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Using Models of Job Strain to Investigate the
Health of Informal Caregivers

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Thesis submitted for the degree of Doctor of Philosophy
School of Psychology
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September 2004



CANDIDATES DECLARATIONS

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For Dad 1946-2003

For Nana 1917-2003

'We will cross that hurdle when we come to it'

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THESIS ABSTRACT

The health impact of informal caregiving has been extensively studied, however there are certain limitations to this research and a number of gaps in the literature. This research has not benefited from the use of theory or multiple methods of measurement. This thesis examines the usefulness of two explicit theories, the Demand-Control (D-C) and the Effort-Reward Imbalance (ERI) models of job strain using a range of measurement instruments. The thesis examines the usefulness of these models in secondary data on Stroke and newly designed studies in Congestive Heart Failure (CHF), which has received limited attention. The present thesis focuses primarily on informal caregiving in CHF. Chapter 2 provides a narrative review on the literature examining informal caregiving in CHF. Chapter 3 uses the D-C Model to predict caregiver emotional distress in both cross-sectional and prospective longitudinal analyses in a data set of Stroke patient/caregivers dyads. Chapter 4 conducts similar analyses using the D-C and the ERI Models to predict Care Work Strain in a new sample of CHF patient/caregivers dyads. Chapter 5 examines the effect of a patient exercise intervention on Care Work Strain in a randomized controlled trial design. The review in Chapter 2 revealed that informal caregiving in CHF is associated with poorer emotional outcomes and difficulties that are unique to CHF. In Chapter 3 and 4 there was strong cross-sectional support for main effects for Control and Reward on emotional distress in Stroke and Care Work Strain in CHF caregivers. In Chapter 5 contrary to prediction, Care Work Strain was significantly higher in the exercise intervention group. Overall, there was some support for the models of job strain, particularly main effects for Control and Reward. There may be some potential for integrating these two constructs theoretically. Therefore further application of the models to informal caregiving is recommended.

Chapter 1

1. **Introduction**

Informal caregiving refers to the provision of unpaid voluntary social support for chronically ill family or friends. Over the past couple of decades research examining the physical and psychological impact of informal caregiving on those providing care has amassed in several disparate health-related disciplines. The main impetus of this research effort is the consistent finding that informal caregivers are at increased risk of a range of physical and psychiatric morbidity (Vitaliano, Zhang, & Scanlan, 2003; Pinquart & Sorensen, 2003a; Pinquart & Sorensen, 2003b; Schulz & Beach, 1999) and that social support to the chronically ill i.e. the caregiving, exerts a beneficial effect on care-recipient health (Cohen, 1988). The primary justifications for the study of this phenomenon is to reduce the health risk associated with informal caregiving and to provide some scientific understanding of the costs and benefits of informal caregiving to individuals and to society.

Empirical papers investigating issues surrounding informal caregiving and health have appeared in journals from a diverse range of fields including: gerontology, academic and applied psychology, medical sociology, occupational therapy, public health, social work, nursing, psychiatry and epidemiology. Given the disparate nature of this research endeavour an unwieldy and disjointed body of findings has emerged. However, it could be argued that theoretical models and methods from psychology in particular have been largely responsible for much of the scientific refinement and attempts at synergy in this often diffuse literature, particularly research relating to stress and coping. The prolific work of psychologist Richard Schulz and colleagues (Schulz et al., 2004; Schulz et al., 2002; Schulz et al., 1999; Schulz & Quittner, 1998; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz, Visintainer, & Williamson, 1990) from the University of Pittsburgh, for example, has been greatly influential in bringing about increasing degrees of sophistication to this research effort. This work has highlighted the role of psychological concepts and methods in understanding important caregiver physical and psychological health outcome measures. Rigorous theoretical testing

of 'stress process' models (Bookwala & Schulz, 2000; Nieboer et al., 1998; Schulz, Tompkins, & Rau, 1988) has been consolidated by several recent papers describing and discussing a range of theoretically derived interventions to reduce negative outcomes for caregivers (Gitlin et al., 2003; Schulz et al., 2003; Martire et al., 2003; Schulz et al., 2002; Bourgeois, Schulz, & Burgio, 1996). The REACH (Resources for Enhancing Alzheimer's Caregiver Health) intervention studies in particular, have been pivotal in driving this work forward. This is a multi-site intervention trial for caregivers of persons with Alzheimer's disease designed to reduce caregiver burden and depression. The results from these studies clearly indicate that these theoretically derived interventions have positive effects for caregivers reducing burden and depression (Gitlin et al., 2003).

As a result of this and other research there is now increasing appreciation of the role of psychological theory and methods in understanding and addressing many issues relating to informal caregiving, however much work remains to be done, and psychology can contribute greatly in moving this field of inquiry forward. As with many rapidly growing research domains in applied psychology, caregiver research is not without its problems. While there is no doubt about the quantity of the ongoing work in this field, there are still clear gaps in the literature and question marks remain regarding the quality of many studies of caregiver health. This thesis presents studies that have attempted to address a number of the empirical, theoretical, conceptual and methodological problems of previous studies.

Overview of Chapter 1

Chapter 1 will describe and discuss the key issues relating to research, conceptualization and measurement issues in the caregiving literature. This will be divided into 5 sections (1) Firstly, several reasons why informal caregiving has and may continue to be a heavily studied topic in psychology and related disciplines will be discussed. (2) A review of the important variables and their measurement in the field will then be presented and criticisms that have often been leveled at theoretical positions in this literature will be considered. (3) A review of the theoretical models underpinning this research will be presented. (4) The proposed theoretical framework and the rationale for the present studies will be discussed. (5) The bias towards research concerning the caregivers of patients with dementing illness, particularly Alzheimer's Disease (AD), and the neglect of a range of physical illnesses, including a focus on Congestive Heart Failure will be discussed.

1.1. Why Study Informal Caregiving?

There are several scientific and social reasons why informal caregiving warrants the attention of researchers. Often these reasons are interlinked as scientific inquiry is often guided by the social problems of the day, however the distinction will be made in this section to aid the organization of this material. The foremost of which will be outlined and discussed in the following sections.

