouses and individuals rather than economic or rational arguments because these alone are unable to take into account moral values and standards. Such services would ease the pressure on home carers to do more than they are contracted to do.

The issues surrounding 'delinquent' care are not couple specific, other than the fact that they are less likely to receive such support. Nonetheless, they are relevant in that they have significant implications for the ongoing quality of the service to all its users.

Service Use: Comparison of the Service Providers' and the Couples' Points of View

The couples and the service providers attributed almost antithetical meanings to the function of home care. The couples used home care to manage their care needs. It was a tool or coping mechanism. The service providers, especially the home carers, perceived home care as a service that rescued older people who were failing to cope.

In the complex and harsh reality of the day-to-day care, whether older couples are failing to cope and home carers are stepping in to rescue them or whether home carers enable older couples to manage might appear to be a rather contrived academic question or a matter of semantics; but it has real implications. How service providers perceive service use is likely to impact on their general approach to the delivery of the service, their interactions and discourse with users. In turn these are likely to determine how older couples experience their use of the service. An enabling perspective should promote a needs-led approach to service delivery that empowers, encourages, and supports service users to express their opinions and use services as tools or cogs in their coping strategies.

A rescue perspective should produce the opposite results. It is likely to foster a 'to do for' approach to an interaction and discourse that emphasise or reiterates the users' dependence and failings resulting in the further erosion of the service users' independence, skills, self-confidence, self-esteem and sense of control.

The home carers were familiar with the idea of service user choice but they acknowledged that they exercised the control over service delivery. They interpreted this control as evidence that service users were satisfied with their input. They gave no thought to the part that ageism or the service users' vulnerability, identities, reputations and lack of skills of articulation and assertion played in the lack of control that most service users exercised. The minority of service users who clearly stated what they wanted, the home carers viewed, not as pro-active in their use of the service but as difficult, complaining or awkward. This suggests that the home carers need guidance and support to develop a clearer understanding of service user involvement and choice and how to implement these principles in their practice so as to put control into hands of service users. Yet the effectiveness of such measures could flounder depending on how home carers feel about service user choice. For many of the home carers caring, including provision of home care, was closely bound up with their personal identities and sense of self-worth. Since they assumed the service users' lack of direction was a commendation, by implication, they may interpret being told what to do and how as personal criticism and thereby the erosion of their morale.

Although the home carers acknowledged that they controlled the delivery of the service, they were confident that they provided what the service users wanted because they knew them, what they liked and what mattered to them. The couples who regularly received this service from a specific provider largely bore out this claim. This 'knowledge' and its realisation or practice as sentient activity or sensitive caring were regarded as a sign of quality by service users and the home carers' immediate management. Furthermore, they attributed the home carers' ability to deliver such care and gain such knowledge to their personal qualities rather than honed skills. From this perspective, the skills and knowledge that underpin sensitive caring cannot be taught or developed. In getting to know service users the home carers did not rely on the detail within service users' care plans; they interacted. In this process they drew on and applied skills that they had developed through their experiences as women and in particular as women taking care of others. In her research into care and sensibilities, Mason (1996) stresses that women are more commonly skilled in sentient activity than men but such skills are not gender specific; they can be learnt or developed. The validity and benefits of the kind of 'knowledge' that home carers had developed and used to offer sensitive caring should be more widely acknowledged within caring services. The skills and techniques involved in their acquisition and application should not be dismissed as facets of caring personalities or intuition but recognised and valued for what they are, namely highly developed interpersonal skills and techniques. Moreover, the development and practice of such skills and hence sensitive caring within care services should be promoted and supported within care services through mentoring and training. However, any such developments must address the issue of gender bias currently found within sensitive caring. In getting to know and in supporting service users, the home carers interacted and identified with them as women. This meant that they were able to provide women with more finely tuned sensitive caring than they could offer men.

This study was unable to examine whether the situation is reversed in cases where men deliver the service because all the home carers were women. Consequently, whether an increase in the numbers of men employed within this service would suitably address this imbalance remains an open question. However, the issue of how to provide older men and women with a comparable degree of sensitive caring must be resolved because home care, in spite of the dominance of women, is not exclusively a women's service.

