UNIVERSITY OF SOUTHAMPTON

Combining Work and Elder Caring Roles: The Positive and Negative Consequences for Women

by Clare Lyonette

Thesis submitted for Doctor of Philosophy

Department of Psychology
Faculty of Social Sciences

July 2003

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF SOCIAL SCIENCES
DEPARTMENT OF PSYCHOLOGY

Doctor of Philosophy

COMBINING WORK AND ELDER CARING ROLES: THE POSITIVE AND NEGATIVE CONSEQUENCES FOR WOMEN

by Clare Lyonette

The increase in the number of older people within the population has generated a corresponding increase in the need for care. At the same time, however, there are fewer women of caring age in this country, and of these, a large percentage are in employment. This has led to a situation in which more women are being expected to combine roles. Although the consequences of combining roles have been studied in women, there have been very few really comprehensive assessments of the most important factors involved in combining elder caring with work roles, and how these factors may contribute to better or worse mental health over time.

This study commenced with a qualitative analysis of semi-structured interviews with working-age carers, which identified two personal factors, the quality of relationship with the elder and the motivations in elder caring. As these factors had not been adequately measured in previous research, two new measures were developed and included in a questionnaire survey, which also included measures of work-related, care-related and other factors. The surveys were distributed to a large number of self-selected female carers working in the NHS, identified from a preliminary screening survey. Follow-up surveys were distributed after one year.

Personal factors were shown to be the most important predictors of carer outcomes: poorer relationship quality and higher external perceived pressures to care significantly contributed to higher stress, and better relationship and higher intrinsic motivations to care predicted higher satisfaction with caring. Other risk factors for stress were high caring involvement at work and co-residence with the elder. Comparisons of working carers and working non-carers showed that carers were significantly more likely to suffer mental health problems than non-carers (although these findings must be interpreted with caution in view of the self-selected, unrepresentative sample). There was also some evidence to suggest that women caring at home and at work were more likely to suffer worse mental health than those caring in only one role. Carer stress, work stress and work demands predicted worse mental health in carers. Work stress also predicted increase in mental health problems over time. Better health status of the carer, lower external pressures to care and higher work satisfaction predicted better mental health. Younger age of the carer and lower work stress also contributed to better mental health over time.

A combination of higher-intensity work and caring roles appear detrimental to carers' mental health, whereas lower-intensity work and caring roles appear to provide benefits. The possibility of negative and positive cycles of factors is discussed, as are the wider implications for carers, care-recipients and employers.

Contents

Chapter 4:

Chapter 5:

Chapter 6:

___ Time 1:

___ Time 2:

___ Time 1:

________ Comparisons of mental health outcomes for high-caring and low-caring workers:

___ Time 2:

________ Comparisons of mental health outcomes for high-caring and low-caring workers:

___ Time 1:

________ Associations between positive affect and all independent variables:

_______ Associations between GHQ "caseness" and all independent variables:

___ Time 2:

_______ Time 1 predictors of mental health outcomes at Time 2, after controlling for Time 1 outcomes:

Chapter 11:

Policy implications:

List of Tables

List of Figures

List of Appendices

GLOSSARY

Throughout this thesis, I have used various abbreviations to refer to variables included in the quantitative analyses. These will be outlined and explained here to provide a reference point and clarification for readers.

Chapter 5: The screening survey

OCC = Occupation of the respondent.
Hours = Number of hours the respondent normally works.
DMW = Days missed from work in the past four weeks.
TLW = Number of times respondent was late to work in the past four weeks.
LWE = Number of times respondent left work early in the past four weeks.
IAW = Interruptions at work to deal with family matters in the past four weeks.
FLEX = Flexibility at work to deal with family matters.
WS = Work stress.
HPW = Hours per week spent caring.
RHW = Reduced hours of work to care.
DIFF = Difficulty combining work and caring.
DEPR = Unhappiness/depression in the past four weeks.

Chapter 7: The development of the two new measures of personal factors

RECS = Relationships in Elder Care Scale (quality of relationships in elder caring)
MECS = Motivations in Elder Care Scales
EXMECS = Extrinsic Motivations in Elder Care subscale
INMECS = Intrinsic Motivations in Elder Care subscale

Chapters 8, 9 and 10: The Time 1 and Time 2 surveys

PAMs = Professionals Allied to Medicine
P&Ts = Professional and Technical staff
Admin = Administrative staff
Carework = level of caring involvement at work
GHQ = General Health Questionnaire (measure of mental health)
"Caseness" = classification of minor psychiatric disorder, using the GHQ

Acknowledgements

I would like to thank my primary supervisor, Lucy Yardley, for her continuous and generous support from the start, even in the face of the many obstacles I threw her way. Without her guidance, I most certainly would not be writing this today. I would also like to thank my co-supervisor, Bob Stratford, for his help and support, particularly in the early stages of the research. Other people within the department whom I would particularly like to mention are my advisor, Constantine Sedikides, for his calm encouragement, and Lisa Henly, whose help was always instantaneous. A general thank you goes to all other members of the department who have helped me throughout the course of my PhD.

I would like to thank the Economic and Social Research Council and the Faculty of Social Sciences at the University of Southampton for their support in funding this study.

Many thanks to my husband, Rob, for never giving up his faith in me (or his patience), and my two children, Georgia and William, who never asked too much of me. Thanks also to my parents and the rest of my family for their encouragement and support.

Finally, I would like to thank all the carers and non-carers who unselfishly gave up so much of their time to be interviewed or to answer questionnaires, in spite of the many time pressures they faced. My thanks also go to the directors and organisers of the local carers' groups who allowed me access to their members, and also to the managers of the two NHS Trusts who allowed me to contact their employees.

Chapter 1

INTRODUCTION TO THE RESEARCH

There are currently over 5.7 million informal carers in the United Kingdom, with half of these caring for someone over the age of 75 (Office of Population Censuses and Surveys, 1995). Although a substantial number of all carers are male, 3.3 million are female, and of those carers devoting at least 20 hours a week to caring, over 60 per cent are women. At the same time, women's increasing participation in the workforce has led to a situation in which a large number of women are attempting to juggle many roles at once, creating the potential for increased pressure and adverse effects on health.

Due to improved medical management and better standards of living, increasing numbers of older people are surviving for long periods of time with physical and mental disabilities. It has been proposed that across Europe as a whole, there will be a 213 per cent increase in the population aged 80 years or more between 1980 and 2025 (Dooghe, 1992), and a similar rapid increase is expected in the United States (Kane & Penrod, 1995). Indeed, the recent UK Census figures (Office of National Statistics, 2002) demonstrated that 1.1 million people in this country are currently over the age of 85, representing almost two per cent of the population, compared with only 0.2 million in 1951 (0.4% of the population). The link between increased ageing and dependency (Henwood, 1992), combined with governmental policies which have focused upon care within the community, means that the number of informal carers is also likely to rise.

While there have been huge increases in the numbers of older people within the population, there are also fewer women of caring age in this country, as the ratio of middle-aged women compared with those over the age of 70 has shrunk dramatically (Askham, Grundy & Tinker, 1992). Around 62% of female carers in the UK currently combine work with their caring responsibilities to provide income to help with formal caring costs, but also to maintain social networks (Hutton, 1999). Of the 12.7 million women currently in paid work in the UK, about 3.5 million work in care-related occupations, often on a part-time basis. Based on previous work examining the numbers of carers in employee jobs (e.g. National Carers' Survey, 1990; Princess Royal Trust, 1995), around half a million women are estimated to be female carers also employed in care-related occupations. American researchers have estimated that almost half of all employed women in the US work in the service industry, mostly in nursing, teaching, social work and other care-related occupations (Marshall et al., 1990). These figures are set to rise, as the service industry's share of the labour force increases rapidly, leading to greater numbers of women employed in care-related jobs. In a study which theorised about the "double jeopardy" of caring both at home and at work, Marshall et al. (1990) found that women in this situation are more at risk of stress and other adverse health outcomes than other working carers. These results are important, as the type of paid work a carer undertakes may therefore be a crucial predictor of mental health.

While there has been much research, particularly in the US, into the type of caring tasks performed by employed carers, to date there has been little attention paid to the particular types of employment undertaken by carers, and how particular work-related, care-related and other factors add together to create either positive or negative experiences for women. The research described in the following chapters examines in detail the beneficial and detrimental aspects of combining work and caring roles, with a comprehensive assessment of employment and caring roles undertaken by female carers. A particular focus will be on the extent to which work and carer roles draw on the same resources. Both positive and negative aspects of combining work and caring roles will be examined and discussed.

Structure of the thesis

The research combines both quantitative and qualitative methodology, and will be described in detail as it progresses from preliminary models of work and caring factors associated with both positive and negative mental health, developed from the qualitative study, to later revised and enhanced models generated from the additional results of quantitative data analyses.

Chapter 2 outlines the theoretical background to the research, with different theories of multiple roles discussed in light of the research presented here. These will be evaluated for their applicability to the current research in Chapter 11. Chapter 3 describes the previous literature on work and caring roles in women and discusses gaps and inconsistencies in the research which the present study aims to address. In Chapter 4, the advantages and disadvantages of the methodology employed in the research are discussed, with a focus on the combined use of both qualitative and quantitative methods.

Chapter 5 details the development and results of the screening survey, the first of three surveys distributed to a sample of female NHS employees in the present research. The qualitative study is presented in Chapter 6, which was undertaken with a small group of working-age female carers, identified from local carers' groups. Chapter 7 then describes the development of two new measures used in the present research, relating to personal factors involved in caring for an elderly person.

Chapter 8 presents the results of the second survey with a large group of working carers, in which the influence on carer outcomes of work-related, care-related, personal and other factors was examined. Chapter 9 then describes the results of matched comparisons between carers and non-carers working in the same occupations, and the mental health impact of combining caring at home *and* at work. An analysis of the baseline and follow-up surveys continues in Chapter 10, which examines the main predictors of mental health in working female carers over time. Finally, Chapter 11 discusses the main findings from the study, theoretical and policy implications, limitations of the research and directions for future research. Final models of the most important factors predicting both positive and negative mental health will also be discussed.

Chapter 2

COMBINING WORK AND ELDER CARING ROLES: THEORETICAL BACKGROUND TO THE RESEARCH

Introduction

This chapter considers different theoretical approaches to multiple role involvement, in order to identify the potentially positive and negative consequences of combining work and elder caring roles. Previous research on women's multiple role involvement will be discussed in the context of the theories reviewed, with a focus on their applicability to this research on women's work and caring roles.

The scarcity approach to multiple role involvement

Freud (1961) was possibly the earliest proponent of the "scarcity" approach to multiple role occupancy, proposing that there is a limited source of energy within the individual, a view which has been taken up and revised by several theorists. As early as 1957, Merton referred to "potential disturbance of a stable role-set" as a normal occurrence for the individual (1957a: 370). In 1960, Goode introduced the term "role strain" to refer to difficulties involved in performing multiple roles, and concluded that the outcome of attempting to meet several demands was invariably negative. As the individual does not have enough energy for every role, a set of compromises must be made. These two theorists based their views on the overlapping problems of what Sieber later described as "role overload" and "role conflict" (1974: 567). Role overload refers to those constraints imposed by time: as individuals increase their role obligations, they are inevitably confronted by a barrier of time, forcing them to choose one or some roles over others. On the other hand, role conflict refers to the different and conflicting expectations of roles.

In a study which focused on interrole and intrarole conflict in working mothers, Williams et al. (1991) showed that interrole juggling resulted in greater negative affect and less task enjoyment than instances in which no juggling occurred. Enjoyment was also lower during interrole than intrarole juggling. The authors concluded that the negative consequences of role juggling may result from reduced control over events and outcomes and that the effects of role juggling may be higher for mothers who are high in both family and job involvement.

The ego depletion approach

Baumeister et al. (1998) tested hypotheses of ego depletion, first proposed by Freud, as a way of learning about the self's executive function. The theory of ego depletion proposes that the self's acts of volition draw on some limited resource, like strength or energy, so that one act of volition will have a detrimental impact on subsequent acts of volition (1998: 1252). Four experiments were carried out, in which some participants were asked to perform an initial act of self-control. When a second, unrelated task was introduced, these participants were less likely to succeed or persist at the task than others who had not had to perform self-control in the first task (one example of exerting self-control was to force oneself to eat radishes rather than chocolates). The researchers concluded that two seemingly unrelated tasks do in fact draw on the same limited resource. Therefore, individuals are limited in their capacity for active volition. This theory, if supported, would have important implications for working carers, with any acts of self-control in the caring role leading to difficulties in the work role, and vice-versa. Even for those working in occupations unrelated to caring, an initial act of self-control within the caring role is likely to create a detrimental effect on work, due to the fact that both tasks draw on the same limited resource.

Baumeister also proposed that ego depletion may play a central role in psychological difficulties, such as burnout and learned helplessness, in which "unusual exertions of affect regulation" are involved (1998: 1263). Baumeister and colleagues also suggested that the value of social support could be partly explained by friends taking over the individual's volitional tasks, allowing them time to recover. In the case of working carers, those women who receive support from their peers may be more able to cope with heavier caring demands than those without such support. In the same way, help in the caring role, either from other relatives or formal carers, may minimise the negative effects of caring.

The role enhancement and expansion approaches

In 1974, Sieber published an article challenging the assumption that multiple roles produce role strain as a consequence of role conflict or overload, and addressing the possible rewards of taking on additional roles. Sieber proposed that the benefits of role accumulation can outweigh stress, yielding net gratification. The potential rewards from role accumulation include role privileges or rights, with the greater the number of roles, the greater the number of privileges enjoyed by an individual. Sieber cited the example of the adult student with multiple roles, who uses the demands of his other roles to justify absence from class or failure to complete assignments. Similarly, a potential privilege for working carers would be the opportunity to justify non-performance or reduced performance in the work role as a consequence of caring. Another potential reward discussed by Sieber is the overall status security offered by buffer roles, which act as supports against failure in any one role. Sieber used the example of the individual who "loses himself" in his work as a response to personal domestic problems. Rewards also include resources for status enhancement and role performance, such as invitations to social gatherings, gifts, use of company property, etc. In addition, the individual becomes more valuable to each of his or her role partners as a potential source of rewards. The final example Sieber described as potentially rewarding was the enrichment of the personality and ego gratification. Different personalities may suffer or thrive when undertaking multiple roles, and Sieber referred to the special talents and skills required in order to manage this situation: "...despite the likelihood of role conflict for the working mother, women are seeking a wider role repertoire to increase their resources, privileges and sense of personal worth" (1974: 577).

To relate this theoretical approach to the work/elder caring interface, it could be argued that the work role acts as a buffer against the strains of caring at home, while also generating increased rewards such as social support and financial gains. Taking on a working role, in addition to a caring role, could also potentially increase self-esteem. Similarly, by taking on a caring role in addition to a working role, women may increase their self-esteem and sense of worth.

Marks (1977) also challenged earlier assumptions that multiple roles are over-demanding, by proposing an "expansion" theory of human energy: instead of viewing energy as "draining", it is in fact "creating". The energy-expansion theory describes the available supply of energy as abundant and expansible, with human activity producing, as well as consuming, energy. Marks outlined in detail the literature on the scarcity theory of human energy and discussed difficulties with the evidence: "If energy is seemingly abundant for some people, then we can no longer appeal to some universal human condition or natural fact to account for those instances in which it is found to be scarce" (1977: 925). In his discussion of the "social construction" of human energy, he proposed that individuals themselves decide how to use their energy and which demands are to be honoured, with particular types of commitment systems responsible for whether or not strain occurs. Marks' idea of choice in roles is based on the observation that energy seems to be "found" for anything to which we are highly committed. Alternatively, we appear to "find" little energy for anything to which we are uncommitted, and "doing these things leaves us feeling spent, drained or exhausted" (1977: 927). Unlike Goode, Marks stated that time, as well as energy, is flexible, depending upon particular circumstances. In this way, the individual's over-committed interests tend to encroach upon the time and energy being produced for any under-committed interests. Over-committed people will therefore want to restrict their involvement in those under-committed interests (1977: 931). Marks referred to the theory of scarcity "excuses", which he proposed get implicit support from scarcity theories. In reality, he stated, when people are under-committed, they attempt to avoid accountability by appealing to a limited amount of time and energy, so excusing themselves.

It may follow that reported carer strain or burden is merely the result of under-commitment to the caring role. Similarly, reported work stress may be the outcome for an individual under-committed to the work role. Those in more satisfying occupations may be more committed and therefore find more energy for the work role. Alternatively, those committed to caring may be less likely to report strain, by increasing time and energy for the carer role. High commitment to both roles may explain some of the variation in mental health outcomes among working carers.

Amatea and Fong (1991) argued that, for professional women with a greater number of roles, as well as higher levels of personal control and social support, lower levels of strain were likely. The authors concluded that the fewer the roles for this group of women, the greater the strain, lending support to the enhancement or expansion theory of roles. However, another study of professional women (Tiedje et al., 1990) reported that balancing multiple roles did not inevitably lead to perceptions of enhancement, and that occupying demanding roles did not always lead to conflict. The authors argued that high enhancement/low conflict women were potentially able to handle often conflicting situations at both work and home, demonstrating the importance of individual perceptions of roles.

The identity accumulation hypothesis

In a 1983 paper, Thoits outlined the "identity accumulation hypothesis", a reformulation of the social isolation hypothesis (Faris, 1934), in which the more identities (roles) a person possesses, the less psychological distress he/she exhibits. She discussed previous work which focused on the "commitment" a person has to a particular identity, also suggesting that as social positions are culturally ranked, they are therefore differentially valued (1983: 177). Commitment to a particular identity or role may depend upon its positive valuation within a culture. In the context of work and caring roles, the role of paid worker is more highly valued than that of the informal carer, who in effect carries out her work, unseen and generally unacknowledged. However, employment itself varies in its social and cultural ranking, with lower-status jobs carrying less value than higher-status positions. A caring role may therefore be more positively valued among those with lower-status jobs than those in other occupations.

Thoits also discussed the argument that the fewer the number of identities possessed by the individual, the greater is the stake in each one. If only one identity is available to the individual, the degree of commitment to that identity should be high, irrespective of its positive cultural value. For informal carers with fewer roles, commitment to the caring role may be higher, in spite of its status. Those with many other roles may have less of a stake in the caring role, thereby rendering it less important or less satisfying. In a large-scale study, Thoits then tested time and energy conceptions alongside network-embeddedness concepts (Stryker & Serpe, 1982; 1983), and results showed that individuals who possessed numerous identities reported less psychological distress than isolated individuals. However, the more identities possessed by an integrated individual (i.e. those with multiple roles), the greater distress at subsequent identity loss, and the greater the ameliorative effect of identity gain (1983: 184). Thoits claimed support for the network-embeddedness notion of commitment (Stryker & Serpe, 1982; 1983), in which interdependence occurs among different roles. The more identities possessed, the more likely the individual is to have formed overlapping ties with others, thereby making identity loss more disruptive. Those working carers who have many conflicting and interdependent roles, such as caring for young children or multiple elder caring responsibilities, as well as work commitments, may be more likely to report greater distress at the loss of a particular identity. Those leaving work to care for an elderly person, for example, may be more at risk of negative mental health outcomes, as a consequence of the disruption to overlapping ties with others.

Role quality versus quantity

In their work on women's multiple roles, Baruch and colleagues (1986; 1987) argued that the enhancement and scarcity hypotheses are incomplete because they focus on role quantity, rather than quality. "The nature and quality of a woman's experiences within a role, not merely role occupancy per se, are critical to understanding the processes affecting her well-being" (1987: 133). In discussing Karasek et al.'s (1982) work on occupational conditions associated with health risks, Baruch et al. (1987) proposed that how controllable or predictable a task or event is affects the degree to which it is stressful: "A surgeon and a nurse, for example, may face similar levels of demands, but they differ greatly in their power to control how they deal with these demands and thus in the stressfulness of their occupational role" (1987: 131). The workplace can offer such benefits as challenge, control, structure, positive feedback and self-esteem, and a valuable set of social ties. However, jobs that combine high levels of demand with little autonomy (typically low-paid and low-level) are more likely to involve stressors that impair health (1987: 134). The authors concluded that women are more likely to find themselves restricted to such jobs due to social factors such as discrimination. In the case of working carers, what should be a rewarding role (i.e. work) can in fact lead to added stressors due to the lack of controllability and autonomy within that role. If the quality of experience in both work and caring roles is low, higher levels of stress may be more likely.

Results from a later study examining role quality (Barnett, Marshall & Singer, 1992) showed a modest but significant correlation between psychological distress and job-role quality, varying as a function of family-role status. The authors here claimed a degree of support for the role-expansion perspective: "Women with family roles have several potential sources of such rewards as challenge, helping others, and decision authority, whereas women without family roles must find these rewards at work or suffer the consequences" (1992: 642). Using the theoretical framework of role quality, Noor (1995) found that high occupational status experienced by professional women moderated the negative effects of work overload, whereas secretaries were adversely affected by work overload. Unlike the previous study, family roles were not related to wellbeing, running counter to the assumption that family situations, rather than work conditions, have a stronger impact on women's well-being. Noor concluded that "differences in job characteristics may affect outcomes independently of the role-quality experiences" (1995: 100). With work and caring roles, the characteristics of the work as well as of the caring undertaken may therefore be of paramount importance in perceptions of role overload.

Spillover theory

Other researchers have used the concept of "spillover" when examining multiple roles in women. Stress and coping mechanisms can spill over from one individual to another or from one role to another, and can be both positive and negative (Voydanoff, 1988; Zedeck & Mosier, 1990). As an example, working carers may be more prone to stress if they are employed in caring professions, due to the psychological spillover of one role into the other (negative spillover). On the other hand, educational spillover could allow these carers a greater ability to cope due to the opportunity to learn certain skills in one role which can be applied in their other role (positive spillover). Zedeck and Mosier (1990) examined different theories of the relationships between work and the family, including spillover. In discussing spillover, they asserted that work can be additive, in that one's feelings about a job are a component of one's feelings about life in general. Again, they argued that spillover can be positive or negative: if work is boring, this may lead to an energy deficit, with the worker consequently not achieving certain things expected of her.

Focusing specifically on work characteristics and resulting stress in doctors, Swanson, Power and Simpson (1998) found that role complexity was related to stress for both male and female doctors. The authors found that role complexity was also related to reduced occupational workload for females only. In discussing spillover theory, they claimed that "medical work which is "people intensive" and emotionally demanding may leave the individual feeling drained and uncommunicative with spouse or family" (1998: 240), and that constant availability to patients was a contributing factor to role strain. Bacharach, Bamberger and Conley (1991) had earlier examined a group of nurses and engineers and also found that, for both groups, work-based role conflict was an important antecedent of work-home conflict, and increased burnout an important and direct consequence of work-home conflict. The authors claimed that perspectives which view the work and home realms as independent must therefore be reconsidered, lending support to spillover theory. They also added that several researchers had found that conflict between work and home is heightened for employees working long and inflexible hours. Similarly, Voydanoff (1988) found that those work role characteristics most strongly related to work/family conflict were the number of hours worked and workload pressure for both men and women in all occupations. Autonomy and schedule control served as moderators of the relationships between work role characteristics and work/family conflict, with perceived control playing a limited role in moderation.

Other theories of multiple roles

Compensation theory proposes an inverse relationship between work and family. Individuals make differential investments of themselves in the two settings, and make up in one for what is missing in the other (Zedeck & Mosier, 1990). A further view, known as segmentation theory, sees work and family as distinct environments. Individuals can function successfully in one without being influenced by the other. Zedeck and Mosier also discussed instrumental theory, in which one environment is a means by which things are obtained in the other. As an example, good work outcomes lead to a good family life. Conflict theory, on the other hand, proposes that satisfaction in one environment or role entails sacrifice in another. The two environments are incompatible because they have distinct norms and requirements. The researchers concluded their paper by asserting that the focus of work and family studies should be on the nature of the work that is done, rather than the fact that the work is being done (1990: 242).

Summary of main theories of multiple role occupancy

- The scarcity theory proposes that there is a limited source of energy within the individual, leading to inevitable difficulties in performing multiple roles.
- The theory of ego depletion proposes that the self's acts of volition draw on some limited resource, like strength or energy, so that one act of volition has a detrimental impact on subsequent acts of volition.
- The enhancement or expansion theories argue that the benefits of accumulating roles outweigh stress, leading to positive outcomes. Energy is abundant and expansible, with human activity producing, as well as consuming, energy.
- The identity accumulation hypothesis claims that the more identities (roles) a

person possesses, the less psychological distress he/she will exhibit. However, those with more roles are also more likely to suffer at the loss of any one role.

- The role quality perspective argues that it is the quality, not the quantity of roles, which determine health outcomes.
- Spillover theory argues that stress and coping mechanisms can spill over from one role to another, and can be both positive and negative.

Overall summary

Previous research into multiple roles shows that there is some support for each of the theories outlined. As some of the predictions from multiple role theorists are conflicting, the supporting evidence for each leads to the conclusion that the effects of multiple roles must be complex, varying in different circumstances. However, several researchers have found that the quality of individual roles is a more important determinant of stress among women than the quantity of roles occupied. In particular, the quality of the work role appears to be vital in assessing working carers' perceptions of multiple roles. Each of the theories described above will be examined for their applicability in the light of the research findings to be presented during the course of the thesis. Final discussions will focus on which, if any, of the theories is supported by the research.

Chapter 3

COMBINING WORK AND ELDER CARING ROLES: A REVIEW OF THE LITERATURE

Introduction

In order to review current and past research findings in the field of women's combined work and caring roles, a series of literature searches was initially conducted between November and April, 1999-2000. All major databases which were likely to hold records of relevant literature were accessed: MedLine and MedLine Express, PsycLit, Embase and Cinahl (years 1980-present). Another systematic literature review, using the same databases, was undertaken in 2002, and again in 2003, to find any recently-written papers. Other papers were identified from conference attendance, referral from colleagues and subscriptions to gerontology journals. A large number of US and Canadian research studies were collected, but a growing body of UK research was also identified, particularly in recent years.

Previous research studies which have examined the effects of combining work and caring roles have tended to focus on different areas of interest. Section 1 of this chapter will outline those studies focusing on gender differences in caring, which will serve as a justification for including only female carers in the PhD research. Section 2 will then discuss the effects of women's employment on the provision of care and implications for the future of elder care, Section 3 will outline and discuss the effects of caring on employment and how specific work-related and care-related factors affect carers' mental health, and Section 4 will discuss the potentially positive aspects of combining work and caring roles. The chapter will detail any omissions or inconsistencies in the research to date, and will then focus on the aims of the current research in attempting to address these problems.

Section 1: Gender differences in caring

Several researchers have looked at the differences between male and female carers in relation to the kinds of caring tasks undertaken and the number of hours spent on those tasks, the combined effects of employment and caring, and the effects of caring on levels of carer stress.

Amount and type of caring

Previous studies have demonstrated that women provide more care than men. As early as 1983, Stoller was examining the provision of adult care, particularly by daughters, and showed that women provided a greater number of hours of assistance than men, most pronounced in domestic tasks, but less so in financial management and handling personal business. More recent papers have also demonstrated that women provided more intensive types of care, such as personal care, hands-on assistance and the essential recurrent tasks involving direct physical contact (Jutras & Veilleux, 1991; Kramer & Kipnis, 1995; Starrels et al., 1997). Starrels and colleagues (1997) also demonstrated that women experienced more carer stress, as a result. In a study comparing married couples, Gerstel and Gallagher (1993; 1994) showed that wives gave significantly more care than husbands, spent more time giving that care, and gave to a larger number of people. Although Neal, Ingersoll-Dayton and Starrels (1997) also found that women were significantly more involved in caring than men, no significant gender differences were found in the types of tasks assumed, unlike the previous studies outlined. However, it was reported that males were less likely to provide social/emotional support and undertake household tasks. Other studies found no significant differences at all between men and women in the amount of caring undertaken (Boaz & Muller, 1992; Goldsmith & Goldsmith, 1997).

Effects of employment

In a Canadian study, Gignac, Kelloway and Gottlieb (1996) found that women reported significantly more family interference with work and more work interference with family than men. Among women, caring impacted on the workplace indirectly by arousing conflict between family and work. The authors suggested that this may be explained by the differences in the amount and type of tasks undertaken by women, as outlined in the previous section. Women may be called on to perform their work and family roles simultaneously, unlike men, who may be able to deal with work and family roles sequentially, and therefore separate themselves from the caring role whilst at work. Neal et al. (1990) similarly found that men reported fewer interruptions at work due to caring and less difficulty combining work and family. Earlier, Stoller (1983) found that employment significantly reduced the level of caring assistance provided by sons, but not by daughters. However, Jutras and Veilleux

(1991) found that caring had less of an effect on the professional life of the carer than expected: interestingly, more men cut back on work hours, declined additional responsibilities, and left work to assist their spouse (this could, however, be due to the larger number of male spousal carers than other types of male carers). The authors concluded that men seem to have more difficulty assuming multiple responsibilities, whereas the role traditionally ascribed to women does not collapse when women adopt new roles. Gerstel and Gallagher (1994), however, suggested that as women's jobs begin to resemble those of men, so does the breadth and depth of wives' caring, raising interesting questions about the future of caring and employment roles in women.

Differences in stress

In a review of research in the UK, Laczko and Noden (1992) claimed that when carers were asked about their employment, almost half of all female participants reported some stress, compared with less than a quarter of male respondents. However, although Jutras and Veilleux (1991) found that level of caring assistance strongly influenced the amount of overall burden experienced, women did not differ from men in global burden scores. Starrels et al. (1997) reported that carer stress was positively related to the level of caring tasks undertaken, amount of time taken off work (especially for men), physical limitations and problem behaviour of the elder, but was negatively related to household income. Women were more likely to care for a female relative than men, and men reported significantly higher incomes than women. Assistance from the elder was shown to reduce carer stress, but female carers received less assistance than men. The authors suggested that this may be due to the notion that caring is less normative for men than women, so making parents particularly appreciative of their sons' efforts.

Summary of Section 1

Although findings are inconsistent, it appears that female carers do more than male carers, in both the kinds of caring and the number of caring tasks performed, specifically in relation to hands-on, personal care. Women appear to receive less appreciation and support than men, and also receive lower incomes. Level of assistance was shown to be directly related to levels of carer stress. Taken together, these findings would help to explain why women tend to report greater levels of carer stress than males, and why more focus should be placed on women's attempts to balance work and caring roles. The evidence reported above led to the decision to sample only female carers in the present study.

Section 2: The effects of employment on caring and implications for the future of caring

An area of concern which has generated much research has focused on the effects of women's employment on the provision of care. As reported in Section 1, Gerstel and Gallagher (1994) suggested that as women's work roles become more similar to men's, so too will women's caring roles become similar to men's. If women's employment reduces the amount of informal care provided, then recent care in the community initiatives will be set to fail.

Does employment lead to reduced caring?

Some of the studies reported in Section 1 suggested that employment status did not affect the provision of care by women to elders (Stoller, 1983; Jutras & Veilleux, 1991; Kramer & Kipnis, 1995). A recent study by Doty, Jackson and Crown (1998) concluded that increased female labour force participation is having less of an effect on the availability of informal eldercare than predicted. The authors suggested that the conflict between employment and eldercare affects only a minority of carers and their care recipients because the role of primary carer for an older person tends to be assumed by those who have already left the labour force, a point which will be discussed more fully in Chapter 6. Robison, Moen and Dempster-McClain (1995) found that, although a more traditional lifestyle (having more children, marrying earlier, and volunteering more) appeared to increase the rate of caring, employment did not preclude taking on caring responsibilities. In fact, working continuously was positively related to becoming a carer. The authors suggested that these women may have more health, stamina and vitality to take on caring, although the direction of causality was not assessed. College-educated women who did not devote their lives to raising children were shown to be less willing to also devote themselves to caring, although those who were better off psychologically may take on some caring, with a general sense of life satisfaction increasing the rate of caring. The authors concluded that notions about trade-offs between employment and other roles were not supported.

Using data from a US national survey, however, Marks (1996) found that working full-time was associated with less likelihood of caring for both men and women. The author concluded that the national evidence found in this study suggests that full-time employment does compete for time and energy with caring, and that caring responsibilities cross gender, race, family structure, socioeconomic and employment status boundaries.

The effect of hours worked

An early study by Stueve and O'Donnell (1989) demonstrated that time spent on caring by female carers depended in part on the severity of impairment, proximity to the care recipient, and the number of hours worked, with part-time workers doing as much caring as homemakers. Those working full-time weighted their jobs more heavily than those in part-time jobs (perhaps because of better career opportunities and pay) and felt they had more to lose in giving up their jobs. A positive association was shown between the amount of care provided and feelings of distress, providing further support for findings from the previous section (e.g. Jutras & Veilleux, 1991). However, this study also claimed that many full-time female employees were forced to alter work schedules, as husbands were no more likely to help out if their wives were working full time. The authors suggested that families may expect less from a full-time employee, and shift responsibilities on to those who are not working. Boaz and Muller (1992) also found that full-time employment reduced caring by 20 hours per week, but part-time employment had no effect. Hours of care increased with the disability of the care recipient, and for those carers co-resident with the care recipient eleven more hours per week of care were provided than non-co-resident carers. It was concluded that carers who were employed in full-time work were less likely to make work accommodations, and so reduced their hours of care substantially. In a Canadian qualitative study, Guberman and Maheu (1999) found that the main caring accommodations undertaken by working female carers included getting help from families, public, private and community services and reducing caring work.

Types of care provided

Gerstel and Gallagher (1993; 1994) suggested that the types of caring tasks undertaken by women, rather than the number of hours of care provided, may be affected by employment status. The authors claimed that homemakers did significantly more unpaid caring work than employed wives and tended to focus their caring efforts intensely rather than disperse their care broadly. Although they found no differences between homemakers and employed wives in performing household, practical, labour-intensive tasks, they concluded that employed wives were more likely to give money and advice rather than greater amounts of hands-on labour. Stueve and O'Donnell (1989) similarly found that those with full-time jobs tended to visit less often and provide less instrumental support, engaging in those activities that took less effort, such as phone calls, but cutting back on hands-on care. Goldsmith and Goldsmith (1997) found a significant relationship between income and lifestyle change, with higher income leading to less change in lifestyle, supporting results from other researchers (e.g. Fredriksen & Scharlach, 1997). Rather than taking on the care themselves and so restricting their lifestyle choices, those women with higher incomes may be more able to pay for care services which would allow them to pursue their own interests, both at work and at home.

An earlier study by Matthews, Werkner and Delaney (1989) suggested that, although working women attempted to provide care, lack of flexibility at work and the restricted hours available for services such as medical appointments created difficulties. In this study, the authors examined the relationship between daughters' employment status and involvement in the provision of services to parents, using a sample of 50 pairs of sisters. Unlike the previous studies, results showed no differences between nonemployed and employed sisters, with both making equal contributions to caring. At the same time, no significant differences were recorded between sisters in their perceptions of their contributions. For help with household chores and provision of emotional and moral support, however, nonemployed sisters were more likely to report providing help. These women also provided relatively more services for parents in the worst health.

Quality of care provided

Hawkins (1996) found that more concern was expressed by employed daughters than non-employed daughters that they might not be caring for their parent in the best manner, and that they did not have enough money to meet caring costs. Stephens, Franks and Atienza (1997) similarly claimed that limited time and attention provided to the parent was the most common type of negative spillover from employment to the caring role.

Summary of Section 2

Although previous findings are not entirely consistent, it appears that female carers in full-time employment undertake less hands-on, personal care than those either in part-time employment or those not employed. However, due to the inaccessibility of certain services outside of working hours such as medical appointments, it seems inevitable that working carers may have to resort to paid care or to shifting such responsibility onto other family members not in work. It is impossible to determine whether or not full-time workers in most of the studies described would prefer to provide the care themselves or to manage the care provided by others. It was also shown that those women in part-time employment provided as much care as women who were not employed. Again, it is not clear whether this was by choice or as the result of reduced incomes leading to fewer available alternatives such as paid care. These women may also have reduced their hours of work in order to care for an older person. Only qualitative research has to date provided information on the motivations involved in women's attempts to combine work and caring roles. Guberman and Maheu (1999) suggested that women are either career-oriented or care-oriented. Various motivations for caring were discussed, including feelings of love and reciprocity, internalised feelings of debt, obligation and guilt, lack of adequate and accessible alternatives in the family or formal help (1999: 99). Motivations for working included financial necessity, love of profession, or an escape from caring. This study provides some indication of the various motivations involved in women's attempts to combine work and caring roles.

Section 3: The effects of caring on employment and impact on carers' mental health

A large body of research has focused on the effects of caring on the carer's paid work. Employers in the US are becoming increasingly aware of the need to acknowledge this large section of the working population, although in the UK employers have been slow to recognise potential problems (Gilhooly & Redpath, 1997). This section of the chapter includes research designed to highlight the problems faced by both employers and carers, and will be divided broadly into work-related factors and care-related factors, as most researchers have examined specific aspects of the work and caring interface. Research which has examined the effects of both care-related and work-related factors on carers' mental health will also be discussed.

The effects of caring on specific work-related factors

Working status

In the previous section, the effects of working status on the provision of care was examined. Other research has also examined whether or not the provision of care affects women's working status. A US study (McKinlay, Crawford & Tennstedt, 1995) claimed that a longer duration of caring was associated with negative impact on an unemployed carer's decision to work. Murphy et al. (1997) also reported in an Australian study that over a third of non-employed daughters were unable to work due to caring, and 20% had already given up work due to caring responsibilities. Other research has also shown that those with higher caring commitments often end up leaving work as a consequence of their caring role and that the prospect of having to make work accommodations kept some people from working at all (Stone & Short, 1990; Murphy et al., 1997). In one of the few longitudinal studies undertaken in this area, Franklin, Ames and King (1994) examined employment adaptation in female employed carers, including short-term work adjustments, leave of absence and leaving the workplace. Carers in full-time or part-time employment made substantial work adjustments upon assuming the carer role, but short-term work adjustments and leave of absence significantly decreased after three months. The authors suggested that the carer may adjust *so successfully to the eldercare role that she finds it less of a* necessity to make changes to her employment role (1994: 38). However, several care recipients with higher care demands who were more likely to influence employment changes were no longer in the study after three months. Other studies have shown that between 22% and 24% of respondents may eventually leave work to provide care (Scharlach & Boyd, 1989; Pavalko & Artis, 1997). Two qualitative studies also found that caring was frequently given as a reason for the likelihood of leaving work, with holiday and rest days often used for caring responsibilities (Phillips, 1994; Guberman & Maheu, 1999). Another US study (Scharlach, Sobel & Roberts, 1991) showed that work disruptions associated with caring were found to be significantly associated with carer strain and the likelihood of job turnover. Job turnover was also more likely when the employee was in poorer health and dissatisfied with social support. In an early study, Brody et al. (1987) showed that the problems experienced by the women who had left work and those who were conflicted because of parent care resulted from work-related pressures in combination with caring for a severely disabled relative. Those who had left work had the oldest and most severely disabled mothers, had been helping the longest and were more likely to be co-resident, although the conflicted women were close behind. More women in these groups reported lifestyle disruptions, and were more likely to be sole helpers. Those who had quit work had less education, lower incomes, had held jobs of lower status and their mothers received the least paid help. Non-working women often thought of employment as "just a job", rather than as a career, and the women who had left work had less egalitarian views of women's roles than the workers. Dellasega (1990) found that nonemployed carers tended to experience more problems with their own health, and felt significantly more stressed, although it is suggested that this may be due to older age and poorer health status. Murphy et al. (1997) found that carers who had relinquished other roles or had fewer roles felt more resentment about caring. Those forced to resign, and without a partner, were the most resentful. However, Hawkins (1996) found that employed daughters had significantly higher stress scores than non-employed daughters. Barnes, Given and Given (1995) looked at the effects of caring on three groups of women: employed daughters, daughters who were never employed, and daughters who left work to care. Daughters who left work to care were caring for more dependent and incontinent parents than the other groups, a finding similar to that reported in the Murphy et al. study (1997). They also attended to parents more frequently in self-care activities. The parents were also older than those of the employed daughters. The authors concluded that daughters who terminate employment appear to have the greatest need for support in their caring endeavours, as carer strain was greatest among this group of women.

Number of hours worked

A recent study by Spiess and Schneider (2003) reported that for midlife women in Europe, starting or increasing caring responsibilities is associated with a decrease in working hours, and in a study of health-care workers in the UK, Rands (1997) showed that working carers were typically working part-time and earning incomes in the lowest brackets. However, in a US study looking at female carers in different working situations, Boaz and Muller (1992) showed that more educated carers were more likely to work full time, and that those with more job experience (seniority) were more likely to work full-time and expected to earn more. Responsibility for caring did not affect part-time employment and affected full-time work only slightly.

Neal et al. (1993) found that the number of hours worked predicted adverse outcomes for working carers, although Gottlieb, Kelloway and Fraboni (1994) found no such link. Dellasega (1990) also concluded that neither full nor part-time work significantly increased carer stress. However, Martire, Stephens and Atienza (1997) demonstrated that women working for more hours were buffered from the worst effects of caring stress. For those working part-time, higher levels of carer stress were related to poorer physical health, depression, and less positive affect. For full-time workers, no association was shown between carer stress and these three outcomes. The authors suggested that the beneficial effects of full-time employment were due to the greater amount of respite and resources gained, although longer hours worked related to less positive affect.

Income level

An increasing area of concern for researchers and policy makers is the effect of caring on income level of the carer, and how prolonged caring may also have an impact on carers' income after retirement. Laczko and Noden (1992) showed that UK carers in paid employment in 1991 had significantly lower incomes than other people in paid employment. Less than half of all carers providing 20 hours or more of care per week were employed, suggesting that the proportion of carers in employment decreases as caring responsibilities increase. Results also showed that carers were often passed over for promotion, were disadvantaged when applying for jobs and reported restricted career development, less training and reduced earnings. Those leaving employment to care found it less easy to find work after caring, with ex-carers over 40 having particularly low employment rates. Pavalko and Artis (1997) reported that those who stopped caring during a 3-year longitudinal study in the US did not increase employment later, suggesting that hours lost at this life stage are not recovered. Spiess and Schneider (2003) also found that midlife women in Europe as a whole were unlikely to resume their former working status when caring was reduced or ceased altogether. Employed women, therefore, appear to take on caring tasks at a potential cost to their short and long-term income.

Disruptions at work

An area of concern for employers is the level of work disruption experienced by working carers, and how those disruptions may affect productivity. Scharlach and Boyd (1989) reported that those areas of concern found to be particularly prevalent among working carers included absenteeism, time off during the working day, work interruptions, anticipated job turnover and missed career opportunities. The average respondent reported missing almost nine hours of work in the previous month due to the demands of caring. In a UK qualitative study, Phillips (1994) also found that lack of concentration, arriving late and leaving early, extended lunchbreaks, anxiety about the situation at home, and time off unofficially were of most concern to female carers. Many caring activities such as medical appointments required time off during the day, a finding which echoes some of the previous US research (e.g. Matthews et al., 1989). Also, many difficulties were reported with arranging help from formal services. In an Australian study, Murphy et al. (1997) found that employed carers predominantly found work a source of relief, but one third said they had less energy for work due to their caring demands and almost a third had repeated interruptions at work. Many had altered work schedules by reducing hours and taking unpaid leave. Others had taken a less responsible job, changed jobs or refused a promotion. In all, 63% reported that caring had adversely affected their work in at least one of these ways. Orodenker (1990) claimed that work disruptions significantly increased stress for employed carers. Working women experienced significantly more stress when they were unable to balance the demands of the two roles and were forced to alter work schedules to meet caring demands. Services were frequently denied if a woman was available to assume the caring role, irrespective of her employment status. Stephens, Franks and Atienza (1997) found that being exhausted, disrupted at work and unable to concentrate were the most frequently endorsed types of negative spillover from the carer role to the work role. Stress in both roles was significantly related to depression and to negative spillover, and negative spillover in both directions was significantly related to depression.

Type of employment

Section 2 outlined the importance of work flexibility in women's attempts to combine work and caring roles (Matthews et al., 1989). Scharlach et al. (1991) also found that job flexibility was associated with decreased work interference. In a UK study, Phillips (1994) found that carers working in management had more flexibility to allow for late arrival and early leaving, whereas women who worked full-time on the factory floor had limited access to a phone, little flexibility in their jobs to reorganise their schedules, little opportunity to pursue a career, and very few were in management positions. Many of the women held part-time jobs, chosen specifically to suit their caring responsibilities. Matthews et al. (1989) reported that for those carers who were working, lack of flexibility reportedly led to frustration and the possibility of employed daughters taking holiday time to care, although the job decisions of the respondents were only rarely affected by the needs of their parents. Neal et al. (1990) claimed that those working carers reporting the least flexibility at work also reported the most difficulty combining work and family. Those with less flexibility reported more interruptions, whereas professional and managerial employees reported significantly fewer interruptions than other employees. Part-time job status was associated with less difficulty combining employment and family. The findings also indicate that higher levels of stress were more likely to be found in carers than higher levels of absenteeism. Guberman and Maheu (1999) underlined the importance of flexibility, as well as other workplace conditions: autonomy, unionisation and level of responsibility, relationship with superiors and colleagues and their attitudes towards eldercare.

Martire et al. (1997) found that, although women who were more satisfied at work generally experienced fewer depressive symptoms than women who were less satisfied, high work satisfaction was associated with much greater levels of depression under high levels of carer stress. The authors suggested that this may be due to the conflict perceived between the two roles: employment is more important to these particular women's self-concept, and work interruptions may be especially problematic for women who are satisfied with their work, conclusions which are consistent with the earlier Brody et al. (1987) study. Satisfaction in both roles was directly related to greater wellbeing, even after controlling for stress levels.

Fredriksen and Scharlach (1997) showed that job classification, hours worked, work demand, workplace support and job flexibility contributed significantly to role strain among employed carers at a university. Those working in staff positions (i.e. those employed in clerical, service and trade jobs) provided higher levels of caring assistance and experienced less flexibility, control and support than academics and administrative staff. Staff workers also had lower levels of personal, family and work resources with which to offset the potential for carer stress. Staff workers provided more hours of care and were more likely to be co-resident with the care recipient, whereas academics were more likely to be providing indirect care and greater levels of financial assistance.

In the only known study of its kind, Marshall et al. (1990) looked at the effects of caring both at home *and* at work, with a sample of caring professionals. The authors reported on the experiences of the 326 respondents whose jobs always or almost always involved responsibility for clients or patients, although they were not necessarily also informal elder carers. Results showed that when caring taxed personal and material resources, there was a high risk for psychological distress, poor health and reduced wellbeing. The authors referred to their previous research which demonstrated that work is "good medicine" for women due to its buffering effects (e.g. Barnett, Baruch & Marshall, 1987), but concluded that "when women face overwhelming demands from caregiving at work, their mental and physical health suffers" (1990: 275).