1.1.1. Scientific Importance

1.1.1.1. A paradigm to study the stress-health relationship.

The use of caregiver studies to understand the elusive concept of stress has many distinct scientific advantages (Vedhara, Shanks, Anderson, & Lightman, 2000; Park, Folkman, & Bostrom, 2001; Pearlin, Mullan, Semple, & Skaff, 1990). Firstly, it allows the naturalistic study of an increasingly ubiquitous chronically stressful experience and therefore offers a far superior degree of ecological validity in comparison to laboratory based stress research. Caregiver stressor onset can be acute e.g. caregiving following a first Stroke (Forsberg-Warleby, Moller, & Blomstrand, 2001) or Myocardial Infarction (MI) (Coyne & Smith, 1991), or more gradual and chronic e.g. caregiving for a relative with progressive Alzheimer's Disease or dementia related disorder – (ADRD) (Haley, Levine, Brown, & Bartolucci, 1987) or Congestive Heart Failure (CHF) (Rohrbaugh et al., 2002). The experience of caregiving often includes multi-modal stressors of enormous contextual variability i.e. behavioural, emotional, and cognitive. In turn, the antecedents, mediators, moderators and consequences (strains outcomes and gain outcomes) of caregiver stressors can be studied at each of these levels and indeed at physiological levels in either cross-sectional or prospective longitudinal designs. Finally, caregiving occurs in particular social environments that may or may not be conducive to strain or gain reactions. The quality of the caregiver's environment could also be a main focus for investigation. In essence, the informal caregiving of chronically ill or disabled family or friends offers a useful paradigm in which to study the stress-health relationship. This allows studies at several levels of analysis

The choice of caregiver populations in some recent and highly influential psychophysiological and in particular psychoneuroimmunology (PNI) studies demonstrates the widely held recognition that this research paradigm offers a great deal to the scientific study of the stress-health relationship at both behavioural and physiological levels (Vedhara et al., 1999; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Kiecolt-Glaser et al., 1987). These studies have shown that caregivers show impaired immune or neuro-hormonal response and increased cardiovascular response compared to non-caregivers. This is one of the potential pathways whereby caregiving may exert its effects on health. Other potential mediators of the caregiving-health relationship have been identified, including the health behaviour of the caregiver (Burton, Newsom, Schulz, Hirsch, & German, 1997).

1.1.1.2. An application of systems theory to understand health and illness.

Caregiving is by definition an interpersonal, or perhaps more precisely symbiotic, phenomenon. Some researchers have argued that the study of the impact of caregiving on the care-recipient and the caregiver is an application of a trans-disciplinary approach to science known as systems analysis which incorporates both reductionism and holism (Patterson & Garwick, 1994). This approach is most clearly delineated in 'general systems theory' (von Bertalanffy, 1968), which defines a system as set of elements in a patterned relation to each other. The systems approach postulates that a change in one part of the system will have an effect on other parts of the system and in turn the relationship between systems (Kerns & Weiss, 1994). Systems theory postulates that there are general laws that may be applicable to all systems regardless of the entities that they consist of e.g. humans, organs, molecules and atoms. The self-regulatory, reciprocal nature of the caregiver/care-recipient dyad has obvious relevance and is an example of such a system, which may be separate from the family system. From a systems perspective, the behaviours, emotions cognitions and somatic states of the caregiver and the care-recipient can be understood only by examining the interrelationship in the caregiver/care-recipient dyad or the family system.

Approaching the study of chronic illness in this way has a long history (Litman & Venters, 1979; Litman, 1974). Figure 1.1 illustrates the boundaries in the hierarchy of nested systems in which a care needing individual exists i.e. the care-recipient. Children and siblings are between the boundaries of the caregiving dyad system and the family system, as the caregiving dyad more typically consists of one single distinct dyadic relationship, even when there may be a number of individuals in the family system capable of providing informal care if the spouse is not present, unable or unwilling to provide care. Relatives also fall between the boundary of the family system and the community as there may be great variation in the extent to which these individuals come into contact with the care needing members of their extended family. These differences may be particularly marked across cultures (Dilworth-Anderson, Williams, & Gibson, 2002).

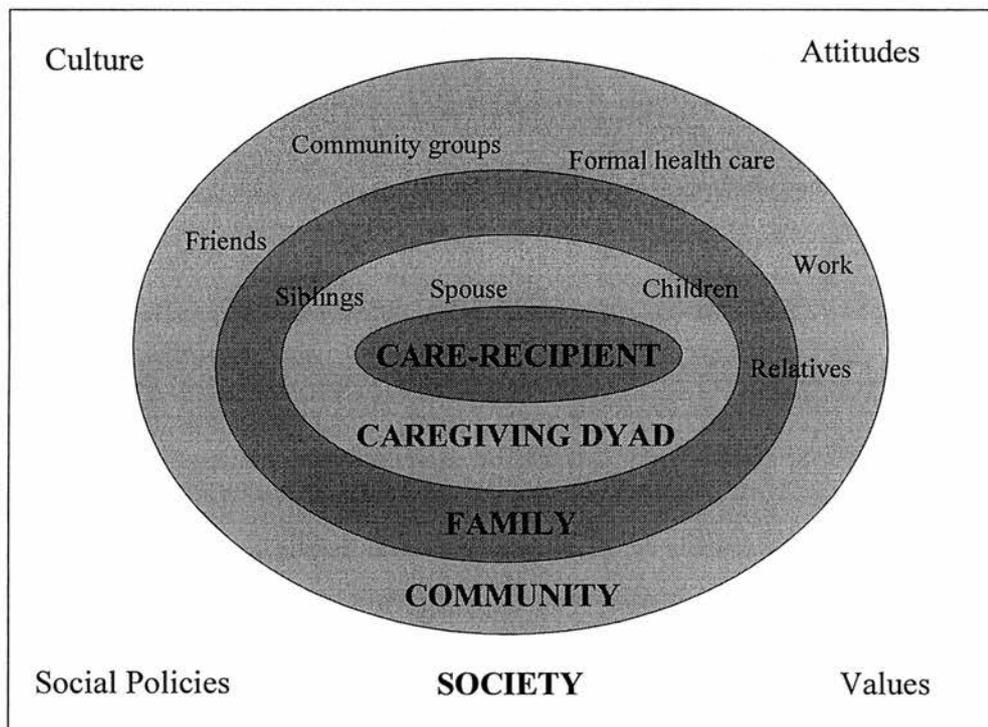


Figure 1.1.

The ecosystem of a care needing chronically ill older adult i.e. the care recipient. Adapted from (Patterson et al., 1994)

The empirical findings relating to health and social relationships clearly support the notion of analysing of an individual's health in terms of the family or caregiving dyad system (Patterson et al., 1994). For example, although caregiving is associated with increased risk of psychological and physical illness in the caregiver, the availability of informal care in the form of social support is generally associated with better health in the individuals receiving support (Cohen, 1988; Cohen & Wills, 1985). Therefore using the caregiving dyad or the family as the unit of analysis to understand adaptation to both chronic illness and the caregiving role may be necessary (Patterson et al., 1994). In clinical and non-clinical samples individuals who lack social support, or who are in other words socially isolated, are at increased risk for poorer health outcomes (Brummett et al., 2001; Murberg & Bru, 2001; House, Landis, & Umberson, 1988). Therefore the caregiver may have an important role to play in the maintenance of the care-recipient's health and there is also some evidence that the care-recipient may have a role to play in the caregivers health, particularly their mental health (Folkman & Moskowitz, 2000; Beach, Schulz, Yee, & Jackson, 2000). A systems framework therefore represents an intuitively appealing paradigm for the study of health, illness and healthcare. However there has been a lack of empirical progress with this approach.