Summary of Contributions

The completion of these objectives has contributed to the understanding of how older spouses perceive and experience care as well as to the identification of strengths and weaknesses in community care policies, provision and practices. By understanding care in terms of relationships it has provided an alternative perspective on care that emphasises the complexity of the spousal care experience. Firstly, this study has drawn attention to how gender and spousal interdependency combined to structure care within long-term marriages in later life,

how caring is bound up with the personal and spousal identities and moral values. These findings challenge established gender-based understandings of care.

Secondly, it has demonstrated the need for the adoption of an expanded definition of care to include, at the very least, masculine domestic activities, within community care policies and provision in order to adequately and appropriately support older couples within their communities.

Thirdly, it has shown that spousal caring relationships are sited within networks of supportive social relationships. Older couples should be viewed in the context of their social networks rather than isolation and offered support to sustain their socially valued roles and relationships, including their marriages, friendships and kinships.

Finally, it has revealed how the individual-focus of home care hampers its recognition of the significance of the duality of older couples' care needs and experiences and thereby impairs its ability to provide an optimal service to married service users. In respect of this, it should not be overlooked that whilst currently older couples make up only a minority of home care service users, demographic predictions suggest their numbers, proportionally and actually, are set to rise.

POLICY IMPLICATIONS

Older married couples represent a minority within the home care service user population but it is a significant minority and demographic projections point to its actual and proportional expansion. In spite of this, limited research has been conducted or published on home care service provision to older couples. Hence, this study has made an early contribution to understanding this aspect of service provision. In particular, it has highlighted the need for policy makers to recognise older couples as a service user group and respond appropriately to their specific needs. The spouses' experiences suggest that care policies and services currently underestimate the breadth and complexity of the care needs of older couples.

Masculine domestic activities are important to their independency and as such should not remain hidden from official scrutiny but should be examined and assessed as care needs. Their absence or superficial treatment at every level of care policy and practice is unsatisfactory and potentially injurious to the independence of older couples.

This study also suggests that the failure of community care services to recognise and respond to such needs shows their lack of sensitivity to and disregard for the value and meaning that some men attach to these activities and the contribution that they make to the reciprocal balance within marriages based on a traditional division of domestic labour.

Thus, to support older spouses effectively to live in(ter)dependently as couples within their communities demands that community care policies and services acknowledge the extent and complexity of their care needs and, accordingly, expand their definition of care. Assessments of needs should explore with older spouses whether they have difficulties with the maintenance of

their homes and gardens, with travel and with participation in social activities and what the loss of these activities means to them. Wherever possible, identified difficulties should be followed up with an allocation of or direct referral to suitable service provision. Where this is not possible information about where to access advice on available sources of help should be offered. To facilitate this, service providers require access to information about a much wider range of types of provision than they currently have. This may result in a need for training. Improved dissemination of information about existing services should help older couples access suitable services but the improvement and expansion of existing services and development of new ones are required to address the inadequacies and gaps within current provision. Ultimately care service provision should be comprehensive and seamless and so match the care experience of older couples.

Whilst recognising its service user bias, this study provided further support for the conclusion drawn by Qureshi and Walker (1989) and Finch and Mason (1993) that community care policies are out of step with how people understand their family responsibilities. The couples cared about their kith and kin and felt that they cared about them but they did not want their kith or kin to routinely assist them to meet their basic everyday hands-on care needs. Instead, they preferred and believed it right to use services for this purpose. Moreover, they suggested that their use of services supported and protected their family relationships. However, again, it must be acknowledged that the recruitment materials and methods used in this study may have inhibited the involvement of older spouses who wanted and received or were prepared to rely on their families for practical assistance.

The service providers did not share the couples' views on informal care and service use. On the contrary, they assumed that the use of home care meant the service users' families neither cared about nor had any real interest in them. Furthermore, conscious of the economic constraints on the service and scarcity of community resources, they encouraged service users to utilise their families as fully as possible as a care resource.