The effects of specific care-related factors on work

Caring status

Comparative data from working carers and working non-carers has provided important information on the specific effects of caring on work. Previous research has shown that employed carers overall were more likely to experience interference between work and family than employed non-carers (e.g. Scharlach & Boyd, 1989; Neal et al., 1990). Neal et al. (1990) also found that interruptions at work took place two or three times more often for caring employees than non-caring workers, and carers reported higher levels of stress than non-carers. Other researchers have shown that women with multiple caring responsibilities, i.e. childcare and eldercare, appeared to be at the greatest risk of experiencing family interference with work, and personal and job costs (Gibeau & Anastas, 1989; Neal et al., 1990; Gottlieb et al., 1994; McKinlay et al., 1995).

Resident status

Previous researchers have examined the resident status of the elder, specifically whether or not the elder is co-resident with the carer, and how that may affect work. Robison et al. (1995) reported on a study undertaken with a sample of women interviewed in 1956 and re-interviewed in 1986. Women born later reported living more often with the elder, an unexpected finding. The authors suggested that this may reflect the increasing numbers of older people with chronic debilitating diseases: daughters who may originally live too far away to provide daily care are forced to take the elder into their own home or to move into the elder's home. Brody et al. (1987) previously reported that co-residence was a risk factor for women leaving work to care. A British study, commissioned by the Employment Department, and based on British Household Panel Survey data (Corti & Dex, 1995), showed that over a third of female co-resident carers of working age said that family commitments had prevented them from looking for a job, four per cent had not been able to accept a job that they had been offered, and twice as many as non-caring women said that they had had to leave their jobs or reduce their hours of work.

Co-residence was previously shown to be a risk factor for increased stress among working carers (Gottlieb et al., 1994). Orodenker (1990) reported that women who had never been employed were more likely to be co-resident and in poor health, factors likely to compound carer stress. Murphy et al. (1997) found that the intensity of caring was highest for co-resident carers, who also reported more overload, more resentment and less life satisfaction. However, Goldsmith and Goldsmith (1997) found that carers and non-carers were not significantly different on role overload scores if the carer was co-resident with the elder. Also, no significant differences in work/family time conflicts were demonstrated for co-resident carers, results which contradict Brody et al.'s argument for the greater stress associated with co-residence (1987). McKinlay et al. (1995) similarly reported that co-residence with an older person and personal impact were not associated, perhaps because co-residence eliminates the work of managing two households, so detracting less from the carer's social and leisure time.

Intensity of care/impairment

Orodenker (1990) claimed that intensity of care and level of impairment in the care recipient were not significant determinants of stress for working carers. However, she did find that among older carers, time spent caring was a crucial determinant of carer stress. Hawkins (1996) compared employed daughters with non-employed daughters and also found no significant relationship between impairment levels and stress. Other research, however, has shown that those looking after elders with greater impairment also suffered most stress and most difficulty in combining work and family (Neal et al., 1993). Another US study (McKinlay et al., 1995) demonstrated that persistence of personal impact was associated with caring for a more disabled older person or one whose disability increased over time, although this impact was mediated by the use of formal services. Voydanoff and Donnelly (1999) demonstrated that the number of hours spent helping and caring for parents was positively associated with psychological distress. However, hours helping parents were negatively related to distress for those with high levels of job satisfaction, marital happiness, and family closeness, and positively related for those with high levels of marital disagreements. It was concluded that marital happiness and job satisfaction buffered the relationship between hours helping and caring for parents and psychological distress. Reporting on the results of a longitudinal study, Lechner and Gupta (1996) claimed support for the "wear and tear" notion: significant functional decline of a relative increased carer stress over time.

Providing vs. managing care

Fredriksen and Scharlach (1997) reported that those carers with higher-status jobs, higher incomes and more job flexibility were more likely to be care managers than care providers, and were significantly less likely to leave work as a result of their caring responsibilities. Those in lower-status jobs also reported more role strain. Orodenker (1990), however, reported that those carers who were co-ordinating outside help reported more stress, a finding which runs contrary to Archbold's distinction between the stress experienced by care providers and care managers (1983).

Relationship to elder

McKinlay et al. (1995) reported that caring daughters were most likely to report negative impacts and married co-resident daughters were at higher risk of personal impact than those unmarried. Daughters also reported the highest rates of impact on family relationships and employment decisions. Both daughters and female other relatives were more likely to report impact on employment decisions than males, wives and female non-relatives.

Length of time caring

A longitudinal study in the US, employing a 4-year follow-up, aimed to assess how managing the dual roles of caring and employment changes over time (Lechner & Gupta, 1996). While follow-up response rate was low, the authors reported that respondents' experiences at work remained fairly stable over time, although overall job satisfaction declined significantly. Carers indicated that the past four years of caring had changed their lives significantly for the worse: they had less free time, lessened physical and mental health, a weaker financial base, and less optimism about future plans. However, no changes were reported in work performance and respondents reported feeling better about themselves as a result of caring, demonstrating the positive aspects of caring. Significantly higher stress scores were recorded at follow up, with carers reporting less confidence in themselves, less ability to control important events, more nervousness, less ability to cope, and feelings of being more overwhelmed by difficulties. No significant declines were shown in physical wellbeing. Parents received more formal services at follow up, and almost half of the carers had been thinking about admitting their parents to a home. In another longitudinal study, using a nationally representative sample of working carers, McKinlay et al. (1995) reported that the risk of institutionalisation was twice as likely at the next follow-up for those cared for by someone reporting negative personal impact (negative impact on sleep, health, leisure, privacy, financial situation and management of household chores), regardless of the elder's disability level. However, the majority of elders continued to receive help from the same carer, regardless of the negative impacts reported.

Help with caring

McKinlay et al. (1995) also reported that unemployed carers who had reported that caring had had a negative impact on the decision to work (left work or did not seek employment) were significantly more likely than other carers to report a larger amount of care from secondary providers by the next follow-up. The authors concluded that caring exerts the greatest toll on the carer's personal life, and that caring impacts persist over time and are not mitigated to any great extent by assistance with care.

Summary of Section 3

Overall, it appears that caring can have a detrimental effect on employment, with women often reducing their working hours or leaving work altogether. Carers who leave work to care for an older person rarely make up for lost work hours and lost income after caring has ceased by returning to their former employment status. Other common problems related to caring are an inability to take up promotions and extra training, factors which restrict career development and overall level of income. Disruptions at work are common, but appear to be less problematic for those in jobs with more flexibility and higher status. Most previous studies have included employment as a dichotomous variable, not focusing on the different work situations of employees: flexibility is only one of many possible work characteristics which could affect the balance between work and caring. An often-overlooked group of female carers are those who have left work to care and who appear to care for the most severely disabled elders.

Co-resident status may also be linked with lower income and employment prospects, although its association with stress varies. Other care-related factors which appear to affect carers' mental health are relationship to the elderly person and length of time caring. However, the relationships between other care-related factors and stress in working carers are inconsistent.

Most of the research was also cross-sectional in nature, casting some doubt on the usefulness of the findings. Associations between outcome measures and work-related or care-related variables do not provide any evidence about direction of causality, and only longitudinal research can help to determine the causes of negative health outcomes in working carers. Work and caring situations are prone to change, and more research is needed to look at how these two roles interact, and which factors predict negative outcomes over time.

Section 4: Potentially positive aspects of combining work and caring roles

Most research on women's work and caring roles has focused on the potentially negative aspects of combining roles. However, a low score on a negative mental health outcome measure provides little information on the positive aspects of combining roles, and in the same way, a low score on a positive outcome measure does not directly relate to the negative aspects of combining roles. A recent study (Huppert & Whittington, 2003) provided evidence for the independence of positive and negative wellbeing and suggested that measures of both should be included in future research on health outcomes. As not all individuals respond the same way to multiple role occupancy, it is vital that researches examine which particular circumstances give rise to negative outcomes and which give rise to positive outcomes.

In spite of all the potentially negative factors involved in combining work and caring roles, Scharlach and Boyd (1989) also claimed that for many working carers, any negative aspects are outweighed by the salutary aspects of combining work and caring. Another study by Scharlach (1994) argued against the reliance in the past on a conflict model of role interaction. Instead, his findings suggest support for a role enhancement or positive spillover model, in which the caring role can actually enhance job performance by helping carers to be more sensitive to the needs of others. UK studies have also noted some of the positive aspects of combining work and caring: it was reported that working often provided respite from the caring situation and enhanced feelings of self-worth (Phillips, 1994; Rands, 1997). Rands (1997) also claimed that 78% of respondents wanted to continue working. In a US study, Hawkins (1996) similarly reported that although taking additional days off and adjusting working hours were frequently reported by working carers, 80% of respondents claimed to be satisfied with their current employment status. Stephens et al. (1997) claimed that the most common type of positive spillover reported in combining work and caring was being in a good mood in one role because of the positive experiences in the other.

Summary of findings from previous studies

- Female carers do more caring than males, whether employed or not. As level of caring assistance is directly related to levels of carer stress, it is not surprising that women also report greater levels of carer stress than males.
- Although results are inconsistent, it appears that female carers in full-time employment generally undertake less hands-on, personal care than those either in part-time employment or not employed. However, employed women are no less likely to take responsibility for the care of an older person.
- Part-time employees provide as much care as those women who are not employed.
- Caring can have a detrimental effect on employment, due to interruptions and time

off to fulfil caring responsibilities. Such work disruptions are significantly related to increased levels of carer stress.

- Caring can also negatively affect employment opportunities for working carers.
- Working carers with more flexibility within the workplace report lower levels of stress. However, the majority of female care providers are in part-time, less flexible and lower-paid jobs. Female care managers are more likely to be in higher-paid jobs with greater flexibility.
- Many women with less career-orientated jobs reduce their working hours to care, but women in higher-salaried jobs are less likely to adjust their lifestyles, and less willing to give up work to care.
- Those women who have left work to care are less well-educated, have fewer resources and care for the most severely disabled relatives. There is also some evidence that they suffer more resentment and other negative outcomes in the caring role than other female carers.
- Co-residence, parental caring, longer time caring and higher-intensity caring may lead to increased carer stress, although findings are inconsistent.
- Employed carers, whether male or female, experience more stress than employed non-carers.
- High levels of job satisfaction and better relationships with other family members provide a buffer against the negative effects of combining work and caring roles.

Critique of the literature and directions for this research

Although there has been much research on women's attempts to combine work and caring roles, most studies have focused specifically on the effects of care-related factors on work. The effects of particular work-related factors *and* care-related factors on carer and health outcomes have generally been overlooked. Those studies which have examined specific work-related factors have found important effects on negative and positive health outcomes. Most previous research has also been cross-sectional in nature, and therefore direction of causality between variables cannot be determined. The few longitudinal studies undertaken have suggested an increase in carer stress over time. The positive aspects of combining roles have generally been ignored, or inferred from respondents' scores on negative outcome measures.

This research will aim to address these problems by including well-validated and reliable measures of work-related factors, as well as care-related factors, in a series of surveys. In order to ensure that all potentially important factors in the work/caring interface are represented in the surveys, interviews with working-age women will also be undertaken. To clarify direction of causality between variables, a follow-up survey after one year will aim to examine any changes in work and caring roles, and which particular factors predict that change. The positive aspects of combining work and caring roles will also be examined by including valid and reliable measures of positive carer and health outcome measures.

Chapter 4

OUTLINE OF THE METHODOLOGY EMPLOYED IN THE RESEARCH

Introduction

Various research methods were employed at different stages of this study. Figure 4.1 demonstrates that a combination of three postal surveys (the screening survey, Time 1 and Time 2 surveys) and a series of semi-structured interviews with working-age carers was used to provide a rich body of data with which to address the specific questions of interest, as discussed in Chapters 5, 6, 8, 9 and 10.

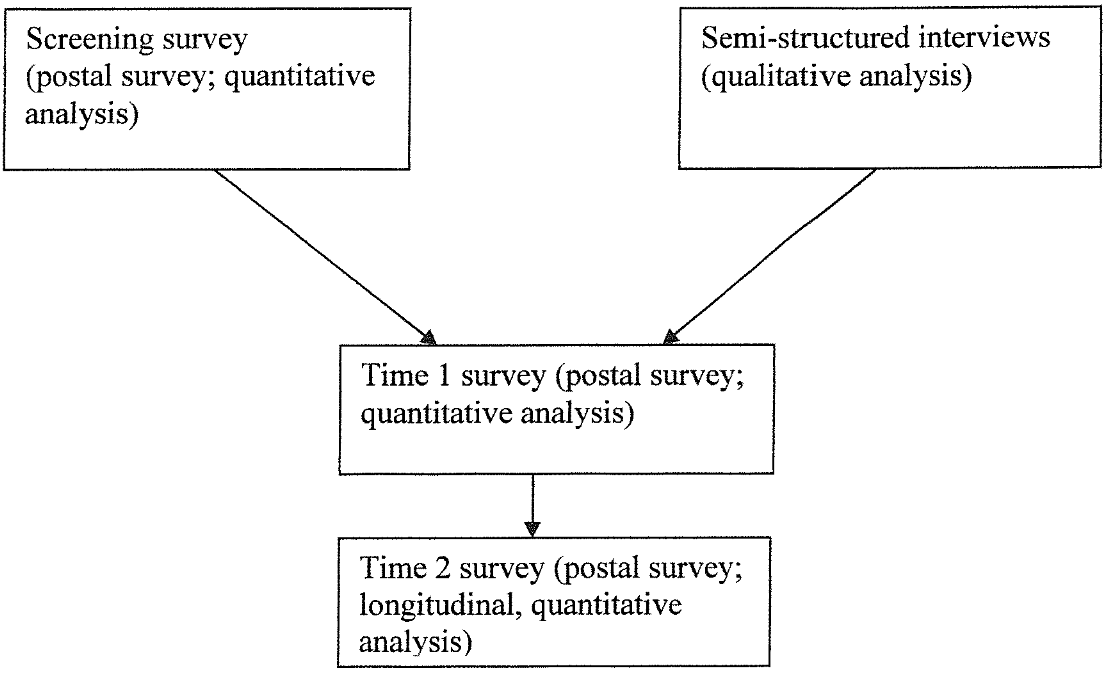

Figure 4.1: **Plan of the research methodology**

The initial screening survey (Chapter 5) was developed to generate a large sample of working female carers who would also be willing to respond to the later stages of the research, and was designed to measure briefly those factors of interest which had been identified from previous research. Several of the single-item measures of work-related and care-related factors included in the screening survey were indicative of whole scales. If shown to be influential factors in the screening survey, the scales were then included in the Time 1 and Time 2 surveys, in order to measure the importance of these factors more fully. Other single-item measures included in the screening survey provided preliminary information on the effects of specific care-related disruptions at work, as identified in previous research studies of working carers. An inductive approach was also employed to identify any further factors of importance which may not have been examined in previous research (Chapter 6). Qualitative analysis of semi-structured interview data led to the development of two new measures of personal factors involved in work and caring, which had not previously been measured in a diverse group of carers. These two measures were then included in the Time 1 survey to test their relative importance in predicting carer and health outcomes. In order to examine the effects of any changes in work and caring roles, and which factors predicted that change, a follow-up survey containing the same valid and reliable measures was distributed after one year to the same respondents (details of Time 1 and Time 2 surveys in Chapters 8, 9 and 10).

This chapter will briefly outline the choice of sampling and research methods, the advantages and disadvantages of the methods chosen, the use of combined qualitative and quantitative methods and the ethical issues involved in the research. Specific methods of data analysis employed in the research will be discussed in later chapters.

Sampling methods: carer samples versus employee samples

In a paper which examined the shortcomings of previous research on women's work and elder-caring roles, Tennstedt and Gonyea (1994) discussed the potential problems associated with targeting either a carer sample (i.e. elder-carers who were also employed) or an employee sample (i.e. employees who were also caring for an elder) for the purposes of research. The two methods generated different prevalence rates of working carers, due mainly to the response rate and also the definition of carer employed in the research. While the current research was not concerned with measuring the prevalence rates of working carers, a large group of working female carers was required to investigate the main research questions, and of these, a sub-sample of working carers employed in caring occupations was also needed. Both sampling methods were therefore discussed and evaluated for the research. In the initial stages of the research, it was thought that a suitable sample may best be obtained by approaching carers' associations, with a view to targeting those members currently in work (carer sample). It was felt that this method would reduce the potential for a low response rate, often encountered when targeting employee samples (e.g. Phillips, 1994). By attending several local carers' meetings, I planned to approach working carers directly, explain in my own words the purposes of the research and ask for volunteers who would be willing to be interviewed. However, the co-ordinators of two local carers' associations in the south-east advised that most of the carers attending carers' group meetings were retired and therefore ineligible for this research, with employed women being less likely to have the time to participate in the meetings. It was then thought that carers may be contacted by post via the carers' associations to which they were affiliated. After contacting the Carers' Association and the Princess Trust, however, I was informed that there were major restrictions involved in accessing the names and addresses of carers in this way.

Eventually, it was decided that instead of attempting to target a sample of carers who were also employed (carer sample), a more productive approach would be to target a sample of employed women who were also elder carers (employee sample). In order to do this, several employers were contacted directly by post, with a focus on those employers more likely to employ women involved in caring work, e.g. the National Health Service. By including a control group of non-caring employees working in similar occupations, comparative information on work-related problems and the mental health of working carers and non-carers was also generated. Without such a comparison group, it would not be possible to determine if work-related problems were more prevalent among employed carers than employed non-carers, whether or not they were associated directly with caring responsibilities or were influenced by other factors (Tennstedt & Gonyea, 1994), and whether or not carers were more likely to experience negative mental health outcomes.

As a consequence of using an employee sample, however, a comparison group of non-working carers was not available for quantitative analysis. Although several of the women interviewed in the qualitative stage of the research (Chapter 6) had either given up work to care or had never worked, it was not possible to determine quantitatively the predictors of both negative and positive health and carer outcomes for those who were not currently in paid work. Researchers have previously demonstrated that women who have given up work to care reported greater adverse outcomes (Dellasega, 1990; Barnes et al., 1995; Murphy et al., 1997).

Advantages of using an employee sample for this research

- Wider coverage to obtain a large sample of working carers.
- Greater potential for targeting those women of interest to the research, i.e. carers also working in caring professions.
- Fewer restrictions in accessing employee samples.

Disadvantages of using an employee sample for this research

- Lack of non-working carers as a comparison group.
- Potential for low response rate.
- Sample is work-site specific and results are not generalisable to other employee samples (Tennstedt & Gonyea, 1994).

Postal survey methods

Originally, it was decided that face-to-face interviews would be best suited to the research question, in order to gain more in-depth, qualitative data. However, due to the change in approach, this was felt to be impractical as face-to-face interviews would be impossible to undertake with such a large group of women. It was hoped that a large, representative sample of female employees would be identified by designing a short screening survey for distribution, with single-item measures of specific work and care-related factors which would be addressed more fully in the later surveys. Single-item measures relating to care-related disruptions at work were also included. However, it was anticipated that a relatively low response rate might be recorded, despite efforts to ensure response. Many of the employees may consider the study not relevant, so reducing response (Tennstedt, Dettling & McKinlay, 1992). This could be especially the case for non-carers, even though the survey for this group of respondents took less time to complete. Other potential problems which may affect response rate and honesty of answers were also discussed and evaluated (see "disadvantages of using postal surveys for this research"). After analysis of both the screening survey and the interview data (see "semi-structured interviews"), longer postal surveys were developed and distributed for the Time 1 survey and the Time 2 follow-up survey after one year. These surveys included well-validated and reliable measures of several work-related and care-related factors measured by single items in the screening survey. Measures of those factors found to be most important to the women interviewed in the qualitative stage of the study were also included. It was felt that those working carers who responded to the screening survey and expressed a willingness to respond to a further survey were sufficiently interested in the research to answer a longer set of questions. Non-carers were again sent a shorter version of the survey, encouraging a better response rate.

Advantages of postal surveys for this research

- Access to a large, heterogeneous sample of working carers, not available via other methods.
- Access to a control group of working non-carers to provide comparative information.
- Anonymity of data for respondents (screening survey).
- Surveys can be completed in respondents' own time.
- Pre-coding of questionnaire responses allows for quicker analysis of data.

Disadvantages of postal surveys for this research

- Potential for low response rate, due to perceived confidentiality of the data, the use of internal mail for distribution and return, time constraints imposed by combining both work and caring roles, cultural differences (e.g. language difficulties), and high turnover rates among certain occupational groups.
- Potential for respondents to misread or misunderstand questions, leading to returned questionnaires which are incomplete or unusable (Newell, 1993).
- Reliance on self-report data.
- Inability to approach carers directly and explain relevance and importance of study.
- Cost of developing, printing and distributing surveys.

Semi-structured interviews

Semi-structured interviewing involves the interviewer asking certain questions in the same way to each respondent, but allows for more flexibility than postal surveys. The interviewer can alter the sequence of questions and probe for clarification when important issues are discussed (Fielding, 1993). In the research described here, it was important to try to ascertain those issues of most importance to female carers in their attempts to balance work and caring responsibilities. Although postal surveys would be useful in measuring existing issues (screening survey), interviews would help to elicit any new and perhaps previously unmeasured factors which could then be included in further surveys with large numbers of respondents (Time 1 and Time 2 surveys).

The interviewer's own presence invariably affects the outcome of an interview, during the interview itself and also during the analysis of data. The subject of "reflexivity" in qualitative research has recently grown in importance, as different interviewers are likely to vary in their perception of certain responses (King, 1998; Smith, 1998; Camic, Rhodes & Yardley, 2003). To ensure that I reflected upon my own influence during the interview process, all efforts were made to discuss any issues relating to reflexivity with my supervisor. The issue of reflexivity will be discussed in more detail in Chapter 6.

Another related problem with using qualitative methods is the evaluation of their validity. Smith (1998) suggests possible criteria for evaluating qualitative research. Chapter 6 will outline the procedures involved in ensuring the validity of the data analysis from the semi-structured interviews.

Advantages of semi-structured interviews for this research

- Use of inductive approach to identify previously unmeasured factors of importance.
- Potential preliminary identification of the predictors of negative and positive outcomes for non-working carers, not possible via survey methods using employee samples.
- Potential for generating more in-depth, narrative reports of combining work and caring roles.
- To complement and enhance the quantitative data from the surveys.

Disadvantages of semi-structured interviews for this research

- Small sample due to carers' groups restrictions, willingness of carers to be interviewed and time constraints of researcher.
- Homogeneous group of carers only, due to geographical location and membership of carers' groups.

- Potential influence of interviewer.
- Evaluation of validity of qualitative data analysis.

Longitudinal research

Due to the changing nature of both work and caring roles, it has been well documented that longitudinal research is vital in this field of research (e.g. Martire et al., 1997). In 1994, Tennstedt and Gonyea reported that there were no longitudinal or prospective studies on the intersection of work and caring roles, with all studies up to that time relying on cross-sectional and retrospective data only. As both roles are dynamic, important changes in each role and causal associations between variables cannot be captured by cross-sectional data (Tennstedt & Gonyea, 1994). In order to address this gap in the research and to investigate any changes over time in the situations of individual working carers, it was decided that a follow-up survey, sent out to those working carers and matched non-carers who had expressed a willingness to respond to a final survey, would be distributed one year after the Time 1 survey. This survey would include several of the same measures included in the Time 1 survey, but would omit questions relating to age, relationship to elder, etc., as this information was already available. There was the possibility at this stage of a high attrition rate, due to carers retiring, changing jobs, moving out of the area or not caring for an older person any more. However, it was felt that those carers who had been willing to respond to the previous two surveys would also be likely to respond to the final, shorter survey, if change in circumstances did not exclude them.

Advantages of using longitudinal research

- Potential for examining dynamic nature of work and caring roles.
- Potential for causal associations between variables to be determined.

Disadvantages of using longitudinal research

- Potential for high attrition rate, due to change in circumstances or non-response to follow-up.
- Costs of developing, printing and distributing follow-up surveys.

Combining quantitative and qualitative methods

In spite of arguments that quantitative and qualitative research methods represent competing paradigms, some researchers have proposed the combined use of both methods in future research. McGrath and Johnson (2003) argued that different paradigms have different strengths and weaknesses and that the simultaneous use of both quantitative and qualitative methods will help to avoid the problems underpinning both (2003: 46). Hammersley (1998) also supported the use of methodological eclecticism, in which one method can generate hypotheses for another, and complementarity, where both methods provide different but complementary information. In the research described here, the use of both quantitative and qualitative methods allowed for the collection of a rich and diverse body of data. Hammersley noted: "....the goals of research vary according to the stage that it has reached and ...there is no fixed relationship between the use of qualitative or quantitative methods and a particular stage in a research programme...." (1998: 174). The screening survey provided a sample of working carers and preliminary information with which to develop the Time 1 survey. However, the semi-structured interviews explored more fully the aspects of most importance to working female carers, which led to the development of a preliminary model of the relationship between work and caring roles and two new measures to include in the Time 1 and Time 2 surveys.

Ethical issues

Ethical approval was applied for and received from the University of Southampton's ethical committee before any interviewing was undertaken or surveys distributed. I also attended a research ethics committee meeting at one of the NHS Trust hospitals which agreed to take part in the research (Trust 2). Approval was granted to access employees' names and work-site addresses from the Trust's nominal roll*, and home addresses would only be given by the employees themselves who were willing to take part in further stages of the research. The management team at Trust 1 similarly allowed me to access the names and work-site addresses of employees directly from the nominal roll*. The screening survey was anonymous, unless the respondent wished to respond to a further survey, in which case, name and address were requested. Due to the personal nature of many of the questions involved in the surveys and interviews, a detailed information sheet and consent form were included for all respondents (see Appendices), who were asked to read through all the information before signing the consent form. During the interviews, I ensured that the respondent had read and understood the information sheet and signed the consent form while I set up the recording apparatus. It was anticipated that I may encounter difficulty in eliciting honest, open answers from the respondents, when asking questions about sensitive issues such as the quality of the relationship between carer and elder. It was also possible that some respondents may become upset during the interview when touching on these sensitive issues. It was considered vital that those who agreed to be interviewed were not left feeling uncomfortable and embarrassed about what had been discussed. Researchers have proposed that different strategies may be appropriate within the course of an interview, according to the response of those individuals being interviewed (King, 1998). With this in mind, a decision was taken to stay at the end of each interview to talk through any issues which either I or the respondent felt to be important, and also to end the interview on a lighter, more positive note.

Summary

The study employed a combination of quantitative (survey methods) and qualitative methods (semi-structured interviews), in order to generate a rich body of data with which to address the research questions to be outlined in the following chapters. Chapter 5 will describe the screening survey, Chapter 6 will outline the semi-structured interviews, and Chapters 8, 9 and 10 will discuss the Time 1 and Time 2 surveys.

---

* This study began before the current Data Protection Act came into force.

Chapter 5

THE SCREENING SURVEY: A PRELIMINARY QUANTITATIVE ANALYSIS OF THE DIFFICULTIES INVOLVED IN COMBINING WORK AND ELDER CARING ROLES

Introduction

Previous research investigating the impact on women of combining work and caring roles has tended to ignore the particular kinds of jobs undertaken by female carers, categorising women merely as workers or non-workers. Priority has usually been placed instead upon the nature of the caring role undertaken and how that affects health outcomes.

In a few notable US studies, discussed earlier in Chapter 3, researchers investigated some of the work characteristics involved in female carers' jobs. Fredriksen and Scharlach (1997) showed that job classification, work demand, workplace support and job flexibility contributed significantly to role strain among working carers at a university, emphasising the importance of work characteristics in women's attempts to combine roles. They also found that longer working hours contributed to role strain in carers. However, in a study published in the same year, Martire et al. (1997) found that women working for more hours were buffered from the worst effects of caring stress. This latter study also underlined the importance of work satisfaction in combining work and caring roles. Satisfaction with both work *and* caring was directly related to greater well-being, even after controlling for stress. However, high work satisfaction was associated with much greater levels of depression when high levels of carer stress were also recorded. This study highlights the importance of examining both the positive and negative aspects of work and caring roles, although no specific work characteristics were included in the analysis.

Marshall et al. (1990) investigated the effects of caring both at home *and* at work, with a sample of caring professionals, and concluded that when caring taxed women's resources, there was an increased risk of psychological distress, poor health and reduced well-being. Although the authors limited their examination of work characteristics to five items, they concluded that care-related jobs typically offer little autonomy and challenge. As care-related work tends to be low in status, these findings support those reported in the Fredriksen and Scharlach study (1997), which demonstrated that those carers in lower status jobs experienced less flexibility, control and support than those in higher status jobs, who were more likely to provide indirect care and greater levels of financial assistance. The Marshall et al. study, however, did not restrict the sample of carers to those looking after older people, but included those caring for friends, children, etc.

Other studies have examined work disruptions associated with caring responsibilities at home, such as interruptions and absenteeism (Scharlach & Boyd, 1989; Murphy et al., 1997), arriving late or leaving early, extended lunchbreaks and time taken off unofficially (Phillips, 1994), and have found that these disruptions are predictive of negative outcomes for carers (e.g. Orodenker, 1990; Stephens, Franks & Atienza, 1997).

Unlike many of the previous studies on combining work and caring roles in women, these studies highlight the importance of examining the kinds of occupations undertaken by working carers, and how these occupations interact with the caring role. In order to examine fully how the roles of work and caring interact, a detailed assessment of the characteristics of each individual role is vital in this field of research. In the empirical research reported in the following chapters, work characteristics will be fully explored, as well as a detailed examination of caring characteristics. Contradictory findings, such as those reported in the first two studies regarding the number of hours worked, will be examined and discussed. Both positive and negative outcome measures will be included, as in the study reported by Martire et al. (1997). The findings reported by Marshall et al. (1990) will later be compared with the results of an assessment of those women caring for an older person while also working in a care-related occupation (Chapter 9). The first step in the research plan was to develop and distribute a preliminary screening survey to examine predictors of negative outcomes in a large group of female working carers.

Research questions

- Are working carers more likely to be depressed than working non-carers?
- Which factors predict unhappiness/depression in working carers?
- What kinds of jobs are undertaken by female carers and how does caring impact

on those jobs?

- How important are work characteristics in combining work and caring roles?

Method

NHS Trust Hospitals were selected to provide participants for the screening survey. It was expected that a hospital setting would yield a large sample of women working in a number of different occupations and would also identify the different kinds of jobs undertaken by female carers in particular. This method would also ensure the inclusion of a number of women caring both at home and at work. Early approaches to hospitals in the South-East of England generated little response, and so letters were sent out to the chief executives of all 52 NHS Trusts in the Greater London area. Ten of these expressed an interest in taking part in the research. Eventually, two NHS Trusts were selected for the screening survey, which will be referred to as Trust 1 and Trust 2. Both were large NHS Trust hospitals easily accessible to the researcher, and both were willing to allow surveys to be sent directly to all female employees via their internal mailing systems.

Participants

Only female, working-age employees were targeted (i.e. 16-65), due to the focus of the research. All were believed to be in the employment of the NHS Trust at the time the survey was sent out. Both part-time and full-time employees were included, with no lower or upper limit on the number of hours worked. A total of 3596 women were initially targeted, with 1083 from Trust 1 and 2513 from Trust 2. An additional 546 questionnaires were later sent to all women working as bank staff at Trust 2. Overall, 4142 screening surveys were distributed.

Procedure

Trust 1

An information sheet, consent form and screening survey (3 sheets of A4 paper in total) were sent out, attached to monthly wage slips in September, 2000 (for copies of each, see Appendices 1, 2 and 3). It was agreed, after contact with the head of the Human Resources department at the Trust, that the researcher would personally attach the information sheets, consent forms, surveys and return envelopes to the wage slips, ready to be delivered and later returned by internal mail. This would ensure that all the necessary information was included in each envelope and that any disruption to the Trust would be minimised. The gender of doctors was verified via the nominal roll, whereas all other employees were easily identifiable as Mr, Mrs, Ms or Miss. Due to the initial, low response rate, a short reminder slip was sent out to all targeted employees after one month (October, 2000), which was again attached to wage slips.

Trust 2

At Trust 2, internal address labels were collected from the payroll department, along with the nominal roll, which gave information on the gender of doctors. All other employees were recognisable as Mr, Mrs, Ms or Miss. An information sheet, a consent form, a screening survey and a return envelope were sent out to each employee (see Appendices 1, 2 and 3). In order to increase the response, posters were set up in several busy areas around both Trust hospitals, urging all employees to respond.

Trust 2 Bank staff

Initial analysis of the data from both hospitals showed that there were very few respondents who had reduced the number of hours of work to care for an older person (Question 8). This suggested the possibility that some women may instead have begun to work as bank staff to increase their flexibility. (Bank staff act almost as freelance workers, stating which hours and which days they can work. If there is a shortage of staff on that day, they may be called up and asked to work. They therefore have a high degree of flexibility in their working lives). Although this group had not initially been included in the mailing, female bank staff were now targeted as well. It was expected that this would lower the overall response rate, as many of the bank workers could have left since the original nominal roll was accessed (October, 2000). Also, a large number of bank staff only worked very occasionally, so reducing the probability of them receiving the survey before the response cut-off date of early January, 2001. However, it was felt that these bank workers could be a potentially important group of workers in the study. All Trust 2 bank staff were initially included to gauge the response. If it was shown that this was indeed an important group of respondents, then Trust 1 bank staff would also be targeted.

Ethical issues

The managers of Trust 1 initially requested ethics approval from their own ethics committee, but later decided that this was unnecessary, as it was staff, rather than patients, who were being targeted. Trust 2 did not require ethics approval from their own Trust ethics committee. Ethics approval was sought and received from the University of Southampton before the research went ahead. The information sheet and consent form ensured that all participants were informed of the purposes of the research, and that none were coerced into responding.

Measures

The following summary table outlines questions included in the screening survey.

***Table 5.1*: Summary table of questions included in the screening survey**

Category of question:	**No. of question:**	**Measure of:**
Demographic information	1	Age
	2	Occupation
	3	Hours worked
Work disruptions	4a	Days missed from work
	4b	Times late to work
	4c	Times left work early
	4d	Interruptions at work
Work characteristics	4e	Flexibility at work
	5	Work stress
Caring status	6	Caring status
	7	Hours of caring per week
Combining work and caring	8	Reduced hours of work to care
	9	Difficulty combining work and caring
Outcome	10	Unhappiness/depression

The screening survey was designed to be short, while generating as much information as possible. In order to do this, single-item measures relating to specific work and caring characteristics were included, several of which corresponded to reliable and well-validated scales to be used in the Time 1 survey. The screening survey was divided into two main sections, one relating to work and the other to caring (refer to Appendix 3).

The first section of the survey (Section A) asked for the age of the respondent, information on type of occupation, and the number of hours worked. These first three questions therefore allowed for comparisons to be made between carers and non-carers in each of these areas, as well as between carers in different working situations. Previous researchers have demonstrated differences in the kinds of care undertaken by full-time and part-time workers (Stueve & O'Donnell, 1989; Boaz & Muller, 1992). Hours worked could be an important factor in this research, and may provide clarification of the contradictory findings reported in earlier research (Fredriksen & Scharlach, 1997; Martire et al., 1997). These three questions were intended to be clear and unambiguous, designed specifically for this study.

The next set of questions (Questions 4a, b, c and d) referred to disruptions at work within the past four weeks. This time frame was chosen to allow people to focus on the recent past, which would hopefully generate a more accurate response. The questions were taken from the study carried out by Neal et al. (1993), which examined caring responsibility, personal characteristics, work and family-related demands in caring and non-caring employees. This series of questions succinctly measured the extent to which family responsibilities interfered with work.

The last part of Question 4 then measured the employee's degree of flexibility within the workforce. Flexibility has previously been shown to be important in attempts to balance work and caring (Fredriksen & Scharlach, 1997). By including these questions in the section which all participants were to answer, and not specifically referring to eldercare responsibilities, it was possible to examine any differences in work disruptions between working carers and working non-carers. (Questions 8 and 9 later examined work adjustments and the degree of difficulty involved in juggling work and caring). The six-item measure of job flexibility used by Gerstel and Gallagher (1994) was initially considered but was felt to be too long for the screening survey. It was decided that the single-item measure of flexibility included here would be more practical for the purposes of this research. A more detailed measure of autonomy and control would be included in the main survey (Haynes et al., 1999).

Question 5 was a single-item measure of work stress. It was also taken from the survey instrument developed by Neal et al. (1993). The authors presented the question in a section which asked: "In the past four weeks, to what extent have any of the following areas of life been a source of stress to you?" Seven areas of life were then presented, including: "Your job". Due to the focus on work in the screening survey, only the question relating to work was included, and was therefore worded slightly differently. However, no attempt was made to change the essence of the question. The same four response categories were used as in the Neal et al. study. Other survey instruments were considered for inclusion, such as the seven-item measure of work stress developed by Stephens et al. (1997). However, this would be included in the main survey, and no single item from this measure could be considered as an overall measure of work stress. Due to the necessary brevity of the screening survey, a single-item measure was judged to be preferable.

Section B of the screening survey then focused on caring responsibilities. Question 6 was taken directly from the Neal et al. survey instrument (1993). However, Neal began the question thus: "Do you have responsibilities for helping out relatives or friends who are elderly or disabled?" The rest of the question proceeded as in the screening survey. Because the present study was examining those employees who have eldercare responsibilities only, it was decided to change the wording of the question to specify the age of the relative (aged 65 or over). The word "elderly" was then changed to "frail", in order to address the research focus. The question now excluded employees who were caring for younger, disabled relatives. This question was selected for inclusion because it covered those employees who were co-resident with the older person *or* living elsewhere, and also provided some prompting on the different kinds of caring tasks undertaken. Other survey items considered were often overly-specific in their eligibility criteria, focusing only on particular relationships between carer and care recipient (eg. Martire et al., 1997; Stephens et al., 1997; Murphy et al., 1997). A decision was made not to exclude any carers because of their relationship to the care recipient or because of their resident status, as these groups will be examined in the later stages of the research for any differences in mental health. By focusing on one group of carers only, such as daughter carers (eg. Martire et al., 1997), interesting variations in the data are inevitably lost.

A question was then included to gauge the extent of the employee's caring responsibilities, as the extent of caring may be related to levels of stress. Several studies have used a minimum of six hours of care per week to define a carer, although there is a large amount of variation in the definition of carer in all studies undertaken to date, making meaningful analysis across studies very difficult. This question was used to examine whether the extent of caring is directly related to unhappiness/depression (Question 10). It was felt that the use of pre-defined categories which included a minimum range (one to five hours) would prompt the carer to focus more, creating less opportunity for inaccurate response.

Question 8 was taken directly from the Neal et al. (1993) survey instrument, assessing the extent to which the employee has had to make work adjustments in order to fulfil her caring duties. However, the word "reduced" was added to the original question: "If yes, how many hours per week?" It was felt that some participants might think the question was asking how many hours she was now working, causing discrepancies in the data. Previous research has claimed that carers who were employed in full-time work were less likely to make work accommodations, and instead reduced their hours of care substantially (Boaz & Muller, 1992). Part-time work does not confer the same benefits as full-time work, as both income levels and sources of support are reduced. Those who have reduced their working hours substantially may be less able to afford alternative care arrangements.

The next question was designed to gauge the degree of difficulty which the participant experienced in juggling work and caring demands, and was again taken from the Neal et al. study (1993). It was felt that the question was sensitively worded: if the question had simply asked: "How easy or difficult has it been for you," the participant may have responded in a defensive way, not wanting to appear weak or unable to cope. However, the initial statement allows the participant to examine her own circumstances in relation to others, perhaps encouraging a more honest response. The original question asked: "Circumstances differ, and some people find it easier than others to combine work with family responsibilities". (The rest of the question was the same). As the present study aimed to identify specific problems associated with combining work and caring, it was decided to change "family responsibilities" to "caring responsibilities". Otherwise, participants responding "very difficult" might be referring to problems with other family responsibilities not related to caring. In examining other studies, no alternative single-item measure of the degree of difficulty involved in combining work and caring was apparent.

The final question was taken directly from the General Health Questionnaire (GHQ-12), and was included as a single-item measure of negative affect. Other instruments were considered, but none included a concise measure of the negative health outcomes often reported by carers. No single item measure of stress was available. The six-item Perceived Stress Scale (Lechner & Gupta, 1996) was originally considered and then excluded because of its length. It was felt that negative affect should be gauged in all participants and then compared across caring and non-caring groups. Otherwise, working non-carers would be excluded from answering this question, which would mean a loss of potentially important variation in the data (negative affect is equally possible in all NHS workers, but the research interest lay in whether or not caring at home increases the likelihood and intensity of negative affect).

Data Analysis

Tests of association

A series of t-tests, ANOVAs and chi-square tests were performed on the data to examine bivariate associations. Initial analysis of the data showed that for chi-square tests, the number of respondents in each cell fell below five on several occasions. An example was the test measuring the association between hours per week spent caring (HPW) and the number of times the carer left work early (LWE). A crosstabulation of HPW*LWE showed a significant association between variables ($p<0.005$). However, a closer examination of the table revealed that, in ten cells out of the 18 presented in the crosstabulation, the number of respondents was less than five. This raised serious doubts as to the validity of the use of the chi-square test, which should only be run when less than 20% of the expected frequencies in a large table are under five (Kinnear & Gray, 1997). A decision was made that all crosstabulations with the number of respondents falling below five in any cell should be recoded in order to produce more reliable tests of association. In cases where there were large enough numbers in cells for meaningful analysis, the original coding was used to allow for greater discrimination among groups.

(The recoding of variables used in the analysis is described in Appendix 4). The HPW*LWE test was run again, this time with the recoded values of HPW2*LWE2, and was shown to be not significant at the 0.05 level. This result demonstrates the importance of recoding in situations where the number of respondents is too low for meaningful analysis.

Bonferroni corrections

Due to the number of statistical tests being carried out, there was an increased risk of a Type 1 error (rejecting the null hypothesis when it is true). It was therefore decided to use Bonferroni corrections in order to adjust the significance level of all tests. Bonferroni corrections are based on the principle of dividing up the error rate for a group or family of contrasts among each of the individual contrasts (Howell, 1997). In the research presented here, ten or fewer contrasts were to be performed per group or variable block (occupation effects, age effects, etc). As the original level of significance was 0.05, this would be multiplied by the total number of contrasts (10 x 0.05), making the new significance level p=0.005. In using Bonferroni corrections throughout the research, however, there was the chance that Type II errors may be inflated (rejecting the alternative hypothesis when it is true). However, a decision was taken to ensure a minimum of Type 1 errors, at the risk of overlooking some potentially significant effects in the analysis.

Logistic regression

Logistic regression was used to assess the main predictors of unhappiness/depression, as the dependent variable was dichotomous (in order to ensure sufficient numbers in each category for meaningful analysis, the dependent variable was recoded into two categories, as described above). Independent variables can be interval or categorical. Logistic regression coefficients can be used to estimate odds ratios for each of the independent variables in the model, which will be described in the results section. The odds ratio for a variable describes the change in odds for a case when the value of that variable increases by 1. If the corresponding 95% confidence interval includes the value 1 (no change in odds), it is not possible to conclude that a unit change in a predictor variable is associated with a change in odds of unhappiness/depression (the dependent variable).

Results

Response rate

The response to the screening survey from both Trust hospitals was analysed and is described in Table 5.2. Because of the very poor response from bank staff at Trust 2, it was decided not to target Trust 1 bank staff.

Table 5.2: **Response from the screening survey**

Respondents	**Trust 1**	**% of all**	**Trust 2**	**% of all**	**Bank**	**% of all**	**Total**
C: willing to answer main survey	57	6	212	21	7	1	**276**
NC: willing to answer main survey	42	4	128	13	4	0	**174**
C: will not answer main survey	18	2	22	2	0	0	**40**
NC: will not answer main survey	29	3	66	7	0	0	**95**
NC: unmatched or missing data	60	6	208	21	14	1	**282**
C and NC: returned but not completed	10	1	43	4	0	0	**53**
C and NC: no longer at address	9	1	1	0	72	7	**82**
Male employee	0	0	1	0	0	0	**1**
Sent to same person twice	0	0	1	0	0	0	**1**
Retired	0	0	1	0	0	0	**1**
Total **(n distributed)**	**225** **(1083)**	**23%**	**683** **(2513)**	**68%**	**97** **(546)**	**9%**	**1005** **(4142)**

Code: C = Carers; NC = Non-carers

Total completed surveys: 867 or 21% of the total surveys sent out.

Group effects

Tests of association were then performed to examine group effects (Group = carer/non-carer). For a priori testing of the main study hypothesis: does combining work and caring increase the risk of unhappiness/depression, the 0.05 significance level was maintained. For all other analyses, the significance level was set at 0.005.

Table 5.3: **Levels of unhappiness/depression among carers and non-carers (n=853)**

	DEPR				
	0	**1**	**2**	**3**	
1 = carers	96	124	67	25	312
Expected no.	110	130	55	18	
(% of carers)	(31%)	(40%)	(21%)	(8%)	(100%)
2 = non-carers	205	230	83	23	541
Expected no.	191	225	95	30	
(% of non-carers)	(38%)	(43%)	(15%)	(4%)	(100%)
Total	301	354	150	48	853
(% of Total)	(35%)	(42%)	(17%)	(6%)	(100%)

Code:

DEPR0=not at all unhappy/depressed in the past four weeks
DEPR1=no more unhappy/depressed than usual in the past four weeks
DEPR2=rather more unhappy/depressed than usual in the past four weeks
DEPR3=much more unhappy/depressed than usual in the past four weeks

As can be seen from Table 5.3, there was a significant association between carer status and unhappiness/depression, with a significantly higher proportion of working carers than working non-carers who reported feeling unhappy/depressed rather more or much more than usual in the past four weeks ($\chi2=12.419$; df=3; sig.$p<0.05$).

Tests were then carried out to look at the association between occupation and group status, in order to determine the kinds of occupations undertaken by working carers.

Table 5.4: **Associations between Occupation and Group status (carer or non-carer)**

	OCC					
	1	**2**	**3**	**4**	**5**	
1=carers	19	11	163	54	66	313
Expected no.	20	16	146	71	60	
(% of carers)	(6%)	(4%)	(52%)	(17%)	(21%)	(36.4% of total)
2=non-carers	35	34	238	142	99	548
Expected no.	34	29	255	125	105	
(% of non-carers)	(6%)	(6%)	(43%)	(26%)	(18%)	(63.6% of total)
Total	54	45	401	196	165	861
(% of total)	(6%)	(5%)	(47%)	(23%)	(19%)	(100%)

Code:

OCC1=Managers; OCC2=Doctors; OCC3=Nurses; OCC4=PAMs/P&Ts;
OCC5=Administrative staff

The comparison of occupation by group status showed a trend in the data ($\chi 2=13.499$; df=4; $p<0.05$). A higher proportion of nurses and administrative staff, and a lower proportion of doctors and PAMs/P&Ts were in the caring group, ie. the carers in the sample tended to be in lower status jobs. Other variables were then tested for associations with group status (see Table 5.5).