Despite the plausibility of the systems approach it has not inspired a systematic body of research and much of the literature promoting the systems approach to health has focused on caregiving for children with chronic illness or disability (Campbell & Patterson, 1995; Patterson et al., 1994; Patterson, McCubbin, & Warwick, 1990). It could be argued that the main contribution of a family systems approach to health has been at the level of description rather than prediction or explanation. The 'family-system' may also have more relevance for caregiving for children as it is more likely that more than one caregiver is involved in the case of a chronically ill child, whereas an unchanging single dyadic relationship may be more typical of caregiving in older chronically ill adults (Lyons, Zarit, Sayer, & Whitlatch, 2002). Therefore we focus our attention on the caregiving dyad system in the present thesis. The benefits of focusing studies of

informal caregiving to this level of analysis will be considered in subsequent sections.

1.1.2. Social Importance

In addition to the scientific usefulness of the caregiving paradigm for stress, social support and health research, the social significance of this research effort is manifold. However, the foremost and widely cited justifications include the ageing population, the economic value of informal caregiving, the increasing trend towards early discharge and home-based care for a range of chronic illnesses and the health risks associated with being an informal caregiver. Each of these issues will be described and discussed below.

1.1.2.1. Ageing Population.

The combination of the current demographic shift that is marked by an ageing population and the ever-increasing life expectancy that has been brought about by developments in medical science, has resulted in a substantial increase in the amount of care-needing older adults in many developed countries (Butler, 1997). The fiscal strain of providing public health care to this section of society gives research on informal caregiving an obvious urgency to health care spending and policy making (Dunnell, 2001). This population trend is showing no sign of abating and population estimates predict even sharper increases in the amount of elderly care-needing individuals than current levels. Consequently informal caregiving will become a more ubiquitous social phenomenon. Scotland's demography is a typical case in point and figure 1.2 illustrates how the demography of Scotland has changed and is projected to change over the next 20 years. The overall population is expected to remain at just over 5 million, however with a marked decrease in the 0-44 year old category predicted in the next 20 years and small but significant increases in the 60-74, 75-84 and 85+ year old categories, significant changes will occur in the make up of the population. Clearly older adults will make up a far greater proportion of the population than in the past with consequent increases in the incidence and prevalence of age related chronic illness

and disability. This type of demographic trend is typical of several developed countries (Butler, 1997).

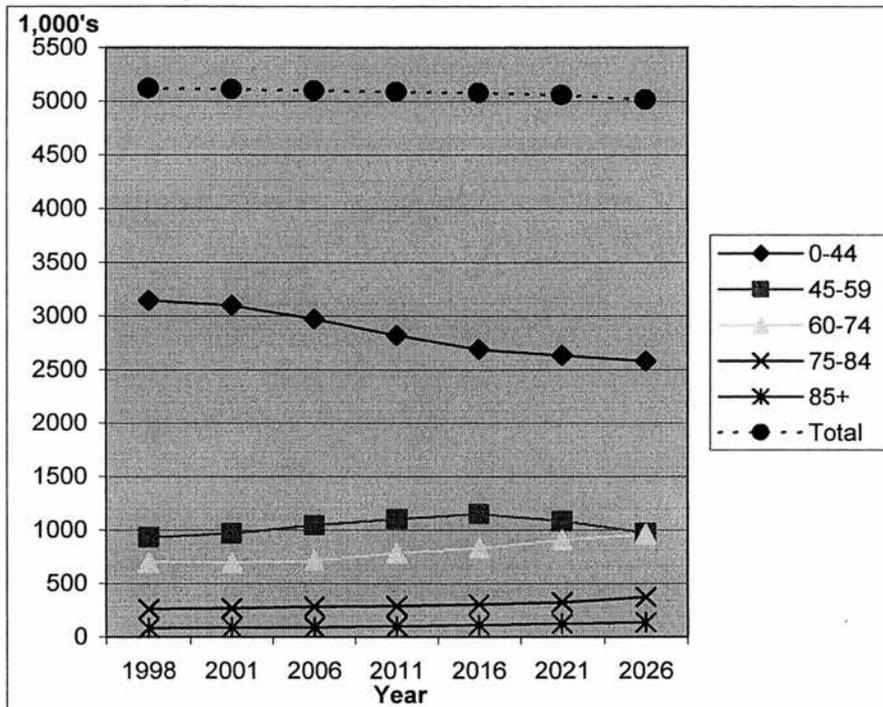


Figure 1.2

Current and projected population trends in Scotland for the next 20 years.

Source: Scottish Executive (2001).

1.1.2.2. The economic value of informal caregiving.

The economic value of informal caregiving has received a great deal of attention in recent times. One recent report has attempted to estimate the present and projected value of caregiver support in the UK (Carers UK, 2002). This report outlined several key points about the costs of caring in the UK. These include:

- Carers' support is worth an estimated £57.4 billion a year which is greater than UK Government and Executive spending on health, which totaled £57 billion in 2001/02.
- The value of carers' support has risen by nearly 70% over eight years.
- There are approximately six million carers throughout the UK.

-
- Every year, an estimated 301,000 people become carers.
 - If the rates of caring remain the same, there could be a shortfall of 2.1 million carers by 2037.
 - At present, a person has a three in five chance of becoming a carer.

Similar studies in the US have put the value of informal caregiving at \$196 billion dollars in 1997, which is greater than the combined estimated value of formal home health care (\$32 billion) and nursing home care (\$83 billion) (Arno, Levine, & Memmott, 1999). It is clear that informal caregivers are providing a valuable service to society, particularly in developed countries where populations are aging and more people are living with chronic illness for more extended periods of time.

Government level recognition of the important role that caregivers play in society and the potential for negative consequences of caregiving has been provided in the form of National Carers Strategy (DoH, 1999), the first of its kind in the UK. This report outlines proposed policy reforms to improve public health provision for caregivers and highlights the vital role that caregivers play in today's society. Similar government policy reforms have been set out in other countries to support informal caregivers in the community such as the national 'Family Caregiver Support Program in the US (Administration on Ageing, 2003) and the Home and Community Care or HACC program in Australia (Department of Health and Ageing Australia, 2004).

Caregiving research is beginning to give more consideration to the economic consequences of caregiving. In a recent randomized controlled trial Patel and colleagues (Patel, Knapp, Evans, Perez, & Kalra, 2004) showed that training the caregivers of stroke patients reduced health care costs for the stroke patient over one year. This finding suggests that providing support and training for caregivers may be an effective means of reducing the ever-increasing cost of chronic illness to the National Health Service.