To conceptualise and to treat the kith and kin of older people as care resources dismisses and disregards older people's views and values and hence demeans and devalues them as citizens. This defies notions of service user choice. It is also likely to lead to the erosion of their self-esteem and self-worth and possibly thereby their sense of well-being. Moreover, inadequate service provision does not necessarily lead older people to ask or accept their relatives to make good any shortfall in their need for assistance. Some will (try to) purchase assistance, in some cases at the risk of facing financial problems while others will struggle on with unmet needs and so endanger their general well-being. Alternatively, older people may seek and accept practical help from their relatives only to find the demands of caring change such relationships in ways that diminish their social and emotional support capacity. Indeed, in their longitudinal research into older people's relationships, Burholt and Wenger (1998) identified a decrease in emotional closeness between adult children and older parents overtime. Furthermore, the oldest amongst

the older population who need support are likely to becoming older people themselves and possibly less physically able to meet their parents needs (Burholt and Wenger 1998).

Thus, this study urges service providers as well as policy makers to recognise the limitations and the dangers of family care within service provision. The forced application of assumptions about family within community care practice could ultimately generate greater rather than reduce levels of service use.

In summary, care service providers and policy makers need to listen more closely and carefully to the views of older people if they are to support them with the kind of provision that respects their values, meets practical care needs and supports their supportive networks. Targeting, ever-tighter eligibility criteria and economic stringency together with practices rooted in assumptions about preference for and superiority of informal or family care, at best misunderstand or show a lack of respect for older couples' values and principles and views on how they to meet their needs.

NEED FOR FURTHER STUDY

A number of issues emerged in the course of this study that require further investigation:

(i) Caring Across Long Distances

Over half of the couples had close family living a long way off. In its analysis of their support networks, this study reflected on how the spouses experienced and attributed meaning to support and care from such kin but this is only one side of such caring relationships. In an increasingly ageing population, in which different generations often live far away from each other, how families care across long distances requires further research to identify how services can best support this type of caring. Research into this topic should also include an examination of the long distance travel needs of older people and how these might be addressed.

(ii) Different Types of Intra-generational Caring Relationships

This study originally intended to examine care not only within marriage but also other types of co-resident relationships in later life. This aim was not carried through for the practical reasons outlined in chapter two but the findings of this study suggest that such research is needed to understand their experiences of care and service use of non-spousal caring relationships and to identify their service needs. For instance, older married couples represent the most common co-resident intra-generational caring relationship and household form in later life but within home care, the most extensively used domiciliary service in later life, they form only a minority of service users. Moreover, within this service they and their specific needs are both low profile and, arguably, low priority. This raises questions as to how this service and other care services conceptualise and address the needs of older service users, who form even smaller minorities, and how they experience such provision.

(iii) The Influence of Home Carers on the Realisation of Service User Choice

This study did not firmly establish how skilled the home carers were in seeking the views of service users nor how they felt about being asked to care in specific ways. However, on the basis of their assumptions about why some service users specified how they wanted the services delivered and some did not, this study recommends further research on this issue. This should usefully provide a clearer understanding of how these service providers experience service user choice as carers and women and to reveal the kind of support as well as skills that they require to encourage and foster service user choice and empowerment.

(iv) Men as Home Carers

Characteristic of the gender bias within home care all the service providers who took part in this study were women. Their data reflected how their feminine experiences structured their understanding and approach to service provision. There is a clear information gap about men in home care. How do men who work as home carers perceive and approach the service and their role within it? What models do men base their practice on, what skills and attributes do they bring to home care and do they respond to the gendered needs of men in ways that mirror the femininely sensitive response of their female counterparts? These are all unanswered questions? Moreover, how do older men perceive and respond to men in this role? Such information should aid the development of a more equitable service for both older men and women.

CONCLUSION

For the spouses in this study care was about how they lived their day-to-day lives and realised their relationships with each other and with others as men, women and couples. Despite this, care did not reduce their lives or marriages to caring careers or relationships. They were first and foremost spouses not carers and care recipients. Caring was their way of life because it enabled them to continue to live together independently as older couples within their communities.

APPENDIX 1

ARE YOU WILLING TO TALK TO ME?

Who am I and what am I doing?