Table 5.5: **Group status and other work variables**

Variables	Carers (n) (Group1)	% of total in Group 1	Non-carers (n) (Group 2)	% of total in Group 2	% of overall total (both Groups)
IAW =0	151	50%	371	69%	62%
=1	118	39%	138	26%	31%
=2	31	10%	29	5%	7%
DMW=0	278	91%	465	85%	87%
=1	22	7%	68	13%	11%
=2	5	2%	12	2%	2%
LWE=0	259	84%	447	83%	83%
=1	43	14%	85	16%	15%
=2	5	2%	8	2%	2%
TLW=0	270	88%	440	81%	84%
=1	28	9%	81	15%	13%
=2	8	3%	23	4%	4%
FLEX=1	63	21%	112	21%	21%
=2	189	62%	323	61%	61%
=3	44	14%	65	12%	13%
=4	10	3%	31	6%	5%
WS=0	19	6%	48	9%	8%
=1	55	18%	101	19%	18%
=2	160	52%	303	56%	54%
=3	76	25%	93	17%	20%

Code:

(in the past 4 weeks):

IAW0=no interruptions; 1=1-3 times; 2=4 or more times.

DMW0=no days missed from work; 1=1-3 days; 2=4 or more days.

LWE0=no times left work early; 1=1-3 times; 2=4 or more times.

TLW0=no times late to work; 1=1-3 times; 2=4 or more times.

FLEX0=a lot of flexibility; 1=some; 2=hardly any; 3=none at all.

WS0=no stress at all; 1=hardly any stress; 2=some stress; 3=a lot of stress.

A significantly higher proportion of carers than non-carers reported being interrupted at work to deal with family matters at least once in the past 4 weeks ($\chi2=29.103$; df=2; $p<0.001$). Carers were also shown to be significantly older on average than non-carers ($t=10.661$; df=844; $p<0.001$). This finding is consistent with the fact that most carers are in the middle-age range (Arber & Ginn, 1990).

There were other variable associations which showed a trend in the data, but were not significant at the 0.005 level. Interestingly, a lower proportion of carers than non-carers reported missing days from work in the past four weeks ($\chi2= 6.187$; df=2; $p<0.05$), as well as being late to work in the past four weeks ($\chi2= 7.696$; df=2; $p<0.05$). More carers than non-carers reported a lot of stress at work ($\chi2= 8.007$; df=3; $p<0.05$). Over 70% of both groups (carers and non-carers) reported some or a lot of stress at work.

There was no difference between groups in the number of times they left work early or during the day and the amount of flexibility at work to deal with family matters. Similarly, no significant differences were shown between groups in the number of hours worked.

Predictors of unhappiness/depression for all respondents

Variables were then tested for their association with the dependent variable, unhappiness/depression, for all respondents. Those reporting some or a lot of interruptions at work to deal with family matters were also more likely to report rather more or much more unhappiness/depression in the past four weeks ($\chi2= 40.610$; df=3; $p<0.001$). A significant association was also shown between work stress and unhappiness/depression, i.e. a higher proportion of those reporting a lot of stress at work were also more likely to record rather more or much more unhappiness/depression in the past four weeks ($\chi2= 86.928$; df=3; $p<0.001$).

Other variables showed a trend in the data but were not significant at the 0.005 level. Those working longer hours tended to report rather more or much more unhappiness/depression ($t = -2.535$; df=843; $p<0.05$) and those taking days off work were also more likely to report rather more or much more unhappiness/depression than those not doing so ($\chi2= 11.967$; df=3; $p<0.05$). Similarly, those leaving work early or during the day were more likely to report rather more or much more unhappiness/depression than those not doing so ($\chi2= 9.026$; df=3; $p<0.05$).

There were no associations shown between unhappiness/depression and age, occupation, flexibility and number of times late to work.

Logistic regression

Significant predictors of unhappiness/depression for all respondents were then examined for their importance, using logistic regression. In the first model, those variables showing an association ($p<0.05$) with unhappiness/depression were entered in order of expected importance (initial analyses did not include work stress in the model, as this was expected to be highly related to negative affect, and would throw out all other significant predictors). Group (carer/non-carer) was entered separately into the model in the first instance, as this was the main study hypothesis. Other variables were then entered in order of expected importance: interruptions at work (IAW2); days missed from work (DMW2); hours worked; number of times left work early or during the day (LWE2).

***Table 5.6*: Odds ratios of variables predicting unhappiness/depression for all respondents**

Dependent variable	Independent variables	Odds ratios (+95%CI)
Unhappiness/depression	Group	1.586 (1.118-2.250)
	IAW2	2.539 (1.800-3.582)
	DMW2	2.586 (1.620-4.129)
	Hours	1.015 (0.999-1.031)

(LWE2 was removed from the model as it was not predictive of unhappiness/depression).

As shown in Table 5.6, carers were more than one and a half times more likely to report unhappiness/depression than non-carers in the sample. Those reporting interruptions at work to deal with family matters were more than two and a half times more likely to report unhappiness/depression than those not reporting interruptions. Those missing days from work were also more than two and a half times more likely to report unhappiness/depression than those not missing days from work. Hours worked were shown not to be predictive of unhappiness/depression (as described in the data analysis section, the 95% confidence interval of the odds ratio for the variable includes the value 1, meaning no change in odds).

When not including work stress as a predictor variable, approximately 10% of the variance in unhappiness/depression in a sample of female NHS employees was explained by the model (Nagelkerke R Square = 0.104). Work stress was then included in the model as a predictor variable: approximately 19% of the variation in unhappiness/depression in a sample of NHS female employees was explained by the second model (Nagelkerke R Square = 0.194). Although only a relatively small proportion of the variance in unhappiness/depression was explained by the final model, this is not surprising, given that other important factors in unhappiness/depression such as background factors, personality and other relationship difficulties were not assessed as part of the research.

Other tests of association for all variables for all respondents

Further examinations were made of any associations between predictor variables. Variables were divided into groups or blocks to look at differences in: age, hours worked, occupation, flexibility, work stress, and any other associations. Due to the number of tests being performed, the significance level was set at 0.005.

Age: There were significant differences in age among the five occupation groups (ANOVA: F=5.379; df=4; p<0.001). Doctors tended to be younger on average than other groups, particularly nurses and administrative staff, the latter group being significantly older than all other groups except managers. Younger respondents were late to work significantly more often than older respondents (t=6.275; df=835; p<0.001), as well as leaving work early more often (t=4.345; df=832; p<0.001), and missing more days from work (t=6.173; df=835; p<0.001). Older employees tended to work fewer hours than younger employees, although this was not significant at the 0.005 level. There were no significant associations between age and interruptions at work, flexibility and work stress.

Hours worked: There were significant differences in hours worked among the different occupational groups (ANOVA F=28.401; df=4; p<0.001). Doctors worked significantly more hours on average than any other group, although managers also worked more hours than all groups except doctors. Administrative staff worked the fewest hours on average. (This result is partly due to the large number of part-time workers in all groups except managers and doctors). Those employees working fewer hours per week left work early significantly fewer times than those working longer hours ($t=-3.891$; $df=841$; $p<0.001$). Again, those working fewer hours also reported significantly fewer interruptions at work than those working longer hours ($t=-2.819$; $df=832$; $p=0.005$). Those employees working longer hours reported significantly more work stress than those working fewer hours (ANOVA $F=50.784$; $df=2$; $p<0.001$). There was a tendency for those working fewer hours to report higher flexibility at work to deal with family matters, but this was not significant at the 0.005 level. There were no significant associations between hours worked and number of times late to work, number of times left work early, and days missed from work.

Occupation: Table 5.7 demonstrates that there were significant associations between occupation and number of times late to work ($\chi2=16.973$; $df=4$; $p<0.005$). A significantly higher proportion of Professionals allied to medicine and Professional and Technical staff (PAMs and P&Ts) were late to work more times in the past four weeks than other groups, whereas nurses were late to work fewer times than other groups. Almost 17% of all respondents were late to work at least once in the past four weeks. Managers and administrative staff reported being interrupted at work more times in the past four weeks to deal with family matters than other groups, whereas nurses and PAMs/P&Ts were interrupted fewer times ($\chi2=15.179$; $df=4$; $p<0.005$). Almost 38% of all respondents were interrupted at least once in the past four weeks to deal with family matters (over 50% of managers).

There was also a tendency for a higher proportion of managers than other groups to leave work early or during the day at least once in the past four weeks, whereas a lower proportion of nurses left work early. A slightly higher proportion of managers than other groups reported some or a lot of flexibility to deal with family matters. On the other hand, a higher proportion of doctors and nurses than other groups reported hardly any or no flexibility. Managers tended to report more work stress than other groups (91% reported some or a lot of stress), whereas a higher proportion of administrative staff than other groups reported hardly any or no stress (33%). None of these latter associations were significant at the 0.005 level. There was no association between occupation and days missed from work.

Table 5.7: **Occupational group by work variables**

Variables	**Occupation**										**Total**
	1(n)	**% of Gp 1**	**2(n)**	**% of Gp2**	**3(n)**	**% of Gp3**	**4 (n)**	**% of Gp4**	**5 (n)**	**% of Gp5**	**% of all Gps**
DMW2=0	46	85%	40	89%	358	90%	159	82%	140	87%	87%
=1	8	15%	5	11%	39	10%	34	18%	21	13%	13%
TLW2=0	46	85%	37	82%	350	88%	143	75%	134	82%	83%
=1	8	15%	8	18%	47	12%	48	25%	29	18%	17%
LWE2=0	37	69%	35	80%	340	86%	157	82%	136	83%	83%
=1	17	31%	9	20%	54	14%	35	18%	27	17%	17%
IAW2=0	24	46%	27	60%	254	65%	131	68%	85	54%	62%
=1	28	54%	18	40%	135	35%	62	32%	74	46%	38%
FLEX2=1	49	89%	30	68%	312	80%	161	86%	136	85%	82%
=2	6	11%	14	32%	78	20%	27	14%	24	15%	18%
WS2=1	5	9%	11	24%	102	26%	50	26%	54	33%	26%
=2	31	56%	24	53%	212	53%	114	59%	83	51%	54%
=3	19	35%	10	22%	83	21%	31	15%	26	16%	20%

Code:

Gp1=Managers; Gp2=Doctors; Gp3=Nurses; Gp4=PAMs/P&Ts; Gp5=Administrative staff.

(in the past 4 weeks):
DMW2=Days missed from work: 0=no days; 1=some days (includes 1-3 and 4+ days).
TLW2=Number of times late to work: 0=no times; 1=sometimes (includes 1-3 and 4+ times).
LWE2=Number of times left work early: 0=no times; 1=sometimes (includes 1-3 and 4+ times).
IAW2=Interruptions at work: 0=no interruptions; 1=some interruptions (includes 1-3 and 4+interruptions).
FLEX2=Flexibility at work: 1=a lot or some flexibility; 2=hardly any or no flexibility.
WS2=Work stress: 1=none or hardly any stress; 2=some stress; 3=a lot of stress.

Flexibility at work: There was a significant association between flexibility at work to deal with family matters and work stress ($\chi2=68.969$; df=9; $p<0.001$). A higher proportion of those reporting hardly any or no flexibility at work to deal with family matters reported a lot of work stress (75%). Other variables (other than those already reported) showed no significant associations with flexibility at work.

Work stress: A significant association was demonstrated between work stress and interruptions at work to deal with family matters ($\chi2=44.149$; df=3; $p<0.001$). A higher proportion of those reporting a lot of work stress were also interrupted at work at least once in the past four weeks to deal with family matters (55.2%). Other tests showed no significant associations with work stress.

Other associations: As expected, there were significant associations between the variables measuring disruptions at work (Question 4). Those respondents who reported being late to work more often also reported leaving work early ($\chi2=41.500$; df=1; $p<0.001$), missing more days from work ($\chi2=27.290$; df=1; $p<0.001$) and being interrupted more often at work than those not doing so ($\chi2=19.362$; df=1; $p<0.001$). However, there was no significant association between times late to work and either flexibility at work or work stress. There was a significant association between days missed from work and those leaving work early ($\chi2=12.300$; df=1; $p<0.001$), and between those leaving work early and being interrupted at work more often ($\chi2=39.612$; df=1; $p<0.001$). There were no significant associations between leaving work early more often and reported flexibility or work stress. No significant associations were found between interruptions at work and days missed from work, or between days missed from work and flexibility or work stress.

Predictors of unhappiness/depression for carers only

Tests of association were then carried out on those variables specific to carers only. A higher proportion of those caring for longer hours than other carers reported rather more or much more unhappiness/depression (over 45% of those caring for 40 hours or more reported rather more or much more unhappiness/depression than usual; ($\chi2=10.715$; df=2; $p=0.005$). Those reporting some or a lot of difficulty in combining work and caring were also significantly more likely to report rather more or much more unhappiness/depression (over 45% of all carers; $\chi2=31.350$; df=3; $p<0.001$). There was no significant association shown between unhappiness/depression and reduced hours of work to care.

Other tests of association for all variables for carers only

An examination was also made of any associations between all predictor variables for carers. Variables were divided into groups to look at differences in: hours per week spent caring, reduced hours of work to care, and difficulty combining work and caring.

Hours per week spent caring: For carers, there was a significant association between hours per week spent caring and reported difficulty combining work and caring, with those caring for longer hours recording higher levels of difficulty ($\chi 2=12.414$; df=2; $p<0.005$). There was an interesting trend in the data which showed that those spending more hours caring at home were actually working longer hours than those caring for fewer hours, although this was not significant at the 0.005 level. However, it was also shown that those caring for longer hours were more likely to reduce their working hours to care. (There were so few carers having reduced their working hours that these results need to be tested again with larger numbers of working carers in order to draw meaningful conclusions). Another trend showed that those caring for longer hours reported higher levels of work stress than those caring for fewer hours. However, none of these latter associations reached a significance level of 0.005.

Reduced hours of work: There were no significant associations between reduced hours of work to care and other variables. However, there was a tendency for those carers who had reduced work hours to care to be older than those not reducing work hours. As expected, there was also a trend for those reducing hours to be working fewer hours than those not reducing hours to care.

Difficulty combining work and caring: There was a significant association between those reporting some interruptions at work to deal with family matters and difficulty combining work and caring ($\chi 2=8.984$; df=1; $p<0.005$). Similarly, those reporting higher levels of work stress also reported difficulty combining work and caring ($\chi 2=21.922$; df=2; $p<0.001$). There was a trend for those missing more days from work and leaving work early or during the day to report more difficulty, although these associations were not significant at the 0.005 level.

Logistic regression: carers only

Significant predictors of unhappiness/depression for carers only were then examined for their importance, using logistic regression. Only those variables which showed significant associations with unhappiness/depression at the 0.05 level were included. These were entered in order of expected importance, according to the level of significance shown in the earlier tests of association.

Firstly, those variables which were specific to carers and showed significant associations with unhappiness/depression, were entered:
Difficulty combining work and caring (DIFF2); hours per week spent caring (HPW2).

***Table 5.8*: Odds ratios of caring variables predicting unhappiness/depression in carers only**

Dependent variable	**Independent variables**	**Odds ratios (+95% CI)**
Unhappiness/depression	DIFF2	2.902 (1.688-4.990)
	HPW2	1.436 (1.012-2.039)

Carers reporting difficulty combining work and caring were almost three times more likely to be unhappy/depressed than other carers. Carers spending more hours per week caring were about one and a half times more likely to report unhappiness/depression than other carers. This model explained about 11% of the variation in unhappiness/depression among a group of working carers (Nagelkerke R Square = 0.109).

Secondly, other variables which had earlier shown a significant association with unhappiness/depression were also entered in a block:
Interruptions at work (IAW2); days missed from work (DMW2); number of times left work early or during the day (LWE2). Work stress was not included, as it was expected that this would throw out other predictors, and it was considered important at this stage to examine all predictors.

Table 5.9: **Second block showing odds ratios of all variables predicting unhappiness/depression in carers only:**

Dependent variable	**Independent variables**	**Odds ratios (+95% CI)**
Unhappiness/depression	DIFF2	2.352 (1.332-4.152)
	HPW2	1.381 (0.960-1.985)
	IAW2	1.877 (1.058-3.330)
	DMW2	2.835 (1.119-7.184)
	LWE2	1.930 (0.946-3.939)

After interruptions at work (IAW2) and days missed from work (DMW2) were entered into the model, hours per week spent caring and the number of times the carer left work early or during the day were no longer predictive of unhappiness/depression in carers. Those carers reporting some difficulty combining work and caring were more than twice as likely to report unhappiness/depression than those not reporting difficulty. Carers who reported missing days from work were more than two and a half times more likely to report unhappiness/depression than those not missing days from work. Those carers reporting interruptions at work to deal with family matters were almost twice as likely to report unhappiness/depression as those not being interrupted.

This model explained about 18% of the variation in unhappiness/depression among a group of working carers, improving the goodness of fit of the model (Nagelkerke R Square = 0.177). Other variables expected to predict negative mental health outcomes in working carers will be fully explored in the Time 1 survey. A reliable and valid measure of work stress will then be included as a potential predictor variable, in order to examine its relative influence on carer and mental health outcomes.

Discussion

One of the main aims of this study was to generate a large sample of working carers and non-carers for further investigation in the later stages of the research. The screening survey generated a total of 275 carers and 174 non-carers for further analysis. A large number of these worked in care-related occupations, which would allow for matched comparisons in the Time 1 survey.

Another aim of the study was to identify whether carers reported more depression than non-carers, and which factors predicted negative outcomes in working carers. Group comparisons showed that carers were significantly more likely to be depressed than non-carers in this sample, and for working carers, the most important predictors of unhappiness/depression were difficulty combining work and caring, interruptions at work and days missed from work, even though non-carers reported more days missed from work than carers. For non-carers, interruptions at work and days missed from work were also the most significant predictors of negative outcomes. Longer hours worked did not predict unhappiness/depression in the sample of working carers, contradicting the findings reported by Fredriksen and Scharlach (1997). However, this needs to be further explored in the later surveys. Due to the cross-sectional nature of the data reported here, it is important to acknowledge that associations between all variables could be bi-directional (see Limitations of the study).

When investigating the different kinds of employment undertaken by respondents, there was a tendency for more nurses and administrative staff, and fewer doctors and other medical professionals, to be informal carers at home. This suggests that those women in lower status jobs may be more likely to take on informal caring, a finding which will be further investigated in later stages of the research. However, there were no significant associations shown between occupation and reduced hours of work to care, implying that all women were equally likely to reduce hours to care, no matter what their occupation. Due to the very low number of women who had reduced their hours of work, this result must be treated with caution. It could be that reducing work hours proved impossible for some women, which may have led to them giving up work altogether in order to care. Unfortunately, due to the nature of examining employee samples, this was impossible to gauge. There was also no association between occupation and hours per week spent caring, suggesting that women in lower status jobs are no more likely than those in higher status jobs to be caring for longer hours at home.

Nurses reported being interrupted at work to deal with family matters fewer times, as well as leaving work early and being late to work less often than other groups. At first, this would appear to be a surprising finding, given the higher numbers of carers in this group. This leads into the final research question, which asked how important are work characteristics in combining work and caring roles? When examining the figures relating to flexibility at work to deal with family matters, it was demonstrated that doctors and nurses reported less flexibility than other occupational groups. These employees may be discouraged from being disrupted at work, creating a higher potential for work stress (a significant negative association was shown between flexibility at work and work stress, with those reporting lower flexibility also recording higher levels of work stress). Those women who have greater flexibility at work to deal with family matters may be more able to arrive late or leave work early in order to deal with crises at home. Again, these findings will be further explored in the Time 1 survey.

Limitations of the study

The main limitation of the screening survey was the low response rate, severely restricting the applicability of findings to all working carers and non-carers. It is impossible to say whether the findings reported here would be replicated with other samples of NHS workers, as the survey data does not provide information on *all* employees at the two NHS Trusts, and no information is available on non-respondents.

In spite of the low response rate recorded here, figures were consistent with similar employee surveys undertaken in this country (e.g. Phillips, 1994). As previous estimates have been made of the numbers of working carers in employee samples (Rands, 1997), it was proposed that a conservative estimate of the numbers of working carers in an NHS sample would be in the region of 14%. In applying these figures to the screening survey respondents, around half of all carers targeted were estimated to have replied, increasing the representative nature of the data from working carers. However, the results reported here must still be treated with caution and compared with other studies looking at work and caring in order to draw meaningful conclusions. When assessing the low response from non-carers, it is possible that those experiencing higher stress were more likely to respond to the survey, given the work-related nature of the study. This, in turn, may have affected the comparisons between carers and non-carers, reducing the reported differences in work stress and unhappiness/depression between the two groups. It is also possible that many of the non-caring employees targeted would have felt that the focus of the study (working and caring for an older person) was not relevant to their own situations, and therefore felt less inclined to respond.

In using the internal mailing systems at both Trusts in order to reduce costs, some employees may have been inhibited from returning the survey. All employees were assured in the information sheet that no-one other than the researchers would be allowed access to the data, but the sensitive nature of some of the questions may have prevented some from responding.

As stated in many of the studies covered in Chapter 3, longitudinal research is vital to determine the causal ordering of variables. Many of the associations between variables could be bi-directional: as an example, work stress could easily be a consequence of unhappiness/depression, rather than a cause. The screening survey, therefore, can only provide preliminary conclusions, which need to be followed up with further research focusing on the causal relationships between variables.

Most of the questions in the screening survey were used as single-item measures, and were therefore less reliable than in-depth scales. However, the purpose of the screening survey was to generate only preliminary findings, which would be further tested in the Time 1 survey with a more reliable series of measures.

Conclusions

Significantly more carers than non-carers reported unhappiness/depression in this sample of NHS employees. For working carers, unhappiness/depression was caused by a combination of difficulty combining work and caring, days missed from work and interruptions at work to deal with care-related matters. The results of the screening survey have demonstrated the impact of work disruptions on women's attempts to combine work and caring roles. Work characteristics such as flexibility and work stress were also shown to be important. These findings will be further explored in the Time 1 survey with more reliable and in-depth measures of specific work characteristics.

Chapter 6

A QUALITATIVE ANALYSIS OF THE FACTORS OF MOST IMPORTANCE TO WORKING FEMALE CARERS

Introduction

The screening survey (Chapter 5) provided important preliminary information on the balance between work and caring roles for a large number of women working in the NHS. However, the single-item measures included in the screening survey were based on those factors identified as important in previous research studies. A decision was taken to interview a group of female working carers in order to generate a more comprehensive body of data which could be explored for any other important factors involved in the work/caring interface. Any factors identified as important in the interviews with female carers would then be considered for inclusion as measures in the Time 1 survey (Chapters 8, 9 and 10). Rather than viewing quantitative and qualitative methods as distinct and competing paradigms, it was anticipated that this use of "methodological eclecticism" between both research methods would provide different kinds of information which would effectively complement one another (Hammersley, 1998). Camic, Rhodes and Yardley also argue that "by touching on different aspects of the same phenomena, the two methodological approaches yield a more complete story" (2003: 7).

The interviews specifically targeted a small group of working carers, as well as women who had given up work to care and carers who had never worked. Unfortunately, the screening survey and Time 1 survey described in this research excluded the experiences of those who have given up work to care for an older person, as only current employees were approached. An early US study reported that 28% of caring daughters had left work to care for a parent (Brody et al., 1987), and in a more recent study, Covinsky et al. (2001) demonstrated that as many as 22% of a large sample of carers had either reduced their working hours or had left work to care. Murphy et al. (1997) showed that resentment in the caring role was greatest for those with fewer roles, especially those who had given up work to care. As other research has demonstrated that those who had given up work were also caring for the most severely disabled relatives (Brody et al., 1987; Barnes et al., 1995), it is possible that the survey findings from the research reported here may be biased towards those carers in less stressful situations.

The interview data would provide important information on why some women give up work to care and why others continue to work. Those women who have never worked would also be questioned about their decisions to stay at home, rather than enter the workforce. The qualitative data would then be used to develop a) a preliminary model of the relationship between all the key concepts identified from the interviews, and b) a preliminary model of the relationship between work and caring roles and positive and negative outcomes. These models would be revised and further developed in the later stages of the research.

Research questions

- How do the relationships between work and caring roles differ for a group of (non-NHS) employed women, women who have given up work to care and women who have never worked?
- What are the most important factors in women's attempts to combine work and caring roles?

Method

Design

A series of semi-structured interviews was analysed using thematic analysis. Preliminary models of the relationships between the key concepts identified from the interviews and relationships between work and caring variables were then proposed which would be developed in further stages of the research.

Participants

In order to examine qualitatively the positive and negative aspects of combining work and caring, interviews were carried out with 14 female carers. These women were contacted via the local Carers' Association in High Wycombe, Buckinghamshire, between June and November, 2000. All were of working age, i.e. under 65, and caring for (or had recently cared for) an older person. Contacts were made with the co-ordinators of all the local branches of the Carers' Association who held regular meetings in their homes, and two meetings and a carers' forum were attended in July,

2000. A brief, informal presentation of the research interests was made to all the carers present at each of the meetings and requests were made for volunteers willing to be interviewed. A short article was also published in the local carers' newsletter, asking for volunteers.

Attempts were made to contact carers for interview via different avenues, but this proved to be impossible due to the heavy restrictions in accessing the personal details of carers. It was eventually decided that the most fruitful way of recruiting volunteers was by a direct, personal approach rather than submitting articles to carers' magazines, which yielded only three willing participants. Many of the carers at the local meetings were very keen to participate after they had heard the presentation and understood some of the aims of the research.

Theoretical sampling, as employed in this part of the research, "involves the active sampling of new cases as the analysis proceeds…" and does not "sample multiple cases where this would not extend or modify the emerging theory" (Pidgeon, 1998: 78). At the first meeting, all those who were of working age and had been or were still caring for an elderly relative were contacted, if willing. However, as themes began to emerge from the transcribed data, further sampling involved contacting those carers who varied in their work and caring circumstances, and whose experiences would extend the overall body of data. As an example, the data from those carers interviewed in the early stages encouraged the researcher to actively search for more carers who had left work to care, as it was felt that their experiences had often been overlooked. By comparing the experiences of a number of women who were still working with those who had left work to care and those who had never worked, a rich and diverse body of data would be generated, which would in turn be compared with the experiences of those responding to the screening survey and the Time 1 survey. For more details of individual carers, see Appendix 9.

Development of the semi-structured interview schedule

The interviews followed a semi-structured design: all questions were asked of all carers, although some were asked in a different order, depending on the flow of conversation in each instance. If a particular question had already been covered by a previous answer, this question was then omitted.

The interview schedule

1. How did you come to be caring for your relative?

2. Why did you take on the caring?

3. How do you get on with your relative?

4. What about other family: how do you get on with them?

5. Do you get any help from anyone?

6. Do you have other things that you manage to do besides caring and work (your other responsibilities)?
7. Can you tell me about a time when you found it hard to combine caring with work (your other responsibilities)?
8. Do you think you will continue with all these responsibilities?

9. What are the best things about combining caring with your other responsibilities?

10. Can you think of one thing that would really help you at the moment?

The first question was always the same: "How did you come to be caring for your (relative)?" This question was chosen as the introduction to the interview, as it was felt that this would invite a "narrative" from the carer of the circumstances surrounding the care situation, and would encourage her to relax. All the questions were designed to tap issues which were shown to be important in the work/caring literature or were of interest to the research, and to identify any new ones by allowing the carer to relate details of her own caring experience. These issues were: the reasons for caring, relationship with the older person, relationships with other family members, help from family and friends, limitations to social activities, difficulties combining caring with other roles, future intentions, and the positive aspects of combining caring with other roles. All questions were intended to be as non-directive as possible. As an example, Question 2 asks: "Why did you take on the caring?" An alternative question could have been: "Why did you decide to take on the caring?" However, as Charmaz earlier found in her research on the experiences of people suffering from chronic illness, this assumes that the person actually made a decision (Charmaz, 1990: 1167). In the research described here, this would have been a mistaken assumption, as many of the carers stated during the course of the interviews that no actual decision was ever made to care for their relative.

The wording of each question often differed, depending on the individual carers' circumstances. For example, in most cases, it was important to find out about combining work with caring responsibilities, but for those who had never worked, this was obviously not a relevant question. "Work " was therefore changed to "your other responsibilities" in these cases. However, questions were still asked about their reasons for not working. For those who had given up work to care, probes were introduced for their motivations in doing so. The last question was included after the first interview, as Participant 1 felt it to be important. This question, along with the previous one, also concluded the interview in a more positive, rather than a negative, way. If an important question had been asked and no clear answer was forthcoming during the interview, probes were given to ensure clarification, as it was important not to miss any of the potentially key issues.

Ethical issues

Ethical approval was sought and approved by the University of Southampton Ethics Committee (June, 2000). At the beginning of the interview, all carers were asked to read and sign an information sheet and consent form, a copy of which was retained by the carer (see Appendix 8). The telephone number of the ethics committee was included, as was the researcher's e-mail address, if the carer wanted to ask any questions at a later date. After each interview, a personal letter was sent to the carer to thank her for her time and help, and to explain how the interviews would help in the research.

A decision was made not to leave any carer as soon as the interview was over, especially if she had become upset during the course of the interview. Although this rarely occurred, the researcher always stayed to chat for a while about other things or about other interests, after turning off the tape. The carer was never left alone if she was still upset in any way.

Reflexivity

Several researchers have stressed the importance of the researcher's presence in the qualitative research process, both in data collection and analysis (e.g. King, 1998). In fact, the choice of research topic, theoretical frameworks, procedures and interpretation of the data are all inevitably influenced in some way by the researcher's own values and social roles (Marecek, 2003: 61). In the current study, I was aware that my own experience of family caring, as undertaken by my mother for both her parents and two older aunts, had influenced the choice of research topic, and led me to empathise and identify with the carers I interviewed. I found myself in complete admiration of several of the women in their efforts to continue caring in the face of increased difficulties, and was always sympathetic to any complaints they made about their older relatives or other family members. As an example, Participant 12 described how she was often expected to care for her grand-daughter, while also caring for her older, co-resident mother, even though she wished she could spend more time with her husband:

"You know, like Sundays we say is our day, we still end up with her (grand-daughter) *on a Sunday. She* (daughter) *was down here at four o'clock yesterday and brought her to us and –cheerio then, I'm off...so you know...." (P12, lines 695-697).*

"You can't win..." (Interviewer, line 698).

"No" (P12, line 699).

In this exchange, I responded sympathetically to Participant 12. However, after acknowledging my sympathy with the carers in such a way (Marecek, 2003), I was careful to double-check my interpretations of the interview data both with my supervisor and with a number of carers or ex-carers during the pilot study described in Chapter 7.

Procedure

All interviews were carried out in the carers' homes or office at a prearranged time, which varied according to the work and caring schedules of the carers. Most carers were interviewed during the day, and most of them had arranged a time when their relative was not present. None of the carers were interviewed in front of the older person. The interviews were intended to be as informal as possible, and I always began by attempting to put the carer at her ease. All carers had agreed beforehand to be taped. A tape machine was placed between myself and the carer and switched on after the preliminary discussions had taken place and the consent form was signed. If any interruptions occurred during the course of the interview (e.g. telephone calls), the tape was turned off temporarily, until the interview resumed. The interviews tended to last for an hour or more, although in some cases they went on for considerably longer (the interview with Participant 10 lasted for over 2 hours).

Data Analysis

Transcribing and coding

All interviews were fully transcribed and then coded, following the principles involved in thematic analysis (Boyatzis, 1998). Using data-driven coding methods, in which codes are constructed inductively from the raw information, the transcripts were initially analysed to identify common or similar themes. Related themes were then grouped to form codes, described here as key concepts. As an example, individuals' responses referring to the themes of guilt, lack of choice and perceived responsibility were grouped, along with other themes, to form the key "motivations" concept. Boyatzis describes the use of the "hybrid" approach to code development when only one unit of analysis is being studied (in this case, female carers). Instead of comparing and contrasting across subsamples, as recommended with data-driven methods, the researcher uses his or her own theories or previous research as a guide to articulating meaningful and important themes (1998: 52). Although the sample of carers in this part of the research varied in their work and caring situations, it was important to identify concepts which represented factors of importance for *all* female carers. Therefore, no attempt was made to distinguish between subgroups at this stage, but rather to identify themes common to all of those interviewed. Questions had been included about relationships with the older person and other family members, due to the researcher's interest in the family dynamics of caring. Reasons for caring had also been introduced because of the researcher's interest in why some working women take on care for an older person and others do not. However, it was only by transcribing the interviews that themes such as responsibility, duty, guilt and the elder's growing dependence began to emerge and develop into the key "motivations" concept.

Results

Participants' profile

Of those interviewed, ten were looking after a parent (three of these had previously been caring for both parents), one had until recently been caring for a parent-in-law, one had been caring for a parent and a severely disabled daughter at the same time, one had been caring for a disabled husband and was still caring for a parent-in-law in a minor way, one was caring for a disabled husband and had until recently also been caring for a parent. Of the fourteen interviewed, six had given up work to care for their relative, one had initially given up work but had since returned to a different job, one had been unemployed for some time but was still looking for work, four had continued to work in the same jobs as before, and two had never worked, due to their caring responsibilities. Twelve of the carers had primary responsibility for their relatives, one shared responsibility equally with a sibling, and one acted as a secondary carer by helping her brother who was co-resident with their older mother. Six of the carers were, or had been until recently, co-resident with their relatives, whereas eight had caring responsibilities for relatives living independently or in sheltered accommodation. Eight of the carers were married, one had remarried since the death of her disabled husband, four were divorced, and one was single.

Group profiles

Working carers

Of the five women who still worked, it appeared that work provided a temporary relief from caring responsibilities, and was an important role in the carer's life, for both financial and psychological reasons. In spite of the difficulties in combining work and caring, most were unwilling to give up their jobs. Participant 2 (P2) had initially given up work but had then returned to a different job:

"I was becoming depressed, and I was, you know, I was then missing work, missing the company, um, and finding that, you know, every day at home looking after dad was...day in, day out, was, was very-very monotonous, very much the same, it was a

very quiet life and I just needed, I needed some, I needed something more than that" (P2, lines 56-59).

Most of the women who were currently working had part-time, less demanding jobs and were also caring for a less dependent relative or had more help with caring. Participant 2 was divorced and had found a less demanding job after she had been caring for her co-resident father for a while. Participant 3 was also divorced and worked for a local parish in administrative work while sharing parent care equally with her sister. Participant 11 was a divorced care worker whose brother and a group of paid carers provided most of the caring for their mother, and Participant 14 was a married care coordinator who worked from home and whose mother lived in her own home close by. Only one, Participant 6, remained in a full-time, professional job at a university, which she was finding increasingly difficult to balance with her caring responsibilities towards her mother who had recently been ill:

"...I was under a lot of pressure to find somewhere for her, because it was...a flu epidemic, because it was, they were up to crisis...management, I...I-I had to meet with the social workers in hospital, um, and I took time off for that and I said yes, let's start looking for residential care...and that became difficult, it was a time when we were very busy here, so I was sort of taking a couple of hours and then coming to work...and...um...then I was dashing off and looking for places, and I was getting home in the evening sort of eight, half past eight, having been round for hours, to have the hospital on the phone saying, you know, we're sorry, we understand but have you found anywhere yet, and, um...I-I found that quite difficult to handle..." (P6, lines 226-234).

Women who had given up work to care

Of the six women who had given up work to care, four had previously worked in full-time, professional jobs (Participants 1, 7, 8 and 12). None of these women had wanted to give up work, and most had attempted to continue with their work until it became too difficult to combine both roles:

"Just hard- well, I was phoning up and um, and you know, I couldn't concentrate on my job properly, I wasn't going to the office as much as I used to and...er, it just

really, I-if I, I think if I hadn't have left I think I'd have had a breakdown..." (P12, lines 61-63).

Only one woman (Participant 4), who had been working in a non-professional, caring occupation, had wanted to give up work and described caring for her mother as an excuse to retire early. However, she was still resistant to her mother's increasing demands and was keen to remain as independent as possible. Participant 9 had been caring for her severely disabled husband and her mother-in-law while working in a shop. She described her employers as unsympathetic to her circumstances, and eventually she left. Participant 13 had been unemployed for a year in her work as a freelance accountant, a situation which she blamed mostly on the demands of caring for her mother. She was determined to work again as soon as she could, and a personal letter from Participant 13 a few months later confirmed that she had found work.

When probing into the motivations behind leaving work, it was found that most carers did not take the decision lightly, but had found the demands of both roles too stressful. Specifically, their work roles were suffering as a consequence of the increasing demands of their caring roles. As an example, Participant 1 described how she could not do her full-time teaching job properly and she eventually left two years before she was due to retire. At the time, she was caring for both her sick father and her mother, who was suffering from dementia.

"I was getting her up (mother) *at about six o'clock in the morning when it was still dark and she didn't understand what was happening, and trying to dress an old lady with Alzheimer's was very, very, very di...and I was having to take her to Bourne End to drop her off, and then get to Maidenhead to my school, and encountering all the traffic along the way, and do a day's teaching, and then go back to Bourne End, pick her up, bring her here and give her something to eat, and then take her in the car to go and visit my father, who was at death's door, and then come home and give my mother her supper and, and, and dress her and put her to bed, get up and start again next morning, well you know, where did I, where did I mark my books and where did I prepare my lessons...I mean I just couldn't, couldn't do it, and...everybody could see that I couldn't do it" (P1, lines 73-85).*

Overall, there did not appear to be any association between those women who had given up work to care and better quality of relationship with the older person, as all of those who had left work also reported some relationship problems with the older person. Participant 8 left her job when she knew that her mother was coming to live with her, and reported several problems with their current relationship.

"...when she came to me, she wouldn't – didn't want to fit in, you know, she–she will never look upon this as her home, I know she won't, 'cause her home to her is the one....that she left, so...she's been a little bit awkward (laughs), *to say the least. But then you've got to try and look at it from her point of view and think....you know, well what would I be like in–in that position when you've given up everything, but then I think...I might be happy that someone's looking after me and just be contented to see the rest of my days out...and...sit tight and ....just let someone else do the work, you know, instead of being ...awkward* (laughs), *but I know everybody's different...." (P8, lines 177-184).*

Women who had never worked

Only two of the women had never worked (Participant 10 and Participant 5, who had given up work immediately after she got married). Both had been involved in intensive, long-term care situations: Participant 10 was married to a disabled man, who still worked part-time in his own business, and at the same time, she had also cared for her co-resident mother for several years before she died. Her caring responsibilities towards her husband had prevented her from finding regular work:

"It's- I couldn't go out to work and-and have, I mean, really, I wanted to go out to work, it was the stage when ...was because I could not give anybody reliable hours. I never knew er, what time my husband was going to leave the house in the morning, and I had to help him into the car. I ne-I never knew what time he was coming home in the evening and...also while the children were young, out of school hours...but the-the most important reason was, I didn't know what time I could leave the house in the morning" (P10, lines 411-416).

Participant 5 had cared for her severely disabled daughter until very recently when she had been admitted to a residential home. She had also cared for her mother for most of her life, as she had always suffered from minor psychiatric problems. Her mother's physical health also declined later in life. Her mother had lived next door until her death, where Participant 5 had also cared for her brother until his early death from cancer. Although both Participants 5 and 10 reported having relationship problems with their mothers, neither demonstrated any resentment toward their main caring responsibilities (for Participant 10, her husband, and for Participant 5, her daughter). Participant 10 stated that she knew what to expect when she married her husband as he was already disabled, and Participant 5 was totally accepting of her caring role towards her daughter:

"I just wouldn't have, I just wouldn't have been without it, she was Linda and that was it, you know..." (P5, lines 326-327).

Overall, in this sample of women, it appears that for those in higher status, full-time and more demanding jobs, the pressure of attempting to combine work with higher dependency caring generally led to the carer giving up work to care. Only one carer (Participant 6), whose mother was still relatively independent and who lived in her own home, was continuing in her full-time professional job. One carer (Participant 9) had worked in a lower-status job, but higher-dependency caring and a poor work relationship led to her give up work. Those in lower-status jobs, combined with lower-dependency caring, tended to retain their jobs for both psychological and financial reasons. Only one woman (Participant 2) changed her job to be able to meet the increasing demands of her co-resident father. Those who had never worked were the carers with the most intense, long-term caring situations, and often took on dual (Participant 10) or even triple caring roles (Participant 5). Their higher-dependency caring roles meant that they were unable to take on any work, even at a later stage in their lives. Although Participant 5 had recently placed her daughter in a residential home and her mother had died, she was herself nearing retirement age. This carer was increasingly worried about her future financial commitments and expressed some resentment that she had not been compensated for her long-term caring duties over the years.

To summarise, women working in lower-status, part-time jobs were more likely to be still working if their relative was less dependent. Those in higher-status, full-time jobs were more likely to have given up work to care, especially if their relative was more dependent. Those who had never worked tended to be in more highly-dependent, long-term caring situations. However, other factors were also shown to be important in these women's decisions to stay at work, give up work or never to have worked.

Development of key concepts from interviews with all carers

Seven major concepts were generated as a result of the interviews with all 14 carers. These were: motivations for caring, quality of relationship with the elder, importance of support from family and friends, the subjective experience of caring, work issues, and to a lesser extent, provision versus management of care and maintaining self. The positive and negative consequences of combining caring with other roles were described as outcomes. The three main concepts which emerged as novel and of most interest to the research were: motivations for caring, quality of the relationship with the elder, and the subjective experience of caring, the central factor. Other concepts had been covered extensively in previous research.

Motivations for caring

Several of the carers had no sibling (Participants 1, 2, 6, 13 and 14), and felt that they had no choice but to take on the care of their older relatives. Other carers complained that siblings, three of whom were brothers, were often unwilling to take on any caring duties (Participants 4, 8, 10 and 12). Only one woman, Participant 11, was a secondary carer, with her brother providing most of the care for their older mother, who had always shared a home with him. Motivations also included the elder's expectation of care:

"....she thinks that we've got to look after her the way she looked after her mother" (P3, line 30).

".....that is the way he felt about it and that's the, that's the family ethos, and the old culture from which they came, that you look after your own, and there's some sort of shame in, you know, in, in not doing so. And that's sort of, part of my, er, my sort of guilt feeling that...I have to do it, really" (P1, lines 482-485).

Quality of relationship with the elder

The quality of the relationship with the elder emerged as a very important aspect in the negative and positive emotions involved in caring, with problems often arising in the struggle for power between the elder and the carer. Many of the older relatives resisted attempts by the carer to take control:

".....she still loves to maintain the mother-child relationship" (P4, line 187-188).

Other carers talked about past problems in the relationship with the elder, and how that affected their current caring relationship. Some showed resentment in their caring role, due to these past difficulties:

"...it is quite tough dealing with her because when you realise that her behaviour has actually damaged you in the past, you know, so having to still deal with her..." (P13, lines 237-239).

The subjective experience of caring

The subjective experience of caring was the central factor in all the carers' reported experiences, encompassing the onset of care, the dynamic nature of caring, type of caring tasks undertaken, and the stresses and satisfactions involved in caring. The uncertain duration of caring was often discussed:

"...I thought it was going to be short-term, I thought...I can give my father a year of my life, my father's not going to last..." (P1, lines 340-341).

Participant 5, who had been caring for both her disabled daughter and her mother at the same time, described the problems involved in dividing her time between the two:

"Yeah, she, er, she was, er, I mean, she didn't need a lot of, um...looking after at, at the last days, but, although she wasn't...um...she wasn't bed-ridden, she wasn't physically that, er...as I say, she get these...the last weeks she did get...(unclear) *the last couple of weeks she got very...doubly incontinent and, um...she was vomiting a lot, you know. I really did think...I really did get to the stage when I thought...one of them, I can't, I just can't be* (unclear) *to both" (P5, lines 84-89).*

Many described the elder's dependence as a gradual process, although one woman, Participant 2, was thrown into the caring role suddenly when her mother died, and she was faced with caring for her dependent father. She also described how the demands of the caring situation affected her work and personal lives. In one example, she had been invited to stay behind after work for half an hour to celebrate the completion of a group project. Although she decided to stay, she remained worried about her father:

"I got home at ten to six last...Friday. Well, you know, it-it's not on, is it, it is, you know, worrying, it's worrying for him, it's worrying for me that, you know, what I'm doing, um, my next door neighbour was in here as well, and-and he-he'd got a very long face, as much as to say where have you been, what, you know, what have you been doing, he didn't exactly help the situation, and I thought, it's, you know, and at that stage, I'm tired, I'm worn out..." (P2, lines 240-245).

At this stage, a preliminary model was developed to describe the relationship between the key concepts identified as important in combining work and caring roles for all the women interviewed (Figure 6.1). Important personal factors identified from the interviews, as well as work and caring factors, were included in this model, demonstrating that factors other than those measured in the screening survey also contribute to positive and negative outcomes for carers. The subjective experience of caring, although the central concept, also appeared to have a bivariate relationship with quality of relationship with the elder: while the quality of relationship appeared to affect the overall experience of caring, the relationship itself could also be affected by extreme dependency and stress. Motivations involved in elder caring could also have a bi-directional relationship with the nature of caring: those reporting more negative motivations to take on caring such as responsibility, duty, lack of alternatives, could also report higher stress as a consequence of such perceived pressure, or higher stress could affect the perceived pressures to care for the elder. These issues will be further examined in the later stages of the research. Upon further detailed examination of the interview transcripts, maintaining self and issues surrounding the provision versus the management of care appeared to be less important for these carers than the other main themes. For this reason, they were omitted from the model and from further quantitative analysis in the Time 1 survey.

This model would be further revised in later stages of the research, as the importance of personal, care-related and work-related factors would be analysed quantitatively (Chapters 8, 9 and 10).