In a recent study in Canada, Chappell, Havens, Hollander, Miller and McWilliam (2004) have shown that home care is significantly less costly than residential care even when the informal caregiver time is valued at replacement

wage. This finding lends support to the idea that informal caregivers caring for high dependency individuals who would be otherwise in formal institutionalised care should be supported at a financially equivalent replacement wage. While this would involve spending a great deal more money on informal caregivers it may be cost-effective in both the short and long term if it keeps individuals out of costly full-time residential care.

These findings clearly illustrate that the current and predicted economic consequences of informal caregiving are of considerable magnitude and that a review of policy towards informal caregivers in light of economic considerations may be warranted.

1.1.2.3. Increasing Trends toward 'Hospital at Home'

In several clinical conditions home care is increasingly being used and advocated as a substitute for hospital care. There is a growing realization that the home is a more favored, often more beneficial and arguably more effective site of illness management than institutionalized care (Wilson, Wynn, & Parker, 2002; Fried, van Doorn, O'Leary, Tinetti, & Drickamer, 1999). In addition to the obvious benefits for patients, there are health care savings to be made by promoting this type of care. Providing adequate resources and support for caregivers to care for ill or disabled relatives at home alleviates the strain that would otherwise be borne by health services. Several studies have shown that 'Hospital at Home' services can deliver high levels of patient and caregiver satisfaction and such services do not increase the health risk to certain patient groups (Wilson et al., 2002).

In many of the most prevalent clinical conditions of older adults there is an ever-increasing body of research demonstrating the benefits of early discharge (Rudd, Wolfe, Tilling, & Beech, 1997) and post discharge support (Stewart & Horowitz, 2002). Congestive Heart Failure (CHF) is one such condition that places an enormous burden on health services (Stewart et al., 2002). Several recent studies have demonstrated the efficacy of comprehensive discharge planning and post-discharge support for CHF (Phillips et al., 2004) and the argument for improving the community management of this illness is becoming stronger (Piepoli et al., 2002; Hughes et al., 2000). If the trend towards hospital at home for

chronically ill older adults continues then issues surrounding informal caregivers will be of critical importance given the important role that they may assume and the obvious consequences that this may have for them.

1.1.2.4. Health Effects of Informal Caregiving

Although there is considerable variability in how individuals adjust to their role as caregivers, it is clear that informal caregivers are an at-risk population for poor health themselves. After adjusting for sociodemographic factors, prevalent disease, and sub-clinical cardiovascular disease, Schulz & Beach (1999) found in a four year follow-up that spousal caregivers that were experiencing caregiver strain at study entry had mortality risks that were 63% higher than noncaregiving controls. Other well-designed prospective studies have confirmed the health risk (Vitaliano et al., 2002; Shaw et al., 1997). Two recent rigorous meta-analysis have also reached the conclusion that caregiving is consistently related to poor physical and psychological health with the effect on psychological health being greater (Vitaliano et al., 2003; Pinquart et al., 2003b). Many informal caregivers are older adults with poor health themselves (Department of Health, 1999). Given the vulnerability of this group for poor health, research should attempt to develop ways of reducing the health inequalities that are associated with being an informal caregiver.

1.1.2.5. *Conclusion*

The study of informal caregiving clearly offers a useful paradigm to investigate many issues relating to health and illness at several levels of scientific analysis. If current demographic trends continue health services may need to consider informal caregivers to a greater degree than they have in the past when setting out health policy. It seems likely that greater integration of informal caregivers into formal systems of health care will be necessary in the future.

1.2. What are the most robust findings in the study of caregiver health?

Despite the vast extent of this literature there have been relatively few robust findings in this field of research. However a number of reliable findings have

emerged from this body of work. A selection of the most robust and widely-cited findings are included in the table 1.1. Further discussion and consideration of these findings will be provided in subsequent sections in the thesis.

Table 1.1

Robust findings in the caregiver literature.

Key Finding	Key papers or Meta-analysis/ Reviews
1. Caregivers have worse physical and psychological health than non-caregivers.	(Vitaliano et al., 2003; Pinquart et al., 2003b; Schulz et al., 1999)
2. Females are more likely to be caregivers.	(Stone, Cafferata, & Sangl, 1987)
3. Female caregivers report higher levels of burden and emotional distress than males.	(Yee & Schulz, 2000; Barusch & Spaid, 1989)
4. Non-spousal caregiving is associated with poorer outcomes than spousal caregiving.	(Young & Kahana, 1989)
5. Dementia caregiving has a greater impact on caregivers than non-dementia caregiving.	(Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999)
6. Caregivers have impaired immune response compared to non-caregivers	(Kiecolt-Glaser et al., 1991; Kiecolt-Glaser et al., 1987)
7. Caregiving can also have a positive impact on caregiver psychological health.	(Folkman, 1997; Kramer, 1997)
8. Complex caregiver interventions can reduce perceived burden and depression.	(Gitlin et al., 2003; Sorensen, Pinquart, & Duberstein, 2002)

1.3. Operational Definitions

1.3.1. Caregiver health and well-being

‘Caregiver health’ (and well-being) is perhaps the most generic term that could be used to describe the broad body of work that describes the studies conducted in this thesis and those that are referred to. If we subscribe to the World Health Organisation definition of health then health is ‘a state of complete physical, mental and social well being and not merely the absence of disease or infirmity’

(WHO, 1948). Therefore research examining inter alia caregiver burden/ strain, emotional distress and self-reported health and quality of life falls under the rubric of 'caregiver health' research. However it is important to consider how these outcomes are related and which might be most appropriate for a given research question and study design.

Empirically caregiver burden appears to be the most sensitive measure of caregiver health, as it is the most responsive to intervention (Schulz et al., 2002) and it shows the strongest relationship with caregiver stressors e.g care-recipient physical and cognitive impairments (Pinquart et al., 2003a). This is followed by measures of emotional distress (Gitlin et al., 2003). Self-reported health and some physiological indicators of health may have the weakest relationship with caregiver stressors and may be the least responsive measure to caregiver interventions. Demonstrating effects on these types of measures requires prospective longitudinal studies and/or large sample sizes and/or tightly controlled experimental conditions, as caregiving may take a considerable amount of time before it exerts discernible effects on these measures of health and meta-analysis suggest small to moderate effect sizes of these types of variables (Vitaliano et al., 2003).