My name is Alison and I am a part-time student. I am studying how older people think and feel about giving and receiving help, support and care from someone that they live with who is of a similar age such as a friend, brother, sister or but not someone younger such as a son or daughter.

How am I carrying out my research?

I would like to talk to anyone who fits the above categories, who are aged over 65 and who are providing or receiving help, support and care. I would meet both individuals together e.g. a husband and wife.

What would taking part in this research involve?

I would initially contact you by phone and make arrangements to meet. When we meet it would be more or less be a case of talking to me about your experience of care. If in the course of discussions anything arises that you would prefer not to talk about the subject can be dropped. I usually spend between an hour and one and half hours with a couple/ partners.

What type of topics would be discussed?

I am interested in finding out about what is involved in caring for / being cared for by a person you live with. For example,

- How you cope with needing or giving care. What aspects of care you dislike/ enjoy, worry about and why.
- How you think and feel about help (or lack of it) provided by paid carers such as home carers and district nurses and unpaid carers such as family, friends.
- Whether giving or receiving care influences the way you think about and see yourselves.
- Which aspects of your life care has changed and how you feel about such changes. For example, has it affected your leisure activities /social life etc.?

What will happen to the information you provide me with?

All information that I am given will be treated as confidential and with respect. When I write up the findings of my study I will not use people's real names or give any other details that would allow them to be identified. Therefore, your information, whilst very important, will remain anonymous.

 We ----- (please give name) would be willing to talk to you and can be contacted on -----(please give telephone number).

We -----(please give name) would like more information before deciding whether to talk to you and can be contacted on -----(please give telephone number).

We would not be willing to talk to you.

Please return your slips to

ARE YOU WILLING TO TALK TO ME?

Who am I and what am I doing?

My name is Alison and I am a part-time university student studying care and older couples. Home care is very important to many older disabled people as a significant source of care and contact with the outside world. So how does home care influence the how older couples feel and think about giving and receiving help, support and care? This is one of the main questions that I am asking and trying to answer as part of my research.

How am I carrying out my research?

I am meeting with older couples, service organisers and people, who work directly with older couples, such as home carers and listening to their views on care.

What type of topics am I interested in?

I am particularly interested in finding out from home carers about

- How you assist older couples/ partners
- What training or support you get to help you carry out your work
- What contact you have with older people's family, other professionals e.g. district nurses etc.
- What sort of relationships you have with the people that you assist.

What would being interviewed involve?

I would initially contact you by phone and make arrangements to meet you. When we meet it is then more or less a case of simply talking about your work. With your agreement I will tape our discussion.

What will happen to the information that you provide?

I will treat all information with respect and as confidential. When I write up the findings of my study I will not use the real names of people or places and will disguise any other identifying details. Thus, your information, whilst very important, will remain anonymous.

 I ----- (please give name) would be willing to talk to you and can be contacted on --
----- (please give telephone number).

I ----- (please give name) would like more information before deciding whether to talk to you and can be contacted on ----- (please give telephone number).

I would not be willing to talk to you.

Please return your slips to

APPENDIX 2

INTERVIEW GUIDELINE FOR USE WITH OLDER COUPLES

Context

Could you tell me a little about the background to your current situation for example how long have you had a problem with, when did you develop, What sort of problems or limitations does having cause for you ? How did the current pattern of care develop? Have there been significant events or major turning point in the way your disability / the current pattern of care developed? Why were these so significant?

Coping, Self Care & Care within the Relationship

On a day-to-day basis how do you manage or cope with your disability?
What sort of changes has this meant for your day-to-day routine and your overall life style? E.g. is there anything in particular that you either do or do not do to help you cope? How do you feel about these changes? What do you think makes you feel this way?
What types of things do you require help with? Who provides you with the help you need? How do you feel about receiving this help? What type of care do find or would you find the most difficult to receive from your partner / other carers? Why?
Is there anything you need help with but which your partner is unable to assist you with? Is there anything you would either do or do more of if it were not for your disability?

In what ways do you look after your partner? How do you cope with your partner's disability and or looking after your partner? For example, is there anything you would either do or do more of if it were not for caring for your partner?