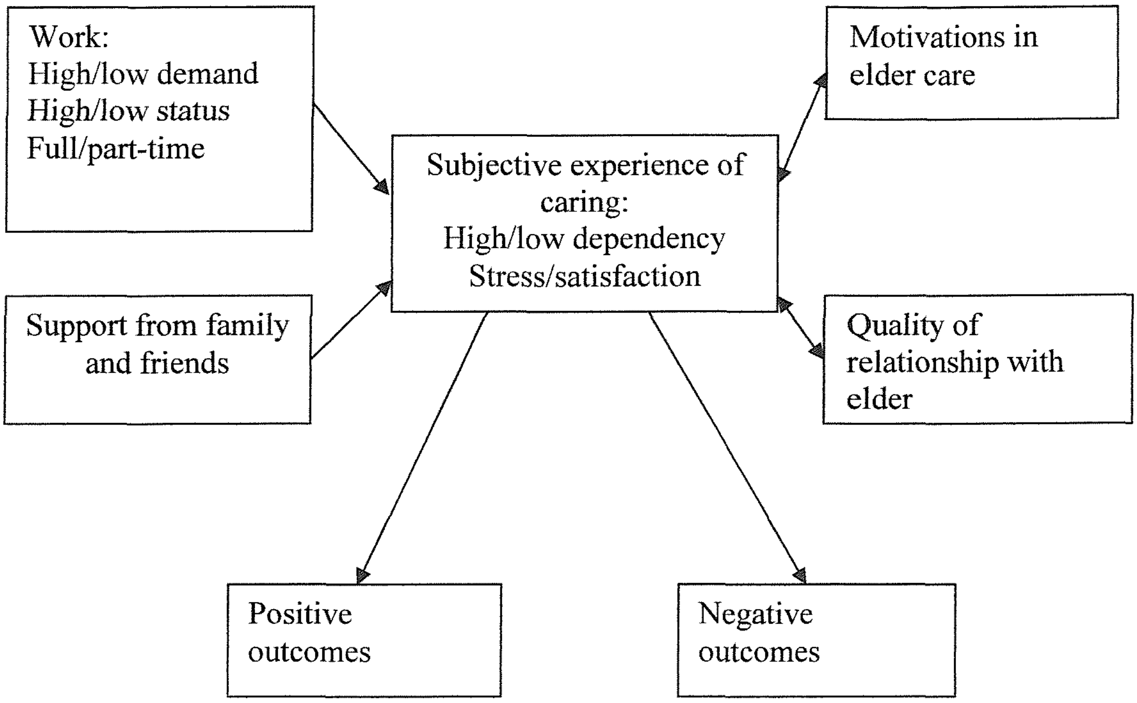

***Figure 6.1*: Preliminary model of the relationship between main concepts in combining work and caring roles**

Measures of each of the main concepts generated from the interview data and included in the model were considered for inclusion in the main survey (Chapters 8, 9 and 10).

Validity of the research findings

One of the main criticisms of qualitative research is the alleged inability for others to judge the quality of the data presented, as in quantitative research methods (McGrath & Johnson, 2003). However, qualitative researchers have been increasingly attentive to such allegations and have more recently applied certain criteria to judge quality of evidence, some of which were employed in the study described here. One way of assessing the evidence is to use "triangulation" of results via multiple data sets and multiple observers (Ratcliff, 2003). The findings outlined in this qualitative study were therefore compared with the data collected in the quantitative studies. Any discrepancies as well as similarities in the findings were discussed and evaluated (see Chapters 8, 9, 10 and 11).

Another way of examining quality of evidence is by consensual validation (Eisner, 2003). Regular discussions took place between myself and my supervisor regarding the analysis and interpretation of the qualitative data. A pilot study was then undertaken to develop two new measures of personal factors (Chapter 7). This involved the participation of some of the interviewed carers and other ex-carers known to the researcher. Aspects of the relationship quality and motivations involved in elder caring, considered by the interviewer to be important, were discussed with these participants: any overlooked factors were considered for inclusion, and others which were considered less important by the participants were re-evaluated.

Eisner (2003) also proposed the use of "referential adequacy" in determining validity. A qualitative study is described as adequate if the work "organises perception so that awareness and meaning are enhanced" in the reader (2003: 26). The work presented here provides a detailed and rich description of carers' experiences in their efforts to combine work and caring, and offers interpretation of the data to enhance the reader's awareness of the difficulties involved.

Discussion

The qualitative research was designed to examine the different relationships between work and caring roles for a group of employed women, women who had given up work to care and women who had never worked. Figure 6.2 provides a preliminary model of the relationship between work and caring roles for the women who had given up work to care and those still in work. Due to the small number of those who had never worked, it was decided that further research was needed before making any firm conclusions about the relationship between roles for this group of women.

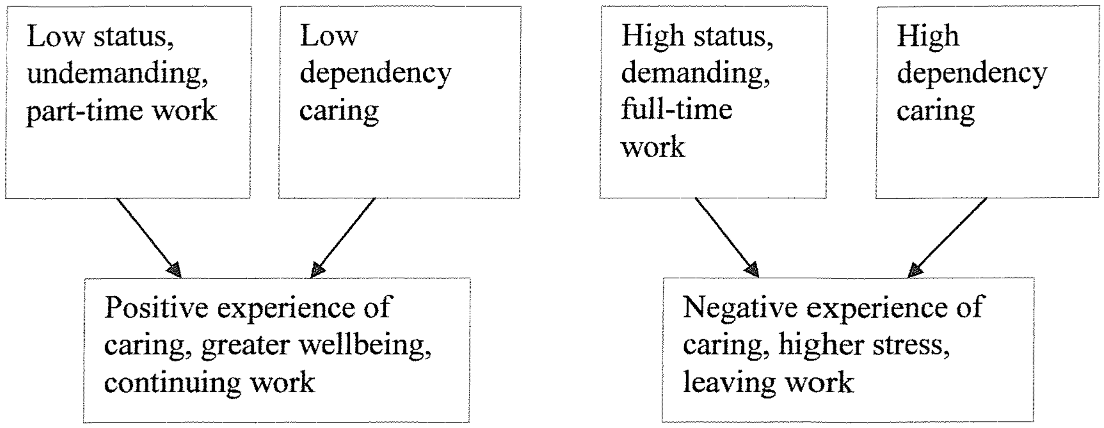

Figure 6.2: **Preliminary model of the relationship between work and caring roles and positive and negative outcomes**

For those carers still in work, jobs with fewer demands and constraints appeared to provide a psychological buffer against the strains of caring for an older person. However, for many of the single and divorced women, financial concerns were also important in their decision to continue work. Those who had attempted to continue working in more demanding, professional, full-time occupations had generally given up work to care, as the demands of caring had increased. Only one of the interviewed carers had wanted to give up work. For these women, the work role was given up in order to cope with the increasing demands of the caring role.

Results from the screening survey showed that most of the employed carers in the sample worked in lower-status jobs such as nursing and administrative work. It was impossible to say with any certainty from the results of the screening survey whether lower-status jobs led to a greater likelihood of informal caring or whether informal caring led to a greater likelihood of women being employed in lower-status jobs. As mentioned earlier, employee samples necessarily exclude the experiences of those who have already given up work. It may be that those carers in higher-status jobs in the NHS sample had already given up work to care, as with the sample of women interviewed here, whereas those in lower-status jobs may have continued with their work for psychological and financial reasons. Most of the women interviewed reported strains in their relationship with the older person, and there did not appear to be any association between quality of relationship and giving up work to care. Those who had never worked tended to have more long-term, intensive experiences of caring, as well as dual or even triple caring roles. It is possible that perceived availability to care and previous experience with caring leads to increased caring responsibilities, with other family members shifting the primary responsibility for care onto those women not currently in work, a finding which would support previous research (e.g. Stueve & O'Donnell, 1989; Gerstel & Gallagher, 1993; 1994).

Another of the aims of the qualitative research was to generate a comprehensive list of important factors in women's attempts to combine work and caring roles. All of the women interviewed in this stage of the research recounted different experiences and circumstances in their caring situations. However, certain key concepts began to emerge from the data, and with the use of constant comparison, it was possible to compare and contrast individual situations. All of the women focused on the subjective experience of the caring undertaken: although this was different in all situations, it had an impact on all the other issues raised, and was instrumental in the carers' reports of the positive and negative consequences of combining caring with their other roles. Other key concepts, most important from a psychological perspective, were the quality of the relationship with the older person (both past and present relationship were discussed), and the motivations involved in caring for an older relative. These two concepts, as well as the others in the model, fed into the central concept, the subjective experience of caring, and had a major influence on the carer's attitude towards her caring role and her other responsibilities.

The three main concepts described above, along with the others included in Figure 6.1, will be tested and analysed further in the later stages of the research. Because of the importance of both quality of relationship with the elder and motivations involved in elder caring, it was decided that two new measures would be developed for the Time 1 survey, as these had not been measured adequately in previous research (See Chapter 7). The subjective experience of caring has previously been measured by different instruments, one of which would be chosen for the Time 1 survey.

Limitations of the Study

Although the group of women interviewed here was intended to be as diverse in their work and caring situations as possible, the sample was limited in its representation of the experiences of all carers. All the women were self-selected and most were members of caring groups. It could be that these women had more time than others involved in more demanding care and working situations. On the other hand, it could be that those women in less stressful circumstances are less likely to join carers' groups as a source of support. All were from white, lower to middle-class backgrounds, with English as their first language. Other minority groups were therefore not represented in any way, limiting the applicability of results. The US study by Covinsky et al. (2001) demonstrated that reduced employment due to caring is more likely in families of ethnic minorities and of those with specific clinical characteristics. Further research is needed to examine the situations of women from different cultural backgrounds in the UK.

Conclusions

By comparing the different experiences of women still in work, those who had given up work to care and those who had never worked, it was possible to identify links between work and caring roles. Those who had less demanding work and caring roles were more likely to be still in work, whereas those in more demanding work and caring situations tended to have given up work to care, irrespective of quality of relationship with the elderly person. Those who had more intensive, long-term caring situations were less likely to work at all, and often had dual caring roles.

The interviews reported in this part of the research provided a rich body of data, generating key concepts which will be further explored and measured throughout the research. The subjective experience of caring, the quality of the relationship with the elder, and motivations involved in elder caring, emerged as the most important and interesting factors in this stage of the research.

Chapter 7

DEVELOPMENT OF TWO NEW MEASURES, THE RELATIONSHIPS IN ELDER CARE SCALE (RECS) AND THE MOTIVATIONS IN ELDER CARE SCALE (MECS)

Introduction

The qualitative study described in Chapter 6 demonstrated the importance of personal factors such as quality of relationship and motivations in elder care and their influence on the overall caring experience. It was therefore considered vital to include measures of both in the Time 1 survey (Chapters 8, 9 and 10), in order to identify their relative value in predicting both carer and mental health outcomes.

An extensive review of the relevant literature was undertaken between 2001 and 2002, in order to assess the suitability for this study of any previously developed measures of quality of relationship and motivations in elder care (PsycLit, MedLine, Cinahl). Many previous researchers who have examined quality of the elder/carer relationship selected specific aspects of relationship quality as the focus of their work. Archbold and colleagues (1990) found that low mutuality in a relationship led to greater strain, and Townsend and Franks (1995) reported that emotional closeness and conflict mediated the impact of parents' functional and cognitive impairment on carer stress and depression. Other researchers have examined aspects of relationship quality within specific groups of carers. Using a measure of perceived intimacy, Walker, Martin and Jones (1992) found that intimacy was negatively related to frustration and anxiety for daughter-carers. Similarly, Pohl et al. (1995) reported that greater attachment between mothers and daughters led to a longer duration of caring and a more positive perception of caring. Other researchers have examined differences in closeness of the relationship between wife and daughter carers (Seltzer & Wailing Li, 1996), or differences in relationship quality between co-resident daughters or daughters-in-law and elders (Peters-Davis, Moss & Pruchno, 1999). Some researchers have used only single-item measures of relationship quality in their work (e.g. Mui & Morrow-Hill, 1993), or Cantril ladders (Stoller & Pugliesi, 1989), raising questions as to the reliability of the results.

Several studies investigating relationship quality as part of the research have included items from the Positive Affect Index (Bengtson & Schrader, 1982) to measure relationship quality in elder care (e.g. Chang, Noonan & Tennstedt, 1998; Lawrence et al., 1998; Seltzer & Wailing Li, 1996; Yates et al., 1999). However, this is a general measure of relationship quality, not specifically designed for use in research on elder care relationships.

None of the measures used in previous research into the quality of the relationship with the elder seemed entirely suitable for evaluating the overall quality of the relationship across a diverse range of caring situations. One consequence of the use of different limited measures of relationship quality is that while these have provided important evidence that quality of relationship is predictive of carer outcomes, findings are difficult to compare across studies. It was therefore decided that an inductive approach would be used to develop a new measure of relationship quality which would apply to all types of relationships between carers and older people, and which would examine more comprehensively the quality of those relationships.

There appeared to be a similar need for a generic measure of motivations in elder care. Previous research has again focused on demonstrating the importance of particular motivations, such as filial obligation (e.g. Albert, 1992; Finley et al., 1988; Seelbach & Sauer, 1977) and reciprocity (Carruth, 1996; Horowitz & Shindelman, 1983). Others have looked at motivations in particular elder care relationships, such as mother-daughter caring (Cicirelli, 1993), or in particular types of caring situations, such as dementia care (Carruth, 1996). While these studies have provided vital evidence that obligation, affection and reciprocity are important motivations in elder caring, it is again difficult to compare results across different studies, due to the use of diverse measures and caring contexts. In a Canadian qualitative study, Guberman, Maheu and Maille (1992) reported that the main motivations for care (including care of adult children) encompassed love (including reciprocity), inadequate institutional or community resources, the profound need to help others, duty and obligation, the expectation of care, and women's socioeconomic dependence. These findings suggest that previous quantitative studies may not have measured all relevant motivations. Consequently, we decided to employ an inductive approach to also develop a more comprehensive measure of motivations in elder care, for use with all carers of older people.

Objectives

The two main objectives for this part of the research were:

- To develop two new measures for inclusion in the Time 1 survey.
- To test the measures for reliability, using standard methods.

Method

Participants

Of the 4142 screening surveys sent out in an earlier stage of the research (Chapter 5), 275 working carers expressed a willingness to respond to the Time 1 survey. All respondents were under 65, and had caring responsibilities for an older person. No restrictions were made with regard to the carer's relationship to the older person, the number of hours spent caring or the elder's place of residence. Questionnaire packs were sent out to the 275 working carers with stamped addressed envelopes attached (for full details of the Time 1 survey, see Chapters 8, 9 and 10). Measures included work-related factors, care-related factors and the two new measures of personal factors, as well as single-item measures.

Procedure

Relationships in Elder Care Scale (RECS)

Initially, all items generated from the interview transcripts which related to relationship quality were treated as potential questions for the care relationship measure (for details of transcribing and coding procedures, see Chapter 6). The large pool of items was formed into a preliminary set of questions and distributed to a group of six carers or ex-carers for initial piloting. Four of these were carers who had been interviewed in the qualitative study, who were contacted by letter, asking for their voluntary participation in this part of the research. They were all still heavily involved in caring responsibilities. Two were women known personally to the researcher who had had caring responsibilities in the recent past. Other carers who were contacted did not reply before the cut-off date for respondents. None of the carers were coerced into responding. The initial piloting yielded some new suggestions for items to be included. It was considered important at this stage to include as many items as were thought important, but not to include too many items relating to any particular aspect.

Items selected for inclusion: The items from which the questions were to be developed were:

1. Quality of current relationship
2. Frustration with elder
3. Embarrassment over elder's behaviour
4. Elder's changed character
5. Stubbornness of elder
6. Power struggle
7. Change in relationship
8. Feeling protective towards elder
9. Quality of past relationship
10. Negativity of elder
11. Elder's resistance
12. Sympathy for elder
13. Understanding of elder
14. Money issues
15. Respect for elder
16. Admiration for elder
17. Generational differences

At this stage, there appeared to be four main constructs in the relationship scale, each containing at least three items:
1) quality of the relationship (three items: 1, 6, 7 and 9)
2) negative response of the carer towards the elder (three items: 2, 3, 4 and 17)
3) positive response of the carer towards the elder (four items: 8, 12, 13, 15 and 16)
4) negative attributes of the elder (seven items: 5, 10, 11 and 14).

Wording of questions: The original interview transcripts were examined once more for the actual wording of questions to be included. As far as possible, the questions contained the interviewee's own wording, e.g. the struggle for power (Carer C). The questions were designed to be easily understood and unambiguous, without any directive or evaluative language. Some of the questions were worded negatively and others positively, e.g. the elderly person can be very negative; the elderly person understands that I have a life of my own. In this way, any potential for negative bias in the questions would be minimised. A five-category Likert scale was used for responses: Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree. Negative items were scored in the opposite direction from the positive items (for questions, see Time 1 survey in Appendix 5).

All questions from the RECS were randomly selected for order of questioning to eliminate any bias from the researcher. They were then set out in the random order chosen, and prepared for inclusion in the Time 1 survey.

Motivations in Elder Care Scale (MECS)

As with the RECS, all items generated from the interview transcripts which related to motivations were considered for inclusion as questions in the new scale. The large pool of items was formed into a preliminary set of questions and distributed to the same group of six carers or ex-carers for initial piloting. The initial piloting yielded some new suggestions for questions to be included. As with the RECS, it was considered important at this stage to include as many items as were thought important, but not to include too many items relating to any particular aspect.

Items selected for inclusion: The items from which the questions were to be developed were:

1. No choice
2. Guilt
3. Elder's expectation of care
4. Perceived disapproval of others
5. Duty
6. Growing dependence of elder
7. Responsibility
8. Only person available to care
9. Expense of nursing home
10. Elder's resistance to other forms of care

11. Proximity to elder
12. Desire to care
13. Automatic decision to care
14. Carer's resistance to other forms of care
15. Living up to one's principles
16. To provide safety
17. Caring nature
18. Family tradition to care

At this stage, it appeared that four main constructs, containing at least three items, were emerging from the items included:

1) Practical motivations (four items: items 6, 8, 9 and 11)
2) Negative motivations (six items: items 1, 2, 3, 4, 10 and 14)
3) Positive motivations (four items: items 12, 13, 16 and 17)
4) Beliefs or principles (four items: items 5, 7, 15 and 18).

Wording of questions: As with the RECS, the wording of questions was taken directly from the interview transcripts where possible, and no directive or evaluative language was used. A 5-point Likert scale was used, and questions were included in random order. An open question was also included to ensure that no potentially important motivations had been missed. If it was shown that additional motivations were included by several respondents to the Time 1 survey, these could be considered for inclusion as questions in the Time 2 survey (Chapters 8, 9 and 10).

Data analysis

All data from the Time 1 survey were analysed (for full details of data analysis, see Chapters 8, 9 and 10). Exploratory factor analysis was used to examine the importance of each factor, and Cronbach's alpha was used to test the reliability of the new measures, the RECS and the MECS. Further tests of construct validity would take place with an assessment of the associations between the measures and carer outcomes in Chapter 8.

Results

Psychometric evaluation of the RECS

Initial exploratory principal component analysis with Varimax rotation was first performed on the data from the Relationships in Elder Care Scale (RECS), in order to see which factors were important in the analysis. A scree plot demonstrated that there were four main factors with Eigen values greater than one, explaining over 58% of the variance. Of these four factors, factors 1 and 2 explained over 44% of the total variance (32% and 12%, respectively), with a significant tailing off after these first two factors. The correlation matrix of all items was examined for any anomalies. The determinant of the correlation matrix demonstrated that it was free from multicollinearity or singularity ($p>0.0001$), the Kaiser-Meyer-Olkin measure of sampling adequacy was 0.843, demonstrating its suitability for proceeding with the factor analysis, and Bartlett's test of sphericity identified that the correlation matrix was not an identity matrix ($p<0.001$). Therefore, after initial analysis with the 4-factor solution, it was decided to explore the 2-factor solution for all 17 items of the RECS. Only those items with factor loadings greater than 0.4 or -0.4 were included, which led to the deletion of three items: embarrassment over the elder's behaviour, change in the relationship and sympathy for the elder.

Reliability of the RECS

A Cronbach's alpha was performed on the original 17 items to check the reliability of the scale as a whole, and then if each item was deleted in turn. Five items (elder's changed character, change in the relationship, embarrassment over the elder's behaviour, sympathy for the elder and feeling protective towards the elder) were found to detract from the internal consistency of the scale, and were therefore removed. Three of these items had also shown low factor loadings in the factor analysis. Although generational differences had demonstrated a relatively low factor loading of .443, it was retained because of its contribution to the overall reliability of the scale. The final 12 items demonstrated good internal reliability, with a Cronbach's alpha of 0.87. The scale included both positive and negative aspects of the care relationship (see Table 7.1).

Table 7.1: **Factor loadings after Varimax rotation of the principal factor extraction for the 12 items of the RECS, in order of highest to lowest loadings (2 factor solution)**

RECS items	**Factor 1**	**Factor 2**
Respect for elder	**.779**	.203
Admiration for elder	**.765**	.282
Quality of past relationship	**.731**	.014
Quality of current relationship	**.587**	.343
Understanding of elder	**.574**	.465
Money issues	**.508**	.368
Generational differences	**.443**	.365
Negativity of elder	.086	**.659**
Stubbornness of elder	.168	**.637**
Frustration with elder	.359	**.631**
Elder's resistance	.049	**.611**
Power struggle	.385	**.533**

A Cronbach's alpha had earlier been performed on the data to determine whether or not the items should be divided into two subscales (Factor 1 subscale and Factor 2 subscale), and although they demonstrated adequate reliability, with alpha levels of 0.86 and 0.75 respectively, they proved to be not as reliable as the single 12-item scale. There was a moderate correlation between the two factor subscales of 0.595. It was therefore decided that the 12-item scale should be used for further analysis. The sum of these 12 items (RECSSUM) was then calculated for all respondents for further data analysis within the Time 1 survey.

Psychometric evaluation of the MECS

An initial exploratory principal component analysis with Varimax rotation was then performed on the items in the Motivations in Elder Care Scale (MECS). A scree plot revealed six main factors with Eigen values greater than one, explaining over

67% of the variance. However, the first two factors explained over 40% of the variance (26% and 14%, respectively), the scree plot showed significant tailing off after these factors, and the remaining factors were difficult to interpret, loading on only a few items. As with the RECS, the correlation matrix of all items was examined for any anomalies. The determinant of the correlation matrix demonstrated that it was free from multicollinearity or singularity ($p>0.0001$), the Kaiser-Meyer-Olkin measure of sampling adequacy was 0.789, demonstrating its suitability for proceeding with the factor analysis, and Bartlett's test of sphericity identified that the correlation matrix was not an identity matrix ($p<0.001$). A second principal components analysis was then undertaken, using a two-factor solution, with only those items loading greater than 0.5 or -0.5 included. At this stage, five items were deleted as they proved to have factor loadings less than 0.5: caring as a family tradition, lack of alternatives, the elder's resistance to other forms of care, expense of a residential or nursing home and proximity to the elder. The item relating to responsibility as a motivation in elder care loaded on both factors: positively on Factor 1 and negatively on Factor 2, and was retained for further analysis.

***Table 7.2*: Factor loadings after Varimax rotation of the principal factor extraction for the 13 items of the MECS, in order of highest to lowest loadings (2 factor solution)**

MECS items	**Factor 1**	**Factor 2**
No choice	**.773**	-.189
Guilt	**.751**	-.202
Elder's expectation	**.750**	.046
Perceived disapproval of others	**.716**	.113
Duty	**.701**	-.381
Growing dependence of elder	**.569**	-.321
Responsibility	**.558**	***-.543***
Desire to care	.104	**.745**
Automatic decision to care	-.047	**.717**
Carer's resistance to other forms of care	.036	**.668**
Living up to one's principles	-.056	**.636**
To provide safety	-.258	**.622**
Caring nature	-.149	**.562**

Reliability of the MECS

A reliability analysis was performed on all the original 18 items of the MECS by calculating Cronbach's alpha for the scale as a whole, and then if each item was deleted in turn. A low Cronbach's alpha score of 0.54 suggested that the scale was not a unitary measure. When the items were re-examined, they showed clear sub-division and were therefore divided into two subscales. The EXMECS (Extrinsic motivations to care) comprised the first seven items in Table 7.2 (relating to feeling external pressures to adopt the caring role) and demonstrated good internal reliability (Cronbach's alpha = 0.84). All items contributed to the reliability of the scale. The INMECS (Intrinsic motivations to care) comprised the remaining six items in Table 7.2 (relating to a personal desire to provide care) and also had satisfactory internal reliability (Cronbach's alpha = 0.77). All items contributed to the reliability of the scale. The two subscales were therefore retained for further analysis.

Discussion

The main objectives for this part of the research were to develop two new measures for inclusion in the Time 1 survey and to test these measures for reliability, using standard methods. The qualitative stage of the research (Chapter 6) identified several previously unmeasured aspects of both relationship quality and motivations in elder care. The new items generated using this inductive approach are consistent with the findings of the qualitative study of motivations in elder care undertaken by Guberman et al. (1992) which also identified multiple factors. However, this latter study also included motivations involved in the care of adult children, and therefore differed somewhat from the motivations identified during the research described here. The new scales, the RECS and the two subscales of the MECS, were also developed to allow for the measurement of relationship quality and motivations in different elder care relationships and caring situations, making it easier to integrate results across different studies. Instead of focusing exclusively on specific carers such as daughter-carers, or on specific diseases such as dementia caring, it would now be possible to measure personal factors with a diverse group of elder carers. However, it should be noted that the measures were developed from interviews with a small group of women who were caring mainly for older parents. Although they appear to be useful in studies with a diverse group of female carers, the majority of women responding to the surveys were also caring for older parents. The measures may not apply equally well to other carers such as male carers or those caring for a spouse. Only further research with different samples of carers could determine if the measures were indeed useful across all groups of carers. After psychometric testing and revision of items, both the RECS and the two subscales of the MECS demonstrated good internal reliability, and will be further tested in the follow-up study, including an assessment of their stability over time. Although the face validity of the measures is high because items were developed to represent carers' responses, thereby representing the constructs of interest to the research, further tests of construct validity will take place during data analysis in Chapter 8.

Conclusions

Two new measures were developed for inclusion in the Time 1 survey to measure personal factors involved in elder caring, specifically the quality of the elder/carer relationship and the motivations involved in elder care. Both measures demonstrated good internal reliability, and will be tested for their predictive value in carer and mental health outcomes in the main survey and for reliability over time in the follow-up survey.

Chapter 8

AN EXAMINATION OF THE RELATIVE INFLUENCE ON CARER OUTCOMES OF WORK-RELATED, CARE-RELATED AND PERSONAL FACTORS

Introduction

The qualitative interview data described in Chapter 6 highlighted the importance for working-age female carers of personal factors involved in the caring role, notably the motivations involved in elder caring and the quality of relationship with the elder. The qualitative analysis suggested that these two factors interrelated with the key concept identified from the interview data, the subjective experience of caring (see Chapter 6, Figure 6.1). The development of two new measures of relationship quality and the motivations involved in elder care (Chapter 7) was therefore undertaken, so that the relative influence of the two factors on carer outcomes could be examined quantitatively in a large group of working female carers. This chapter describes a survey-based study of the influence of relationship quality and motivations in elder care, using carer stress and satisfaction scales to measure the subjective experience of caring. The data analysed in this chapter were obtained as part of a larger survey of factors influencing mental health outcomes in working carers (see following chapters).

In order to examine the relative influence of personal factors on carer outcomes compared with other factors, work-related and care-related factors were also included in the survey. Some of the previous research on the influence of these factors on carer outcomes has focused on only one factor, such as the personal aspects of caring (e.g. Horowitz & Shindelman, 1983) or the care-related aspects of caring (e.g. Starrels et al., 1997). Other researchers have focused on the relative or combined influence of two of these factors on the overall caring experience, such as personal and care-related factors (e.g. Albert, 1992; Carruth, 1996; Cicirelli, 1993; Lawrence et al., 1998; Lyons, Zarit, Sayer & Whitlatch, 2002; Peters-Davis et al., 1999; Townsend & Franks, 1995; Yates, Tennstedt & Chang, 1999), or work-related and care-related factors (e.g. Fredriksen & Scharlach, 1997; Gottlieb et al., 1994; Martire et al., 1997;

Murphy et al., 1997; Scharlach, Sobel & Roberts, 1991). To date, however, there has been very limited work on the relative or combined influence of all three of these factors on carer outcomes. In a Canadian qualitative study, Guberman & Maheu (1999) found that several factors influenced women's attempts to combine work and employment, including work-related factors such as workplace conditions, personal factors such as motives for working and caring, and care-related factors such as the demands of elder caring, and these factors in turn impacted upon elder caring and employment outcomes. This qualitative study underlines the importance of including all potentially influential variables when assessing the overall caring experience.

Previous longitudinal research on work and caring roles in women has been limited (e.g. Franklin, Ames & King, 1994; Lechner & Gupta, 1996; Pavalko & Artis, 1997) and several authors have commented on the need for further longitudinal data (e.g. Martire et al., 1997). Neither work nor caring roles are likely to remain static over time, and an examination of change in carer outcomes is vitally important. Cross-sectional data can only demonstrate an association between variables at a single time point, and does not determine causal relationships. By identifying the specific predictors of any changes, it may be possible to provide information about those women at risk of increased stress. As an example, decreased support for the carer or increased work demands over time may lead to a corresponding increase in carer stress, whereas lower levels of demand at work or increased support could increase levels of satisfaction for carers in combining roles. For the current study, a follow-up survey after one year was therefore designed to examine any changes in carer outcomes and which factors were responsible for that change.

This study was carried out to examine those personal, work-related and care-related factors which contributed cumulatively to carer stress and satisfaction over time. In order to examine the influence of personal factors on carer outcomes, the new measures of motivations in elder caring (MECS) and relationships in elder caring (RECS) were employed. These measures would be tested for reliability and validity during data analysis. If shown to be valid and reliable, the measures could also be useful in future research on the effects of work and caring roles in women.

Research questions

- How important are personal factors, relative to work-related and care-related factors, in predicting carer stress and satisfaction?

- Do levels of carer stress and satisfaction change over time and which factors are responsible for any change?
- Are the new measures of personal factors, developed for the study, valid, reliable and useful for future research into women's work and caring roles?

Method

Coding of occupational groups

All respondents were coded according to their responses to the screening survey regarding occupation. In a study of stress in the NHS workforce (Haynes et al., 1999), employees were divided into seven occupational groups, and a decision was made to follow this coding procedure as closely as possible:

1=Managers
2=Doctors
3=Nurses
4=Professions Allied to Medicine (PAMs)
5=Professional and Technical staff (P&Ts)
6=Administrative staff
7=Ancillary staff

The results of the screening survey showed that only three ancillary staff responded (Group 7). It was therefore decided to exclude this group from further analysis and to discard their data. There were now six groups remaining, but preliminary analysis with SPSS showed an insufficient number of carers in the P&T group (n=4), making meaningful analysis impossible. Groups 4 and 5 (PAMs and P&Ts) were therefore combined to make a new Group 4, and to then change the existing Group 6 (administrative staff) into the new Group 5. The decision to combine these two groups (PAMs and P&Ts), rather than others, was taken because it was felt that there was a degree of similarity between their occupations. Although many in the PAMs group would experience more care-related work than many P&Ts (e.g. psychologists v lab technicians), both groups held professional or technical roles rather than specific care-related or hands-on assisting roles. Doctors were initially considered when deciding upon a combination group (i.e. with PAMs), but it was felt that the stresses experienced by doctors may be specific to this group only. By combining them with another group, these potential differences may be lost. The new groups were coded as

follows:
1=Managers
2=Doctors
3=Nurses
4=PAMs and P&Ts
5=Administrative staff

Participants

Due to the low response rate to the screening survey, it was not possible to make any claims as to the representative nature of the respondents. However, a total of 275 working carers expressed a willingness to respond to the Time 1 survey.

Measures

The following section details the measures included in the Time 1 and Time 2 surveys. Surveys were divided into four main sections: A, B, C and D, relating to sociodemographic variables, work-related factors, care-related factors and mental health outcomes, which will be described in Chapter 9.

Table 8.1: **Summary table of measures included in the Time 1 and Time 2 surveys**

Category of variables measured:	**Specific measure of:**
Sociodemographic and single-item measures	Marital status ° (Neal et al., 1993) Change in occupation and hours worked + (Neal et al., 1993) Hours currently worked + (Neal et al., 1993) Carer's health status * (Maddox & Douglass, 1973)
Work-related	Autonomy/control * (Haynes et al., 1999) Work demand * (Haynes et al., 1999) Peer support * (Haynes et al., 1999) Work satisfaction * (Stephens et al., 1997) Work stress * (Stephens et al., 1997) Carework involvement * (Schaefer & Moos, 1993)
Care-related	Change in carer status + (Neal et al., 1993) Relationship to elder ° (Neal et al., 1993) Resident status of elder * (Neal et al., 1993) Length of time caring ° (Neal et al., 1993) Help with caring * (Neal et al., 1993)
Personal	Quality of caring relationship * (Lyonette & Yardley, 2003) Motivations in elder caring * (Lyonette & Yardley, 2003)
Carer outcomes	Carer stress * (Stephens et al., 1997) Carer satisfaction * (Lawton et al., 1989)

* Measures included in both Time 1 and Time 2 surveys

° Measure included only in Time 1 survey

\+ Measure included only in Time 2 survey

Sociodemographic and single-item variables

Section A "About yourself", included single-item measures of marital status and self-reported health status. Information was already available on age, occupation and hours worked from the screening survey, which would be included in the analysis. As there was only a short period of time between the distribution of the screening survey and the Time 1 survey, it was felt that occupation and hours worked were unlikely to have changed, except in rare cases. At Time 2, a question was included to gauge any change in respondents' jobs after one year. If they had changed, respondents were asked to state the type of job they were currently involved in, as it was vital to ascertain the combination of work and caring tasks undertaken at the same time. It was important to assess marital status as it has previously been suggested that unmarried carers take on more care than married carers (Stoller, 1983), and may be more at risk of negative outcomes (Murphy et al., 1997), although it could be that the extra responsibilities involved in marriage increase the likelihood of negative outcomes for female carers (Stephens & Franks, 1995).

Self-assessed health status was measured by a single item, described by Scharlach et al. (1991) as "the usual single-item measure" originally developed by Maddox and Douglass (1973). Health status of the carer could be a potentially confounding variable, as those with health problems of their own may be more at risk of negative outcomes (Schulz, Tompkins & Rau, 1988). Those in poor health may also find it more difficult to combine work and caring. The same question was included at Time 2.

Work-related variables

Work characteristics

Section B then asked for details of work characteristics. As demonstrated in Chapters 5 and 6, specific work characteristics are important in women's experiences of the work/caring interface. The first three measures were taken directly from the measures of perceived work characteristics, developed by Haynes and colleagues (1999), and designed for use in studies of the psychological well-being of health service employees (see Appendix 5). The measures included were designed to assess a) autonomy/control, b) work demand and c) peer support. These three were chosen specifically as they related to factors previously found to be important in the literature (e.g. Fredriksen & Scharlach, 1997). Other scales developed by Haynes et al. (1999)

were thought to be less relevant to the current research and would have made the surveys too long. All three scales exhibited acceptable internal reliabilities, with Cronbach's alpha scores reported by the authors to range from 0.70 to 0.92. The authors reported that the measures are usable for research purposes across the major occupational groups, with the possible exception of ancillary staff, which recorded a Cronbach's alpha of 0.70 in the Haynes et al. study (the authors reported a very low response rate for this occupational group, consistent with the results from the screening survey described earlier. Ancillary staff had already been excluded from this analysis). All scales demonstrated good construct validity, discriminating across occupational groups and jobs. Relationships with outcome variables were tested and shown to be consistent with predictions from the literature (Haynes et al., 1999).

Other measures considered for the Time 1 and Time 2 surveys included: Karasek's (1987) measures of work demand (four items); workplace control (three items); workplace support (two items); and Scharlach et al.'s (1991) measure of workplace flexibility (eight items). However, as the Haynes measures were used with a large sample of NHS workers and were more in-depth than those mentioned above, they were deemed to be more appropriate for the present study.

Work satisfaction

The Stephens, Franks and Atienza (1997) measure of work satisfaction was chosen as the most appropriate for the current research, as it was relatively short, did not overlap with the other employment measures, and was developed for a US study assessing both positive and negative aspects of combining work and caring roles, and so was designed specifically with this research focus in mind. The authors developed the measure of work satisfaction by using eight items derived from previous research studies. Each item was rated on a four-point scale, ranging from one to four. Overall scores therefore range from eight to 32, with higher scores reflecting greater satisfaction. Cronbach's alpha for the scale was 0.78, as reported by the authors (Stephens et al., 1997). This measure was also included in the Time 2 survey.

Other measures were considered for inclusion, especially the 15-item measure used in the Haynes study to assess work satisfaction (Warr, Cook & Wall, 1979). However, it was felt that the Warr et al. scale contained too much overlap with the measure of work stress, and that the Stephens measure was more specific to working carers, as well as being shorter.

Work stress

The Stephens et al. (1997) measure of work stress was also selected for inclusion. As this measure had been designed for use with the measure of work satisfaction previously described, it was felt that it would be the best measure for the current study. Work stress was assessed with seven items taken from previous research studies. Scores range from one to four, with overall scores ranging from seven to 28. Higher scores indicate higher levels of work stress. Cronbach's alpha for the measure was 0.78, as reported by the authors (Stephens et al., 1997). This measure was also included at Time 2.

Patient care tasks

The measure of "patient care tasks", developed by Schaefer and Moos (1993) was the only one found which measured the extent of caring for people in a working environment, which was crucial to the research question. The measure of patient care tasks is a subscale of the Work Stressors Inventory (WSI), a 54-item inventory grouped into three domains with nine items in each: task stressors (which include the measure described here), relationship stressors and system stressors. Scores range from zero to four, with overall scores for the subscale therefore ranging from zero to 36. The patient care tasks subscale is described as one which assesses "problems associated with providing care to patients and their families, such as caring for a patient who wants to die or talking to complaining family members" (Schaefer & Moos, 1986). Cronbach's alpha for the subscale is 0.82, as reported by the authors, and all of the subscales were reported to be quite stable over time (average $r = 0.65$). The measure was also included at Time 2.

Care-related variables

Relationship to the elder

Section C then refers to caring responsibilities. Previous research has suggested that a closer kin relationship increases carer stress (e.g. Cantor, 1983) and so the first question assessed the carer's relationship to the older person. Rather than excluding specific categories of carers, we included all those caring for an elder in order to measure any differences in stress and satisfaction. The particular format of this question was used by Neal et al. (1993) and was felt to be clear and easy to follow. At

Time 2, a question was included to determine whether or not the respondent was still caring. If not, the respondent was asked to state why, and then to proceed to Section D (health outcomes). If the respondent was still caring, she was instructed to continue with all questions.

Resident status of elder

A further question assessed the resident status of the older person in both the Time 1 and Time 2 surveys. It has previously been shown that co-residence can exacerbate levels of carer stress (Goldsmith & Goldsmith, 1995; Neal et al., 1993; Stoller & Pugliesi, 1989). This question and its format were taken directly from Neal et al. (1993).

Length of time caring

Length of time caring was also measured, as it may be that length of time since caring began can affect levels of stress (e.g. Mui & Morrow-Howell, 1993).

Level of help provided with caring

A further question was also taken from the Neal et al. survey instrument (1993), to assess the level of care provided by the respondent, and the amount of help provided by others. Previous work has suggested that greater levels of support to the carer reduces the risk of depression (Yates et al., 1999). Both primary and secondary carers would be included in the study (i.e. those receiving no help with caring and those receiving help), but these would later be compared for differences in positive and negative outcomes. This question was again included at Time 2.

Personal variables

Relationships in Elder Care Scale (RECS)

A scale was used to assess the quality of relationship with the older person, shown to be an important factor in women's attempts to combine work and caring (Chapter 6). The development of the Relationships in Elder Care Scale (Lyonette & Yardley, 2003) was covered in detail in Chapter 7. Other measures of relationship quality with elders were considered, but none was adequate for the particular research focus (for an assessment of other measures, see Chapter 7). Cronbach's alpha for the scale was 0.87 (see Chapter 7), demonstrating high internal reliability. The measure was also included at Time 2.

Motivations in Elder Care Scale

A further scale was used to assess the motivations involved in elder caring, shown to be an important factor in the interview data (Chapter 6). (For development of the Motivations in Elder Care Scale (Lyonette & Yardley, 2003), see Chapter 7). No adequate and specific measure of motivations in diverse elder care contexts is known to have been developed. The scale was clearly divided into two subscales, and internal reliability was tested. The Cronbach's alpha for the EXMECS subscale was 0.85, and for the INMECS subscale 0.77 (see Chapter 7). The measure was included in the Time 2 survey.

Carer outcome variables

Carer stress

The Stephens et al. (1997) 21-item measure selected examines the perceived stress experienced by the carer in carrying out specific caring tasks, and was chosen, along with the following scale, to measure the subjective experience of caring, identified as the key concept in the qualitative study. In this stage of the research, this measure would be used as one of the main carer outcome measures, but would be included as a potentially predictive variable with the main health outcomes, mental health and positive affect, in the next stage (Chapter 10). Although it is not possible to deduce from the "did not happen" category whether the older person required such tasks to be performed, or whether such tasks were performed by someone else, this measure was the only one found which allowed for an assessment of perceived stress experienced by the carer. It was felt that, for the purposes of this study, the subjective experience of carer stress was more informative than the level of disability of the older person, and so this measure was considered more appropriate than measures of ADL limitations. It was also felt that by including a measure of disability as well as a measure of carer stress, the overall survey would become too long. The Stephens et al. study (1997) in which the measure was developed focused only on daughter carers, and so the wording of the questions was slightly changed, eg. "Feeding your parent, making sure he/she eats well", was changed to "Feeding the elderly person, making sure he/she eats well". Scores range from one to four to indicate the amount of stress experienced in that particular caring task. Overall scores could therefore range from zero to 84, with higher scores reflecting higher stress levels in the caring role. Cronbach's alpha for the scale was reported as 0.87 (Stephens et al., 1997). The measure was also included in the Time 2 survey.

Carer satisfaction

The next series of questions were included to assess positive aspects involved in the subjective experience of caring, which have often been overlooked in the literature. The five-item caregiving satisfaction scale was developed by Lawton et al. (1989), as part of the Caregiving Appraisal measure, and was previously used in the Martire et al. study (1997). In this stage of the research, this measure would act as the other main carer outcome measure, but would be included as a potentially predictive variable with the main outcomes, mental health and positive affect, in a later stage (Chapter 10). Again, because of the focus of this study, the wording of the questions was slightly changed, e.g. "Helping your parent makes you feel closer to him/her" was changed to "Helping the elderly person makes you feel closer to him/her". Otherwise, the wording remained unchanged. The measure is short and clearly worded, and was considered appropriate for inclusion in this study because of its focus on positive aspects of caring. Each item was rated on a four-point scale, ranging from one to four, with overall total scores ranging from eight to 32. Higher scores reflected greater satisfaction with caring. Cronbach's alpha for the scale was reported by the authors to be 0.78 (Lawton et al., 1989). The measure was included at Time 2.

Procedure

An information sheet and the complete questionnaire pack were sent out to all participants selected for inclusion. A stamped addressed envelope was included with each. All surveys were identifiable with a code number, relating to the returned screening surveys. The information sheet was short, politely reminding participants that they had stated their willingness to complete a further survey. No consent form was considered necessary, as all participants had completed one in the earlier stages of the research. The same procedure was implemented with all willing respondents at Time 2.

Data Analysis

Bivariate Pearson's product-moment correlations (for continuous variables) and

ANOVAs and t-tests (for categorical variables) were used to examine the relationships between each predictor variable and the outcome measures, carer stress and satisfaction. The carer stress outcome measure was shown on analysis not to be normally distributed at Time 1. In order to correct for this, the square root of the carer stress measure was calculated. This demonstrated a normal distribution, and was used for all further analysis (one-sample Kolmogorov-Smirnov test =.626; p=.829). The same procedure was followed for Time 2, i.e. the square root of the carer stress measure at Time 2 was employed in all analyses. Those predictors showing significant associations with the main outcome variables at Time 1, carer stress and carer satisfaction, were then entered into two separate stepwise multiple regression analyses to explore their predictive value.

Within-subjects comparisons of Time 1 and Time 2 carer stress and satisfaction were tested using matched samples t-tests. In order to test for any predictors of change over time in the main outcome measures, a series of correlations and associations between all Time 1 predictor variables and Time 2 carer outcomes were performed. To examine Time 1 predictors of Time 2 carer stress and satisfaction, after controlling for Time 1 carer outcome scores, partial correlations were also performed. Those Time 1 variables showing predictive value ($p<0.05$) at this stage were then entered into two separate forward stepwise regression analyses with the Time 2 main outcomes as the dependent variables and the corresponding main outcome measures at Time 1 entered at the first step. This procedure allowed for an examination of any causal relationships between variables.

Due to the number of statistical tests being carried out, there was an increased risk of a Type 1 error (rejecting the null hypothesis when it is true). It was therefore considered necessary to use a more conservative significance level of 0.005 for data analyses.

Missing data

If any of the scales at Time 1 or Time 2 had less than three missing responses, they were examined for their overall responses. The modal response for each scale was then inserted. If there were three or more missing responses, the data from the scale for this respondent was omitted.

Results

Time 1

Response rate

Of the 275 carers targeted at Time 1, 13 returned the survey without filling in the caring section and were therefore excluded from further analysis. One respondent's data was incomplete, one had since left work to care, one was caring for a disabled child, rather than an elderly person, and one was returned uncompleted. A further seven returned the survey, but reported that the older person had recently died. All of these were excluded from the data analysis. Of the remaining 251 carers targeted, a total of 204 responded (74% of the total who originally expressed a willingness to answer the Time 1 survey). The data from one carer were found to be significantly skewed (Carer 133) and were therefore omitted, leaving a total of 203 carers for analysis.

Carers' profile (Time 1 and Time 2)

***Table 8.2*: Descriptive data for all respondents at Time 1 and Time 2**

Variables		**Time 1 (n=203)**	**Time 2 (n=110)**
Age (mean):		49.28 (s.d. 7.19)	50.32 (s.d. 6.30)
Marital status:	Single	13 (6.5%)	9 (8.2%)
	Married	174 (86.6%)	96 (87.3%)
	Divorced/separated	11 (5.5%)	4 (3.6%)
	Widowed	3 (1.5%)	1 (0.9%)
Occupation:	Managers	14 (6.9%)	9 (8.2%)
	Doctors	6 (3%)	4 (3.6%)
	Nurses	111 (54.7%)	59 (53.6%)
	PAM/P&Ts	33 (16.3%)	20 (18.2%)
	Admin	39 (19.2%)	18 (16.4%)
Hours worked (mean):		29.07 (s.d. 9.61)	29.94 (s.d. 9.62)

Variables (contd.):			
Health status:	Poor or fair	28 (14.1%)	26 (23.9%)
	Good or excellent	171 (85.9%)	83 (76.1%)
Relationship to elder:	Daughter	121 (62.4%)	68 (63.6%)
	Daughter-in-law	32 (16.5%)	19 (17.8%)
	Spouse	5 (2.6%)	0 (0%)
	Friend/neighbour	17 (8.8%)	10 (9.3%)
	Other	19 (9.8%)	10 (9.3%)
Elder's resident status:	Own home	153 (76.5%)	81 (75%)
	Carer's home	21 (10.5%)	12 (11.1%)
	With other relative	5 (2.5%)	1 (0.9%)
	With other friend	0 (0%)	1 (0.9%)
	Nursing home	21 (10.5%)	13 (12%)
Help with caring:	No help	34 (17%)	20 (18.3%)
	Some help	73 (36.5%)	46 (42.2%)
	Caring shared equally	64 (32%)	30 (27.5%)
	Caring done mostly by others	29 (14.5%)	13 (11.9%)
Length of time caring (mean):		5.84 years (s.d. 5.6)	6.60 years (s.d. 4.81)

Table 8.2 shows that of the 203 carers at Time 1, the vast majority were caring for a parent, although 32 were caring for a parent-in-law, five for a spouse, 17 for a friend or neighbour, and 19 for a non-specified "other". No-one was caring for a sibling (nine respondents did not enter an answer). The majority of elders lived in their own homes with only 21 being cared for in the carer's home. Five of the elders lived with another relative and 21 lived in a nursing home or care facility. None lived with a friend. Three respondents did not record an answer. The average length of time that

the carers had been caring was almost six years, although this varied considerably between carers, with one carer caring for over 40 years, and one caring for only three months. Over 61% of carers had been caring for five years or less, and over 88% for ten years or less.