1.3.2. What is an 'informal caregiver'?

Arguably, the most fundamental definition needing elucidation in this literature is that of the caregiver (also referred to as the carer). The enormous variation in how these individuals are identified and defined in this literature has been noted in several important reviews (Malonebeach & Zarit, 1991; Barer & Johnson, 1990). Flexible definitions of the caregiver tend to be less helpful and are often criticized as potential confounds (Martire & Schulz, 2001; Vitaliano, Young, & Russo, 1991) when the findings of caregiver studies are reviewed. This is certainly a fundamental issue and disagreement over the definition of an informal caregiver may threaten the validity of the whole field of research.

Caregivers have been frequently defined as the individual who most often provides informal (unpaid and voluntary, usually friends or relatives) assistance with a minimum number of either the activities of daily living (ADL'S) e.g.

feeding, dressing and mobility, or instrumental activities of daily living (IADL's) e.g. shopping, preparing meals and taking medication. The term 'primary support person' is sometimes used to describe the person that assumes this role for care recipient (Schulz et al., 1988). While such definitions are useful there is often no standardized method of establishing who this individual may be. For example, do you ask the caregiver, the care recipient or some other health-professional about who provides what level of care? In addition studies have shown that there is often considerable discrepancy between the caregiver and the care recipient's assessment of care needs (Knapp & Hewison, 1999; Bookwala & Schulz, 1998; Mackenzie, Robiner, & Knopman, 1989) with caregivers generally reporting greater care needs than care recipients. Therefore care-recipients may not identify family members as caregivers, while family members may see themselves as obvious caregivers and possibly vice versa. It is clear that the definition of informal caregivers requires more rigorous parameters than have been routinely used in this literature.

In order to illustrate the variability that exists in defining caregivers Table 1.2 illustrates how caregivers have been operationalised in a number of seminal and highly cited research papers in a range of clinical conditions. The definitions used in these studies show considerable discrepancy. For example a number of studies have used only spousal caregivers (Schulz et al., 1999; Kiecolt-Glaser et al., 1991), see table 1.2. It is not clear whether these studies can be usefully compared to heterogenous samples of caregivers or whether effects found for spousal caregivers should be expected in non-spousal caregivers. Furthermore studies of adult children providing care for their parents may represent another distinct caregiving group given the close genetic relationship between caregiver and care-recipient. The burgeoning field of evolutionary psychology, more specifically kinship theory (Trivers, 1971), would argue that the degree of relationship between two individuals profoundly effects how they behave towards each other (Daly & Wilson, 1988). From this perspective the degree of genetic relatedness is one of the most powerful predictors of extreme behaviour, such as homicide, yet few caregiving studies have examined the role of relatedness in explaining caregiver behaviour.

In addition (Dura & Kiecolt-Glaser, 1990) have argued that sampling bias exists in many studies of informal caregivers. This study showed that there were significant differences between caregivers that were interviewed in their own homes versus caregivers that attended university hospitals for interview, with caregivers being interview at home reporting significantly higher levels of depression.

Table 1.2

Comparing recruitment and definition of caregivers.

Study	Times cited June 04 WoS*	Illness category	Definition of caregiver
(Schulz et al., 1999)	179	Dementia	Spousal caregivers. Caregivers were defined as individuals whose spouse had difficulty with at least 1 activity of daily living “due to physical or health problems or problems with confusion.”
(Given et al., 1993)	68	Cancer	Each patient was asked to identify his or her primary caregiver. In a subsequent telephone interview the caregiver was asked to verify their role as primary caregiver.
(Kiecolt-Glaser et al., 1991)	302	Dementia	Spousal caregivers. Caregivers had to be providing 5 or more hours of care a week. Recruited from three local dementia evaluation centers, neurologist referrals, AD support groups, respite care programs and governmental support programs.
(Schulz & Williamson, 1991)	145	Alzheimer’s (AD)	Primary caregivers of family members with possible or probable AD. AD patients were recruited from sources of AD and related diseases diagnostic centers.
(Schulz et al., 1988)	106	Stroke	Primary-support-person of individuals who had a stroke within the previous 3 to 10 weeks and who were living in the community before the stroke. Patients recruited from 9 different hospitals. Friend or relative identified as ‘primary-support- person’.
(Haley et al., 1987)	205	Dementia	Family caregivers of elderly patients with dementia were recruited from a local Alzheimer’s society, social service and health care agencies, newspaper and radio advertisements and professional referrals.

*WoS Web of Science

1.3.3. What is caregiving or 'Care work'?

In addition to providing physical assistance with activities of daily living, care work can also involve emotional support and enduring a range of problem behaviours. These behaviours are often the result of cognitive decline in certain clinical conditions e.g. dementing illnesses such as Alzheimer's Disease (AD). However problem behaviours may also be related to the psychological distress that accompanies many non-dementing chronic illnesses or disabilities. A large body of research has described the various negative emotional responses that often accompany declines in functional ability CHF- (Freeland et al., 2003); Stroke- (Burvill et al., 1995); Myocardial Infarction- (Frasure-Smith, Lesperance, & Talajic, 1995). This can result in a variety of problem behaviours in the care recipient, including those with intact mental status. As a result family caregivers often have to endure, attend to or actively monitor ill family members behaviours and mood. The cognitive effort involved has been compared to that required for an experimental or vigilance task (Orbell & Gillies, 1993). Several caregiving studies have shown that behavioural problems are often perceived as more stressful than patient self-care impairments (Schulz et al., 1995; Haley et al., 1987). Therefore it may be important to take both task assistance and behavioural problem management into consideration, but particularly although not exclusively, those care-recipients where cognitive deficit is present, when formulating variables aimed to measure caregiver work or caregiver demand.

1.3.4. Methods of Measurement

By far the most common form of measurement technique in this research is the self-report questionnaire. The use of self-report questionnaires has clear benefits e.g cost effectiveness, convenience, ease of administration to large samples, established reliability, validity and sensitivity, in this type of research, however there are a number of limitations to this type of measurement, which will be discussed in the following sections. Observational and physiological methods of measurement have been used less frequently. These will be described and discussed in the following sections.

The over-reliance on self-report measures as both predictor and outcome variables is a particular problem of this literature. This gives rise to a number of problems in particular method variance, which is a particular affliction of self-report measures (Podsakoff, Mackenzie, Lee, & Podsakoff, 2003). Common method variance refers to the variance that is attributable to the measurement method rather than the constructs the measures represent. One source of common method variance is negative affectivity. This has been one of the most discussed sources of method variance in studies examining the stress-health relationship using self-report measures as independent and dependent variables (Watson & Pennebaker, 1989). Negative affectivity refers to the propensity of respondents to view themselves and the world around them in generally negative terms. When both independent and dependent variables are obtained using self-report from the same individual then negative affectivity may be a potential confound (Lazarus, DeLongis, Folkman, & Gruen, 1985). Other commonly discussed types of method biases include social desirability and acquiescence. Social desirability refers to the tendency of some people to respond to items more as a result of their social acceptability than their true feelings. Acquiescence refers to the propensity for respondents to consistently agree (or disagree) with questionnaire items independent of their content. When this type of error variance is systematic it can have a serious confounding influence on empirical results providing misleading results. There are a number of different procedural and statistical techniques that can be used to control method biases (Podsakoff et al., 2003), however using multiple modes of measurement is one of the most prudent.