Is there anything you do or do not do to help you manage? Have you had any other experience of looking after someone? What sort of changes has this meant for your day-to-day routine and your overall life style? How do you feel about these changes? What do you think makes you feel this way? What type of care do find or would you find the most difficult to provide for your partner? Why?

Are there any ways in which your partner looks after you?

Do you have any pieces of equipment or use any special techniques to cope with your or your partner's disability e.g. a wheelchair or special cutlery? Are there any pieces of equipment or techniques that you would like to have? Have you given up using any pieces of equipment / techniques? Why?

Have you made any changes to your home e.g. not using upstairs rooms?

Terminology

Professionals might call you a carer – how would you describe yourself? Would you consider applying term carer to yourself? How would you define a carer?

You have how would you describe this ? As a disability?

Care from Other Sources

Does anyone else help you or your partner? Who helps you and with what? In respect of services, how did you decide and begin to get help from this service / these services? Who benefits from the receipt of this care/ support? How do you feel about this help? What makes you feel this way? How do you feel about someone coming into your home to provide care? Are there any differences between care from your partner and care from a service provider/

other carer? Why are they different? What are the advantages and disadvantages of using a care service?

Impact of Care

What do you think are the consequences of disability / caring for you? {e.g. changes in social life, financial circumstances, life style, responsibilities within your household and or relationship etc}? Are there any aspects of your care situation that you find difficult or are unhappy about? Why? Are there any aspects of your caring situation that you enjoy, like or feel positive about? What recent events have you enjoyed? Is there anything that you are looking forward to?

Why do you think your partner looks after you? Why do you care for your partner?

APPENDIX 3

INTERVIEW GUIDE FOR USE WITH HOME CARE ASSESSORS AND ORGANISERS

1. Could you outline your job?
2. What type of households do your service users live in? Approximately, what is the proportion of older services users who live with someone, such as a spouse, sibling or partner, of a comparative age? [If the figure given seems quite low the why this might be.]
3. To what extent does the service (including the paperwork) recognise / accommodate couples? [E.g. would a couple be defined as service user and partner two individual or service users or a couple or in some other way?]
4. What contact do you have with directly with older couples? What contact do you have with home carers and others who are involved with service users e.g. their families, other professionals?
5. How are referrals made to you? What happens once a referral has been received?
6. How do you introduce yourself when you met service users? How do you explain your role to older couples? How are you received? Could you talk me though how you complete a home care assessment (or depending on response to previous question other type of intervention / contact)? What are the basic criteria that have to be met for a couple to be allocated home care? Why might you refuse a service? How do you decide what level of service is required? What sort and level of input do potential service users have in the assessment, allocation and revision of service procedure? Do service users receive a copy of their assessment of needs, a service agreement etc.? How do you ensure that the service is delivered to couples in a way that find they acceptable? How do you become aware of changes in the needs of service users and what happens when you learn of such changes?
7. How do you view service users' partners? (Whether and how this question is put will depend response to question 3. Also as necessary, suggest that service providers sometimes see a service user's partner as an equal co carer alongside a home carer, as someone whom a home carer assists with the caring, as someone who is no longer able to care for their partner but who do not personally need care, someone who needs home care for their own care needs).
8. What other sources of assistance or care do couples / service users and their partners have? How does home care fit into the overall care provision?
9. What type of comments do you receive about the service e.g. complaints, compliments, action such as withdrawal from the service. Who makes such comments? How do you deal with these?
10. What is care? Would you define it differently depending on who was caring for whom? What are the key attitudes and skills that home carers need to have? How do you ensure this is the case?

11. What did you do before becoming a home care organiser/assessor? What training or induction did you get when you began this work? What qualities and experience do you think you need to do your job (attributes, training experience)?
12. Are there any guidelines, policies or regulations that you have to follow to help you in your job? How do you think or feel these influence how you work? Can you give examples? Do you think service users, their families and home carers are aware of these policies, guidelines etc.? Why? How do you explain the guidelines etc. to the service users, their families and home carers? What sort of reaction do you get?