A large number of carers reported being the main carer, with some help from others, but 34 reported having no help from others. Another third claimed to be sharing the care equally with others, and 29 were receiving the most help. Three respondents recorded no answer.

The average age of the carers was 49.28 years, and the average number of hours worked by carers was just over 29 hours. A minority of carers reported to be in poor or fair health, with the majority reporting good or excellent health.

Relationships between all Time 1 predictor variables and Time 1 carer outcomes

Work-related variables

Table 8.3 shows the associations between work-related variables and carer outcomes. Carer stress was significantly positively associated with higher work demand, work stress and carework involvement, and significantly negatively associated with work satisfaction and peer support. Carer satisfaction was significantly positively associated with peer support and negatively associated with carer stress.

Table 8.3: **Correlations between Time 1 work-related variables and carer outcomes (n=203)**

Variable	1	2	3	4	5	6	7	8
1 Autonomy	-							
2 Work Demand	.148*	-						
3 Peer support	.143*	__-.209**__	-					
4 Carework	.059	__.365***__	.045	-				
5 Work Satisfaction	.152*	__-.487***__	__.440***__	__-.209**__	-			
6 Work stress	-.063	__.640***__	__-.248***__	__.230**__	__-.585***__	-		
7 Carer stress	.018	__.199**__	__-.212**__	__.212**__	__-.259***__	__.214**__	-	
8 Carer satisfaction	.013	.042	__.272***__	.117	.088	-.060	__-.244***__	-

*Significant at the 0.05 level   ** Significant at the 0.005 level   *** Significant at the 0.001 level

Personal variables

Personal variables and their associations with carer outcomes, carer stress and carer satisfaction, were then explored. Table 8.4 shows that carer stress was significantly positively associated with poorer quality of relationship and higher extrinsic motivations to care. Carer satisfaction was significantly positively associated with better quality of relationship and higher intrinsic motivations to care and negatively related to higher extrinsic motivations to care.

Table 8.4: **Correlations between Time 1 personal variables and carer outcomes (n=203)**

Variable	1	2	3	4	5
1 Relationship quality	-				
2 Extrinsic motivations	__.275***__	-			
3 Intrinsic motivations	__-.302***__	__.285***__	-		
4 Carer stress	__.443***__	__.456***__	.088	-	
5 Carer satisfaction	__-.630***__	__-.213**__	__.451***__	__-.244***__	-

** Significant at the 0.005 level   *** Significant at the 0.001 level

Care-related variables

T-tests and ANOVAs were then carried out to look for any associations between care-related variables and carer outcomes. There was a significant association between resident status of the elder and carer stress, with those caring for a co-resident older person recording significantly higher levels of stress than all other groups (F=7.111; df = 3; $p<0.001$). However, as there were only 21 carers co-resident with the elder, these results must be treated with caution. There was also a tendency for those receiving the least help with caring to record higher stress but these results were not significant at the 0.005 level.

Other tests of association showed that those caring for a parent also recorded significantly higher extrinsic motivation scores than those caring for a friend or neighbour (F = 4.629; df = 4; $p<0.001$). However, in each of these cases, the low number of carers in the comparison group reduced the reliability of the findings. Those receiving the least help with caring also recorded significantly higher extrinsic motivations to care than those receiving the most help (F = 11.769; df = 3; $p<0.001$), although again, there were small numbers in each of the groups. Poorer quality of relationship was significantly associated with greater extrinsic motivations to care ($p<0.001$) and lower intrinsic motivations to care ($p<0.001$). Poorer quality of relationship was also significantly positively associated with longer time caring (r=.211; $p<0.005$). There was a tendency for those caring for longer to record higher extrinsic motivations to care but this was not significant at the 0.005 level.

Other variables

Tests of association were then carried out for other variables and carer outcome measures. There were no significant associations between carer outcomes and marital status, carer's health status, occupation, age or hours worked.

Predictors of Time 1 carer outcomes

Stepwise regression analyses were then carried out to identify the combinations of variables predictive of carer outcomes at Time 1. All variables significantly correlated with carer stress and carer satisfaction ($p<0.005$) were entered into two separate forward stepwise regression analyses. Although resident status of the elder showed a significant association with carer stress, it was not included in the regression analysis due to the low numbers in the co-resident group.

Table 8.5: **Stepwise regression model of Time 1 carer outcomes for working carers (n=203)**

Step	**Dependent variables**	**Predictor variables**	**Beta**	**R2**	**Change in R2**	**F change**	**Sig. of F change**
	Carer stress:						
1		EXMECS	**.368*****	.215	.215	52.461	<0.001
2		RECS	**.336*****	.319	.104	29.121	<0.001
3		Carework	**.216*****	.365	.047	5.690	<0.05
	Carer satisfaction:						
1		RECS	**-.469*****	.397	.397	128.490	<0.001
2		INMECS	**.367*****	.473	.076	27.997	<0.001
3		EXMECS	**-.191****	.501	.028	10.884	<0.005

** Significant the 0.005 level *** Significant the 0.001 level

Code:

RECS: quality of relationship with elder

EXMECS: extrinsic motivations to care

INMECS: intrinsic motivations to care

Extrinsic motivations to care (EXMECS) and quality of relationship with the elder (RECS) were the most significant independent predictors of carer stress (see Table 8.5). Higher carework involvement also contributed to the final model. These three independent variables accounted for over 36% of the variance in carer stress for this sample of working carers at Time 1. For carer satisfaction, better quality of relationship with the elder (RECS) and higher intrinsic motivations to care (INMECS) were shown to be the most significant independent predictors; lower extrinsic motivations to care also contributed to the final model. Taken together, these three variables accounted for over 50% of the variance in carer satisfaction for this group of working carers.

Time 2

Response rate

Of the 193 carers targeted at Time 2, 164 carers responded (85% in total). Forty-three were no longer caring for an elderly person: 20 of these reported that the older person had died since the last survey, 12 gave no reason, six stated that the older person needed less help than before, four of the older people had recently gone into residential care and one carer had moved away from the area. Five carers returned the surveys unanswered, giving various reasons such as retirement, change in circumstances or length of survey. Six of the carers were no longer working and their data were therefore omitted from further analysis. A total of 110 carers remained for analysis, 57% of those who were sent follow-up surveys.

Carers' profile

Table 8.2 shows that the average age of all carers was just over 50 at Time 2. A total of 93 remained in the same job as a year ago (84.5%) and 17 had changed jobs (15.5%). Four had retired in that time and one had left work to care (these were not included in the following analysis). Table 8.2 also shows the percentages of respondents in each occupational group, which remain fairly consistent over time. Other sociodemographic details are also outlined in Table 8.2.

Non-respondents

An examination was made of non-respondents to the follow-up survey. Non-respondents recorded an average carer stress score of 3.21 (s.d. 1.46) at Time 1, compared with 4.27 (s.d. 1.64) for respondents. An independent samples t-test showed that these figures were significantly different ($t = 3.71$; $df = 150$; $p<0.001$), indicating that Time 2 respondents had significantly higher stress scores at Time 1 than non-respondents. For carer satisfaction, non-respondents recorded an average score of 17.56 (s.d. 3.06), compared with 16.25 (s.d. 3.91) for respondents. An independent samples t-test showed a trend in the data ($t = -2.185$; $df = 97.41$; $p<0.05$), with Time 2 respondents recording lower satisfaction scores at Time 1 than non-respondents. These figures would suggest that those carers with lower stress and higher satisfaction scores were less likely to respond to the Time 2 survey.

Within-subjects comparisons of carer stress and carer satisfaction over time

In order to examine within-subjects changes in carer stress and carer satisfaction over time for remaining carers, matched samples t-tests were conducted. Mean stress scores at Time 1 and Time 2 were 4.266 (s.d. 1.65) and 4.57 (s.d. 1.77), respectively. Results indicated that carers recorded significantly higher stress scores at Time 2 than at Time 1 (t = -3.022; df = 107; p<0.005). Mean satisfaction scores at Time 1 and Time 2 were 16.30 (s.d. 3.87) and 16.49 (s.d. 4.09), respectively. Results indicated that there were no significant changes in carer satisfaction scores over time (t = -.636; df = 107; p = .526).

Relationships between all Time 1 independent variables and Time 2 carer outcomes

In order to determine causal relationships between predictor variables and carer outcomes, a series of tests of association was first undertaken to examine associations between Time 1 independent variables and Time 2 carer outcomes (see Table 8.6). Categorical variables were re-coded into two-category variables at this stage so that they could also be included in the correlational analysis (marital status = married/not married; relationship to elder = daughter or daughter-in-law/other carer; resident status = co-resident with carer/not co-resident; help with caring = little or no help/some or a lot of help). These new categories retained the most important distinctions between groupings, as determined by the results of the Time 1 survey, allowing for further analysis of differences. Carer stress and carer satisfaction at Time 1 were then controlled for, and a series of partial correlations were undertaken with each outcome variable, so as to determine predictors of change in stress and satisfaction scores.

Table 8.6: **Correlations and partial correlations between Time 1 predictor variables and Time 2 carer outcomes (n=110)**

Variables		Time 2 outcomes: correlations		After controlling for Time 1 outcomes: partial correlations	
		Carer stress T2	Carer satisfaction T2	Carer stress T2	Carer satisfaction T2
Work	Autonomy/control	.006	.038	-.012	.130
	Work demand	.058	.056	-.183	.102
	Peer support	-.171	.304**	.028	.154
	Work satisfaction	-.214*	.068	.036	.044
	Work stress	.194*	-.010	-.083	.042
	Carework	.098	.157	**-.230***	.172
Personal	Relationship	.450***	-.523***	.190	-.100
	Extr. motivations	.505***	-.034	.124	.030
	Intr. motivations	.091	.484***	-.140	**.221***
Care	Kin relationship	-.241*	.055	-.192	.001
	Resident status	-.233*	.065	-.057	.007
	Length of time caring	.152	-.006	-.081	.121
	Help with caring	-.215*	.034	.050	-.065
Other	Age of carer	.182	-.134	**.295****	.006
	Health status	-.166	-.048	.003	-.160
	Marital status	-.111	-.006	-.134	-.122
	Hours worked	-.017	-.056	.023	**-.260***

* Significant at the 0.05 level ** Significant at the 0.005 level *** Significant at the 0.001 level

Time 1 predictors of carer outcomes at Time 2 (after controlling for Time 1 outcomes)

Forward stepwise regression analysis was then performed to look at the relative and combined predictive value of Time 1 independent variables on Time 2 carer outcomes, after controlling for Time 1 outcomes. All those variables showing significant partial correlations at the 0.05 level with each outcome variable were entered into two separate regression analyses. For carer stress, Time 2 stress was entered as the dependent variable; Time 1 carer stress was then entered on the first step, followed by age and level of carework. For carer satisfaction, Time 2 satisfaction was entered as the dependent variable: Time 1 carer satisfaction was then entered on the first step, followed by hours worked and intrinsic motivations.

Table 8.7: **Stepwise regression model of Time 2 carer outcomes for working carers, controlling for Time 1 outcomes (n=110)**

Step	**Dependent variable**	**Time 1 Predictors**	**Beta**	**R2**	**Change in R2**	**F change**	**Sig. of F change**
	Carer stress (Time 2)						
1		Carer stress	**.819*****	.673	.673	217.74	<.001
2		Age	.159*	.698	.025	8.778	<0.05
	Carer satisfaction (Time 2)						
1		Carer satisfaction	**.635*****	.498	.498	102.16	<0.001
2		Hours worked	-.155*	.519	.021	4.435	<0.05
3		Intrinsic motivations	.164*	.538	.019	4.259	<0.05

* Significant at the 0.05 level ** Significant at the 0.005 level *** Significant at the 0.001 level

Carer stress at Time 1 was shown to be the main predictor of Time 2 carer stress, explaining over 67% of the variance in carer stress at Time 2, and indicating a high degree of stable individual differences over time. However, older age also accounted for about 3% of the change in carer stress over the year, suggesting a causal link between these variables. Level of carework involvement did not predict any further variability in carer stress and was therefore excluded from the model. For carer satisfaction, Time 1 satisfaction scores were shown to be the main predictor of Time 2 satisfaction scores, explaining over 49% of the variance, and suggesting a high degree of stability over time. However, fewer hours of work and higher intrinsic motivations to care also explained about 4% of the change in carer satisfaction over the year, suggesting a possible causal effect of fewer hours of work and higher intrinsic motivations to care on carer satisfaction.

Reliability of the RECS and the MECS

Analyses were then undertaken to examine the reliability of the Relationships in Elder Care Scale (RECS) and the two subscales of the Motivations in Elder Care Scales (MECS) over time. At Time 2, a reliability analysis on the 12 items of the RECS produced a Cronbach's alpha of .85 (Time 1 = .87). RECS6 (negativity in the elder) and RECS7 (resistance of the elder) appeared to be contributing less to the final scale than at Time 1, with slightly increased alpha levels if each item was deleted (RECS6 = .86; RECS7 = .85). However, the two items were retained for data analysis in the Time 2 survey. In order to examine test-retest reliability, relationship scores at Time 1 and relationship scores at Time 2 were tested for their level of association. Pearson's product-moment correlations showed a score of .738 ($p<0.001$), demonstrating good test-retest reliability.

A reliability analysis on the seven items of the EXMECS subscale produced a Cronbach's alpha of .83 (Time 1 = .85). EXMECS6 (perceived disapproval of others) appeared to contribute less to the final scale at Time 2, with a slightly increased alpha score of .8314 if the item was deleted. The item was retained for data analysis in the Time 2 survey, however. Test-retest reliability was good, with a correlation value of .772 ($p<0.001$) between Time 1 and Time 2 extrinsic motivations scores. The six items of the INMECS subscale were also tested for reliability at Time 2, and demonstrated a Cronbach's alpha of .7355 (Time 1 = .77). MECS11 (living up to one's principles) appeared to contribute less to the subscale, with a slightly increased alpha of .7367 if the item was deleted. However, the item was retained for data analysis in the Time 2 survey. Test-retest reliability was examined and generated an adequate correlation value of .545 ($p<0.001$) between Time 1 and Time 2 scores on the INMECS. Overall, both the RECS and the two subscales of the MECS demonstrated good internal reliability over time.

Validity of the RECS and the MECS

Although face validity of the new measures was high (see Chapter 7 for details), construct validity was also tested by examining associations between the new scales and carer outcomes. It was predicted that those with better relationship quality would report higher carer satisfaction and that those with poorer relationship quality would report higher carer stress (e.g. Snyder, 2000; Stoller & Pugliesi, 1989; Walker et al., 1992). Our findings were consistent with these predictions from the literature. It was also predicted that those with higher intrinsic motivations to care would report greater carer satisfaction, whereas those reporting greater perceived external pressures to care would record higher carer stress scores (e.g. Cicirelli, 1993). Again, the findings from this study were consistent with predictions from the literature, demonstrating support for construct validity of both scales.

Discussion

The main objective of this study was to examine quantitatively the influence of personal factors on carer stress and satisfaction, after revealing their importance in the qualitative study. Work-related and care-related factors were also included as potential predictors of carer outcomes.

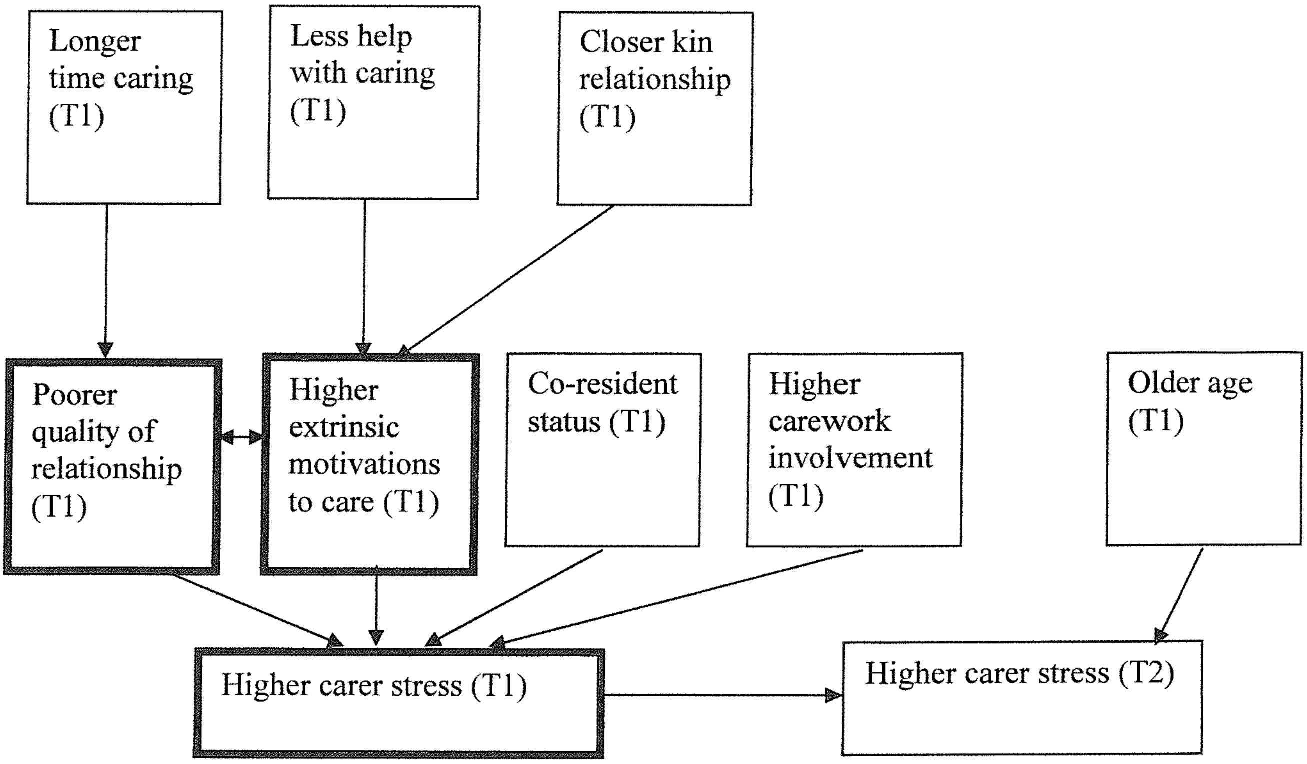

Figure 8.1: **Predictors of carer stress for working carers over time**

Based on the survey results, Figure 8.1 shows that higher extrinsic motivations to care and poorer quality of relationship with the elder were the main predictors of carer stress at Time 1. These results suggest that many working carers take on caring for an older person as a result of feelings of guilt, duty, responsibility, and lack of choice, associated with the growing dependence of the elder, the elder's expectation of care and the perceived disapproval of others if they do not take on the care. The perception of such external pressures to care is in turn associated with increased levels of carer stress. These findings are consistent with those of Cicirelli (1993), who found that a sense of obligation was positively associated with greater burden in daughter-carers. In our study, increased carer stress was also independently associated with a poor relationship with the elder, including feelings of frustration linked with perceptions of the elder as negative, stubborn, changed, and resistant to the carer's efforts, and engaged in a power struggle with the carer. While many previous researchers have shown that aspects of the care relationship can be associated with negative outcomes (e.g. Archbold et al., 1990; Lyons et al., 2002; Walker et al., 1992), the research reported here extends these findings by including aspects of the quality of the care relationship such as the struggle for power and the elder's resistance to caring efforts, and by demonstrating the importance of the carer-elder relationship across a wide range of caring situations.

Other factors contributing to higher stress scores in the main survey were co-resident status and higher levels of caring involvement at work. These findings support previous research which has demonstrated that those women sharing a home with the older person report higher levels of stress (Brody, 1987; Orodenker, 1990; Gottlieb et al., 1994; Murphy et al., 1997). The link between caring involvement at work and stress supports the study by Marshall et al. (1990), which outlined the potential risks for women who combine caring both at home and at work. These results will be explored more fully in Chapter 9.

For carer satisfaction, better relationship quality and greater intrinsic motivations to care were the most significant predictors at Time 1 (Figure 8.2). Those working carers reporting respect and admiration for the elder, higher quality of past and current relationship, as well as the elder's understanding, lack of generational differences and fewer money issues, also reported greater carer satisfaction. Quality of relationship and intrinsic motivations to care were significantly associated.

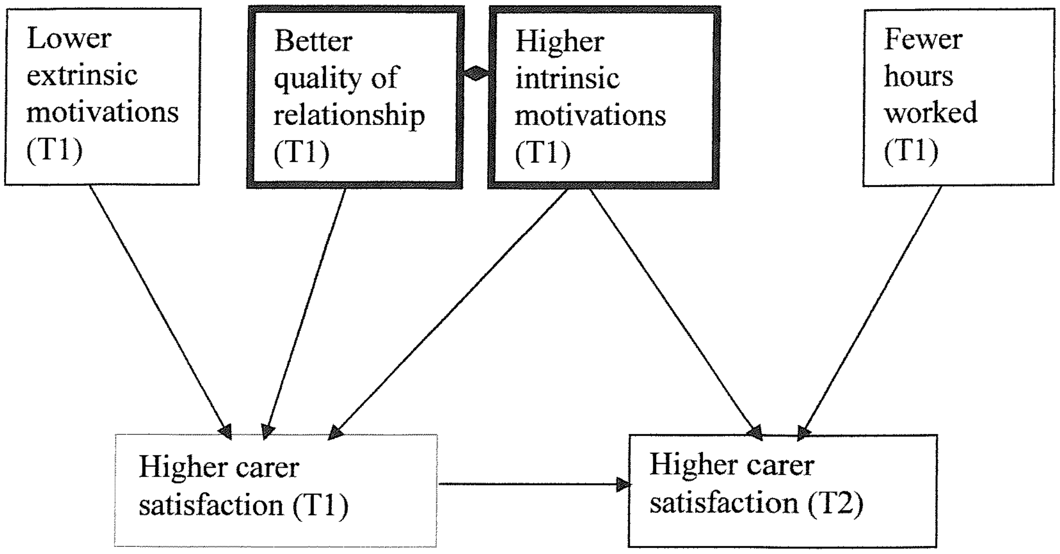

Figure 8.2: **Predictors of carer satisfaction for working carers over time**

These findings support earlier work which has looked at positive aspects of the care relationship and their influence on carer outcomes (Cicirelli, 1993; Pohl et al., 1995; Stoller & Pugliesi, 1989). However, Cicirelli (1993) and Pohl et al. (1995) examined only the quality of relationship in mother-daughter caring. The results reported here suggest that relationship quality in diverse elder care situations predicts levels of carer satisfaction. Women who were more satisfied with the caring role also described themselves as 'natural' carers who wanted to care for the elder, made an automatic decision to do so, were resistant to alternative forms of care, wanted to provide safety for the elder, and saw caring as a way of living up to their principles. Again, a combination of personal factors was shown to be more predictive of carer satisfaction than either work-related or care-related factors for this group of working female carers. Guberman et al. (1992) earlier identified some of the motivations outlined above in their qualitative study of female carers, but the study reported here expands on this research by also measuring the predictive value of such motivations on carer outcomes.

When examining individual changes in carer stress and satisfaction scores, stress was shown to increase significantly over time, supporting the findings of a previous longitudinal study (Lechner & Gupta, 1996). These results might suggest that working carers are at risk of increased negative carer outcomes over time, whereas satisfaction levels tend to remain stable. However, respondents to the follow-up survey had reported significantly higher stress scores at baseline than non-respondents. It may be that those women who were not experiencing a great deal of stress were less interested in completing the follow-up survey. It is also possible that only those carers who were already stressed became worse over time. Consequently, the increase in stress over time observed in this study may simply be a characteristic of this self-selected sample, and not representative of the wider population of carers.

The follow-up survey data demonstrated that the initial level of carer stress was the most significant predictor of stress scores after one year, indicating that those who were stressed at Time 1 were also more likely to be stressed at follow-up. However, age of the carer also accounted for some of the change in stress scores at follow-up, suggesting a direct causal link between older age and increased stress over time. Older women who are providing care to an elder, as well as working, may be at greater risk of carer stress due to factors such as increased health problems of their own.

Initial level of carer satisfaction was the greatest predictor of satisfaction scores at follow-up, suggesting that those who were satisfied with caring at Time 1 were also more likely to be satisfied at follow-up. In addition, the number of hours worked by the carer contributed to change in follow-up satisfaction scores. Those working fewer hours were more likely to report increased satisfaction over time, suggesting a direct causal relationship between these variables. This finding lends support to studies which reported that more hours worked predicted adverse outcomes among working carers (Neal et al., 1993; Fredriksen & Scharlach, 1997). Results from the qualitative study (Chapter 6) also suggested that those women working fewer hours and in less demanding jobs, combined with lower dependency caring, were more likely to report positive outcomes. However, Martire et al. (1997) found that women who worked *more* hours were buffered from the worst effects of carer stress, although they also found that longer working hours were associated with lower positive affect, a finding which would concur with the research presented here. The screening survey (Chapter 5) had demonstrated no association between number of hours worked and unhappiness/depression, but the single-item outcome measure employed was less likely to generate sensitive and reliable findings than the full scale of carer stress used in the main survey.

Intrinsic motivations to care also contributed to change in follow-up satisfaction scores. Indeed, the intrinsic motivations measure was the only scale included in the research which showed a causal relationship with the carer outcome measures (age and hours worked were included as single-item measures). Both subscales of the MECS and the single RECS scale demonstrated good reliability and validity over time and could be used with a diverse group of carers in further studies of work and caring issues.

While there was evidence to suggest a causal relationship between intrinsic motivations and carer satisfaction, there was no evidence to suggest a causal link between other personal factors and carer outcomes. However, it is possible that two-way relationships exist between several variables included in this analysis. For example, highly-stressed carers may report poorer quality of relationship as a *consequence* of stress, rather than a cause. It appears from the results presented here that perceived relationship difficulties may arise partly as a consequence of resistance to the interdependence of both carer and elder roles, and that relationship problems are therefore linked to the motivations involved in caring. This possibility is consistent with the observation that, in this study, there were highly significant associations between quality of relationship and both extrinsic and intrinsic motivations to care. Pohl et al. (1995) demonstrated links between both mother-daughter attachment and conflict and positive beliefs about caring, although only conflict predicted negative beliefs. Recent work by McKee (2002) noted that disagreement between the carer and the elder over level of dependence was associated with a range of variables, including the care relationship, and that this disagreement predicted outcomes over time such as worsening carer stress. Another recent study from the US (Lyons et al., 2002) reported that relationship strain perceived by the carer, but not by the elder, was significantly associated with disagreement between the carer and the elder over their appraisals of caring difficulties. Using discourse analysis to look at how carers and elders talked about relationship difficulties, Forbat (2002) noted that past relationship difficulties were often used to justify problems in the current care relationship, and that the carer identity was often rejected by either the elder or the carer herself.

In the study described here, those carers receiving the least help with caring and those caring for a parent or a parent-in-law recorded higher extrinsic motivations to care. These external pressures to care directly predicted higher levels of carer stress.

The potential for a negative cycle in work and caring is apparent from the model (see outlined boxes in Figure 8.1): those receiving the least help with caring also tended to be in closer kin relationships; these factors independently related to greater external pressures to care, which, along with a poorer relationship, was directly associated with higher stress. This stress could then feed back into increased relationship difficulties and perceived external pressures to care, creating a spiralling effect of negativity.

In a similar way, intrinsic motivations to care, better quality of relationship and carer satisfaction appear to form a potentially positive cycle in work and caring (see outlined boxes in Figure 8.2). Just as higher intrinsic motivations and better quality of relationship predict carer satisfaction, higher satisfaction with caring could feed back into increased relationship quality and perceived intrinsic motivations to care. These findings are supported by the results of the qualitative study, in which motivations and relationship quality were found to interrelate with the subjective experience of caring, measured in this quantitative study by the carer stress and satisfaction scales.

Conclusions

While several researchers have demonstrated the individual importance of specific factors on different carer outcomes, this study suggests that personal variables were the most significant predictors of both positive and negative carer outcomes, taking precedence over work-related and care-related factors. Longitudinal analysis also showed that in this sample carer stress increased over time, and provided evidence for a direct causal relationship between intrinsic motivations and carer satisfaction. The findings indicate the possibility of a cycle of negativity for carers, involving perceived external pressures to care, poorer quality of relationship with the elder and carer stress, as well as a potentially positive cycle which involves intrinsic motivations to care, better quality of relationship with the elder and carer satisfaction.

Chapter 9

"A WOMAN'S WORK IS NEVER DONE": DOES CARING AT HOME AND AT WORK LEAD TO WORSE MENTAL HEALTH?

Introduction

The previous chapter revealed that level of caring involvement at work was a direct predictor of carer stress in a group of female working carers, suggesting that caring at home *and* at work may be detrimental to carers' well-being. Analyses were now undertaken to examine how caring at home and at work affects mental health, in order to gauge the impact of combining roles with similar demands.

The screening survey (Chapter 5) provided preliminary cross-sectional evidence to suggest that carers in *all* occupations were significantly more likely to report unhappiness/depression than non-carers, indicating that caring at *home* leads to poor mental health in working women. In a previous large-scale longitudinal study of stress in NHS staff undertaken between 1994 and 1998, Borrill et al. (1998) showed that those working in caring professions are at a greater risk of mental health problems than workers in similar, non-caring professions, indicating that caring at *work* also leads to worse mental health in working women. No assessment was made of home-caring status in this study. Although work-related factors may account for some of the mental health problems experienced by those in caring professions, it is hypothesised that the negative psychological spillover between work and home caring may lead to even worse mental health. However, there is also the possibility that positive spillover may occur between roles: women who care at work and at home may be able to apply some of the skills and knowledge they have learned at work to their home-caring situation, and vice-versa, thereby alleviating some of the stress experienced in both roles.

The only research known to have been undertaken in this area suggested that the "double jeopardy" of caring both at home and at work can lead to mental and physical health problems (Marshall et al., 1990). Results showed that when caring taxed personal and material resources, there was a high risk for psychological distress, poor health and reduced wellbeing. In their previous research (Barnett, Baruch & Marshall, 1987), the same authors had argued that work leads to positive mental and physical health outcomes for women due to its buffering effects, but they concluded on the basis of their findings in the 1990 study that the demands of also caring at work lead instead to a decline in health. However, their research was cross-sectional in design, and the authors acknowledge that instead of greater caring costs at work causing poorer mental and physical health, there is the possibility that women in poorer health are more easily overwhelmed by difficulties at work and in their networks (1990: 276). Only longitudinal analyses allow for the identification of any change in mental health outcomes and for the direction of effect between variables to be determined.

The study described in this chapter was designed to compare working carers in high-caring occupations with working carers in low-caring or non-caring occupations, as well as non-carers employed in the same occupations, to examine whether caring at home and at work leads to worse mental health. Carers and non-carers in all occupations would also be examined for any differences in mental health. A follow-up study after one year was also undertaken to identify any changes in mental health, and further analyses would then examine any causal relationships between variables (Chapter 10).

Research questions

- Do working carers have worse mental health than working non-carers?
- Does caring at home *and* at work lead to worse mental health?
- Does mental health in working carers change over time?

Method

Matching of carers with non-carers

A total of 275 working carers and 454 working non-carers, identified from the screening survey, were willing to respond to the Time 1 survey. Significant differences were shown between groups on age and occupation, even after the deletion of those non-carers with missing data, due to the large number of older carers among the respondents. Therefore, 174 working carers and 174 working non-carers were matched for age and occupation. The final decision was taken to match carers with non-carers on a 1:1 basis, and then to keep the data from the remaining carers that could not be matched for analyses which did not involve group comparisons (see Chapters 8 and 10), as the process of matching would help to reduce any potentially confounding effects on the results. To maximise data for within-group analyses of carers, all carers were included, including those with missing data. Because the large number of non-carers provided a larger comparison group than was really necessary, it was decided that those working non-carers with missing data of any kind should be excluded.

When matching, the carers and non-carers to be included for further analysis were randomly chosen from a box containing all potential participants (for example, the initial coding numbers of all 44-year-old nurses were put into a box and the required number were then selected at random). All the remaining non-carers were discarded, as their data was not used in later analysis.

Procedure

An information sheet and a questionnaire pack were sent out to all participants selected for inclusion. A stamped addressed envelope was included with each. All questionnaire packs were identifiable with a code number, relating to the returned screening surveys. The same procedure was implemented with all willing respondents at follow-up.

Measures

For details of measures used in the questionnaire pack and at follow-up, see Chapter 8. Additional mental health outcome measures were also included in this analysis, with carer outcomes acting as potentially predictive independent variables.

Mental health outcomes

Mental health

Section D asked all respondents about their own mental health. The GHQ-12 (Goldberg, 1992) was designed to detect non-psychotic psychiatric disorder in people in community and medical settings. It was constructed to identify "cases", but also to measure the degree of disorder. In this research, it was decided to use the GHQ scoring method, in which responses are coded 0, 0, 1 and 1, rather than the Likert scoring method, where responses score 0, 1, 2 and 3. This would give an overall measure of "caseness" in the study sample, providing a way to identify the proportion of respondents reporting significantly worse mental health than others, and could then be compared with previous research studies using the same scoring method (e.g. Borrill et al., 1998). Scores would therefore range from zero to 12. It was decided that the more conservative cut-off of 3/4, also used by Borrill et al. (1998), would be employed in the present study, as this would reduce the potential for misclassification of respondents. The GHQ-12 is a shorter version of the well-validated full version, the GHQ-60, but is equally valid and reliable. Internal consistency, as assessed by Cronbach's alpha, ranged from 0.82 to 0.90 in a series of studies (Goldberg & Williams, 1988). Split-half reliability was 0.83 and test-retest reliability was 0.73. In testing validity of the GHQ-12, sensitivity was shown to be 93.5%, and specificity in detecting cases of disorder was 78.5% (Goldberg & Williams, 1988). It has been used in many UK community and workplace studies, including the Borrill et al. (1998) study of stress among staff in NHS trusts. The term "stress" is often treated with caution because of the lack of a precise definition, with psychiatrists and clinical psychologists more likely to use terms such as "psychiatric disorder", "psychiatric morbidity" and "mental health". Occupational psychologists are more likely to use terms such as "strain", "burnout" and also "mental health" (Borrill et al., 1998). In this study, the term “mental health” will be used. The study described above found the GHQ-12 to be valid as part of a longer questionnaire in NHS settings. In the US, many carer studies have used the CES-D as a measure of depression (Radloff, 1977), although it is longer than the GHQ-12. It was also felt that the work by Borrill et al. on stress in NHS employees would be a good comparison study. The GHQ-12 was also included at Time 2.

Positive affect

The positive affect subscale of the Positive and Negative Affect Schedule (PANAS: Watson, Clark & Tellegen, 1988) was included to assess positive emotions in the Martire et al. study on work and caring (1997). It has recently been shown that positive aspects of well-being are conceptually distinct from the negative aspects of well-being (Huppert & Whittington, 2003), and by focusing only on negative health outcomes, an in-depth analysis of differences between respondents would not be possible. The complete questionnaire pack now included measures of the negative and positive aspects of caring (carer stress and carer satisfaction), the negative and positive aspects of working (work stress and work satisfaction), and also negative and positive mental health outcome measures (GHQ-12 and the PA subscale of the PANAS).

Scores are obtained on the PANAS by adding item scores (1 to 5) for the ten PA adjectives. Total PA scores therefore range from 10 to 50. Both subscales of the PANAS have demonstrated satisfactory internal consistency on large student samples (over 0.84). Test-retest reliability for the trait measures was 0.68 and 0.71 respectively, according to the authors. Validity in the independence of the two subscales was confirmed by factor analyses (Watson et al., 1988), and by correlations with other measures of distress and psychopathology, such as the Hopkins Symptom Checklist (Derogatis et al., 1974), the Beck Depression Inventory (Beck et al., 1961), and the State-Trait Anxiety Inventory (Spielberger et al., 1970). Moderate positive correlations were shown between these and the NA subscale, and small negative correlations with the PA subscale. The measure of positive affect was also included at Time 2.

Data Analysis

Chi-square tests were used to examine any differences between carer and non-carer groups in GHQ "caseness" at both Time 1 and Time 2, and between high-caring and low-caring employee groups. Chi-square tests and t-tests were also used to examine differences between groups in positive affect and all independent variables included in the analysis at both Time 1 and Time 2. A further series of chi-square tests and t-tests was undertaken to check for differences between respondents and non-respondents at follow-up in GHQ "caseness" and positive affect. McNemar tests for paired data and repeated measures analyses were also used to examine any increase in respondents changing from a GHQ non-case to a "case", increase in positive affect and decrease in self-reported health status after one year.

Due to the number of statistical tests being carried out, there was an increased risk of a Type 1 error. It was therefore considered necessary to use a more conservative significance level of 0.005. The exception was for the main study hypothesis, where the conventional significance level of 0.05 was maintained.

Missing data

If any of the scales at Time 1 or Time 2 had less than three missing responses, they were examined for their overall responses. The modal response for each scale was then inserted. If there were three or more missing responses, the data from the scale for this respondent was omitted.

Results

Time 1

Participants

Of the 174 matched carers targeted, data from 130 were used for analysis (75% response rate). A further 142 non-carers also responded (82% of the total expressing a willingness to respond). The data from these 272 participants were therefore used for analysis (total response rate of 78%).

Time 2

Participants

Overall, a total of 175 participants returned usable Time 2 surveys before the cut-off date. Of the 123 carers targeted, 106 responded (86%). Of these, 27 were no longer caring for a relative or friend, four were no longer working and five did not wish to participate further. A total of 70 remained for analysis (57%).

Of the 138 non-carers targeted, a total of 110 responded (79%). Five of these were no longer working and their data were therefore omitted from further analysis. Data from the remaining 105 matched non-carers were therefore used for analysis (76%).

Participants' Profile at Time 1 and Time 2

Table 9.1 shows comparative data of carers and non-carers at Time 1 and Time 2. The average number of hours worked by all respondents was around 30 hours per week, reflecting the large number of part-time workers in the sample, although carers worked slightly longer hours on average than non-carers at both times. Most of the respondents were married, and the majority of all respondents at both times were nurses.

Table 9.1 **Descriptive data for all respondents at Time 1 and Time 2**

Variables	**Carers Time 1 (n=130)**	**Non-carers Time 1 (n=142)**	**Carers Time 2 (n=70)**	**Non-carers Time 2 (n=105)**
Age (mean):	47.64 (s.d. 7.69)	47.08 (s.d. 8.09)	48.51 (s.d. 6.58)	48.25 (s.d. 7.55)
Marital status:				
Single	10 (7.8%)	9 (6.4%)	8 (11.4%)	8 (7.8%)
Married	112 (87.5%)	110 (78.6%)	61 (87.1%)	82 (79.6%)
Divorced/separated	4 (3.1%)	20 (14.3%)	1 (1.4%)	12 (11.7%)
Widowed	2 (1.5%)	1 (0.7%)	0 (0%)	4 (1%)
Occupation:				
Manager	9 (6.9%)	10 (7%)	5 (7%)	8 (7.6%)
Doctor	3 (2.3%)	5 (3.5%)	1 (1.4%)	3 (2.9%)
Nurse	68 (52.7%)	73 (51.4%)	41 (58.6%)	56 (53.3%)
PAM/P&T	18 (13.9%)	22 (15.5%)	10 (14.3%)	13 (12.4%)
Admin	31 (24%)	32 (22.5%)	13 (18.6%)	23 (23.8%)
Hours worked (mean):	29.85 (s.d. 9.68)	28.72 (s.d. 11.35)	31.05 (s.d. 8.66)	29.18 (s.d. 10.89)
Health status:				
Poor or fair	19 (15%)	14 (10%)	18 (26%)	13 (12.5%)
Good or excellent	108 (85%)	126 (90%)	51 (74%)	91 (87.5%)

Time 1

Comparisons of mental health outcomes for carers and non-carers in all occupations

Tests showed that carers in *all* occupations were significantly more likely to be classified as "cases" than non-carers ($\chi 2 = 4.505$; df = 1; $p<0.05$), with 33.3% (n=43) of carers suffering from mental health problems, compared with only 22% (n=31) of non-carers. No differences were demonstrated between carers and non-carers in positive affect (t = -.054; df = 231.218; t = .957).

Comparisons of mental health outcomes for nursing carers and non-carers only

When comparing mental health in different occupational groups, the small numbers in several groups meant that it was not possible to undertake any meaningful analysis. However, a comparison of carers and non-carers working in the largest occupational group, nursing, was undertaken. As this analysis was related to the main study hypothesis, a significance level of 0.05 was used. A significant difference was shown between matched carers and non-carers in “caseness”, with 34% (n=23) of matched nursing carers recording significant mental health problems, compared with only 18% (n=13) of nursing non-carers ($\chi 2 = 4.749$; df = 1; p = .029). There was no significant difference demonstrated in positive affect between nursing carers and non-carers (t = 1.037; df = 137; p = .302).

Comparisons of mental health outcomes for high-caring workers and low-caring workers

Although nursing carers were shown to record worse mental health than nursing non-carers, it was possible that many nurses were only involved in low-caring work, and that many non-nursing employees may be involved in high-caring work. As one of the main focuses of this study was to move beyond occupation level and instead to assess the impact of specific work characteristics on carer and mental health outcomes, it was decided that a more revealing analysis would be to examine the mental health impact of the actual level of carework involvement undertaken by all employees. In this way, it was hoped that a full examination of the impact of caring both at home and at work would be possible.

GHQ “caseness”: Initially, all matched carers and non-carers were categorised as high or low-caring workers. The median score on the carework scale was chosen as the cut-off point for high or low caring (at Time 1, the median score was 11: all respondents scoring below that figure were categorised as low-caring workers (carework = 1) and above that figure were high-caring workers (carework = 2).

Crosstabulations and chi-square tests were then undertaken to look at any interactions between caring at home (group), caring at work (carework) and GHQ "caseness"(case).

Table 9.2: **Interactions between caring group, level of carework involvement and GHQ "caseness" at Time 1 (n=271)**

			Carework involvement		
Group	Caseness		1	2	Total
1	0	Number Expected number % of total	47 (42.7) 36.4%	39 (43.3) 30.2%	86 (86) 66.7%
	1	Number Expected number % of total	17 (21.3) 13.2%	26 (21.7) 20.2%	43 (43) 33.3%
	Total	Number Expected number % of total	64 (64) 49.6%	65 (65) 50.4%	129 (129) 100%
2	0	Number Expected number % of total	56 (57.8) 39.4%	55 (53.2) 38.7%	111 (111) 78.2%
	1	Number Expected number % of total	18 (16.2) 12.7%	13 (14.8) 9.2%	31 (31) 21.8%
	Total	Number Expected number % of total	74 (74) 52.1%	68 (68) 47.9%	142 (142) 100%

Code:

Group 1 = carers; 2 = non-carers

Caseness 0 = GHQ non-case; 1 = GHQ "case"

Carework 1 = low caring involvement at work; 2 = high caring involvement at work.

Chi-square tests revealed that the interaction between group (carer or non-carer), level of carework involvement and GHQ "caseness" did not quite reach significance

($\chi2$=2.620; df=1; p=.076 (carers); $\chi2$=.563; df=1; p=.293 (non-carers). However, the observed non-significant trend within the data was in the expected direction. A total of 26 (20% of all carers) worked in high-caring jobs *and* recorded significant mental health problems, a higher than expected number, whereas 39 (30% of all carers) worked in high-caring jobs and did *not* record significant mental health problems, a lower than expected number. Over 50% of all carers at Time 1 worked in high-caring jobs. A total of 17 (13% of all carers) worked in low-caring jobs and recorded mental health problems, a lower than expected number, whereas 47 (36% of all carers) worked in low-caring jobs and did *not* record mental health problems, again a higher than expected number.

A total of 13 (9% of all non-carers) worked in high-caring jobs and suffered mental health problems, whereas 55 (39% of all non-carers) worked in high-caring jobs and did *not* record mental health problems. Around 48% of all non-carers at Time 1 worked in high-caring jobs. Eighteen (13% of all non-carers) worked in low-caring jobs and recorded mental health problems, whereas 56 (39% of all non-carers) worked in low-caring jobs and did *not* suffer from mental health problems.

Positive affect: In order to examine the impact of carework involvement on positive affect, the same high and low-caring categories were used in an ANOVA with two between-subjects factors. Analysis revealed that there was no significant interaction between group (carer or non-carer), carework (high or low) and positive affect (F =.583; p=.456).

Comparisons of other variables for all respondents at Time 1

Tests showed that there were no significant differences between carers and non-carers in occupation ($\chi2$ = .523; df = 4; p = .971) or age (t = .573; df = 269; p = .567), an expected result as respondents had been matched on these variables. There was also no difference in self-reported health status ($\chi2$ = 1.513; df = 1; p = .148). There was a tendency for more carers than non-carers to be married and fewer were divorced or separated, although these associations were not significant.

Table 9.3 shows that there were no significant differences shown between carers and non-carers in any of the work variables included in the analysis at Time 1.