It is important to note that some of the variables that are described and discussed in the following sections have been used as both outcome and independent variables in different studies. For example caregiver burden has been variously used used as an outcome and a mediating variable. Whether a variable is a predictor or an outcome variable will depend on the study's research questions and the theoretical framework being used. In the following sections variables are classified according to their most frequent use in this literature.

1.3.5. *Study designs*

While it is difficult to conceive of a truly experimental approach to examining the health effects of informal caregiving, as obviously individuals cannot be randomized to caregiving conditions nor can caregivers be identified before they become caregivers, sophisticated research designs to answer questions concerning caregiver health are possible in this quasi-experimental field. However reviews and meta-analyses that have examined the research investigating caregiver health have found that the majority of studies have used cross-sectional designs (Pinquart et al., 2003a; Pinquart et al., 2003b), which have obvious limitations. However there is now a considerable body of prospective longitudinal research (Vitaliano et al., 2003) and the ever increasing intervention literature has produced a significant body of experimental designs e.g. randomized controlled trials (Gitlin et al., 2003; Sorensen et al., 2002). These types of research designs are necessary in order to establish causal mechanisms in the stress-health relationship.

1.3.6. *What are the most commonly studied variables?*

Measures can probably be most usefully differentiated into those that are sociodemographic, psychological e.g. self-report measures of well-being, emotional distress, caregiver burden, and those that are physical e.g. biomedical indices of physiological function or behavioural measures such as visits to the doctor or medication use. It is important to note that the boundaries between these categories are not always clear as there are physical indicators of health that use self-report e.g. the Short-Form 36 (Hemingway, Stafford, Stansfeld, Shipley, & Marmot, 1997). As there has been a vast array of different measures, particularly self-report measures that have been used in this research each and every instrument will not be considered in the next section. The next section will be divided into independent and outcome variables. In each section a selection of the most popular and widely used measures that have been used to examine the key concepts will be provided.

1.3.6.1. Dependent or outcome variables

Caregiver Burden or Strain

The concept most often reported in the literature is caregiver burden, which has sometimes been used interchangeably with caregiver strain. There have been a number of attempts to delineate what this construct encompasses. George & Gwyther (1986 p 253) described caregiver burden as ‘the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults.’ Montgomery (1990 p. 204) provides the following definition of the concept, ‘the extent to which the caregiving role is judged to infringe upon an individuals life space and be oppressive.’ Vitaliano, Young, & Russo (1991) provided a comprehensive review of the commonly used measures that aim to tap this variable. Several shortcomings of many of the commonly used scales were identified. They found that relatively few of these measures report content validity, convergent/divergent validity, criterion validity or sensitivity to change. Such lack of concern for variable measurement is clearly counter-productive to this research effort. Other researchers have shown that social desirability is a particular problem with measures of caregiver burden, particularly among spousal caregivers (O'Rourke et al., 1996).

Despite these clear limitations, these measures continue to be widely used, with the Zarit Burden Interview (O'Rourke & Tuokko, 2003; Bedard et al., 2001; Zarit, Reever, & Bach-Peterson, 1980) and the Caregiver Strain Index (Thornton & Travis, 2003; Robinson, 1983) being two of the most popular. Other typical measures include the Screen for Caregiver Burden (SCB) (Vitaliano, Russo, Young, Becker, & Maiuro, 1991), Caregiver Reaction Assessment (Given et al., 1992), Caregiving Hassles Scale (Kinney & Stephens, 1989) and the Impact of Informal Caregiving Scale (Orbell, Hopkins & Gillies, 1993). There have been many abbreviated and modified variations of these burden scales used and development of these types of measures is continuing (Thornton et al., 2003). One recent study for example has attempted to develop a task specific burden measure, the ‘family caregiver medication administration hassles scale’ (Travis, Bernard, McAuley, Thornton, & Kole, 2003). Given the ever-increasing complexity of drug

regimens this scale may be a useful addition, however the value of increasing the specificity of burden measures to this extent has yet to be established.

In addition to the negative aspects of caregiving there has also been debate about the positive impacts or consequences of caregiving (Kramer, 1997; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989) and a number of scales have been developed that include measures such as caregiver satisfaction e.g. the Impact of Informal Caregiving Scale (Orbell, Hopkins & Gillies, 1993). The importance of positive psychological states and traits in adaptation and well-being is increasingly emphasized in the wider psychological literature, in particular positive emotional states in the coping process (Fredrickson & Joiner, 2002; Fredrickson, 2001; Folkman et al., 2000).

Some researchers have argued that general well-being is a much more useful concept than situation specific outcome measures such as caregiver burden (George & Gwyther, 1986), as these burden measures do not allow comparison across different populations experiencing different types of stress. In addition it is argued that general measures allow clearer conceptual and empirical separation from caregiver variables that might explain negative health outcomes. These types of general well-being measures may be more useful than caregiving specific measures for certain types of research question. However the argument for retaining caregiving specific measures has also been strongly made (Stull, Kosloski, & Kercher, 1994). Caregiving specific measures, researchers claim, give a deeper understanding of the caregiving process than general well-being measures (Braithwaite, 2000) and caregiver burden in particular may usefully elucidate certain types of caregiver behaviour e.g. relinquishing the caregiving role, placing the care-recipient in institutional care (Pruchno, Michaels & Potashnik, 1990).

There are clear limitations to relying solely on self-report measures of burden such as those outlined by Vitaliano et. al (1991). We need to know the consequences for the varying levels of reported burden, in terms of physical and psychological health of the caregiver or changes in the care-recipient, thereby establishing stronger construct validity for the variable. More recent studies have attempted to reduce the ambiguity surrounding measurement and

conceptualization of burden (Chappell & Reid, 2002; Yates, Tennstedt, & Chang, 1999). However much confusion is still apparent.

Perhaps of most importance, particularly in the medical community is the issue of the clinical significance of these types of measure (Schulz et al., 2002). Clinical significance refers to the effects of interventions or more precisely independent variables on clinically relevant outcomes such as mortality, morbidity, health care use and expenditure. The distinction between statistical and practical significance is pertinent. What do effects on burden or strain measures mean in these sort of clinical terms? If we get a significant increase or reduction in burden as a result of some intervention what does this mean in terms of caregiver health or care-recipient health status? In the recent 'Reach' Alzheimer's caregiver intervention studies a burden measure was developed (Roth et al., 2003) that gave particular attention to the role of clinical significance (Schulz et al., 2002). The effect size achieved on the burden measure was equated to the elimination of a certain number of problem behaviours in the care-recipient.