APPENDIX 4

INTERVIEW GUIDE FOR USE WITH HOME CARERS

1. What type of households do your service users live in? Who do your service users live with? Why do you think there are so few service users living with a spouse or partner? In the case of couples / partners is just one partner or both partners service users?
2. How do you introduce yourself and describe what you do when you first meet a service user and their partner?
3. What type of things do you do as part of your job? Could you talk me through a typical visit to a service user and their partner? How would you describe your job?
4. How does working with a service user who lives with a partner differ from working with a service user who lives alone?
5. What do you think is the most important aspect of your job? Why? Is this also the most important aspect of your job in the case of a service user living with a partner?
6. What other sources of assistance or care are typically available to service users and or their partners? How does home care fit into the overall care provision?
7. What sort of contact do you have with other home carers, home care organisers, other professionals, service users' family etc?
8. How do service users and or their partners shape the assistance and support that you provide, for example do they ask you not to do certain things or to do things in a certain way? How do you feel about this? Are there any differences as to how service users living alone and those living with a partner influence the support you provide?
9. What type of things do you find that service users and / or their partners like or want to ask or talk to you about? Are there differences between the topics service users living alone and those living with a partner choose to talk about?
10. Do service users and / or their partners ask your opinion or seek your advice on any issues? Could you give me examples? How do you handle such questions? Do service users who live alone also ask you about the same type of issues and do you deal with them in the same sort of way?
11. Do your service users have unmet care needs? Do service users and or their partners have unmet needs? How do you deal with gaps in care?
12. How would you describe your relationship with a service user's partner? [Where necessary explain that spouses/partners are sometimes viewed as (i) needing services in their own right, (ii) co-workers (iii) resources.]
13. When working with a service user how do you refer him / her? If clarification required suggests for example, Mr or Mrs, first name, pet name, dear. How was this style of address agreed on? How do you refer to their partner? What do service users call you? Is this the same irrespective of whether the service user lives alone or with a partner?
14. What is care? Would you define it differently depending on who was caring?
15. What did you do before you became a home carer? What makes someone suitable to be a home carer? What training or induction did you get when you began working as a

home carer? What sort of ongoing support or guidance do you receive? What experience or training do you think you need to be a home carer?

16. Are there any guidelines, policies or regulations that you have to follow as a home carer? How do you think or feel these influence how you work with service users and or their partners? Can you give examples? Do you think service users are aware of the guidelines etc.? Why? Do you ever need to explain about the guidelines etc. to the people you assist? How do you explain? What sort of reaction do you get?

APPENDIX 5

Summary of the Spouses' Disabling / Limiting Conditions and their Service Use

Couple	Main Spousal Carer	Disabling Condition(s)/ Limitations of Main Care Recipient	Health and Disabling Conditions/ Limitations of Main Carer	Residents or Tenants of Sheltered Accommodation	Connected to Community Alarm / Warden Call System	Service Use / Services Regularly Used [Excluding Health Services, Hairdressing, and Tradespersons]
Mr Mrs Jarvis	Wife	COAD Osteoporosis resulting in respiratory and mobility problems	Reference made to an illness but not identified.	Yes	Yes	
Mr Mrs Fergusson	Husband	Arthritis, Asthma, Osteoporosis resulting in mobility and dexterity problems	Heart disease but remains fairly fit and active.	No but on retirement moved to a single storey house chosen as suit their care needs.		Wkly domestic assistance from home care
Mr Mrs May	Wife longer term carer but currently both	Mr May Mobility problems and visual impairment Mrs May Osteoporosis resulting in mainly lack of strength		No but moved due to ill-health and disability to single storey accommodation nearer to daughter and more suitable to their care needs.		Wkly domestic assistance from privately employed cleaner and previously, for a short period, from home care. Assistance with transport and shopping from voluntary - sector supported transport scheme.
Mr Mrs Addison	Husband	Osteoporosis resulting in loss of mobility	Well	No but moved to smaller single storey house due to Mrs Addison's care needs.	Yes	Wkly domestic assistance from privately employed cleaner.