Table 9.3 **Comparative work-related data for carers and non-carers at Time 1:**

Variable	Group	N	Mean	s.d.	t	df	Sig.
Autonomy/control	1	129	22.07	4.90			
	2	142	22.59	5.05	-.861	269	.390
Work demand	1	129	17.21	5.89			
	2	142	16.15	6.03	1.454	269	.147
Peer support	1	126	14.93	3.30			
	2	142	14.48	3.58	1.065	266	.288
Work satisfaction	1	128	21.09	3.08			
	2	142	21.34	3.31	-.646	268	.519
Work stress	1	127	9.80	5.38			
	2	141	9.35	4.48	.737	246.010	.462
Carework	1	129	11.09	8.12			
	2	142	10.20	8.52	.876	269	.382

Code: Group 1 = carers; Group 2 = non-carers

Time 2

Non-respondents

A total of five out of 28 caring Time 2 non-respondents (17.8%) were classified as GHQ "cases" at Time 1, compared with 25 out of 70 caring Time 2 respondents (35.7%). This difference was not quite statistically significant ($\chi 2 = 3.002$; df = 1; p = 0.083). Seven non-carers out of a total of 35 (20%) who did not respond to follow-up were also classified as "cases" at Time 1, compared with 24 out of 105 (23%) who did respond. Chi-square tests confirmed that this difference was also not statistically significant ($\chi 2 = .124$; df = 1; p = 0.724). When examining the positive affect data from non-respondents, the average score at Time 1 for matched carers who did not respond at Time 2 was 33.6, compared with 30.70 for matched caring respondents. This difference was not statistically significant (t = -1.703; df = 92; p = .092). For matched non-carers, non-respondents recorded an average positive affect score of 29.85 at Time 1, compared with non-carer respondents, who scored an average of

31.30 at Time 1. This difference was also not statistically significant (t = 1.259; df = 136; p = .210).

Comparisons of mental health outcomes for carers and non-carers in all occupations

At Time 2, tests revealed that carers were again significantly more likely to be classified as "cases" than non-carers ($\chi2$= 15.515; df = 1; p<0.001), with 45.7% (n=32) of carers suffering from significant mental health problems, compared with just over 18% (n=19) of non-carers. There were no differences between carers and non-carers in positive affect (t = -1.676; df = 126.030; p = .096).

Comparisons of mental health outcomes for nursing carers and non-carers only

Due to the small numbers in most occupational groups, it was not possible to make comparisons between groups other than nurses at Time 2. However, a comparison of nursing carers and non-carers at Time 2 demonstrated that carers were again significantly more likely to be GHQ "cases" than non-carers, with 48.8% of carers recording significant mental health problems, compared with 19.6% of the non-carers ($\chi2$ = 9.242; df = 1; p<0.005). There was no significant difference between nursing carers and non-carers in positive affect at Time 2 (t=-1.543; df=95; p=.126).

Comparisons of mental health outcomes for high-care workers and low-care workers at Time 2

Again, all matched carers and non-carers were categorised as high or low-caring workers. For Time 2, the median score on the carework scale was 10: all respondents with scores below that figure were then categorised as low-caring workers (carework = 1) and those with scores above that figure were high-caring workers (carework = 2).

GHQ "caseness": Crosstabulations and chi-square tests were then undertaken to look at any interactions between caring at home (group), caring at work (carework) and GHQ "caseness"(case).

***Table 9.4*: Interactions between caring group, level of carework involvement and GHQ “caseness” at Time 2 (n=105)**

			Carework		
Group	Caseness		1	2	Total
1	0	Number	15	23	38
		Expected number	(13.2)	(24.8)	(38)
		% of total	21.7%	33.3%	55.1%
	1	Number	9	22	31
		Expected number	(10.8)	(20.2)	(31)
		% of total	13%	31.9%	44.9%
	Total	Number	24	45	69
		Expected number	(24)	(45)	(69)
		% of total	34.8%	65.2%	100%
2	0	Number	47	39	86
		Expected number	(44.2)	(41.8)	(86)
		% of total	44.8%	37.1%	81.9%
	1	Number	7	12	19
		Expected number	(9.8)	(9.2)	(19)
		% of total	6.7%	11.4%	18.1%
	Total	Number	54	51	105
		Expected number	(54)	(51)	(105)
		% of total	51.4%	48.6%	100%

Code:

Group 1 = carers; 2 = non-carers

Caseness 0 = GHQ non-case; 1 = GHQ “case”

Carework 1 = low caring involvement at work; 2 = high caring involvement at work.

Chi-square tests revealed that there was no significant interaction between group (carer or non-carer), level of carework involvement and GHQ “caseness” ($\chi2=.821$; df=1; p=.258 (carers); $\chi2=1.976$; df=1; p=.125 (non-carers). A total of 22 (32% of all carers) worked in high-caring jobs and suffered from significant mental health problems, whereas 23 (33% of all carers) worked in high-caring jobs and did *not* suffer from mental health problems. Over 65% of all carers at Time 2 worked in high-caring jobs. Only 9 (13% of all carers) worked in low-caring jobs and recorded significant mental health problems, whereas 15 (22% of all carers) worked in low-caring jobs and did *not* suffer from mental health problems.

A total of 12 (11% of all non-carers) worked in high-caring jobs and suffered from mental health problems, while 39 (37% of all non-carers) worked in high-caring jobs and did *not* record mental health problems. Again, over 48% of all non-carers at Time 2 worked in high-caring jobs. Only seven (7% of all non-carers) worked in low-caring jobs and suffered from mental health problems, whereas 47 (45% of all non-carers) worked in low-caring jobs and did *not* suffer from mental health problems.

Positive affect: In order to examine the impact of carework involvement on positive affect at Time 2, high and low-caring categories were used in an ANOVA with two between-subjects factors. Analysis revealed that there was no significant interaction between group (carer or non-carer), carework (high or low) and positive affect at Time 2 (F=.558; p=.466).

Comparisons of other variables for all respondents at Time 2

There was no significant difference between respondents in marital status ($\chi2$ = 7.365; df = 3; p = .061) and age (t = .241; df = 173; p = .270). There was a tendency for carers to report lower health status than non-carers but this was not statistically significant ($\chi2$ = 5.206; df = 1; p = .023). Table 9.5 shows that carers reported significantly higher levels of carework involvement and higher levels of work demand than non-carers. There were no significant differences shown between carers and non-carers in any of the other work variables included in the analysis, including occupation (numbers in some occupational groups were too small to make meaningful comparisons) and number of hours worked. At Time 2, a total of ten carers had changed jobs in the past year (14.3%), compared with 22 non-carers (21%). This difference was not statistically significant.

***Table 9.5:* Comparative work-related data for carers and non-carers at Time 2 (n = 175)**

Variable	**Group**	**N**	**Mean**	**s.d.**	**t**	**d.f.**	**Sig.**
Autonomy/control	1	70	21.54	4.84			
	2	105	22.47	5.74	-1.109	173	.269
Work demand	1	70	18.04	6.31			
	2	105	15.15	5.67	3.158	173	.002
Peer support	1	70	15.27	3.27			
	2	104	15.05	3.67	.412	172	.681
Work satisfaction	1	70	21.17	2.85			
	2	105	22.08	3.16	-1.930	173	.055
Work stress	1	69	10.07	5.54			
	2	105	8.72	4.59	1.744	172	.083
Carework	1	69	13.07	8.62			
	2	105	9.40	7.97	2.88	172	.005

Code: Group 1 = carers; Group 2 = non-carers

Change in GHQ "caseness" over time for matched respondents: between groups and within groups

Remaining carers and non-carers were compared for any increase in GHQ "caseness" after one year. Although 14 carers (20% of all remaining carers) changed from a GHQ non-case to a "case" after one year, compared with 12 non-carers (11.4% of all remaining non-carers), tests revealed that this difference in increase was not significant ($\chi2 = 2.439$; df = 1; p = .118). A McNemar test for paired data was then used to compare GHQ "cases" at Time 1 and Time 2 within the remaining carers' group. Although 14 non-cases at Time 1 (20%) became "cases" at Time 2, and only seven "cases" at Time 1 (10%) became non-cases at Time 2, these results was not statistically significant. For non-carers, a McNemar test revealed that the difference between Time 1 and Time 2 "cases" was also not significant. Twelve non-cases at Time 1 (11.4%) became "cases" at Time 2, whereas 17 "cases" became non-cases at Time 2 (16%).

Change in positive affect over time

Carers and non-carers were also compared for changes in positive affect after one year. A repeated measures ANOVA with carer/non-carer group as a between subjects variable revealed that there were no significant differences between groups in positive affect after one year (F = 1.758; df = 1; p = .187), and also no significant differences within-subjects (F = 1.456; df = 1; p = .229).

Change in self-reported health status over time for respondents

Carers and non-carers were then examined for changes over time in health status. Although a total of 13 carers (18.6% of carers) recorded decreased health status after one year, compared with eight non-carers (7.6% of non-carers), tests showed that this difference between carers and non-carers was not statistically significant at the 0.005 level ($\chi 2 = 4.771$; df = 1; p = .029).

Discussion

The main objective of this study was to examine whether caring at home *and* at work affected mental health. Although results were not statistically significant, a greater proportion of carers also working in high-caring jobs (40%) were suffering from mental health problems at Time 1, compared with only 19% of non-carers working in high-caring jobs. Moreover, a total of 60.5% of all carer "cases" compared with 42% of all non-carer "cases" were working in high-caring jobs. On the other hand, 60% of carers in high-caring jobs did *not* record significant mental health problems and over a quarter of those carers in low-caring jobs *did* record significant problems at Time 1. At Time 2, an increased proportion of carers (49%) also working in high-caring jobs were suffering from mental health problems, compared with 24% of all non-carers working in high-caring jobs. Again, 71% of all carer "cases" compared with 63% of all non-carer "cases" were working in high-caring jobs. However, still over half of the carers also working in high-caring jobs did *not* record significant mental health problems, and an increased proportion of carers in low-caring jobs (37.5%) *did* record significant problems at Time 2. Although the findings from the baseline survey may indicate a degree of support for the study hypothesis, i.e. that caring at home and at work leads to worse mental health, the number of respondents overall was low, and the trend in the data disappeared at follow-up. The proportion of both carer "cases" *and* non-carer "cases" working in high-caring jobs increased after one year, as well as the proportion of carers working in low-caring jobs but also recording significant mental health problems, cancelling out any differences which were suggested at Time 1. Therefore, these results must be treated with caution. Although caring at work may lead to mental health problems for *all* women, it is not possible to fully ascertain from these figures whether the combination of caring at home *and* at work leads to even worse mental health in women.

Further results from the study indicated that carers in *all* occupations experienced significantly worse mental health than non-carers, supporting the results of the screening survey (Chapter 5), as well as findings from previous research (e.g. Neal et al., 1990). When examining nursing carers and non-carers only, just over a quarter of all nurses at Time 1 (combined carers and non-carers) reported poor mental health, directly comparable with the Borrill et al. study (1998) of stress in NHS staff, in which it was reported that 28% of all nurses were suffering from significant mental health problems, compared with 19% in a comparison group of other non-NHS staff from the British Household Panel Survey ($p<0.001$). However, comparisons between carer and non-carer nurses in this study showed that at both Time 1 and Time 2, less than 20% of non-carers recorded significant mental health problems (similar to the BHPS figures), whereas for carers, the figures were 34% at Time 1 and 49% at Time 2, leading to significantly worse than average mental health overall.

There was no statistically significant difference between groups in increased "caseness" after one year, and although the numbers of carers changing from a non-case to a "case" increased over the year, within-groups differences were also not significant. There was also no significant difference in positive affect between carers and non-carers at either time and no within-groups differences in increased positive affect over time. Carers at follow-up reported significantly higher levels of carework involvement in their jobs than non-carers, as well as higher levels of work demand. These findings are supported by the high-caring versus low-caring analysis, in which the proportion of carers recording high-caring involvement at work increased by 15% at Time 2. Carework involvement was shown to be a direct predictor of carer stress in Chapter 8. However, although these findings seem to suggest a possible link between increasing care demands and worsening mental health, they are difficult to interpret because of selective dropout. Although not statistically significant, a higher percentage of nursing staff responded to the follow-up survey than to the baseline survey, and among carers there was also a non-significant trend towards those with worse mental health at baseline responding at follow-up. Consequently, the increase in cases at follow-up might have been due to a self-selection process whereby those who were experiencing more difficulties were also more likely to respond.

Findings from the screening survey suggested that carers were more likely to work in lower-status occupations, such as nursing or administrative work. However, results from this part of the research demonstrated that a large number of *all* women in this sample were nurses or other care-related workers, with only a small percentage working in more senior positions. This finding broadly reflects the proportions of female employees in different occupations in a health-care sample (Borrill et al., 1998). Comparative analysis between carers and non-carers in different occupational groups was not possible in the present research due to the small numbers in most occupations other than nursing. It may be that female carers who work in jobs with no care-related tasks, as well as having greater individual control and flexibility at work to deal with care-related problems, are buffered from the worst effects of stress in the caring role (e.g. Martire et al., 1997). Although the findings reported here and in Chapter 8 suggest that those jobs involving high levels of carework involvement may be detrimental to carers' mental health, no significant differences were shown in positive affect among those working in low-caring jobs and those in high-caring jobs, suggesting that low carework involvement does not lead to positive mental health outcomes in working carers. Other work-related characteristics giving rise to positive mental health outcomes will be examined in the following chapter.

Conclusions

Working carers reported worse mental health than working non-carers in all occupations, and caring at work may lead to increased mental health problems for both carers and non-carers over time.

Chapter 10

PREDICTING POSITIVE AND NEGATIVE MENTAL HEALTH OUTCOMES FOR WORKING CARERS, USING LONGITUDINAL DATA

Introduction

In order to examine the combination of factors giving rise to both better and worse mental health in working carers in all occupations, measures of work-related, care-related and personal factors were now included in the analysis. Results from the previous chapters suggested that caring involvement at home *and* at work may be associated with increased carer stress and worse mental health. It was also suggested in Chapter 9 that certain work-related factors such as individual control and flexibility to deal with care-related matters may buffer the effects of stress in the caring role. The findings reported in Chapter 8 indicated that the motivations involved in elder care and quality of relationship with the elder were the most important predictors of carer stress and satisfaction. Carer stress and satisfaction were now included as independent variables in order to examine the potential influence on mental health of the subjective experience of caring, identified as the key concept in the qualitative study.

Previous research has rarely included comprehensive measures of work-related, care-related and personal factors when examining the predictors of mental health outcomes, focusing instead on the importance of one or two factors (see Chapter 8 introduction). Working status and caring status have often been included as dichotomous variables, and important variations in the working and caring situations of respondents are inevitably lost (Tennstedt & Gonyea, 1994). Some researchers have identified certain positive outcomes associated with combining work and caring roles (e.g. Martire et al., 1997), but it is only by identifying the work-related, care-related and personal factors which combine cumulatively to explain mental health effects that efforts can be targeted toward the women most in need of help.

Although there have been repeated calls for more longitudinal studies on the effects of combined work and caring roles (e.g. Tennstedt & Gonyea, 1994), research has been extremely limited. Lechner and Gupta (1996) conducted a four-year follow-up study with working carers but attrition was so high that data analysis was limited to examining associations between variables. However, results at follow-up showed that overall job satisfaction for carers declined significantly, even though no significant changes were reported in work performance. Carers recorded significantly higher stress scores at follow-up, although no significant declines were shown in physical wellbeing. Carers also reported that they had less confidence in themselves, less ability to control important events, more nervousness, less ability to cope, more feelings of being overwhelmed by difficulties, less free time, a weaker financial base and lower optimism about the future. However, respondents also reported feeling better about themselves as a result of caring. The elders showed significantly reduced functioning, were receiving more formal help after four years, and almost half of the carers had been thinking about admitting the elder to a home. In another longitudinal study, McKinlay et al. (1995) also reported that institutionalisation was twice as likely at follow-up for those cared for by someone with negative personal impact, regardless of the disability of the elder, even though the majority of elders continued to receive help from the same carer. The authors concluded that caring exerts the greatest toll on the carer's personal life, and that caring impacts persist over time.

The current study implemented a follow-up survey in order to examine changes over time in mental health outcomes. Data analysis would examine individual changes in mental health and positive affect over time for *all* carers, matched and unmatched, and aim to identify those factors which predict any change. This analysis will provide evidence for any causal relationships between variables.

Research questions

- Which combination of work-related, care-related and personal factors is associated with positive and negative mental health in working carers?
- Does mental health change over time for all working carers and if so, which factors predict that change?

Method

Procedure

An information sheet and a questionnaire pack were sent out to all participants selected for inclusion (see Chapter 8). The same procedure was implemented with all willing respondents at follow-up.

Measures

For details of measures used in the questionnaire pack and at follow-up, see Chapter 8, p 119. Additional mental health outcome measures were also included in this analysis (see Chapter 9), with carer outcomes acting as potentially predictive independent variables.

Data Analysis

Bivariate Pearson's product-moment correlations (for continuous variables) and ANOVAs and t-tests (for categorical variables) were used to examine the relationships between each predictor variable and the outcome measure, positive affect. Those predictors showing significant associations with positive affect were then entered into a stepwise multiple regression analysis to explore their relative and combined predictive value at Time 1. Logistic regression analysis was used to examine the predictive value of all variables significantly related to GHQ "caseness" at Time 1.

Within-subjects comparisons of Time 1 and Time 2 data were also tested using matched samples t-tests (positive affect) and McNemar tests for paired data (GHQ "caseness"). In order to test for any predictors of change over time in the main outcome measures, a series of correlations between all Time 1 predictor variables and Time 2 mental health outcomes was first performed. To examine Time 1 predictors of Time 2 positive affect and GHQ, after controlling for Time 1 mental health outcome scores, partial correlations were then undertaken. Those Time 1 variables showing predictive value at this stage were then entered into two separate forward stepwise regression analyses with the Time 2 mental health outcomes as the dependent variables and the corresponding main outcome measures at Time 1 entered at the first step. This procedure allowed for an examination of any causal relationships between Time 1 predictors and change in mental health status over time.

Due to the number of statistical tests being carried out, there was an increased risk of a Type 1 error. It was therefore considered necessary to use a more conservative significance level of 0.005 as the criterion for a truly significant association. The significance level of 0.05 was retained for the partial correlation analysis, as it was important to identify those factors accounting for even small amounts of variance in the main outcome measures.

Missing data

If any of the scales at Time 1 or Time 2 had less than three missing responses, they were examined for their overall responses. The modal response for each scale was then inserted. If there were three or more missing responses, the data from the scale for this respondent was omitted.

Results

Time 1

Response rate and participants' profile

Data from 203 carers were used for analysis (for full details of response rates at Time 1, see Chapter 8, p. 126). For sociodemographic details of respondents at Time 1 and Time 2, see Chapter 8, p 127.

Associations between positive affect and all independent variables

Work-related variables: Pearson's product moment correlations were performed to look at any associations between work-related variables and positive affect for all carers. Table 10.1 shows that positive affect was significantly positively related to work satisfaction and negatively related to work stress and work demand.

Table 10.1: **Correlations between work-related variables and positive affect for all carers at Time 1 (n=203)**

	Autonomy	Demand	Peer support	Work satisfaction	Work stress	Carework
Positive affect	.143*	**-.212****	.149*	**.235*****	**-.235*****	-.006

* significant at the 0.05 level ** significant at the 0.005 level *** significant at the 0.001 level

Personal variables: Pearson's product moment correlations were then carried out for all personal variables and positive affect. Table 10.2 shows that higher positive affect scores were significantly associated with lower extrinsic motivations to care and better quality of relationship with the elder.

Table 10.2: **Correlations between personal variables and positive affect for all carers at Time 1 (n=203):**

	Relationship quality	Extrinsic motivations	Intrinsic motivations
Positive affect	**-.206****	**-.263*****	.003

** significant at the 0.005 level; *** significant at the 0.001 level

Care-related variables: Pearson's product-moment correlations for continuous variables and ANOVAs for categorical variables were conducted to examine associations between positive affect and care-related variables. There were no significant relationships between positive affect and relationship to the elder, length of time since caring began and help with caring. There was a trend in the data to suggest that those women with an elder who lived in his/her own home reported higher positive affect than those with an elder living in a nursing home, but this was not significant at the 0.005 level. Positive affect was also significantly negatively associated with carer stress ($r = -.261$; $p<0.001$). There was a trend to suggest that those with higher carer satisfaction also reported higher positive affect, but again, this was not significant at the 0.005 level.

Other variables: Other variables were then tested for their association with positive affect, using Pearson's product-moment correlations, t-tests and ANOVAs. There were no significant associations between positive affect and age, hours worked, occupation or marital status. However, there was a significant association between positive affect scores and self-reported health status: those carers recording good or excellent health also recorded higher positive affect scores ($t = 3.893$; $p<0.001$).

Predictors of positive affect

All variables showing a significant association with positive affect were then entered into a forward stepwise regression analysis to look at their predictive value. Variables entered into the regression were: carer's health status, extrinsic motivations to care, carer stress, work stress, work satisfaction, relationship quality and work demand.

Table 10.3: **Stepwise regression model of positive affect for working carers at Time 1 (n=203)**

Steps	**Predictor variables**	**Beta**	**R2**	**Change in R2**	**F change**	**Sig. of F change**
1	Extrinsic motivations	**-.266*****	.075	.075	15.084	<.001
2	Carer's health status	**.252*****	.152	.077	16.699	<.001
3	Work satisfaction	.192*	.188	.036	8.190	<.005

* $p<0.05$ *** $p<0.001$

Table 10.3 shows that extrinsic motivations to care was one of the most significant predictors of positive affect scores, with those reporting lower extrinsic motivations to care also recording significantly higher positive affect scores. Self-reported health status was also a significant predictor of positive affect, with those reporting better health also recording higher positive affect scores. Work satisfaction was also shown to contribute significantly to the final model. Other variables included in the initial regression model were not predictive of positive affect. Overall, these three predictor variables explained around 18% of the variance in positive affect for this group of female working carers.

Associations between GHQ "caseness" and all independent variables

Work-related variables: As the GHQ was a dichotomous dependent variable ("case" versus non-case), t- tests were undertaken to look at mean differences between work variable scores and GHQ "caseness". Table 10.4 shows that GHQ "cases" recorded significantly higher work demand scores and work stress scores, and significantly lower work satisfaction scores. There were no significant differences between other work–related variable scores and GHQ "caseness".

***Table 10.4*: Associations between work-related variables and GHQ "caseness" for all carers at Time 1 (n=203):**

Variable	**GHQ "caseness"**	**Mean**	**t**	**d.f.**	**Sig.**
Autonomy/control	0	22.21			
	1	21.87	.454	200	.650
Work demand	0	15.63			
	1	20.01	-5.283	200	.000
Peer support	0	15.18			
	1	14.14	1.958	109.811	.053
Work satisfaction	0	21.93			
	1	20.09	3.938	198	.000
Work stress	0	8.12			
	1	12.27	-5.616	198	.000
Carework	0	10.63			
	1	12.54	-1.577	200	.116

Code: 0=GHQ non-case; 1=GHQ "case".

Personal variables: A series of t- tests was then undertaken to look at mean differences between personal variable scores and GHQ "caseness". Table 10.5 shows that GHQ "cases" were significantly more likely to record lower quality of relationship scores. There were no significant differences between other personal variable scores and GHQ "caseness".

***Table 10.5*: Associations between GHQ "caseness" and personal variables for all carers at Time 1 (n=203)**

Variable	GHQ "caseness"	Mean	t	d.f.	Sig.
RECS	0	27.90			
	1	31.74	-3.515	198	.001
EXMECS	0	23.99			
	1	25.19	-1.60	199	.111
INMECS	0	22.41			
	1	22.74	-.755	199	.451

Code:
RECS = quality of relationship with elder
EXMECS = extrinsic motivations to care
INMECS = intrinsic motivations to care

Care-related variables: T-tests and chi-square tests revealed that there were no significant differences in mean GHQ scores and relationship to elder ($\chi2 = 1.183$; df=4; p=.881), resident status of the elder ($\chi2 = .781$; df=3; p=.854), length of time caring (t = .284; df=184; p=.777), or help with caring ($\chi2 = 3.914$; df=3; p=.271). Table 10.6 shows that there was, however, a significant positive association between GHQ "caseness" and carer stress, although no association was shown with carer satisfaction.

***Table 10.6*: Associations between GHQ "caseness" and care-related variables for all carers at Time 1 (n=203)**

Variable	GHQ "caseness"	Mean	t	d.f.	Sig.
Carer stress	0	3.67			
	1	4.50	-3.336	199	.001
Carer satisfaction	0	16.85			
	1	16.10	1.315	200	.190

Other variables: Other variables were also examined for any associations with the main outcome measure, GHQ "caseness". There were no significant associations between GHQ "caseness" and age (t=1.144; df=199; p=.254), marital status, occupation or hours worked. There was a trend for GHQ "cases" also to report poorer health, but this association was not significant at the 0.005 level.

***Table 10.7*: Associations between GHQ "caseness" and other variables for all carers at Time 1 (n=203)**

Variable	Chi-square	d.f.	Sig.
Marital status	2.621	3	.454
Occupation	1.207	4	.877
Health status	4.531	1	.033

Predictors of GHQ "caseness"

Logistic regression analysis was then used to identify those variables making a significant contribution to the prediction of GHQ "caseness" at Time 1. Variables entered into the forward stepwise model were work stress, work demand, work satisfaction, quality of relationship and carer stress. Table 10.8 represents the three stepwise models after non-predictive variables were excluded.

***Table 10.8*: Odds ratios of variables predicting GHQ "caseness" in all carers at Time 1 (n=196; 7 cases missing)**

Step	Sig.	Independent variables	Exp (B)	95% confidence interval	-2LL (Nagelkerke R^2)
1a	<.001	Work stress	1.184	1.105-1.268	221.820 (.188)
2b	<.001	Work stress	1.173	1.093-1.258	216.181 (.222)
	.020	Carer stress	1.266	1.038-1.544	
3c	.013	Work stress	1.112	1.022-1.209	211.358 (.251)
	.030	Work demand	1.082	1.088-1.161	
	.029	Carer stress	1.251	1.023-1.530	

a Variable(s) entered on step 1: Work stress.
b Variable(s) entered on step 2: Carer stress.
c Variable(s) entered on step 3: Work demand.

Table 10.8 shows that high work stress, work demand and carer stress were the most significant predictors of GHQ "caseness" among this group of female working carers at Time 1. Work satisfaction and quality of relationship were excluded from the final model, as they did not contribute further to the prediction of GHQ "caseness". In order to assess the goodness of fit of the final model, a comparison was made between observed and predicted group membership (group = GHQ "case" 1 or non-case 0), where those with a predicted probability of 0.5 or greater are classified as GHQ "cases" (Norusis, 1999). In this case, 73% of carers were correctly predicted as cases (n=29) or non-cases (n=114). A total of 53 carers were misclassified: 16 GHQ "cases" and 37 non-cases. The Nagelkerke R^2 score for the final model was .251, indicating that about 25% of the variation in GHQ "caseness" for this group of female working carers was explained by a combination of high work stress, work demand and carer stress.

Time 2

Non-respondents

To begin with, analyses were undertaken to examine any differences in mental health outcomes at Time 1 between respondents and non-respondents to the follow-up survey. A total of nine out of 43 Time 2 non-respondents (21%) were classified as GHQ "cases" at Time 1, compared with 41 out of 110 Time 2 respondents (37%). This difference did not quite reach statistical significance, even though there was a distinct trend in the data to suggest that caring "cases" were more likely to respond to follow-up than caring non-cases ($\chi2 = 3.753$; df = 1; $p = 0.053$). This also supports the findings from Chapter 8, which showed that for all carers, there was a statistically significant difference between respondents and non-respondents in carer stress, with respondents reporting higher stress at Time 1 than non-respondents. When examining the positive affect data from non-respondents, the average score at Time 1 for carers who did not respond at Time 2 was 32.60, compared with 30.26 for caring respondents. This difference was again not statistically significant ($t = -1.856$; df = 147; $p = .065$), although a trend in the data was apparent. Those with higher positive affect at Time 1 appeared to be less likely to respond to follow-up.

Within-subjects comparisons for GHQ "caseness" in all carers

At Time 2, a total of 46 carers remained non-cases, and 27 remained "cases".

However, a further 14 carers changed from a "case" to a non-case and 23 carers changed from a non-case to a "case". There was now a total of 50 carers (45.5%) out of a total of 110 who showed significant mental health problems, compared with 60 carers (54.5%) who were non-cases. At Time 1, 41 (37.2%) of these remaining carers had been classified as "cases" and 69 as non-cases (62.7%). However, a McNemar test for paired data revealed that this increase in "caseness" among carers over time was not significant.

Within-subjects comparisons for positive affect

Within-subjects comparisons were then undertaken to examine change in positive affect over time for individual carers. Matched groups t-tests indicated no significant differences in positive affect scores within subjects over time (t = .231; df = 108; p = .818).

Partial correlations between mental health outcomes at Time 2 and all independent variables at Time 1

In order to determine the causal relationships between predictor variables and mental health outcomes over time, a series of correlations was first undertaken to examine associations between Time 1 independent variables and Time 2 mental health outcomes (see Table 10.9). As in Chapter 8, categorical variables were re-coded into two-category variables at this stage so that they could also be included in the correlational analysis (marital status = married/not married; relationship to elder = daughter or daughter-in-law/other carer; resident status = co-resident with carer/not co-resident; help with caring = little or no help/some or a lot of help). These new categories retained the most important distinctions between groupings, as determined by the results of the Time 1 survey, allowing for further analysis of differences. Positive affect and GHQ "caseness" at Time 1 were then controlled for, and a series of partial correlations were undertaken, so that the relative and combined predictive value of each variable could be fully assessed (positive affect). For GHQ "caseness", a series of separate logistic regression analyses were performed, entering GHQ scores at Time 1 on the first step, followed by each separate predictor variable.

Table 10.9: **Correlations, partial correlations and tests of association between Time 1 predictor variables and Time 2 mental health outcomes (n=110)**

Variables		Time 2 outcomes: Correlations and associations		Time 2 outcomes, after controlling for Time 1 outcomes	
		Positive affect correlations	GHQ "caseness" associations	Positive affect partial correlations	GHQ logistic regression scores (odds ratio)
Work	Autonomy/control	.026	t = -1.939	-.060	3.355
	Work demand	-.207*	**t = -3.264*****	-.069	5.166*
	Peer support	.170	t = .825	.087	.160
	Work satisfaction	.159	t = 2.511*	.046	3.714
	Work stress	**-.302****	**t = -3.855*****	-.224*	4.724*
	Carework	.052	t = -2.071*	.043	3.101
Personal and carer outcomes	Relationship quality	-.143	t = -1.336	-.064	.418
	Extr. motivations	-.084	t = -1.408	-.031	2.061
	Intr. motivations	-.020	t = -1.981*	.008	4.444*
	Carer stress	-.150	t = -2.340*	-.041	2.881
	Carer satisfaction	.168	t = 1.365	.113	.969
Care	Kin relationship	.024	$\chi 2 = .006$	.053	.028
	Resident status	.031	$\chi 2 = .113$	-.026	.607
	Length of time caring	.028	t = -.702	.050	1.375
	Help with caring	.126	$\chi 2 = .128$	.121	.047
Other	Age of carer	-.193*	t = -.609	-.245*	1.062
	Health status	**.274****	$\chi 2 = .884$	.101	.201
	Marital status	.044	$\chi 2 = .035$	-.116	.688
	Hours worked	-.037	t = -1.153	-.119	2.124

* significant at the 0.05 level ** significant at the 0.005 level *** significant at the 0.001 level

Time 1 predictors of mental health outcomes at Time 2, after controlling for Time 1 outcomes

Positive affect: Forward stepwise regression analysis was then performed to look at Time 1 predictors of positive affect at Time 2, after controlling for Time 1 positive affect. All those Time 1 variables showing significant associations at the 0.05 level with positive affect at Time 2 were entered into the model. Time 2 positive affect was entered as the dependent variable; Time 1 positive affect was then entered on the first step, followed by age and work stress. Table 10.10 shows that the main predictor of positive affect at Time 2 was Time 1 positive affect scores, explaining over 37% of the variance in Time 2 scores, and indicating a high degree of stable individual differences over time. However, work stress and age also contributed to the model, explaining an additional seven and a half per cent of the variance, after controlling for Time 1 scores. Therefore, lower work stress and lower age accounted for some change in positive affect over time, suggesting a possible causal relationship between these variables.

***Table 10.10*: Regression to show predictors of change over time in positive affect (n=110)**

Step	Predictor variables	Beta	R2	R2 change	F change	Sig. of F change
1	Positive affect (Time 1)	**.555*** **	.375	.375	62.871	<0.001
2	Work stress	-.219*	.406	.032	5.560	<0.05
3	Age	-.211*	.449	.043	8.046	<0.05

*significant at the 0.05 level *** significant at the 0.001 level

GHQ "caseness": Those variables showing a significance value of <0.05 (work demand, work stress and intrinsic motivations to care) were entered into a logistic regression analysis, using forward selection, with Time 1 "caseness" entered on the first step. Table 10.11 shows that in the final model, GHQ "caseness" at Time 1 was the main predictor of Time 2 "caseness": those carers reporting significant levels of stress at Time 1 were more than two and a half times more likely than other working carers to report significant levels of stress at Time 2. However, work stress also contributed to the final model, and the two variables together were responsible for correctly classifying over 70% of "cases". Intrinsic motivations to care and work demand did not contribute to the final model and were therefore removed. Overall, therefore, higher work stress accounted for some of the change in GHQ "caseness" over time, suggesting a possible causal relationship between these variables.

Table 10.11: **Odds ratios of variables predicting GHQ "caseness" in working carers over time (n=110): final model**

Dependent variable	**Independent variables**	**Exp (B): odds ratio**	**95% confidence interval**
GHQ "caseness" Time 2	GHQ "caseness" Time 1	2.730	1.134 – 6.572
	Work stress Time 1	1.142	1.039 – 1.255

Discussion

One of the most important objectives of this survey study was to identify which combination of work-related, care-related and personal factors led to worse mental health and which combination led to better mental health for working carers. Figure 10.1 shows that those carers with high work demand, work stress and/or carer stress were likely to record worse mental health at baseline. Analyses suggested that high work stress led to worse mental health after one year.

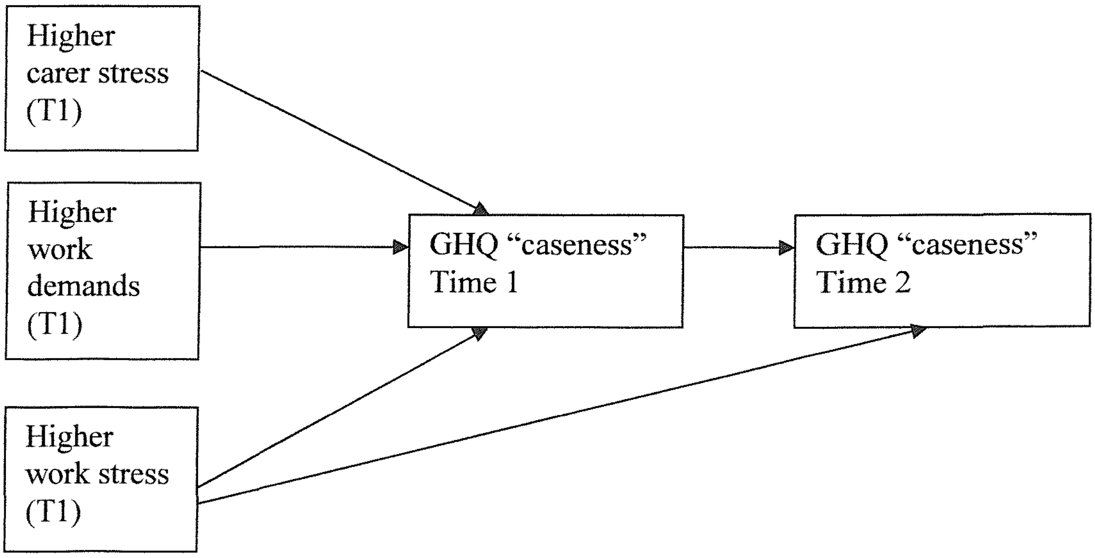

Figure 10.1**: Predictors of GHQ "caseness" at Time 1 and Time 2**

Figure 10.2 shows that those carers who reported fewer external pressures to care for an older person, and who reported better carer health and/or higher work satisfaction, were more likely to experience positive outcomes in their attempts to combine work and caring roles.

***Figure 10.2*: Predictors of positive affect at Time 1 and Time 2**

Lower work stress and lower age of the carer led to higher positive affect over time. Older age was previously shown to be directly linked with carer stress over time (Chapter 8), and taken together, these results suggest that older women find the combination of work and caring roles increasingly stressful, possibly due to increased health problems of their own, whereas younger carers appear more able to combine roles successfully. Higher work stress was also shown to be a direct predictor of worse mental health over time for all carers, irrespective of age, indicating the importance of this factor in both positive and negative mental health outcomes. Work stress had previously been shown to be an important predictor of unhappiness/depression for all respondents in the screening survey. Although it was not possible to demonstrate potentially causal links between other variables and positive affect, this may be as a result of instantaneous relationships, rather than associations over time. Many of the variables appear to have bi-directional associations, a point raised in Chapter 8: as an example, positive affect could be a cause, rather than a consequence of better health status of the carer.

The findings reported here are consistent with the preliminary model exploring the relationship between work and caring factors which was generated from the qualitative data (Chapter 6, p. 101). Those women interviewed in the qualitative study who had been employed in more demanding, professional, full-time jobs, combined with higher-dependency caring, had generally given up work to care. The quantitative data described here also suggest that higher work demand and higher work stress predict worse mental health for those carers still in work. Although the follow-up data did not show a significant number of women leaving work to care after one year, it may be that over a longer period of time, those women with more stressful and demanding jobs, combined with higher-intensity caring at home, leave work as a consequence of the combined stress in both work and caring roles.

Although the focus of this study was to examine the negative and positive aspects involved in combining work and caring roles, a comparison group of non-working carers would have provided some information on how caring *without* a work role affects mental health. Caring may be so distressing that it is detrimental to mental health, with or without a combined work role. For those women not in work, care-related factors may be more predictive of worse mental health. As an example, previous research has shown that those women who gave up work to care were more likely to suffer higher resentment and strain than other carers (Murphy et al., 1997; Barnes et al., 1995). These women were also shown to be caring for those with the greatest levels of impairment. Although it was impossible in the current research to target a sample of non-working carers due to the heavy restrictions involved in accessing carers' details, future research should ideally ensure that a comparison group of non-working carers is included.

Although the results reported here gave important information on positive and negative outcomes in combining work and caring roles, the sample was restricted to those women willing to answer three surveys. Those with more pressing time commitments may have been precluded from responding, although Martire et al.

(1997) suggested that these women may be more likely to respond due to their interest in the research. Comparisons between respondents and non-respondents demonstrated a non-significant trend in the data which suggested that those with worse mental health at Time 1 were more likely to respond to follow-up than those with better mental health, whereas those with higher positive affect were less likely to respond than those with lower positive affect. Comparisons between respondents and non-respondents (Chapter 8) had previously suggested that those who experienced greater carer stress were also more likely to answer the follow-up survey, which supports Martire's view. Chapter 9 also demonstrated a non-significant trend in the data which suggested that those responding to follow-up were more likely to be suffering from worse mental health than non-respondents. The non-significant increase in mental health problems could therefore be due to selective drop-out of those with better mental health, rather than worsening mental health over time. Longitudinal relationships could also be affected by selective drop-out at follow-up.

Although the sample of female carers in the study comprised women from very different occupational backgrounds, including managerial and administrative workers, a large number were nurses, many of whom worked part-time. Although non-NHS employees were interviewed in the qualitative study, these women also tended to be in part-time jobs. In the same way that care-related factors may be more important predictors of mental health outcomes for non-working carers, work-related factors may be more important predictors for those women working longer hours and in non-care-related occupations. There is also the possibility of different cultural factors involved in combining work and caring roles. No assessment was made in the current study of cultural background. Further research should therefore investigate health and carer outcomes in women from different work and cultural backgrounds to determine any differences.

Conclusions

Both higher-intensity caring and more demanding work roles appear to be detrimental to carers' health. Chapter 8 described the potential for negative and positive cycles of work and caring factors. Similarly, worse mental health may feed back into greater negative perceptions of work demand, work stress and carer stress, which may in turn feed back into negative perceptions of relationship quality and motivations to care, creating a negative cycle of work, caring and personal factors.

Better health status of the carer was the main predictor of positive affect in the main survey, but lower work stress and lower age contributed to positive affect over time. A combination of lower-intensity work and caring roles appears to be beneficial to carers' mental health. Higher positive affect may feed back into greater positive perceptions of the motivations to care, carers' health status and satisfaction with work, creating a positive cycle of work, caring and personal factors.

Chapter 11

DISCUSSION

Introduction

There has been a steady growth in the number of research studies carried out into the effects of women's caring roles in recent years, due to the increasing number of older, frail people requiring care. A corresponding decrease in the number of "mid-life" women with no other responsibility than to care for older parents and other relatives has meant that many more women are expected to juggle multiple roles simultaneously. The research outlined in this thesis developed from early hypotheses and objectives, addressing inconsistencies and gaps in previous research, and progressed into a comprehensive assessment of work and caring roles in women. During the course of the research, various new and sometimes unexpected findings came to light which had not been adequately explored before. The most important of these findings will be described in the following sections. The various theories of multiple roles, originally described in Chapter 2, will then be discussed and evaluated in the light of the research findings. Policy implications will also be described, as well as the main limitations of the study.

Main research findings

Identification of the factors of most importance to female working carers

While reading through the extensive literature covering work and caring roles in women (Chapter 3), it was apparent that a comprehensive examination of those factors which cumulatively affect carer and mental health outcomes had rarely been attempted, with most researchers focusing on particular aspects of one or both roles. Furthermore, those researchers who *had* attempted to identify multiple predictors of negative and positive mental health outcomes had generally undertaken quantitative analyses of the influence on various mental health outcome measures of previously identified factors. While there is no doubt that previously identified factors are important, it was felt that other influential factors may have been overlooked. A series of interviews with working-age carers was therefore undertaken to identify via qualitative means the factors of most importance to female carers in their attempts to balance work and caring roles, thereby ensuring their inclusion as measures in later quantitative analyses. The data from these interviews proved vital to the research, as two important factors, seldom included in previous quantitative assessments of those factors predicting mental health, were identified for inclusion as measures in the quantitative stages of the research: i.e. the quality of the relationship with the older person and the extrinsic and intrinsic motivations involved in elder caring. Neither of these factors had been adequately measured in diverse caring contexts in earlier research. The subjective experience of caring, relating to the various stresses and satisfactions involved in the caring role, was identified as the key concept from the qualitative data and was examined quantitatively using previously validated and reliable measures. Other key factors identified from the qualitative study were also included as measures in the survey study, thereby providing both qualitative and quantitative evidence to answer the research questions.

Relative influence of personal factors on carer outcomes and mental health

In order to measure the relative influence on carer outcomes of the quality of relationship with the elder (an inter-personal factor) and motivations involved in elder caring (an intra-personal factor), two new scales were developed for the study and demonstrated good reliability and validity after data analysis from the questionnaire surveys. In quantitative analyses, these personal factors were found to be the most important predictors of carer outcomes for female carers working in NHS occupations. Poorer relationship quality and higher extrinsic motivations to care significantly contributed to higher carer stress, which was later identified as a direct predictor of worse mental health. Better relationship quality, higher intrinsic motivations and lower extrinsic motivations to care significantly contributed to higher satisfaction with caring. Other specific work characteristics and caring characteristics were also measured for their relative influence on the carer outcome measures. The intrinsic motivations measure was identified as the only scale included in the analysis which demonstrated a causal relationship with carer outcomes over time. In the analysis of mental health outcomes, lower extrinsic motivations to care were shown to predict higher positive affect, as well as carer satisfaction, even though these two outcome measures were not directly linked. This series of analyses indicates the importance of personal factors, relative to work-related, care-related and other factors, on carer and mental health outcomes. Without their identification during the qualitative study, these factors would have been overlooked in the subsequent quantitative analyses.

Effects of combining caring at home and at work

One of the main research questions of the study was to ascertain whether caring at home *and* at work led to worse mental health. Although a trend was identified in the data, there was no statistically significant association demonstrated between carework involvement and mental health outcomes. However, a significant association was found between high caring involvement at work and carer stress at baseline (see Figure 11.1), which was itself a direct predictor of poor mental health (GHQ 'caseness'). Nursing carers also recorded significantly worse mental health than nursing non-carers, growing increasingly worse over time. Although occupational category provides little information on level of carework involvement, with some nurses involved in fewer care-related activities than other nurses, and other employees possibly undertaking as many high-caring tasks as some nurses, these combined findings lend some support to the initial hypothesis. Overall, it appears that highly demanding and stressful jobs, as well as care-related activities at work, may lead to worse mental health for working carers.

On the other hand, those carers working in non-caring or low-caring and less demanding occupations may be more capable of "switching off" from their caring responsibilities whilst at work, a finding which would concur with the data from those still working in the qualitative study, who found work an important source of both financial and social support. Although previous researchers have shown that work can be beneficial to women (e.g. Barnett, Baruch & Marshall, 1987), these findings demonstrate how important it is to examine the particular configuration of work and caring roles undertaken which result in either positive or negative mental health.