Emotional problems- Anxiety and Depression

Generic standardized measures of anxiety and depression are often used as outcome variables in caregiver studies. The Center for Epidemiologic Studies Depression Scale or CES-D (Radloff, 1977) has been the most widely used, particularly in studies in the US (Gitlin et al., 2003). The shorter Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) has also been extensively used as an outcome variable (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Andersson, 1996). Other types of commonly used measure of emotional distress include the Beck Depression Inventory (Rabkin, Wagner, & Del Bene, 2000) and the State-Trait Anxiety Inventory (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000). The Profile of Mood States (POMS) (Cameron, Franche, Rene-Louise, Cheung, & Stewart, 2002) and the positive and negative affect scale (PANAS) (Stephens, Franks, & Townsend, 1994) have also been used in a number of studies. These types of measures have well-established psychometric properties and allow comparisons across studies and with established norm values for the measures. In a smaller number of studies the Structured Clinical Interview for

DSM-IV has also been used (Rabkin et al., 2000; Redinbaugh, MacCallum, & Kiecolt-Glaser, 1995).

Perceived stress scales

A number of generic self-reported stress scales have been used as outcomes in caregiver studies, these include the widely used perceived stress scale or PSS (Schwarz & Dunphy, 2003; Hooker et al., 2000), the relatives stress scale (RSS) (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Draper, Poulos, Cole, Poulos, & Ehrlich, 1992). These allow comparison across studies and populations, however as with burden measures the clinical significance of statistically significant effects on these variables has not yet been established. In addition it is unclear what these scales add beyond the well-established trait and state measures of negative affectivity.

Caregiver Satisfaction or 'Uplifts'

There is an increasing trend towards including positive outcomes particularly positive emotions in caregivers studies (Billings, Folkman, Acree, & Moskowitz, 2000; Folkman, 1997). Measures of positive affect, caregiver satisfaction and caregiver 'uplifts' have been examined (Pinquart et al., 2003a). As mentioned above, this is following a broader recent trend in psychology to incorporate positive emotional and behavioural variables into coping research and theory (Folkman, 1997). Generic life satisfaction scales have also been used (Chappell et al., 2002) to assess a general well-being. As with generic emotional distress measures these measure allow comparison with non-caregiving populations.

Self-report general measure of health status or quality of life.

Self-report measures of health related quality of life or more global health status have also been used to assess the health of informal caregivers. The Short-From 36 (SF-36) (Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999) and various abbreviated versions of it and other more global measures of health status such as the General Health Questionnaire (GHQ) (Draper, Poulos, Cole,

Poulos, & Ehrlich, 1992) have been used to assess more global aspects of health rather than emotional or other more specific components of health. Generic quality of life measures have also been widely used such as the EuroQoL (Kalra et al., 2004). Individualized measures of quality of life, such as the Schedule for Individual Quality of Life or SEIQoL are also being increasingly used to examine patient quality of life, however this has yet to be widely applied in studies investigating informal caregiving (Hickey, O'Boyle, McGee, & McDonald, 1997).

Physiological measures

Direct physiological markers of caregiver health have received a great deal more attention in the last 10 to 15 years. These measures are becoming increasingly sophisticated, particularly the immune status measures that are used in psychoneuroimmunology (PNI) studies (Vitaliano et al., 2003; Bauer et al., 2000; Kiecolt-Glaser et al., 1991). These studies have compared caregivers and non-caregivers on various immune parameters such as natural killer cell activity (NKA) or speed of healing of a standardized skin puncture wound. Stress hormones e.g. cortisol (Vedhara et al., 2002), neurotransmitters and antibodies have also been assessed (Mills, Yu, Ziegler, Patterson, & Grant, 1999). Other studies have looked at caregiver cardiovascular responses such as heart rate and blood pressure (Uchino, Kiecolt-Glaser, & Cacioppo, 1992), change in weight (Vitaliano, Scanlan, Krenz, Schwartz, & Marcovina, 1996) or composite measures such as metabolic syndrome (Vitaliano, Scanlan, Siegler, McCormick, & Knopp, 1998) compared to non-caregivers. In addition a notable 4-year prospective study following a large caregiving cohort has clearly shown an increased risk for mortality (Schulz et al., 1999).

Self-reported caregiver health behaviours

A substantial number of studies have used self-report measures of caregiver behaviour (Burton et al., 1997). These include medication use (Haley et al., 1995), physician visits (O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996) and number of days in hospital or bed in the last 12 months (Lorensini & Bates, 1997). If caregivers reduce their healthful behaviour, this may represent a

potential mechanism whereby caregiving may effect health independent of any negative cognitive or emotional states. While there is a strong argument for behavioural outcomes in health research (Kaplan, 1990) the reliability and validity of some of these measures of caregiver health behaviour is not so well-established.

1.3.6.2. Independent variables

Socio-demographics

Age of caregiver, gender of caregiver and kin relationship to care-recipient all have well-established associations with caregiver strain outcomes. Being younger, female and more closely related kin of the care-recipient is associated with poorer outcomes (Pinquart et al., 2003b; Cantor, 1983). Reviews suggest that income is the only socio-economic indicator that has been reliably associated with caregiver health. Lower income is associated with higher levels of depression or distress (Schulz et al., 1995). A recent multi-center study of over 5000 caregivers in the US supported this finding (Covinsky et al., 2003). However the relationship between other indicators of general and specific caregiver SES has not been studied in a systematic way and there are a number of contradictory findings.

Cultural differences in caregiving have been extensively studied, with some evidence that ethnic minorities may have poorer support and outcomes than Whites (Janevic & Connell, 2001), and that they may be more responsive to caregiver interventions (Gitlin et al., 2003), however this type of findings may be hard to separate from the effects of socioeconomic position.

Quantity of time spent caring.

The most obvious variable that was initially thought to be responsible for negative outcomes in caregivers was the quantity of time spent caring. These types of variables are confounded with other variables that are known to be important such as relationship to the care-recipient and co-residency. Given the difficulty of estimating the actual time that a co-resident spouse spends 'caregiving' then this variable has obvious measurement and conceptual difficulties particularly for caregivers and care recipients that are co-residents. Therefore the usefulness of this variable remains unclear.

Quality of the relationship between caregiver and care-recipient

There is a significant body of research demonstrating that various conceptualizations of the quality of the relationship between the caregiver and the care-recipient may have mediating and/or moderating roles between caregiver stressors and outcomes. (Williamson & Shaffer, 2001; Lawrence, Tennstedt, & Assmann, 1998). Specific predictions regarding the effect of relationship quality on caregiver outcomes have varied greatly, however despite the lack of consensus about specific effects reviews generally agree that relationship quality is a variable that should not be overlooked (Pinquart et al., 2003b; Vitaliano et al., 2003).