Mr Mrs Geddes	Husband	Range of mainly skeletal conditions including Spondylitis and Osteoporosis	Heart condition but quite fit	Yes	Yes	Shop Mobility
Mr Mrs Hendry	Wife	Parkinson's disease	Some difficulty with walking and no vision in one eye. Has suffered intermittent poor health through out married life	No	Yes	Wkly assistance with transport needs and shopping from voluntary-sector supported transport service A day per wk public sector day care 1/2 day per wk voluntary sector respite/day care
Mr Mrs Insh	Wife	Stroke resulting in mobility, coordination and communication problems. Also increasingly hearing impaired	Well but get tired	No	No	Daily (Mon - Fri) personal care from home care
Mr Mrs Beattie	Both but wife longer term carer.	Mrs Beattie Osteoporosis, Myalgia, possibly other conditions resulting in mobility problems. Also loss of sight in one eye. Mr Beattie Arthritis and visual impairment		Yes	Yes	Domestic assistance and daily (Mon - Fri) personal care from home care.
Mr Mrs Kerr	Wife	Mobility and communication problems due to brain damage	Quite fit and active but had non limiting arthritis sometimes gets tired	No	No	

Mr Mrs Lawrence	Wife	Stroke resulting in one-sided paralysis hence problems with balance and walking.	Good	No but moved to a single storey house more suited to their care needs	Yes	
Mr Mrs McAllister	Both	Mr McAllister mobility problems Mrs McAllister visual impairment and increasing hearing impairment.		No	No	Wkly domestic assistance from home care
Mr Mrs Nichol	Husband	Arthritis and mobility problems	Personally viewed as good but has had two strokes and Parkinson's Disease resulting in some level of dexterity problems	Yes	Yes	2 x wkly domestic assistance from home care
Mr Mrs Oliver	Wife	Stroke resulting problems with balance and mobility	A degree of arthritis	No	Yes	Privately employed p/t gardener
Mr Mrs Patterson	Wife	Stroke resulting in coordination and mobility problems and partial paralysis	Back problems but general health ok	No but modified their fairly large two storey house by turning dining room into a bedroom and installing a downstairs shower room	Yes	2 x daily personal care from home care Privately employed p/t gardener Privately employed cleaner?
Mr Mrs Reid	Husband	Stroke and recent onset of dementia	Has a pace maker and becoming hard of hearing but general health ok.	Yes	Yes	Daily (Mon-Fri) personal care from home care Wkly domestic assistance from privately employed cleaner Short-term residential respite care

Mr Mrs Hay	Wife	Diabetes, Stroke, Glaucoma and Angina	General health ok but a degree of fatigue.	No but their large house made suitable with stair lift, ramps and modified bathroom	Yes	2 x daily personal care from home care Domestic assistance several times a wk from privately employed cleaner Privately employed p/t gardener Wkly assistance with shopping from voluntary sector organisation Previously but no-longer home-based respite care from voluntary sector organisation
Mr Mrs McKenzie	Wife	Emphysema resulting in mobility and respiratory problems and chronic fatigue	Arthritis and mobility problems	No	Yes	About to start using day care
Mr Mrs Ellis	Wife	Emphysema resulting in respiratory problems and chronic fatigue. Also psychological difficulties.	OK but not as able as at one time - has suffered a stroke, tumour and heart bypass.	No but moved due ill health and disability to small single storey house with level access shower		2 x wkly personal care arranged through home care Privately employed p/t gardener Residential respite care
Mr Mrs Fyfe	Husband	Parkinson's disease, thyroid and cardiac problems	General health ok but has a number of non-limiting conditions, described as 'old person's complaints'	No but lives in bungalow with level access shower installed	Yes	Previously received short-term assistance with personal care from home care A day per wk day care

Mr Mrs Taylor	Husband	Muscular dystrophy	Painful joints and hearing impairment	No	Yes	30 mins daily personal care from home care
Mr Mrs Green	Husband	Mobility problems and onset of dementia	Good health	Yes	Yes	2 x wkly personal care and domestic assistance from home care A day per wk home based respite care from voluntary sector organisation Wkly assistance with shopping from voluntary sector organisation A day a wk day care

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