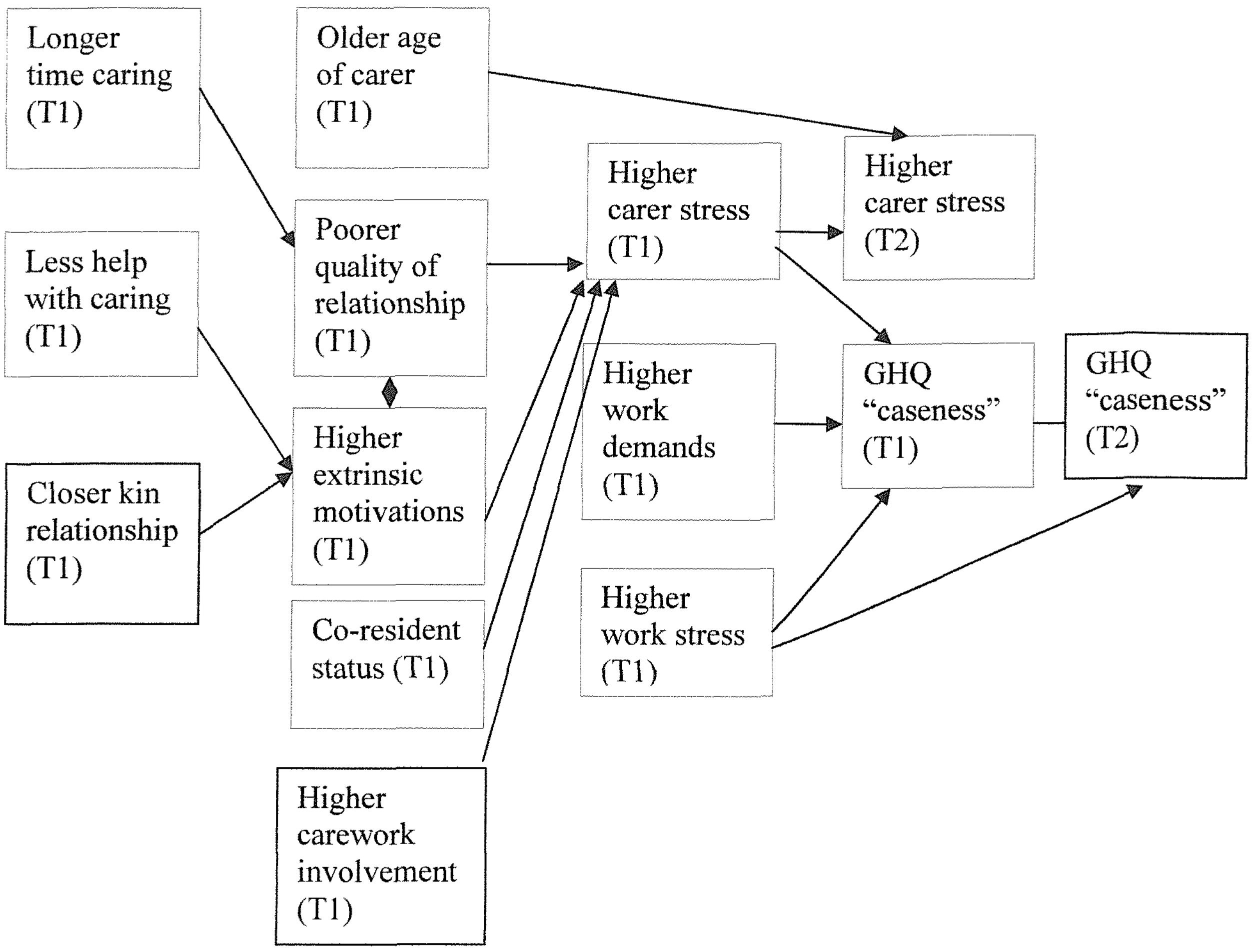

Figure 11.1: **Negative effects of work and caring: relationships between predictor variables and GHQ "caseness" at Time 1 and Time 2**

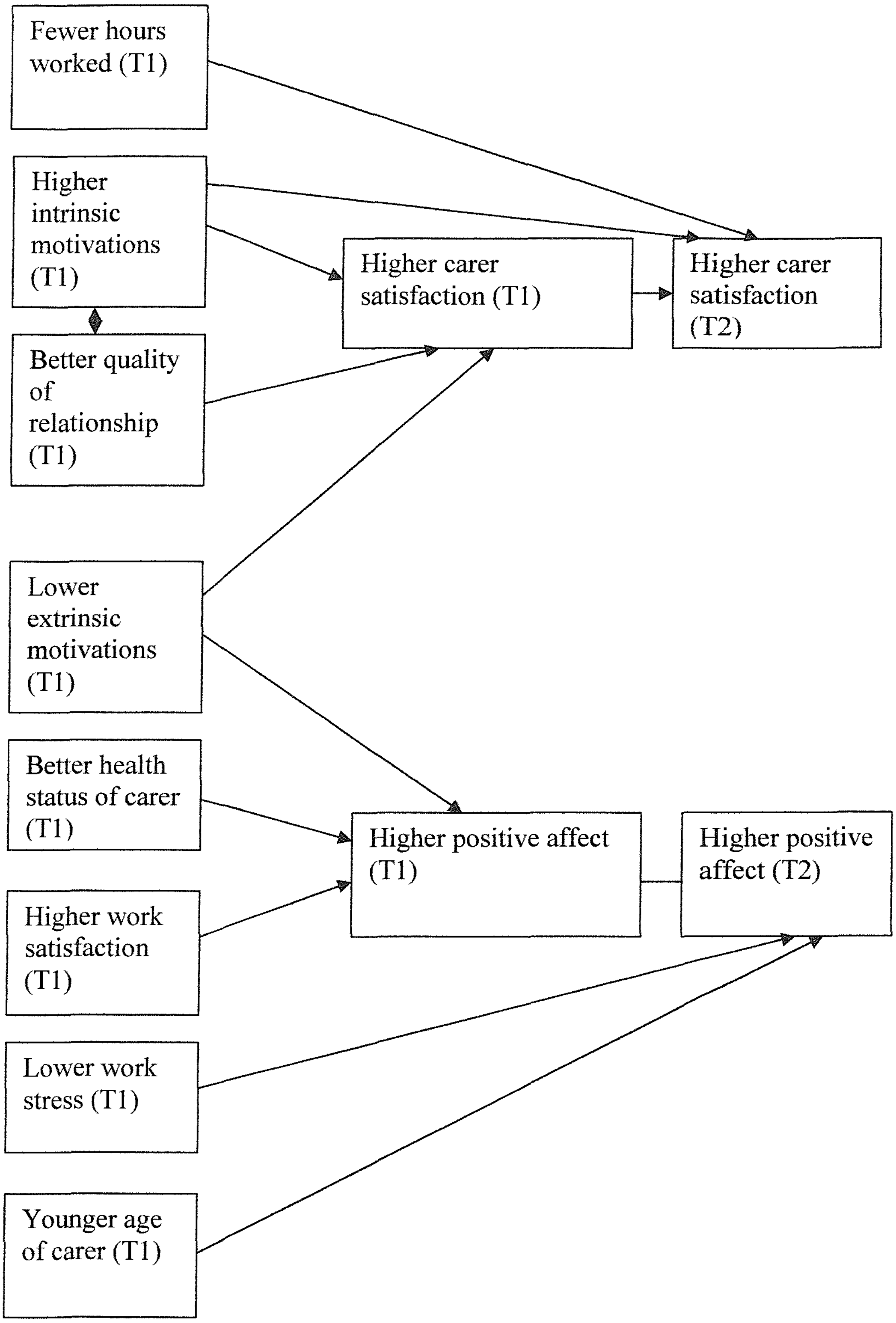

***Figure 11.2*: Positive effects of work and caring: relationships between predictor variables and positive affect at Time 1 and Time 2**

Predictors of better and worse mental health in working female carers over time

Very limited longitudinal research has previously been undertaken to identify those factors predicting mental health outcomes over time, with cross-sectional data only providing evidence of associations between variables at any one time. It was therefore considered vital to identify the causal relationships between variables by undertaking a follow-up survey after one year. Figures 11.1 and 11.2 illustrate the revised models demonstrating the relationships between all predictor variables and the main carer and mental health outcomes over time.

Figure 11.1 shows those factors predicting carer stress, which was then identified as a direct predictor of worse mental health for this sample of working carers. Older carers of a co-resident elder, those reporting a poor relationship with the elder and/or higher perceived external pressures to care, and those working in a care-related occupation, were the most likely to report high carer stress. In turn, those with higher carer stress, and/or with high levels of stress and demands at work, were likely to report worse mental health. These results indicate that women with highly stressful caring situations are less able to detach themselves from the caring role whilst at work if the work role is also stressful and demanding, possibly combined with care-related activities. The inclusion of a diverse range of variables in an examination of the predictors of mental health allows for the identification of the independent, and hence potentially additive, effects of specific work-related, care-related, personal and other factors. Since each identified factor was an *independent* predictor of carer stress or worse mental health, the *cumulative* effects of those factors generates a profile of those women most at risk.

Carers who had a better relationship with the elder, those with lower perceived external pressures to care and/or higher intrinsic motivations, and those working fewer hours, were more likely to experience satisfaction in the caring role. Younger carers with lower stress and higher satisfaction in the work role, and/or lower external pressures to care, were more likely to report higher positive affect. Again, the inclusion of a diverse range of variables allowed for the identification of those independently predictive factors which, when added together, were most likely to generate positive outcomes. Lower extrinsic motivations to care was shown to be an important factor in both carer satisfaction and positive affect, indicating that those with lower perceived pressures to care were more likely to experience positive outcomes. Several of the women in the qualitative study described the lack of choice involved in caring for their older relative, leading to perceived pressures to care: this element of choice may be a crucial factor in the subjective experience of caring. Those carers feeling pressurised to care for an elder may experience more resentment, which could in turn affect the carer's perceptions of other factors involved, such as quality of the relationship and quality of the work role.

The absence of a direct relationship between carer outcomes and positive affect, however, suggests that overall satisfaction with caring does not necessarily contribute to better mental health, whereas stress in caring predicts worse mental health. Women may still be at risk of worse mental health if their work role is stressful and demanding, in spite of a positive experience of caring, whereas those women with lower stress and higher satisfaction in the work role may experience better mental health, irrespective of a negative experience of caring. Again, this provides evidence for the "buffering" effects of work, in which carers can detach themselves from a stressful carer role if the work role itself is not stressful and demanding.

This longitudinal analysis provides evidence for the effects of factors leading to both negative and positive carer and mental health outcomes over time. Most previous research has presented cross-sectional findings which, although important, are unable to identify causal relationships between variables.

Theoretical implications

Chapter 2 outlined the various theoretical approaches to multiple roles which will now be evaluated in light of the main research findings. The scarcity theory proposes that there is a limited source of energy within the individual, leading to inevitable difficulties in undertaking multiple roles. Although there is certainly evidence that some working carers experienced worse mental health than working non-carers, a large number of working carers still managed to retain good mental health whilst undertaking multiple roles. If energy was indeed a limited resource which was consumed equally in any role, all carers with multiple roles of any kind would be expected to experience the same negative outcomes, which is not supported in this research.

The theory of ego depletion (Baumeister et al., 1998) similarly proposes that an individual's strength or energy is a limited resource. However, this theory goes further by claiming that the self's acts of volition draw on this limited resource, so that one act of volition has a detrimental impact on subsequent acts of volition. In the present research, those women with higher intrinsic motivations said they found it "natural" and automatic" to care. This may mean that for these women, caring required less of an act of volition, as it takes more effort to do something unnatural and disliked. However, carers with more intense caring situations, perhaps demanding a higher degree of energy output due to greater self-control or self-regulation, were more likely to report carer stress. At the same time, those with higher stress and demands at work, which could also involve a higher level of energy output due to greater volition, were more likely to report worse mental health. A higher-intensity work role could therefore lead to depleted energy for the caring role, and vice-versa. Although Baumeister et al. (1998) argue that tasks may be unrelated for this energy depletion to take place, the combined energy output of those in both high-stress caring *and* work roles could explain the negative impact of efforts to continue with both roles, as well as increased mental health problems over time. Unlike the scarcity theory which states that *any* combination of roles is detrimental to health, the ego depletion theory focuses on the specific types of roles involved, and how exertion in one role can adversely affect any others.

The enhancement or expansion theories of multiple roles argue that the benefits of accumulating roles outweigh stress, leading to positive outcomes. Unlike the previous theories, these claim that energy is abundant and able to expand, and that human activity produces, as well as consumes, energy. None of the research presented here has given any indication that this is the case. Those with less intensive work and caring roles were most likely to report positive outcomes, suggesting that energy is indeed a limited resource, and that only by reducing energy output in one or both roles is it possible to experience positive outcomes. However, it was noted that carers in more flexible and autonomous jobs with low-caring or non-caring occupational duties were under-represented in the research. Women in such jobs may provide support for an expansion approach by demonstrating a greater ability to juggle a higher-intensity work role with a higher-intensity caring role.

Similarly, the identity accumulation hypothesis claims that the more identities (roles) a person possesses, the less psychological distress she will exhibit (Thoits, 1983), which was again not supported by the present research findings. However, Thoits also suggests that those with more roles are also more likely to suffer at the loss of any one role. This may indeed be true for those who have left work to care, especially as previous research and the qualitative study demonstrated that these women appear to be involved in the highest-intensity caring roles. Losing the support of peers at work and the buffering effects of a work role may contribute to worse mental health (e.g. Murphy et al. 1997). However, no assessment was made in the present study of the number of other roles undertaken simultaneously by the carer, and it is therefore impossible to claim support for this theory.

Thoits also argues that social positions are culturally ranked and differentially valued, and that commitment to a particular role may therefore depend upon its positive valuation within a culture. The current research demonstrates support for the importance of commitment to roles. However, the commitment to caring and work roles appeared to be influenced not by sociocultural value, but by personal factors involved in elder caring. Higher intrinsic *and* extrinsic motivations to care appeared to contribute to the decision to leave work, although there was little evidence from the qualitative study to suggest that those with a better quality of relationship gave up work to care for the elderly person. Several women in the qualitative study gave up work to care, in spite of their involvement in more senior, professional occupations which they valued highly. In fact, it was principally these professional women who had given up work, which directly contradicts the theory of commitment proposed by Thoits. However, it must be noted that those professional women who gave up work may have been more able to do so because they were more financially secure. Those women who were divorced or single were more likely to maintain a working role, partly due to financial considerations, rather than a lack of commitment to the caring role.

The role quality perspective argues that it is the quality, not the quantity of roles, which determines health outcomes. It certainly appears from the results of the present study that it would be simplistic to support either a role expansion or a role scarcity approach. Only by examining the specific configuration of roles was it possible to identify the factors leading to both better and worse mental health. Quality of relationship with the elder was identified as a direct predictor of carer stress, a factor which was then shown to be independently predictive of worse mental health. This highlights the importance of quality within roles, rather than the number of roles performed simultaneously. It was impossible from the present study to identify which working roles may be more beneficial to women while also involved in a caring role, as the majority of respondents were employed in nursing or care-related work, which typically is poorly paid and provides little autonomy and flexibility (Marshall et al., 1990). However, the role quality perspective provides some insight into the findings related to those women caring at home *and* at work: women who perceive both their work and caring roles to be of poorer quality may be more likely to suffer worse mental health.

The findings from women caring in both roles also provided a degree of support for negative spillover theory, in which the negative aspects of caring at home spill over into the work role, and vice-versa. The carer may be unable to break away from the caring role whilst at work, with the work role generating similar demands and challenges as the home-caring role. Moreover, after a tiring day of caring at work, the carer is then expected to continue with similar tasks whilst at home, providing little or no respite from care-related stressors. There was little evidence from the present study to suggest any positive spillover between work and caring roles, however.

In summary, therefore, it is suggested that the perceived quality of roles is a better predictor of mental health than the number of roles performed, and that negative spillover can occur from one role to another with similar demands. Any acts of self-control in one role, as proposed by Baumeister et al. (1998), may also reduce the energy available for other roles, possibly leading to worse mental health.

Policy implications

Implications for working carers

Model 11.1 clearly demonstrates specific risk factors for worse mental health in working carers. If further research with different samples of working carers confirms the results found in the present study, policy makers should address the cumulative influence on carer stress and worse mental health of these various work-related, care-related and personal factors. Whereas it is not possible for policy makers to implement change with respect to some of the care-related factors involved in higher carer stress, such as the carer's kin relationship to the elder, directing help specifically to those women reporting relationship difficulties and perceived external pressures to care may ameliorate these negative aspects of the caring experience, and thereby break the cycle of resentment in the carer role, relationship difficulties and carer stress. Affordable respite care should be made more accessible; this was mentioned by several of the women with higher-intensity caring roles in the qualitative study, who were also the women receiving little or no help with caring at home. More innovative approaches may also be implemented: those women who do not want to provide care and, as a consequence, may suffer greater resentment and stress, should be given the opportunity to choose free formal care for the older person instead of providing care themselves. Those who do choose to provide care but eventually have to give up work to do so should be given the opportunity to take a period of paid leave, with their jobs being guaranteed for a certain period of time, similar to maternity benefits.

If nothing is done to alleviate the stress involved in caring at home, carer stress and worse mental health are set to increase. Those carers in occupations with little flexibility and autonomy may find the demands of caring at home ever more difficult to cope with, possibly leading to the decision to give up work. Leaving work to care for an elderly relative inevitably reduces future financial security, with carers often not returning to work after long periods of caring.

Implications for the care recipients

The difficulties surrounding women's attempts to combine caring with work affect not only the carers themselves, but also the care recipients. Inflexible and highly-demanding working conditions may preclude carers from receiving emergency calls at work or leaving work early to deal with care-related crises at home. Worry over such occurrences could increase levels of stress for both carers and their older relatives. Increased flexible practices at work, such as flexi-time and working from home where possible, must be considered if carers are to continue caring and working. Efforts should also be made to provide certain health services for older people outside of regular working hours, as carers often find it difficult to accompany the older person to doctors' appointments, etc., without taking time off work. Without such policy changes, the shrinking number of women available to care for older people is likely to decline even more, as women who try to work and care are less able to cope. This could lead to increased pressure on home-care services, nursing and residential homes, with inevitable financial and other implications for both the carer and the care recipient, as well as society.

Implications for employers

Without changes being implemented, the implications for employers are also clear: work disruptions and increased absenteeism are likely, as carers take time off unofficially to deal with care-related crises. Employers could also find it increasingly difficult to retain experienced staff, as carers may eventually decide to give up work in order to care for a dependent, older relative. Efforts within the workplace should be targeted towards female carers working in high-caring occupations, as well as those reporting high stress and high work demands, all potential risk factors for worse mental health.

Taken together, these potential implications for carers, care recipients and employers provide a bleak picture of what is likely to happen without policy changes: policy makers need to address *all* risk factors simultaneously and encourage change on both work and caring fronts.

Limitations of the study

Although the research presented here has extended the research into women's work and caring roles by providing a comprehensive assessment of the factors predicting better and worse mental health over time, certain study limitations preclude definitive conclusions from being drawn. The screening survey, which provided the study samples for the later surveys, generated a very poor response rate overall. It was therefore impossible to draw firm conclusions from the results of the preliminary study. Although a large sample of working carers and non-carers responded to the Time 1 and Time 2 surveys, respondents were self-selected and therefore were not representative of the population of working carers as a whole. Those responding to the surveys may have been more highly stressed and therefore more willing to take part, as mentioned in Chapter 10. A truly representative sample may have yielded more women who were combining work and caring roles without experiencing high levels of stress. Any increase in carer stress and worse mental health suggested by the data may also have been as the result of selective drop-out of respondents with less stressful work and caring situations (Chapters 8, 9 and 10 identified trends in the data which suggested that those who did not respond to follow-up had better mental health at baseline).

It should also be noted that the majority of respondents were caring for parents or parents-in-law, even though no restrictions had been placed on the carer's relationship to the older person. It may be that data from women who are caring for a spouse, for example, would generate different results, with higher intrinsic motivations for caring and better quality of relationship perhaps contributing to more positive outcomes. However, spousal carers tend to be older and therefore not of working age: indeed, very few of this sample of working carers were caring for a spouse. The results generated here, therefore, may be only largely applicable to parent carers, as the nature of the kin relationship between carer and care recipient may influence the other factors included in the quantitative analysis. However, in spite of the high proportion of working women caring for a parent found in this sample, around 20% of the sample were caring for someone other than a parent. While many previous research studies have concentrated solely on parent carers, the findings from this research provide some insight into those factors which contribute to mental health outcomes in all female working carers.

Another major limitation of the study was the lack of a control group of carers without a work role. As discussed previously, caring may be so stressful that it leads to worse mental health in all carers, with or without a working role. Only by making comparisons between carers with *and* without working roles would it be possible to identify whether an additional work role leads to worse or better mental health overall. The lack of occupational variety among the respondents also made it largely impossible to identify those jobs which may be beneficial to carers' mental health, indicating a possible bias towards those at risk of more negative outcomes.

Although it was not possible to include all potentially important variables in the analysis without making the surveys too long and therefore possibly further reducing the response rate, it must be noted that there may have been several other variables contributing to better and worse mental health in this sample of working female carers.

Further research

Any future research which aims to examine mental health in working carers should attempt to include a comparison group of non-working carers. This group would provide comparative evidence to show whether or not working is beneficial to carers overall. Without such a group, there is evidence to illustrate the negative and positive aspects of combining work and caring roles only, even though *not* combining roles may be even more detrimental to mental health.

The qualitative study provided some important research questions for future research. Although there was only a very small group of women interviewed, the different experiences of those who continued working, those who had left work to care and those who had never worked generated preliminary models of the relationships between work and caring roles. As those women who have left work to care have been identified in previous research as those with more stressful caring situations than those who continue working (e.g. Murphy et al., 1997), further research should examine how relinquishing an important role such as work affects mental health over time. A comparison group of carers in equally stressful caring situations who have never worked may help to determine any differences in the specific predictors of positive and negative mental health outcomes. This research would be able to test the identity accumulation hypothesis, part of which claims that those with multiple roles were more likely to suffer at the loss of any one role than those without other roles, as relationships and support networks built up during work may be lost.

The data from the study suggested a link between caring at home and at work and worse mental health. However, this finding should be tested further with representative groups of women in more diverse care-related occupations. It may be that only women who work with older people are at risk of worse mental health, rather than those in other care-related jobs. For example, women who work in childcare occupations may experience greater satisfaction with the work-caring role, despite similarities with home-caring. Also, the measure of caring involvement at work related specifically to patient care tasks, whereas working with older people in better health may lead to different outcomes.

Further research should also aim to identify those occupations which lead to positive outcomes for working carers. Focusing on hospital employees allowed us to examine the impact of caring both at home and at work, but the limited numbers of women in other non-caring occupations meant that it was not possible to make comparative analyses across occupations. Future research with a large sample of non-care-related employees working in more diverse occupations may provide important information on the specific work characteristics which enable carers to juggle work and caring roles successfully. The present study concludes that care-related occupations, with higher work stress and higher work demands, appear to be detrimental to carers' mental health. This does not imply, however, that only non-care-related occupations with low stress and low demands are beneficial. Employees in more senior occupations with greater flexibility and autonomy, as well as higher salaries, may offset carer stress by being more able to deal with care-related crises whilst at work, as well as paying for more formal help and respite care for the older person (Fredriksen & Scharlach, 1997). As mentioned earlier, the perceived quality of a role may be a better indicator of mental health than the number of roles occupied.

Conclusions

The research described here has contributed to the literature on combined work and caring roles in women in four main ways:

- By identifying the factors of most importance to working carers via qualitative means: the quality of relationship in elder caring, the motivations involved in elder caring and the subjective experience of caring.
- By identifying the relative influence of personal factors on carer and mental health outcomes: poorer relationship quality and higher external pressures to care led to higher carer stress, which then predicted worse mental health. Better relationship quality and higher intrinsic motivations to care led to higher carer satisfaction. Lower external pressures to care also contributed to higher positive affect.
- By demonstrating the impact of caring both at home *and* at work: those women caring in both roles appeared to be at risk of worse mental health than those caring at home but not at work, or those caring at work but not at home.
- By identifying those factors which contribute to better and worse mental health in working female carers over time: higher stress and demands at work and higher carer stress led to worse mental health. Work stress also contributed to worse mental health over time. Lower extrinsic motivations to care, higher work satisfaction and better health status of the carer led to higher positive affect. Younger age and lower work stress also contributed to higher positive affect over time.

APPENDICES

Appendix 1:

INFORMATION SHEET INCLUDED WITH THE SCREENING SURVEY

Work and Caring Study

Information sheet
I am Clare Lyonette, a research student at Southampton University. You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and if you wish, discuss it with friends and relatives. Let us know if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

There are a lot of women in the UK currently working while also caring for an elderly friend or relative outside of work. This study aims to examine the effects of trying to combine work with caring for an elderly person. However, we would like to hear from you even if you are not currently caring for an elderly person outside of work. Your answers are important to us. A short questionnaire will be distributed to the entire female workforce of two NHS Trust hospitals, including this one. The hospital has been supportive in allowing us to contact you, but no personal details will be passed on to your employer. The questionnaire must be completed out of working hours, and sent back in the envelope provided. If you are willing to participate further, another questionnaire will be sent to you in the next few months. Even if you would rather not participate in a second questionnaire, we would be very grateful if you would fill in this questionnaire, and then send it back. We hope that the research will benefit women who are caring as well as going out to work.

If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This will not affect your work in any way.

All information which is collected in this questionnaire will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it. Any publications or reports written about the results of the study will not contain names of participants.

If you have any questions, please contact me, Clare Lyonette, at c.lyonette@talk21.com.

I thank you for taking part in the study.

Date:

Appendix 2:

CONSENT FORM INCLUDED WITH THE SCREENING SURVEY

Consent Form for Research Participants

(PLEASE FILL IN BOTH COPIES OF THIS FORM AND RETURN ONE IN THE ENVELOPE WITH THE QUESTIONNAIRE)

Statement of Consent

I have read and understood the above informed consent form. I understand that I may withdraw my consent and discontinue participation at any time without penalty or loss of benefit to myself. I understand that the data collected as part of this research project will be treated confidentially, and that published results of this research will maintain my confidentiality. In signing this consent letter, I am not waiving my legal claims, rights or remedies. A copy of this consent letter will be offered to me.

I give consent to participate in the above study.
Yes / No

I understand that the questionnaires will be destroyed after analysis.
Yes / No

Participant's Name: Date
Address:

Tel. No:
Signature:

Researcher's Name: Date
Signature:

I understand that if I have questions about my rights as a participant in this research, or if I feel that I have been placed at risk, I can contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (01703) 592612.

Appendix 3:

THE SCREENING SURVEY AND CODING PROCEDURE FOR QUESTIONNAIRE RESPONSES

Instructions: Thank you for participating in this research. Please answer all questions. All answers are confidential and will not be seen by any persons other than the researchers. We appreciate your honest answers.

Section A:

1. **YOUR DATE OF BIRTH:** ....

2. **YOUR OCCUPATION** (eg. porter, manager, nurse, etc.):
1=Managers; 2=Doctors; 3=Nurses; 4=Professions Allied to Medicine;
5=Professional and technical staff; 6=Administrative staff; 7=Ancillary staff

3. **THE NUMBER OF HOURS PER WEEK YOU USUALLY WORK:**
....

4. **IN THE PAST 4 WEEKS:**

How many days have you missed work?
0=None; 1=1-3; 2=4 or more

How many times have you been late to work?
0=None; 1=1-3; 2=4 or more

How many times have you left work early or left during the day?
0=None; 1=1-3; 2=4 or more

While at work, how many times have you been interrupted (including telephone calls) to deal with family-related matters?
0=None; 1=1-3; 2=4 or more

How much flexibility do you have in your work schedule to handle family responsibilities (please circle)?

1=A lot of flexibility; 2=Some flexibility; 3=Hardly any flexibility; 4=No flexibility at all

5. **IN THE PAST 4 WEEKS, TO WHAT EXTENT HAS YOUR JOB BEEN A SOURCE OF STRESS TO YOU** (please circle)?

0=No stress at all; 1=Hardly any stress; 2=Some stress; 3=A lot of stress

Section B:

6. **DO YOU HAVE RESPONSIBILITIES FOR HELPING OUT RELATIVES OR FRIENDS (AGED 65 OR OVER) WHO ARE FRAIL OR DISABLED? THIS INCLUDES PERSONS WHO LIVE WITH YOU OR WHO LIVE SOMEWHERE ELSE. By helping out, we mean help with shopping, home maintenance, personal care, transportation, checking on them by phone, making arrangements for care, etc.** (please circle):

1=Yes; 2=No

7. **ON AVERAGE, IN THE PAST YEAR, HOW MANY <u>HOURS PER WEEK</u> HAVE YOU HELPED THIS PERSON** (please circle)?

1=1-5; 2=6-12; 3=13-20; 4=21-30; 5=31-40; 6=41 hours or more

8. **HAVE YOU REDUCED THE NUMBER OF HOURS YOU WORK PER WEEK AT YOUR JOB IN ORDER TO CARE FOR THIS PERSON?**

1=Yes (If yes: 2=1-5 hours; 3=6-12 hours; 4=13 hours or more).
0=No

9. **CIRCUMSTANCES DIFFER, AND SOME PEOPLE FIND IT EASIER THAN OTHERS TO COMBINE WORK WITH CARING RESPONSIBILITIES. IN GENERAL, HOW EASY OR DIFFICULT IS IT FOR YOU** (please circle)?

1=Very easy; 2=Easy; 3=Somewhat easy; 4=Somewhat difficult; 5=Difficult; 6=Very difficult

10. **HAVE YOU RECENTLY BEEN FEELING UNHAPPY AND DEPRESSED** (please circle)?

0=Not at all; 1=No more than usual; 2=Rather more than usual; 3=Much more than usual

Please now send this back in the envelope provided. Thank you for your support.

Would you be prepared to fill in another questionnaire at a later date (please circle)?
Yes / No

Reference number:

Appendix 4:

RECODING OF VARIABLES IN THE SCREENING SURVEY

Occupation: OCC recoded into OCC2: 1=managers, PAMs/P&Ts, administrative staff; 2=doctors and nurses.

Days missed from work: DMW recoded into DMW2: 0=no days missed from work in the past four weeks; 1=some days missed from work in the past four weeks (includes 1-3 times, and 4+times).

Number of times late to work: TLW recoded into TLW2: 0=never late to work in the past four weeks; 1=sometimes late to work in the past four weeks (includes 1-3 times, and 4+times).

Number of times left work early: LWE recoded into LWE2: 0=never left work early in the past four weeks; 1=sometimes left work early in the past four weeks (includes 1-3 times, and 4+times).

Interruptions at work: IAW recoded into IAW2: 0=never interrupted at work in the past four weeks to deal with family matters; 1=sometimes interrupted at work in the past four weeks (includes 1-3 times, and 4+times).

Flexibility: FLEX recoded into FLEX2: 1=a lot of flexibility or some flexibility at work to deal with family matters; 2= hardly any or no flexibility at work.

Work stress: WS recoded into WS2: 1=none or hardly any stress at work; 2-some stress; 3=a lot of stress.

Hours per week of caring: HPW recoded into HPW2: 1=1-12 hours of caring per week; 2=13-40 hours per week; 3=40+hours of caring per week.

Reduced hours of work to care: RHW recoded into RHW2: 0=no reduced hours of work to care; 1=some reduced hours of work to care.

Difficulty combining work and caring: DIFF recoded into DIFF2: 1=very easy, easy or somewhat easy; 2=somewhat difficult, difficult, or very difficult.

Unhappiness/depression: DEPR recoded into DEPR2: 0=not at all, no more unhappiness/depression than usual in the past four weeks; 1=rather more or much more unhappiness/depression than usual in the past four weeks.

Appendix 5:

INFORMATION SHEET INCLUDED WITH THE TIME 1 SURVEY

Work and Caring Study

Some time ago, you responded to a questionnaire about work and caring, and indicated that you would be willing to answer another questionnaire. I would like to thank you very much for your participation in this research so far, and now invite you to answer the following questionnaire which asks for more detail about your own circumstances.

The information we receive will not be seen by anyone other than the researchers involved in this project, and no names will appear in any publication which may result from the research.

I hope that you will respond to this questionnaire, as all your answers are very important to us, *whether or not you are caring for an elderly person.* Please answer all questions, and then send back the questionnaire in the envelope provided.

Thank you for your continued help and support.

Clare Lyonette

Appendix 6:

THE TIME 1 QUESTIONNAIRE SURVEY AND CODING PROCEDURE FOR QUESTIONNAIRE RESPONSES

(Words in italics did not appear in the questionnaire)

Instructions: Thank you for participating in this second part of the research. Please answer all questions. All answers are confidential and will not be seen by any persons other than the researchers. We appreciate your honest answers.

Section A: About Yourself

1. ARE YOU (please circle): *(Marital status: Neal et al., 1993)*

1=Single; 2=Married or living with a partner; 3=Divorced or separated; 4=Widowed

2. HOW WOULD YOU DESCRIBE YOUR OWN HEALTH AT THE MOMENT (please circle): *(Carer's health status: Maddox & Douglass, 1973)*

0=Poor or fair; 1=Good or excellent

Section B: About Your Job

THE FOLLOWING QUESTIONS ASK YOU TO DESCRIBE YOUR JOB. PLEASE ANSWER ALL THE QUESTIONS, TICKING THE ANSWER WHICH BEST DESCRIBES THE JOB YOU DO MOST OF THE TIME.

3. (*Autonomy and control: Haynes et al., 1999*):

To what extent do you:

a. Determine the methods and procedures you use in your work?

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

b. Choose what work you will carry out?

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

c. Decide when to take a break?

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

d. Vary how you do your work?

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

e. Plan your own work?

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

f. Carry out your work in the way you think best?

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

4. (*Work demands: Haynes et al., 1999*):

How often do you find yourself meeting the following problems in carrying out your job?

a. I do not have enough time to carry out my work.

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

b. I cannot meet all the conflicting demands made on my time.

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

c. I never finish work feeling I have completed everything I should.

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

d. I am asked to do work without adequate resources to complete it.

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

e. I cannot follow best practice in the time available.

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

f. I am required to do basic tasks which prevent me completing more important ones.

1=Not at all; 2=Just a little; 3=Moderate amount; 4=Quite a lot; 5=A great deal.

5. (*Peer support: Haynes et al., 1999*):

The following questions ask about the extent to which other people provide you with help or support.

To what extent can you:

a. Count on your colleagues to listen to you when you need to talk about problems at work?

1=Not at all; 2=To a small extent; 3=Neither great nor small extent; 4=To a great extent; 5=Completely.

b. Count on your colleagues to back you up at work?

1=Not at all; 2=To a small extent; 3=Neither great nor small extent; 4=To a great extent; 5=Completely.

c. Count on your colleagues to help you with a difficult task at work?

1=Not at all; 2=To a small extent; 3=Neither great nor small extent; 4=To a great extent; 5=Completely.

d. Really count on your colleagues to help you in a crisis situation at work, even though they would have to go out of their way to do so?

1=Not at all; 2=To a small extent; 3=Neither great nor small extent; 4=To a great extent; 5=Completely.

6. (*Job satisfaction: Stephens et al., 1997*):

PLEASE INDICATE HOW STRONGLY YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENTS CONCERNING YOUR JOB.

a. You are being paid a reasonable amount for the work you do.

1=Strongly disagree; 2=Disagree; 3=Agree; 4=Strongly agree

b. Many of the rules and procedures at work make it difficult to do a good job.

4=Strongly disagree; 3=Disagree; 2=Agree; 1=Strongly agree

c. There are benefits not offered at work which should be offered

4=Strongly disagree; 3=Disagree; 2=Agree; 1=Strongly agree

d. You are satisfied with your chances for promotion.

1=Strongly disagree; 2=Disagree; 3=Agree; 4=Strongly agree

e. You are satisfied with the amount of support you receive from your supervisor.

1=Strongly disagree; 2=Disagree; 3=Agree; 4=Strongly agree

f. Work assignments often are not fully explained.

4=Strongly disagree; 3=Disagree; 2=Agree; 1=Strongly agree

g. Your job is enjoyable.

1=Strongly disagree; 2=Disagree; 3=Agree; 4=Strongly agree

h. You are satisfied with the amount of support you receive from the co-worker with whom you work most closely.

1=Strongly disagree; 2=Disagree; 3=Agree; 4=Strongly agree

7. (*Work stress: Stephens et al., 1997):*

PLEASE INDICATE BELOW HOW STRESSFUL EACH OF THE FOLLOWING HAS BEEN FOR YOU IN THE PAST MONTH. FOR EACH THAT DOES NOT APPLY, PLEASE CIRCLE 0 (DOES NOT APPLY) AND MOVE ON TO THE NEXT ITEM.

a) Having more work than you can handle.

0=Does not apply; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful; 4=Very stressful.

b) Working in an unpleasant or unsafe environment.

0=Does not apply; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful; 4=Very stressful.

c) Your job not matching your interest or skills.

0=Does not apply; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful; 4=Very stressful.

d) Job lacking security or stability.

0=Does not apply; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful; 4=Very stressful.

e) Having too much to do at work.

0=Does not apply; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful; 4=Very stressful.

f) Job lacking variety or seeming monotonous.

0=Does not apply; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful; 4=Very stressful.

g) Being unable to have control over the things you do at work.

0=Does not apply; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful; 4=Very stressful.

8. (*Carework involvement: Patient Care Tasks subscale of Work Stressors Inventory: Schaefer & Moos, 1993*):

THESE QUESTIONS ARE ABOUT EVENTS THAT MAY ARISE IN CARING FOR PATIENTS AND THEIR FAMILIES. MARK YOUR ANSWER BY PUTTING AN "X" IN THE APPROPRIATE BOX. PLEASE MARK "NEVER" IF THE TASKS DO NOT APPLY TO YOUR OWN WORK.

In the last month, how often have you:

a) Taken care of patients who do not appreciate the things you do for them?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

b) Been unable to do anything to help a patient improve?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

c) Cared for a patient who wants to die?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

d) Cared for a dying patient?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

e) Cared for a patient who was uncooperative, angry or complaining?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

f) Worked with a patient who did not get better?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

g) Had a patient relapse whom you knew well?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

h) Talked to angry or complaining family members?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

i) Had to give emotional support to family members?

0=Never; 1=Seldom; 2=Sometimes; 3=Fairly often; 4=Often

Section C: About Your Caring Responsibilities in your Home Life

9. *(Kin relationship: Neal et al., 1993)*

WHAT IS YOUR RELATIONSHIP TO THE ELDERLY PERSON? (Please enter the **number** of your answer to the right of each question in the box provided). If you are caring for more than one person, please refer to the person you help the most.

Are **you** the person's :

1=Daughter; 2=Daughter-in-law; 3=Wife; 4=Sister or sister-in-law; 5=Friend or neighbour; 6=Other

10. (*Relationships in elder care: Lyonette & Yardley, 2003*):

THE FOLLOWING STATEMENTS DESCRIBE SOME OF THE ISSUES WHICH ARISE IN A CARING RELATIONSHIP. PLEASE ANSWER EACH QUESTIION, TICKING THE BOX WHICH BEST DESCRIBES YOUR OWN FEELINGS ABOUT YOUR RELATIONSHIP WITH THE ELDERLY PERSON.

a. I have always got on well with the elderly person:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

b. I find the elderly person frustrating:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

c. I find the elderly person's behaviour embarrassing:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

d. The elderly person seems to have changed from the person he/she was:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

e. The elderly person can be very stubborn:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

f. I feel that our relationship is a struggle for power:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

g. The relationship with the elderly person has improved since I began caring for him/her:
1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

h. I feel protective towards the elderly person:
1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

i. I had a good relationship with the elderly person in the past:
1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

j. The elderly person can be very negative:
5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

k. The elderly person doesn't like to be told what to do:
5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

l. I feel sympathy for the elderly person:
1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

m. The elderly person understands that I have a life of my own:
1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

n. The elderly person expects me to pay for things that he/she should pay for:
5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

o. I respect the elderly person:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

p. I admire the elderly person:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

q. The elderly person understands that things have changed since his/her generation:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

11. *(Resident status of elder: Neal et al., 1993)*

WHERE DOES THE ELDERLY PERSON LIVE? (Please enter the number in the box)

1=In his or her own home; 2=In your home; 3=With a relative; 4=With a friend; 5=In a nursing home, care facility, etc.;

12. *(Length of time caring: Neal et al., 1993)*

HOW LONG HAVE YOU BEEN HELPING THIS ELDERLY PERSON:

(Please state in years in months, eg. 2 years and 8 months).

13. *(Level of help provided with caring: Neal et al., 1993)*

IN THE PAST YEAR, WHEN THIS PERSON HAS NEEDED HELP, WHO HAS USUALLY BEEN THE ONE WHO HAS GIVEN IT OR HAS ARRANGED FOR IT TO BE GIVEN? (Please enter the **number** of your answer in the box)

1=I have been the only one; 2=I have been the main one, with some help from others; 3=I have shared equally with one or more others; 4=Others, with my help

14. (*Motivations in elder caring: Lyonette & Yardley, 2003*):

THE FOLLOWING STATEMENTS DESCRIBE SOME OF THE REASONS WHY PEOPLE BEGIN CARING FOR A RELATIVE OR FRIEND. PLEASE ANSWER EACH QUESTION BY TICKING THE BOX WHICH BEST DESCRIBES YOUR OWN SITUATION.

a) I felt that I had no choice but to care for the elderly person:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

b) I would feel guilty if I didn't care for the elderly person:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

c) The elderly person expected me to care for him/her:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

d) I felt that people would disapprove if I didn't care for the elderly person:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

e) It's part of my nature to care for others:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

f) I felt it was my duty to care for the elderly person:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

g) I wanted to make sure the elderly person was safe:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

h) My family has always cared for its own relatives in the past:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

i) I was the only person available to care for the elderly person:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

j) Caring for the elderly person was an automatic decision:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

k) I do not/did not want the elderly person to go into a home:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

l) I wanted to provide care for the elderly person myself:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

m) The elderly person does not/did not want to go into a home:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

n) Caring for the elderly person is a way of living up to my principles:

1=Strongly agree; 2=Agree; 3=Neither agree nor disagree; 4=Disagree; 5=Strongly disagree

o) It was too expensive for the elderly person to go into a home:

5=Strongly agree; 4=Agree; 3=neither agree nor disagree; 2=Disagree; 1=Strongly disagree

p) I lived close to the elderly person:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 1=Strongly disagree

q) The elderly person was gradually becoming more dependent on me:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 2=Disagree; 5=Strongly disagree

r) I felt that I had a responsibility towards the elderly person:

5=Strongly agree; 4=Agree; 3=Neither agree nor disagree; 4=Disagree; 1=Strongly disagree

s) Any other reasons (please state briefly):

15. (*Carer stress: Stephens et al., 1997*):

PLEASE INDICATE BELOW HOW STRESSFUL EACH OF THE FOLLOWING CARING TASKS HAS BEEN IN THE PAST MONTH. FOR EACH TASK YOU HAVE NOT PERFORMED IN THE PAST MONTH, PLEASE CIRCLE 0 (DID NOT HAPPEN) AND MOVE ON TO THE NEXT ITEM.

a) Feeding the elderly person, making sure he/she eats well.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful 4=Very stressful

b) Having to just sit and be with the elderly person.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful 4=Very stressful

c) Arranging services for the elderly person.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful 4=Very stressful

d) Making sure the elderly person gets enough sleep.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful 4=Very stressful

e) Helping the elderly person complete simple tasks.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

f) Helping the elderly person bathe and groom himself/herself.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

g) Taking the elderly person to the doctor.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

h) Seeing the elderly person's wandering or purposeless activity.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

i) Helping the elderly person dress or undress.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

j) Helping the elderly person take medications.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

k) Preparing meals for the elderly person or taking him/her grocery shopping.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

l) Dealing with changes in the elderly person's mood.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

m) Having to make decisions for the elderly person.

0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

n) Helping the elderly person get around the house.
0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

o) Dealing with the elderly person's memory problems.
0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

p) Hearing the elderly person's point of view even when he/she is confused.
0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

q) Managing the elderly person's finances.
0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

r) Dealing with the elderly person's criticisms and complaints.
0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

s) Listening to the elderly person's repetitive questions.
0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

t) Having to supervise the elderly person for his/her safety.
0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

u) Helping the elderly person with his/her laundry.
0=Did not happen; 1=Not at all stressful; 2=Slightly stressful; 3=Somewhat stressful
4=Very stressful

16. (*Carer satisfaction: Lawton et al., 1989*):

THE FOLLOWING STATEMENTS REFLECT HOW PEOPLE SOMETIMES FEEL WHEN TAKING CARE OF ANOTHER PERSON. FOR EACH QUESTION, PLEASE CIRCLE THE ANSWER WHICH BEST DESCRIBES HOW OFTEN YOU FEEL THAT WAY ABOUT TAKING CARE OF THE ELDERLY PERSON.

How often do you feel:

a) that helping the elderly person has made you feel closer to him/her?
1=Never; 2=Rarely; 3=Sometimes; 4=Quite frequently; 5=Nearly always

b) that taking responsibility for the elderly person gives your self-esteem a boost?
1=Never; 2=Rarely; 3=Sometimes; 4=Quite frequently; 5=Nearly always

c) that the elderly person's pleasure over some little thing gives you pleasure?
1=Never; 2=Rarely; 3=Sometimes; 4=Quite frequently; 5=Nearly always

d) that you really enjoy being with the elderly person?
1=Never; 2=Rarely; 3=Sometimes; 4=Quite frequently; 5=Nearly always

e) that the elderly person shows real appreciation of what you do for him/her?
1=Never; 2=Rarely; 3=Sometimes; 4=Quite frequently; 5=Nearly always

Section D: About your own health

(*GHQ-12; mental health: Goldberg, 1992*):

We should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

17. Have you recently:

a) **Been able to concentrate on whatever you're doing?**

0=Better than usual; 1=Same as usual; 2=Less than usual; 3=Much less than usual.

b) Lost much sleep over worry?

0=Not at all; 1=No more than usual; 2=Rather more than usual; 3=Much more than usual

c) Felt that you are playing a useful part in things?

0=More so than usual; 1=Same as usual; 2=Less useful than usual; 3=Much less useful

d) Felt capable of making decisions about things?

0=More so than usual; 1=Same as usual; 2=Less so than usual; 3=Much less than usual

e) Felt constantly under strain?

0=Not at all; 1=No more than usual; 2=Rather more than usual; 3=Much more than usual

f) Felt that you couldn't overcome your difficulties?

0=Not at all; 1=No more than usual; 2=Rather more than usual; 3=Much more than usual

g) Been able to enjoy your normal day-to-day activities?

0=More so than usual; 1=Same as usual; 2=Less so than usual; 3=Much less than usual

h) Been able to face up to your problems?

0=More so than usual; 1=Same as usual; 2=Less so than usual; 3=Much less able

i) Been feeling unhappy and depressed?
0=Not at all; 1=No more than usual; 2=Rather more than usual; 3=Much more than usual

j) Been losing confidence in yourself?
0=Not at all; 1=No more than usual; 2=Rather more than usual; 3=Much more than usual

k) Been thinking of yourself as a worthless person?
0=Not at all; 1=No more than usual; 2=Rather more than usual; 3=Much more than usual

l) Been feeling reasonably happy, all things considered?
0=More so than usual; 1=About the same as usual; 2=Less so than usual; 3=Much less than usual

(Positive affect: Watson et al., 1988)

The following scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past few weeks. Use the following scale to record your answers.

a) interested
1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

b) excited
1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

c) strong
1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

d) enthusiastic

1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

e) proud

1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

f) alert

1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

g) inspired

1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

h) determined

1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

i) attentive

1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

j) active

1=Very slightly; 2=A little; 3=Moderately; 4=Quite a bit; 5=Extremely

Thank you very much for your help with this research. Now please send the questionnaire back in the envelope provided.

I would like to send you a shorter questionnaire in about a year in order to see if any changes have occurred in your situation. This follow-up questionnaire is very important to the research. Please indicate below if you would be happy to be sent another questionnaire.

Yes (I would be happy to answer another questionnaire)

No (I do not want to answer another questionnaire)

I would also like to interview women who are combining work and caring for an elderly person. If you are in such a position and would like to be interviewed informally for about an hour about your experiences, at a time and place which is convenient for you, please circle "yes" below:

Yes (I would like to be interviewed)
No (I would not like to be interviewed)

Ref. No:………………………………………………

Appendix 7:

INFORMATION SHEET INCLUDED WITH THE TIME 2 SURVEY

Work and Caring Study

Some time ago, you responded to a questionnaire about work, and indicated that you would be willing to answer a final questionnaire. I would like to thank you very much for your participation in this research so far, and now invite you to answer the following final questionnaire which asks for details about your own circumstances, which may or may not have changed.

The information we receive will not be seen by anyone other than the researchers involved in this project, and no names will appear in any publication which may result from the research.

I hope that you will respond to this questionnaire, as all your answers are very important to us. Please answer all questions, and then send back the questionnaire in the envelope provided.

Thank you for your continued help and support.

Clare Lyonette
March 2002

Appendix 8:

THE TIME 2 QUESTIONNAIRE SURVEY AND CODING PROCEDURE FOR QUESTIONNAIRE RESPONSES

(Words in italics did not appear in the questionnaire)

Instructions: Thank you for participating in this third and final part of the research. Please answer all questions. All answers are confidential and will not be seen by any persons other than the researchers. We appreciate your honest answers.

Section A: About Yourself

1a). *(Change in occupation: Neal et al., 1993)*

ARE YOU (please circle):

1=In the same job as a year ago; 2=Working in a different job; 3=Now retired; 4=Left work to care

b) If you are now working in a different job, please state your new job below (briefly):…………………………………………………………………

2. *(Hours worked per week: Neal et al., 1993)*

HOW MANY HOURS PER WEEK DO YOU USUALLY WORK?

………………………………………………………………………………………

3. *(Carer's health status: Maddox & Douglass, 1979)*

HOW WOULD YOU DESCRIBE YOUR OWN HEALTH AT THE MOMENT (please circle):

0=Poor or fair; 1=Good or excellent

Section B: About Your Job

(For coding procedure, see Appendix 2).

THE FOLLOWING QUESTIONS ASK YOU TO DESCRIBE YOUR JOB. PLEASE ANSWER ALL THE QUESTIONS, TICKING THE ANSWER

WHICH BEST DESCRIBES THE JOB YOU DO MOST OF THE TIME.

4. (*Autonomy and control: Haynes et al., 1999*):

To what extent do you:

a) Determine the methods and procedures you use in your work?

b) Choose what work you will carry out?

c) Decide when to take a break?

d) Vary how you do your work?

e) Plan your own work?

f) Carry out your work in the way you think best?

5. (*Work demands: Haynes et al., 1999*):

How often do you find yourself meeting the following problems in carrying out your job?

a) I do not have enough time to carry out my work.

b) I cannot meet all the conflicting demands made on my time.

c) I never finish work feeling I have completed everything I should.

d) I am asked to do work without adequate resources to complete it.

e) I cannot follow best practice in the time available.

f) I am required to do basic tasks which prevent me completing more important ones.

6. (*Peer support: Haynes et al., 1999*):

The following questions ask about the extent to which other people provide you with help or support.

To what extent can you:

a) Count on your colleagues to listen to you when you need to talk about problems at work?

b) Count on your colleagues to back you up at work?

c) Count on your colleagues to help you with a difficult task at work?

d) Really count on your colleagues to help you in a crisis situation at work, even though they would have to go out of their way to do so?

7. (*Work satisfaction: Stephens et al., 1997*):

PLEASE INDICATE HOW STRONGLY YOU AGREE OR DISAGREE WITH

THE FOLLOWING STATEMENTS CONCERNING YOUR JOB (please circle).

a) You are being paid a reasonable amount for the work you do.
b) Many of the rules and procedures at work make it difficult to do a good job.
c) There are benefits not offered at work which should be offered.
d) You are satisfied with your chances for promotion.
e) You are satisfied with the amount of support you receive from your supervisor.
f) Work assignments often are not fully explained.
g) Your job is enjoyable.
h) You are satisfied with the amount of support you receive from the co-worker with whom you work most closely.

8. (*Work stress: Stephens et al., 1997*):

PLEASE INDICATE BELOW HOW STRESSFUL EACH OF THE FOLLOWING HAS BEEN FOR YOU IN THE PAST MONTH. FOR EACH THAT DOES NOT APPLY, PLEASE CIRCLE "DOES NOT APPLY" AND MOVE ON TO THE NEXT ITEM.

a) Having more work than you can handle.
b) Working in an unpleasant or unsafe environment.
c) Your job not matching your interest or skills.
d) Job lacking security or stability.
e) Having too much to do at work.
f) Job lacking variety or seeming monotonous.
g) Being unable to have control over the things you do at work.

9. (*Carework involvement: Patient care tasks subscale of Work Stressors Inventory: Schaefer & Moos, 1993*):

THESE QUESTIONS ARE ABOUT EVENTS THAT MAY ARISE IN CARING FOR PATIENTS AND THEIR FAMILIES. MARK YOUR ANSWER BY PUTTING AN "X" IN THE APPROPRIATE BOX. PLEASE CIRCLE "NEVER" IF THE TASKS DO NOT APPLY TO YOUR OWN WORK.

In the last month, how often have you:

a) Taken care of patients who do not appreciate the things you do for them?

b) Been unable to do anything to help a patient improve?

c) Cared for a patient who wants to die?

d) Cared for a dying patient?

e) Cared for a patient who was uncooperative, angry or complaining?

f) Worked with a patient who did not get better?

g) Had a patient relapse whom you knew well?

h) Talked to angry or complaining family members?

i) Had to give emotional support to family members?

Section C: About Your Caring Responsibilities in your Home Life

10. (*Change in carer status: Neal et al., 1993)*

ARE YOU STILL CARING FOR AN ELDERLY PERSON OUTSIDE OF WORKING HOURS? (Please circle):

Yes / No

If yes, please continue with all questions. If not, please give the reason and then go on to Section D, Question 17:

....

11. (*Relationships in elder caring: Lyonette & Yardley, 2003*):

THE FOLLOWING STATEMENTS DESCRIBE SOME OF THE ISSUES WHICH ARISE IN A CARING RELATIONSHIP. PLEASE ANSWER EACH QUESTION, TICKING THE BOX WHICH BEST DESCRIBES YOUR OWN FEELINGS ABOUT YOUR RELATIONSHIP WITH THE ELDERLY PERSON.

a. I have always got on well with the elderly person.

b. I find the elderly person frustrating.

c. The elderly person can be very stubborn.

d. I feel that our relationship is a struggle for power.

e. I had a good relationship with the elderly person in the past.

f. The elderly person can be very negative.

g. The elderly person doesn't like to be told what to do.

h. The elderly person understands that I have a life of my own.

i. The elderly person expects me to pay for things that he/she should pay for.

j. I respect the elderly person.

k. I admire the elderly person.

l. The elderly person understands that things have changed since his/her generation.

12. *(Resident status of elder: Neal et al., 1993)*

WHERE DOES THE ELDERLY PERSON NOW LIVE (please enter the number in the box)?

1=In his or her own home; 2=In your home; 3=With a relative; 4=With a friend;
5=In a nursing home, care facility, etc.;

13. *(Level of help provided with caring: Neal et al., 1993)*

IN THE PAST YEAR, WHEN THIS PERSON HAS NEEDED HELP, WHO HAS USUALLY BEEN THE ONE WHO HAS GIVEN IT OR HAS ARRANGED FOR IT TO BE GIVEN? (Please enter the **number** of your answer in the box)

1=I have been the only one; 2=I have been the main one, with some help from others;
3=I have shared equally with one or more others; 4=Others, with my help

14. *(Motivations involved in elder caring: Lyonette & Yardley, 2003):*

THE FOLLOWING STATEMENTS DESCRIBE SOME OF THE REASONS WHY PEOPLE CARE FOR A RELATIVE OR FRIEND. PLEASE ANSWER EACH QUESTION BY TICKING THE BOX WHICH BEST DESCRIBES YOUR OWN SITUATION.

a. I felt that I had no choice but to care for the elderly person.

b. I would feel guilty if I didn't care for the elderly person.

c. The elderly person expected me to care for him/her.

d. I felt that people would disapprove if I didn't care for the elderly person.

e. It's part of my nature to care for others.

f. I felt it was my duty to care for the elderly person.

g. I wanted to make sure the elderly person was safe.

h. Caring for the elderly person was an automatic decision.

i. I do not/did not want the elderly person to go into a home.

j. I wanted to provide care for the elderly person myself.

k. Caring for the elderly person is a way of living up to my principles.

l. The elderly person was gradually becoming more dependent on me.

m. I felt that I had a responsibility towards the elderly person.

15. (*Carer stress: Stephens et al., 1997*):

PLEASE INDICATE BELOW HOW STRESSFUL EACH OF THE FOLLOWING CARING TASKS HAS BEEN IN THE PAST MONTH. FOR EACH TASK YOU HAVE NOT PERFORMED IN THE PAST MONTH, PLEASE CIRCLE "DID NOT HAPPEN" AND MOVE ON TO THE NEXT ITEM.

a. Feeding the elderly person, making sure he/she eats well.

b. Having to just sit and be with the elderly person.

c. Arranging services for the elderly person.

d. Making sure the elderly person gets enough sleep.

e. Helping the elderly person complete simple tasks.

f. Helping the elderly person bathe and groom himself/herself.

g. Taking the elderly person to the doctor.

h. Seeing the elderly person's wandering or purposeless activity.

i. Helping the elderly person dress or undress.

j. Helping the elderly person take medications.

k. Preparing meals for the elderly person or taking him/her grocery shopping.

l. Dealing with changes in the elderly person's mood.

m. Having to make decisions for the elderly person.

n. Helping the elderly person get around the house.

o. Dealing with the elderly person's memory problems.

p. Hearing the elderly person's point of view even when he/she is confused.

q. Managing the elderly person's finances.

r. Dealing with the elderly person's criticisms and complaints.

s. Listening to the elderly person's repetitive questions.

t. Having to supervise the elderly person for his/her safety.

u. Helping the elderly person with his/her laundry.

16. *(Carer satisfaction: Lawton et al., 1989)*:

THE FOLLOWING STATEMENTS REFLECT HOW PEOPLE SOMETIMES FEEL WHEN TAKING CARE OF ANOTHER PERSON. FOR EACH QUESTION, PLEASE CIRCLE THE ANSWER WHICH BEST DESCRIBES HOW OFTEN YOU FEEL THAT WAY ABOUT TAKING CARE OF THE ELDERLY PERSON.

How often do you feel:

a) that helping the elderly person has made you feel closer to him/her?

b) that taking responsibility for the elderly person gives your self-esteem a boost?

c) that the elderly person's pleasure over some little thing gives you pleasure?

d) that you really enjoy being with the elderly person?

e) that the elderly person shows real appreciation of what you do for him/her?

Section D: About your own health

17. (*GHQ-12; mental health: Goldberg, 1992*):

We should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.
Thank you very much for your co-operation.

Have you recently:

a. Been able to concentrate on whatever you're doing?

b. Lost much sleep over worry?

c. Felt that you are playing a useful part in things?

d. Felt capable of making decisions about things?

e. Felt constantly under strain?

f. Felt that you couldn't overcome your difficulties?
g. Been able to enjoy your normal day-to-day activities?
h. Been able to face up to your problems?
i. Been feeling unhappy and depressed?
j. Been losing confidence in yourself?
k. Been thinking of yourself as a worthless person?
l. Been feeling reasonably happy, all things considered?

18. (*Positive affect: Watson et al., 1988*):

The following scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past few weeks. Use the following scale to record your answers.

interested
excited
strong
enthusiastic
proud
alert
inspired
determined
attentive
active

Thank you very much for your help with this research. Now please send the questionnaire back in the envelope provided.

Ref. No...

Appendix 9:

CONSENT FORM FOR WOMEN INTERVIEWED IN THE QUALITATIVE STUDY

I am Clare Lyonette, a research student at Southampton University. I am requesting your participation in a study regarding work and caring in women. This will involve an interview lasting approximately 1 hour. You will be asked about your own experiences of combining caring with your other responsibilities. Personal information will not be viewed by anyone other than the researchers involved in this project. Results of this study will not include your name or any other identifying characteristics. All audiotapes will be kept in a locked cabinet and destroyed at the end of the study. Verbatim quotations may be reproduced in published material, but will remain anonymous.
Your participation is voluntary and you may withdraw your participation at any time. If you have any questions, please ask them now, or contact me, Clare Lyonette, at c.lyonette@talk21.com.

Signature
Name

Statement of Consent
I……………………………………………………………………have read the above informed consent form. I understand that I may withdraw my consent and discontinue participation at any time without penalty or loss of benefit to myself. I understand that the data collected as part of this research project will be treated confidentially, and that published results of this research will maintain my confidentiality. In signing this consent letter, I am not waiving my legal claims, rights or remedies. A copy of this consent letter will be offered to me.

I give consent to participate in the above study.
Yes / No

I give consent to be audiotaped.
Yes / No.

I understand that these audiotapes will be destroyed after analysis.
Yes / No.

Signature
Name

I understand that if I have questions about my rights as a participant in this research, or if I feel that I have been placed at risk, I can contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ.
Phone: (01703) 592612.

Appendix 10:

INDIVIDUAL DETAILS OF CARERS INTERVIEWED IN THE QUALITATIVE STUDY (CHAPTER 6)

Participant 1 (P1, interviewed in June, 2000):

Participant 1 was a 59-year-old woman with 2 adult children, living with her husband in a large, detached house in Marlow, Buckinghamshire. P1 was an only child. At the time of the interview, she was caring for her co-resident father who had multiple disabilities, one of which meant that he was connected to breathing apparatus most of the day, and therefore remained in his room for most of the time. Previously, P1 had also been caring for her mother who was diagnosed with Alzheimer's Disease, and who had lived at a distance with her father. At the time, P1 had been working as a full-time teacher but had eventually given up work as a consequence of her caring responsibilities. P1's mother was admitted to a nursing home after she became increasingly ill and her father was unable to cope due to his own health problems. Her father then moved in with P1 and her husband. P1 had continued to visit her mother, accompanied by her father, until her death four years ago. P1 received some regular formal help with caring.

Participant 2 (P2, interviewed in June, 2000):

Participant 2 was a divorced woman in her late fifties with 2 adult children. P2 was an only child. She lived with her co-resident father in a small but comfortably furnished bungalow in Hazlemere, Buckinghamshire. At the time of the interview, her father was elderly, frail and occasionally incontinent. P2 had been caring for her father since her mother died suddenly four years ago. At the time, she had given up work to care for her father but had eventually gone back into a less demanding and stressful job in a charity. She had suffered on and off from depression in that time. P2 received no formal help with caring, but had recently found someone to occasionally sit with her father in the evenings so that she could go out with friends. She occasionally used respite care but was worried about the possible closure of the local unit.

Participant 3 (P3, interviewed in June, 2000):

Participant 3 was a divorced woman in her early fifties, with 2 adult children. P3 had two sisters. She lived alone in a small but comfortably furnished house in Penn, Buckinghamshire. At the time of the interview, P3 was caring for her elderly mother who lived close by in a small ground floor maisonette. She shared the care equally with one of her two sisters, who was also divorced. Both managed to take regular breaks from caring as the other was prepared to step in. P3 was still working part-time for the church, and her sister worked part-time in a hospital. At the time of the interview, P3 had recently met a man who she was interested in and was unsure how this would affect her caring responsibilities. She and her sister regularly arranged for formal care services for her mother, which often proved unsatisfactory.

Participant 4 (P4, interviewed in July, 2000):

Participant 4 was a woman in her early sixties with 2 adult children, living with her husband in a large bungalow in Penn, Buckinghamshire. She had one brother, twelve years younger than herself. P4 was caring for her elderly and frail mother who had moved to live nearby in her own home. She had given up work as a classroom assistant in a school for disabled children, partly because of health problems of her own and partly because of her caring responsibilities towards her mother. She also claimed not to have enjoyed her job even before her mother became increasingly dependent. At the time of the interview, P4 did most of the caring for her mother, but arranged for her mother's house to be cleaned by someone else. She received very little help from her brother, a situation she was unhappy with.

Participant 5 (P5, interviewed in July, 2000):

Participant 5 was a 62-year-old divorced woman, living alone in a small but comfortably furnished flat in Hazlemere, Buckinghamshire. P5 had cared for her severely disabled daughter for 29 years before admitting her to an institution four years ago, where she had since been deteriorating. While she was caring for her daughter, she had also cared for her mother, who died eight years ago, as well as her brother, who earlier died of cancer. She gave up work when her daughter was born. We decided to focus on the care of her mother for the purposes of the interview, and include the caring she did for her daughter as an additional commitment.

Participant 6 (P6, interviewed in July, 2000):

Participant 6 was a 50-year-old married woman with no children living with her husband in a village outside Southampton. P6 had one sister who died of Motor Neurone Disease 18 months previously. At the time of the interview, she was caring for her increasingly dependent mother who lived in her own house close by. She also was caring in a minor way for an older lady who had cared for her and her sister when they were children. P6 arranged for private formal help for her mother, after several difficulties with social services. P6 was a full-time technician at the University of Southampton, and was interviewed in her office there.

Participant 7 (P7, interviewed in July, 2000):

Participant 7 was a married woman in her mid-sixties with 2 adult children, living in a large detached house in Holmer Green, Buckinghamshire. She had been caring for her co-resident mother-in-law for 14 years before she was admitted to a nursing home, where she died a year before the interview. Previously, she had been caring for both of her in-laws in her own home after her father-in-law had been diagnosed with cancer. Her father-in-law died after remaining in P7's home for some time, and after that time her mother-in-law remained in the home. P7's husband had helped with caring for his mother, but P7 explained that his mother had not wanted her son to do any personal caring for her. P7 was currently working as a part-time volunteer at the Carers' Centre in High Wycombe, but had earlier given up her full-time job as a school secretary because of difficulties in combining work with caring for her mother-in-law. P7 and her husband had had no help in the home until a crisis point was reached when they had to call in an overnight nurse to allow them to sleep. Her mother-in-law had grown progressively worse until both P7 and her husband felt that they could not cope any more, which led to her being admitted into a nursing home.

Participant 8 (P8, interviewed in August, 2000):

Participant 8 was a 64-year-old woman with 2 adult children living with her husband in a large, detached house in Penn, Buckinghamshire. She had one sister who worked part-time. At the time of the interview, she had been caring for her elderly co-resident mother for four years. Previous to that, she had been caring at a distance, while working full-time as a coordinator for a company which organised craft fairs. At the time of the interview, P8 was increasingly able to take holidays as her sister had eventually agreed to take her mother for short periods of time. Before that, she had been the sole carer and had felt that she needed to give up work to cope with caring for her mother, who had been very sick when she first moved in to her house.

Participant 9 (P9, interviewed in August, 2000):

Participant 9 was a woman in her mid-fifties with no children, recently remarried after her first husband died 5 years ago, and living with her new husband in a small but comfortable house in Chesham, Buckinghamshire. Her first husband was a tetraplegic and she also had some continuing caring responsibilities for her parents-in-law while he was ill. At the time of the interview, she was still visiting her mother-in-law once a week in a home. She was also currently involved in helping care for her 26-year-old nephew who had recently been diagnosed with Multiple Sclerosis. While looking after her first husband, P9 had worked in a gift shop, but she left after she found them to be very unsympathetic to her situation. During the time of her husband's increasing disabilities and need for care, she had organised formal care services, which had been very difficult.

Participant 10 (P10, interviewed in August, 2000):

Participant 10 was a 63-year-old married woman with 3 adult children, living in a large, converted bungalow in Chesham, Buckinghamshire. Her husband had suffered from muscular dystrophy since he was born, and P10 was his main carer. Her husband continued to work in his own business. While she was caring for her husband, P10's mother had come to live with them for the last 3 years of her life. Her mother had been suffering increasingly from dementia. P10 had never worked due to her caring commitments toward her husband, but had occasionally rented out rooms in her house to students and other lodgers. Her husband had regular formal help with lifting and the house was converted to suit his requirements.

Participant 11 (P11, interviewed in August, 2000):

Participant 11 was a divorced woman in her early sixties with 2 adult children. She was a secondary carer for her dependent mother, who was living with her unmarried brother nearby. P11 had worked part-time in caring services and arranged for most of the formal care for her mother. At the time of the interview, she was involved in several voluntary activities, including taking groups of disabled people on holidays. She also had a regular caring commitment towards her grandchildren.

Participant 12 (P12, interviewed in September, 2000):

Participant 12 was a married 59-year-old woman with two children, living with her second husband in a large and comfortable house in Loudwater, Buckinghamshire. At the time of the interview, she was caring for her elderly, co-resident mother, and was also heavily involved in caring for her granddaughter. Her daughter had suffered from mental illness for several years, and P12 had been primarily responsible for the care of her granddaughter whenever crises occurred. P12 had one younger brother who died suddenly at a young age and she was still involved in helping out with his daughters. She also had an elder brother who refused to help out with the care of his parents. When her younger brother died, her parents were both in poor health and she had decided to sell her own home; she and her second husband then moved into her parents' home to care for them, where they still lived. Her father died after 11 years, and her mother had suffered several serious crises with her health over the years, and was now suffering from Alzheimer's Disease. P12 had been working as a full-time financial advisor at the time of taking on the care for both parents, but eventually decided to give up work due to the difficulties in managing both roles. P12 occasionally used respite services in order to go away on holiday, but was worried about the possible closure of the local unit.

Participant 13 (P13, interviewed in September, 2000):

Participant 13 was a single woman in her late fifties, living in a small but comfortable house in Marlow, Buckinghamshire. At the time of the interview, she was caring for her mother who suffered from Alzheimer's and lived in her own flat in Marlow. P13 was a qualified accountant but had not worked for a year, due mainly to the pressures of caring for her mother. However, she informed me in a personal letter about 3 months later that she had since found some work. P13 was not an only child, but would not elaborate on other siblings, and claimed to be the only relative available to care for her mother. P13 was growing increasingly worried about her mother who wandered from home several times and was often disorientated.

Participant 14 (P14, interviewed in November, 2000):

Participant 14 was a married woman in her late fifties with two adult children, living with her husband in a comfortable house in High Wycombe, Buckinghamshire. At the time of the interview, P14 was caring for her elderly mother who was suffering from dementia. Her mother lived in her own home, but was close by. She was also involved in caring for her aunt who lived close by. P14 worked from home as a coordinator for Age Concern and was also involved in voluntary work. She had one sister who lived on the Isle of Wight and was able to take her mother for occasional holidays, although her mother was now reluctant to go. P14 or her husband visited her mother daily in order to prepare food for her, as her mother was becoming increasingly forgetful. Her mother would call several times a day, and P14 explained that she only answered the first call of the day to ensure that she was fine, but would then leave the other calls and check on her later. P14 arranged for a woman from her mother's church to visit twice a week to clean the house and keep her mother company, and occasionally would check on her when P14 was away.

BIBLIOGRAPHY

Albert, S.M. (1992). Psychometric investigation of a belief system: caregiving to the chronically ill parent. *Social Science and Medicine* **35** (5), 699-709.

Amatea, E.S. and Fong, M.L. (1991). The impact of role stressors and personal resources on the stress experiences of professional women. *Psychology of Women Quarterly* **15**, 419-430.

Arber, S. and Ginn, J. (1990). The meaning of informal care: gender and the contribution of older people. *Ageing and Society* **12** (4), 429-454.

Archbold, P. (1983). Impact of parent-caring on women. *Family Relations* **32**, 39-45.

Archbold, P.G., Stewart, B.J., Greenlick, M.R. and Harvath, T.A. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health* **12**, 375-384.

Askham, J., Grundy, E. and Tinker, A. (1992). *Caring: the importance of third-age carers. The Carnegie Inquiry into the Third Age.* Research paper No. 6: London.

Bacharach, S.B., Bamberger, P. and Conley, S. (1991). Work-home conflict among nurses and engineers: mediating the impact of role stress on burnout and satisfaction at work. *Journal of Organizational Behaviour* **12**, 39-53.

Barnes, C.L., Given, B.A. and Given, C.W. (1995). Parent caregivers: a comparison of employed and not employed daughters. *Social Work* **40** (3), 375-381.

Barnett, R.C., Baruch, G.K. and Marshall, N.L. (1987). Progress report, National Institute of Occupational Safety and Health, Contract No. R-01-0H01968-01 (Wellesley, Mass: Wellesley College Center for Research on Women).

Barnett, R.C., Marshall, N.L. and Singer, J.D. (1992). Job experiences over time, multiple roles and women's mental health: a longitudinal study. *Journal of Personality and Social Psychology* **62** (4), 634-644.

Baruch, G.K. and Barnett, R. (1986). Role quality, multiple role involvement and psychological well-being in midlife women. *Journal of Personality and Social Psychology* **51**(3), 578-585.

Baruch, G.K., Biener, L. and Barnett, R.C. (1987). Women and gender in research on work and family stress. *American Psychologist* **42** (2), 130-136.

Baumeister, R.F., Bratslavsky, E., Muraven, M. and Tice, D.M. (1998). Ego depletion: is the active self a limited resource? *Journal of Personality and Social Psychology* **74** (5), 1252-1265.

Beck, A.T., Ward, C.H., Mendelson, M., Mock, J. and Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry* **4**, 561-571.

Bengtson, V.L. and Schrader, S.S. (1982). Parent-child relations. In Mangen, D.J. and Peterson, W.A. (eds.) *Social Roles and Social Participation,* University of Minneapolis Press, Minneapolis, Minnesota, 154.

Boaz, R.F. and Muller, C.F. (1992). Paid work and unpaid help by caregivers of the disabled and frail elders. *Medical Care* **30** (2), 149-158.

Borrill, C.S., Wall, T.D., West, M.A., Hardy, G.E., Shapiro, D.A., Haynes, C.E., Stride, C.B., Woods, D. and Carter, A.J. (1998). *Stress among staff in NHS Trusts.* Final Report (August), Institute of Work Psychology, University of Sheffield, and Psychological Therapies Research Centre, University of Leeds.

Boyatzis, R.E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development.* Sage: London.

Brody, E.M., Kleban, M.H., Johnsen, P.T., Hoffman, C. and Schoonover, C.B. (1987). Work status and parent care: a comparison of four groups of women. *The Gerontologist* **27** (2), 201-208.

Camic, P.M., Rhodes, J.E. and Yardley, L. (2003). *Qualitative research in psychology: expanding perspectives in methodology and design.* Washington, DC: American Psychological Association.

Cantor, M.H. (1983). Strain among caregivers: a study of experience in the United States. *The Gerontologist* **23** (6), 597-604.

Carruth, A.K. (1996). Motivating factors, exchange patterns, and reciprocity among caregivers of parents with and without dementia. *Research in Nursing and Health* **19**, 409-19.

Chang, B.H., Noonan, A.E. and Tennstedt, S.L. (1998). The role of religion/spirituality in coping with caregiving for disabled elders. *The Gerontologist* **38** (4), 463-470.

Charmaz, C. (1990). "Discovering" chronic illness: using grounded theory. *Social Science and Medicine* **30**, 1167-1172.

Cicirelli, V.G. (1993). Attachment and obligation as daughters' motives for caregiving behaviour and subsequent effect on subjective burden. *Psychology and Aging* **8** (2), 144-155.

Corti, L. and Dex, S. (1995). Informal carers and employment. *Employment Gazette*, March, 101-107.

Covinsky, K.E., Eng, C., Lui, Li-Yung, Sands, L.P., Sehgal, A.R., Walter, L.C., Wieland, D., Eleazer, G.P and Yaffe, K. (2001). Reduced employment in caregivers of frail elders: impact of ethnicity, patient clinical characteristics, and caregiver characteristics. *Journal of Gerontology (Series A): Biological Sciences and Medical Sciences* **56A** (11), M707-M713.

Dellasega, C. (1990). The relationship between caregiving and employment: a study of stress in employed and unemployed caregivers of elderly persons. *AAOHN Journal* **38** (4), 154-159.

Derogatis, L.R., Lipman, R.S., Rickels, K., Uhlenhuth, E.H. and Covi, L. (1974). The Hopkins Symptom Checklist (HSCL): a self-report symptom inventory. *Behavioural Science* **19**, 1-15.

Dooghe, G. (1992). Informal caregiving of elderly people: a European review. *Ageing and Society* **12**, 369-380.

Doty, P., Jackson, M.E. and Crown, W. (1998). The impact of female caregivers' employment status on patterns of formal and informal eldercare. *The Gerontologist* **38** (3), 331-341.

Eisner, E.W. (2003). On the art and science of qualitative research in psychology. In P.M. Camic, J.E. Rhodes and L. Yardley (eds.). *Qualitative research in psychology: expanding perspectives in methodology and design.* Washington, DC: American Psychological Association.

Faris, R.E.L. (1934). Cultural isolation and the schizophrenic personality. *American Journal of Sociology* **40**, 155-169.

Fielding, J. (1993). Coding and managing data. In N. Gilbert (ed.) *Researching social life.* London: Sage.

Finley, N.J., Roberts, M.D. and Banahan, B.F. (1988). Motivators and inhibitors of attitudes of filial obligation toward aging parents. *The Gerontologist* **28** (1), 73-78.

Forbat, L. (2002). Caregiving relationships: two sides to the story. *Proceedings of the British Psychological Society conference,* Blackpool, March.

Franklin, S.T., Ames, B.D. and King, S. (1994). Acquiring the family eldercare role: influence on female employment adaptation. *Research on Aging* **16** (1), 27-42.

Fredriksen, K.I. and Scharlach, A.E. (1997). Caregiving and employment: the impact of workplace characteristics on role strain. *Journal of Gerontological Social Work* **28** (4), 3-22.

Freud, S. (1961). *Civilization and its discontents.* New York: Norton.

George, L.K. and Gwyther, L.P. (1986). Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *The Gerontologist* **26,** 253-259.

Gerstel, N. and Gallagher, S. (1993). Kinkeeping and distress: gender, recipients of care and work-family conflict. *Journal of Marriage and the Family* **55**, 598-607.

Gerstel, N. and Gallagher, S. (1994). Caring for kith and kin: gender, employment and the privatization of care. *Social Problems* **41** (4), 519-539.

Gibeau, J.L. and Anastas, J.W. (1989). Breadwinners and caregivers: interviews with working women. *Journal of Gerontological Social Work* **14** (1/2), 19-40.

Gignac, M.A.M., Kelloway, E.K. and Gottlieb, B.H. (1996). The impact of caregiving on employment: a mediational model of work-family conflict. *Canadian Journal on Aging* **15** (4), 525-542.

Gilhooly, M.L.M. and Redpath, C. (1997). Private sector policies for caregiving employees: a survey of Scottish companies. *Ageing and Society* **17**, 399-423.

Given, C.W. and Given, B.A. (1987). *Caregiver responses to managing elderly patients at home* (HHS Grant 1-RO1-AG06584, Year 2 Progress report, funded by the National Institute on Aging, US Dept. of Health and Human Services). Unpublished manuscript.

Goldberg, D. (1992). *General Health Questionnaire (GHQ-12).* Windsor: NFER-NELSON.

Goldberg, D. and Williams, P. (1988). *A user's guide to the General Health Questionnaire.* Windsor: NFER-NELSON.

Goldsmith, E.B. and Goldsmith, R.E. (1995). Full-time employees as caregivers to the elderly. *Journal of Social Behaviour and Personality* **10** (3), 719-730.

Goode, W.J. (1960). A theory of role strain. *American Sociological Review* 25 (August): 483-496.

Gottlieb, B.H., Kelloway, E.K. and Fraboni, M. (1994). Aspects of eldercare that place employees at risk. *The Gerontologist* **34** (6), 815-821.

Guberman, N., Maheu, P. and Maille, C. (1992). Women as family caregivers: why do they care? *The Gerontologist,* **32** (5), 607-617.

Guberman, N. and Maheu, P. (1999). Combining employment and caregiving: an intricate juggling act. *Canadian Journal on Aging* **18** (1), 84-106.

Hammersley, M. (1998). The relationship between qualitative and quantitative research: paradigm loyalty versus methodological eclecticism. In Richardson, J.T.E. (ed.) *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*, BPS Books: Leicester.

Hawkins, B. (1996). Daughters and caregiving: taking care of our own. *AAOHN Journal* **44** (9), 433-437.

Haynes, C.E., Wall, T.D., Bolden, R.I. and Stride, C. (1999). Measures of perceived work characteristics for health services research: test of a measurement model and normative data. *British Journal of Health Psychology* **4**, 257-275.

Henwood, M. (1992). *Through a Looking Glass Darkly: Community Care and Elderly People.* King's Fund Institute, London.

Horowitz, A. and Shindelman, L.W. (1983). Reciprocity and affection: past influences on current caregiving. *Journal of Gerontological Social Work* **5** (3), 5-20.

Howell, D.C. (1997). *Statistical Methods for Psychology (fourth edition).* Belmont, California: Wadsworth Publishing Co.

Huppert, F.A. and Whittington, J.E. (2003). Evidence for the independence of positive and negative well-being: implications for quality of life assessment. British *Journal of Health Psychology* **8** (1), 107-122.

Hutton, S. (1999). *The employment of those undertaking informal care: a longitudinal analysis.* York: Social Policy Research Unit.

Jutras, S. and Veilleux, F. (1991). Gender roles and caregiving to the elderly: an empirical study. *Sex Roles* **25** (1/2), 1-18.

Kane, R.A. and Penrod, J.D. (1995). *Family Caregiving in an Aging Society: Policy Perspectives.* Thousand Oaks, California: Sage.

Karasek, R.W., Schwartz, J. and Theorell, T. (1982). *Job characteristics, occupation and coronary heart disease.* (Contract no. R-01-0H00906). Cleveland, Ohio: National Institute of Occupational Safety and Health.

Karasek, R.A. (1987). *Selection of job stress questionnaire items for NHANES III.* Los Angeles, California: University of Southern California.

King, E. (1998). The use of self in qualitative research. In J.T.E. Richardson (ed.) *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*, Leicester: BPS Books.

Kinnear, P.R. and Gray, C.D. (1997). *SPSS for Windows made simple (second edition).* East Sussex: Psychology Press.

Kramer, B.J. and Kipnis, S. (1995). Eldercare and work-role conflict: toward an understanding of gender differences in caregiver burden. *The Gerontologist* **35** (3), 340-348.

Laczko, F. and Noden, S. (1992). Combining paid work with eldercare: the implications for social policy. *Health and Social Care* **1**, 81-89.

Lawrence, R.H., Tennstedt, S.L. and Assmann, S.F. (1998). Quality of the caregiver-care recipient relationship: does it offset negative consequences of caregiving for family caregivers? *Psychology and Aging* **13** (1), 150-158.

Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M. and Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences* **44** (3), 61-71.

Lechner, V.M. and Gupta, C. (1996). Employed caregivers: a four-year follow-up. *The Journal of Applied Gerontology* **15** (1), 102-115.

Lyonette, C. and Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient *(in press, due for publication in Ageing and Society, July edition* **23**).

Lyons, K.S., Zarit, S.H., Sayer, A.G. and Whitlatch, C.J. (2002). Caregiving as a dyadic process: perspectives from caregiver and receiver. *Journal of Gerontology: Psychological Sciences* **57B** (3), 195-204.

Maddox, G.L. and Douglass, E.B. (1973). Self-assessment of health: a longitudinal study of elderly subjects. *Journal of Health and Social Behavior* **14**, 87-93.

Marecek, J. (2003). Toward a qualitative stance in psychology. In P.M. Camic, J.E. Rhodes and L. Yardley (eds.) *Qualitative research in psychology: expanding perspectives in methodology and design.* Washington, DC: American Psychological Association.

Marks, N.F. (1996). Does it hurt to care? Caregiving, work-family conflict and midlife well-being. *Journal of Marriage and the Family* **60**, 951-966.

Marks, S.R. (1977). Multiple roles and role strain: some notes on human energy, time and commitment. *American Sociological Review* **42**, 921-936.

Marshall, N.L., Barnett, R.C., Baruch, G.K. and Pleck, J.H. (1990). Double jeopardy: the costs of caring at work and at home. In Abel, E.K. and Nelson, M.K. (eds.) *"Circles of Care: Work and Identity in Women's Lives"*, State University of New York Press.

Martire, L.M., Stephens, M.A.P. and Atienza, A.A. (1997). The interplay of work and caregiving: relationships between role satisfaction, role involvement, and caregivers' well-being. *Journal of Gerontology: Social Sciences* **52B** (5), S279-S289.

Matthews, S.H., Werkner, J.E. and Delaney, P.J. (1989). Relative contributions of help by employed and nonemployed sisters to their elderly parents. *Journal of Gerontology: Social Sciences* **44** (1), 536-544.

McGrath, J.E. and Johnson, B.A. (2003). Methodology makes meaning: how both qualitative and quantitative paradigms shape evidence. In P.M. Camic, J.E. Rhodes and L. Yardley (eds.) *Qualitative research in psychology: expanding perspectives in methodology and design.* Washington, DC: American Psychological Association.

McKee, K.J. (2002). Outcomes of disagreement between carer and care-receiver over activities of daily living. *Proceedings of the British Psychological Society conference,* Blackpool, March.

McKinlay, J.B., Crawford, S.L. and Tennstedt, S.L. (1995). The everyday impacts of providing informal care to dependent elders and their consequences for the care recipients. *Journal of Aging and Health* 7 (4), 497-528.

Merton, R.K. (1957). *Social theory and social structure.* Glencoe, Illinois: The Free Press.

Miller, B. (1990). Gender differences in spouse caregiver strain: socialization and role expectations. *Journal of Marriage and the Family* **52**, 311-321.

Mui, A.C. and Morrow-Howell, N. (1993). Sources of emotional strain among the oldest caregivers. *Research on Aging* **15** (1), 50-69.

Murphy, B., Schofield, H., Nankervis, J., Bloch, S., Herrman, H. and Singh, B. (1997). Women with multiple roles: the emotional impact of caring for ageing parents. *Ageing and Society* **17**, 277-291.

National Carers' Survey (1990). *Carers at work.* Opportunities for Women: London.

Neal, M.B., Chapman, N.J., Ingersoll-Dayton, B., Emlen, A.C. and Boise, L. (1990). Absenteeism and stress among employed caregivers of the elderly, disabled adults, and children. In D.E. Biegel and A. Blum (eds.), *Aging and caregiving: theory, research and policy.* Newbury Park, California: Sage.

Neal, M.B., Chapman, N.J., Ingersoll-Dayton, B. and Emlen, A.C. (1993). *Balancing work and caregiving for children, adults and elders.* Family Caregiver Application Series, Volume 3. Newbury Park, California: Sage.

Neal, M.B., Ingersoll-Dayton, B. and Starrels, M.E. (1997). Gender and relationship differences in caregiving patterns and consequences among employed caregivers. *The Gerontologist* **37** (6), 804-816.

Newell, R. (1993). Questionnaires. In N. Gilbert (ed.) *Researching social life.* London: Sage.

Noor, N.M. (1995). Work and family roles in relation to women's well-being: a longitudinal study. *British Journal of Social Psychology* **34**, 87-106.

Norusis, M.J. (1999). *SPSS Regression Models 10.0.* Chicago, Illinois: SPSS Inc.

Office of National Statistics (2003). *Census 2001.* London: ONS.

Office of Population Censuses and Surveys (1995). *General Household Survey.* Her Majesty's Stationery Office, London.

Orodenker, S.Z. (1990). Family caregiving in a changing society: the effects of employment on caregiver stress. *Family and Community Health* **12** (4), 58-70.

Pavalko, E.K. and Artis, J.E. (1997). Women's caregiving and paid work: causal relationships in late midlife. *Journal of Gerontology: Social Sciences* **52B** (4), S170-S179.

Peters-Davis, N.D., Moss, M.S. and Pruchno, R.A. (1999). Children-in-law in caregiving families. *The Gerontologist* **39** (1), 66-75.

Phillips, J. (1994). The employment consequences of caring for older people. *Health and Social Care* **2**, 143-152.

Pidgeon, N. (1998). Grounded theory: theoretical background. In J.T.E. Richardson, (ed.) *Handbook of Qualitative Research Methods for Psychology and the Social Sciences,* Leicester: BPS Books.

Pohl, J.M., Boyd, C., Liang, J. and Given, C.W. (1995). Analysis of the impact of mother-daughter relationships on the commitment to caregiving. *Nursing Research,* **44** (2), 68-75.

Princess Royal Trust (1995). *Carers in employment: a report on the development of policies to support carers at work.* London.

Radloff, L.S. (1977). The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement* **1**, 385-401.

Rands, G. (1997). Working people who also care for the elderly. *International Journal of Geriatric Psychiatry* **12**, 39-44.

Ratcliff, D. (2003). Video methods in qualitative research. In P.M. Camic, J.E. Rhodes and L. Yardley (eds.) *Qualitative research in psychology: expanding perspectives in methodology and design.* Washington, DC: American Psychological Association.

Robison, J., Moen, P. and Dempster-McClain, D. (1995). Women's caregiving: changing profiles and pathways. *The Journal of Gerontology: Social Sciences* **50B** (6), S362-S373.

Schaefer, J.A. and Moos, R.H. (1993). Relationship, task and system stressors in the health care workplace. *Journal of Community and Applied Social Psychology* **3**, 285-298.

Scharlach, A.E. (1994). Caregiving and employment: competing or complementary roles? *The Gerontologist* **34** (3), 378-385.

Scharlach, A.E. and Boyd, S.L. (1989). Caregiving and employment: results of an employee survey. *The Gerontologist* **29** (3), 382-387.

Scharlach, A.E., Sobel, E.L. and Roberts, R.E. (1991). Employment and caregiver strain: an integrative model. *The Gerontologist* **31** (6), 778-787.

Schulz, R., Tompkins, C.A. and Rau, M.T. (1988). A longitudinal study of the psychosocial impact of stroke on primary support persons. *Psychology and Aging* **3**, 131-141.

Seelbach, W.C. and Sauer, W.J. (1977). Filial responsibility expectations and morale among aged parents. *The Gerontologist* **17** (6), 492-499.

Seltzer, M.M. and Wailing Li, L. (1996). The transitions of caregiving: subjective and objective definitions. *The Gerontologist* **36** (5), 614-626.

Sieber, S.D. (1974). Toward a theory of role accumulation. *American Sociological Review* **39**, 567-578.

Smith, J.A. (1998). Evolving issues for qualitative psychology. In J.T.E. Richardson, (ed.). *Handbook of Qualitative Research Methods for Psychology and the Social Sciences*. Leicester: BPS Books.

Snyder, J.R. (2000). Impact of caregiver-receiver relationship quality on burden and satisfaction. *Journal of Women and Aging* **12** (1/2): 147-167.

Spielberger, C.D., Gorusch, R.L. and Lushene, R.E. (1970). *Manual for the State-Trait Anxiety Inventory*. Palo Alto, California: Consulting Psychologists Press.

Spiess, C.K. and Schneider, A.U. (2003). Interactions between care-giving and paid work hours among European midlife women, 1994 to 1996. *Ageing and Society* **23**, 41-68.

Starrels, M.E., Ingersoll-Dayton, B., Dowler, D.W. and Neal, M.B. (1997). The stress of caring for a parent: effects of the elder's impairment on an employed, adult child. *Journal of Marriage and the Family* **59**, 860-872.

Stephens, M.A.P. and Franks, M.M. (1995). Spillover between daughters' roles as caregiver and wife: interference or enhancement? *Journal of Gerontology: Psychological Sciences* **50B** (1), P9-P17.

Stephens, M.A.P., Franks, M.F. and Atienza, A.A. (1997). Where two roles intersect: spillover between parent care and employment. *Psychology and Aging* **12** (1), 30-37.

Stoller, E.P. (1983). Parental caregiving by adult children. *Journal of Marriage and the Family* November, 851-858.

Stoller, E.P. and Pugliesi, K.L. (1989). Other roles of caregivers: competing responsibilities or supportive resources? *Journal of Gerontology: Social Sciences* **44** (6), S231-S238.

Stone, R.I. and Short, P.F. (1990). The competing demands of employment and informal caregiving to disabled elders. *Medical Care* **28** (6), 513-526.

Stryker, S. and Serpe, R.T. (1982). Commitment, identity and role behavior. In W. Ickes and E.S. Knowles (eds.) *Personality, roles and social behavior*. New York: Springer-Verlang.

Stryker, S. and Serpe, R.T. (1983). Towards a theory of family influence in the socialization of children. In A. C. Kerckhoff (ed.) *Research in the sociology of education and socialization,* Vol. 4. Greenwich, Connecticut: JAI Press.

Stueve, A. and O'Donnell, L. (1989). Interactions between women and their elderly parents: constraints of daughters' employment. *Research on Aging* **11** (3), 351-353.

Swanson, V., Power, K.G. and Simpson, R.J (1998). Occupational stress and family life: a comparison of male and female doctors. *Journal of Occupational and Organizational Psychology* **71**, 237-260.

Tennstedt, S., Dettling, U. and McKinlay, J. (1992). Refusal rates in a longitudinal study of older people. *Journal of Gerontology: Social Sciences* **47** (6), S318-S328.

Tennstedt, S.L. and Gonyea, J.G. (1994). An agenda for work and eldercare research: methodological challenges and future directions. *Research on Aging* **16** (1), 85-108.

Thoits, P.A. (1983). Multiple identities and psychological well-being; a reformulation and test of the social isolation hypothesis. *American Sociological Review* **48**, 174-187.

Tiedje, L.B., Wortman, C.B., Downey, G., Emmons, C., Biernat, M. and Lang, E. (1990). Women with multiple roles: role compatibility perceptions, satisfaction, and mental health. *Journal of Marriage and the Family* **52** (February), 63-72.

Townsend, A.L. and Franks, M.M. (1995). Binding ties: closeness and conflict in adult children's caregiving relationships. *Psychology and Aging* **10** (3), 343-351.

Voydanoff, P. (1988). Work role characteristics, family structure demands, and work/family conflict. *Journal of Marriage and the Family* **50**, 749-761.

Voydanoff, P. and Donnelly, B.W. (1999). Multiple roles and psychological distress: the intersection of the paid worker, spouse, and parent roles with the role of the adult child. *Journal of Marriage and the Family* **61**, 725-738.

Walker, A.J., Martin, S. S. K. and Jones, L.L. (1992). The benefits and costs of caregiving and care receiving for daughters and mothers. *Journal of Gerontology: Social Sciences* **47** (3), S130-S139.

Warr, P.B., Cook, J.D. and Wall, T.D. (1979). Scales for the measurement of some work attitudes and aspects of psychological well-being. *Journal of Occupational Psychology* **52**, 129-148.

Watson, D., Clark, L.A. and Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. Journal of Personality and Social Psychology **54**, 1063-1070.

Williams, K.J., Suls, J., Alliger, G.M., Learner, S.M. & Wan, C.K. (1991). Multiple role juggling and daily mood states in working mothers: an experience sampling study. *Journal of Applied Psychology* **76** (5), 664-674.

Yates, M.E., Tennstedt, S. and Chang, B.H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *Journal of Gerontology: Psychological Sciences* **54B** (1), P12-P22.

Zedeck, S. and Mosier, K.L. (1990). Work in the family and employing organization. *American Psychologist* **45** (2), 240-251.