Measures of care recipient functional impairment.

Measures of the consequences of care recipient disease i.e. cognitive or physical impairment have not shown consistent relationships with caregiver well being (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pagel, Becker, & Coppel, 1985; Zarit et al., 1980). This may be due in part to the problems associated with defining and measuring these constructs (Johnston & Pollard, 2001) or possibly due to differences between proxy reports and objective measures of functional ability (Loewenstein et al., 2001). However reviews suggest that greater care-recipient cognitive or physical impairment is related to higher burden and depression (Pinquart et al., 2003a) and that variation of effects found may be explained by sampling techniques. For example larger effects are found in probability as opposed to convenience samples.

Measures of care recipient behaviour problems

The influence of care-recipient behaviour problems on caregiver strain outcomes was perhaps most clearly shown in a study by Pruchno & Resch, (1989b). This study showed that levels of behaviour problems were associated with poorer caregiver outcomes. This explained why Alzheimer's disease caregivers experienced greatest distress in the early to mid stages of the illness when care-recipient behavioural problems were at there greatest. A meta-analysis by Pinquart & Sorensonet (2003a) confirmed the importance of behavioural

problems in predicting caregiver burden and depression particularly in Alzheimer's Diseases (AD) and related disorders. It is important to note however that care-recipient behaviour problems are usually measured using self-reported scales and the relationship with self-reported measures of burden or depression may always be strong particularly if both measures are provided by the caregiver, due to the influence of negative affectivity on both measures (Watson et al., 1989). Therefore this relationship may be spuriously over-inflated. For example non-depressed caregivers may not notice behaviour problems or may not be bothered by them, whereas depressed caregivers may over-report the presence of behavioural problems and the associated bother of managing these behaviours. In addition care recipient behaviour problems may be more typical of specific clinical conditions such as Alzheimer's Disease and this may have more limited use as a predictor in the more typical caregiving scenario.

Psychological variables

A litany of personality and contextual psychological variables have been identified as predictors of caregiving outcomes. The most commonly studied psychological variables include perceived social support (Haley et al., 1995), caregiver personality variables such as mastery and neuroticism (Bookwala et al., 1998; Hooker, Frazier, & Monahan, 1994), caregiver appraisal (Haley et al., 1996), ways of coping (McKee et al., 1997), perceived control (Park et al., 2001), self-esteem (Chappell et al., 2002) and caregiver resources (Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Making sense of such a vast array of concepts is difficult and many of the variables may be measuring the same underlying construct. For example there have been many formulations and operationalisations of the concept of personal control, which may not represent separate constructs (Skinner, 1996). The many competing theories and few attempts at theoretical integration in psychological research, particularly of emotions, does not lend itself the production of a coherent body of findings. Such is the extent of investigations into psychological factors that influence caregiver health and well-being that a comprehensive review is beyond the scope of the present thesis. Several informative reviews of this literature have been produced (Martire & Schulz,

2001) and readers should consult these for a more detailed exposition of the psychological factors that influence caregiver health.

1.3.7. Conclusion

There have been notable improvements in studies investigating the physical and psychological impact of informal caregiving over the past couple of decades. In particular there has been considerable advances in improving the measurement of some key variables, a greater range of study designs e.g. prospective longitudinal and randomized controlled trials have been used and there has been increasingly sophisticated analytical procedures used e.g. structural equation modeling to test theoretical models. However the development of theory has received limited attention. In particular there have been no attempts to link the caregiving literature with other research efforts examining chronic stress. This I will argue in the next section has hindered the development of cumulative body of knowledge on the stress-health relationship particularly in informal caregiving. The next section will critically discuss the theoretical frameworks that have been applied in these studies and examine a number of models of stress from the job strain literature, which may have some unexploited potential in examining the impact of informal caregiving.

1.4. Theoretical models used to study caregiver health.

1.4.1. How is caregiving hazardous to health?

In order to pursue a theoretical model of stress and health for informal caregiving we must first be clear that caregivers represent some deviation from population norms in terms of health. It has long been asserted that informal caregiving is associated with poorer physical and psychological health (Zarit et al., 1980; Kiecolt-Glaser et al., 1987; Cohen & Eisdorfer, 1988), however systematic quantitative reviews of the literature examining this claim have only been conducted and published in last couple of years (Vitaliano et al., 2003; Pinguart et al., 2003b). These reviews have confirmed that the weight of evidence supports the claim that caregivers have poorer physical and psychological health than

demographically matched non-caregivers. Therefore the answer to question ‘is caregiving hazardous to health?’ appears to be yes according to the current data. This legitimises the question of ‘how does caregiving influence the health of informal caregivers?’

An adequate explanation of the health inequality suffered by informal caregivers has not yet been developed. Conceptual and critical reviews of this vast and disparate literature (Vitaliano, Zhang, & Scanlan, 2003; Kramer, 1997; Barer et al., 1990) have noted that many of these studies have made few attempts to use, test and develop theoretical positions or explanatory models of caregiver health and well-being. This has resulted in a body of work that is data rich but theory poor, which has impeded the swift progression of this field of research. While we have vast amounts of data on caregiver physical and psychological health, there is little organization to this information and this may not be conducive to understanding and improving caregiver health and well-being and ultimately answering the next logical research question in caregiving research, ‘how does caregiving influence the health of informal caregivers?’

1.4.2. Why do we need theory to understand caregiver health?

It is important to note that an atheoretical approach is not always problematic in itself, so long as it is justified. For example exploratory work or qualitative methods can contribute greatly to the advancement of the field, particularly in the early stages of the research effort to understand social phenomena such as informal caregiving. As caregiving is by definition a social phenomena then these atheoretical approaches such as this may indeed be useful. However if quantitative exploratory methods have to be used, then the likelihood of Type I error must be considered and alpha levels adjusted according to the number of analysis performed. In particular the detection of unpredicted interactions between independent variables are particularly likely to give rise to spurious findings. However analysis of interaction effects continues to be conducted in this research without an explicit reason for testing for such effects. Therefore atheoretical approaches may be of limited use in quantitative research. In addition atheoretical qualitative approaches may be questionable unless some very specific aspect of the

caregiving situation is being examined, as there has been intensive inquiry into this area for almost 25 years. Therefore most of the key themes relating to informal caregiving and health have already been identified.

The use of a clear theoretical model of caregiver health and well-being has several advantages which are being increasingly articulated (Pillemer, Suito, & Wethington, 2003). Firstly it allows the researcher to organize the findings from a range of studies into a coherent explanatory structure. Clear predictions can then be derived from the theoretical model. For example main versus interactive effects can be specified. This makes for a much more coherent and cohesive enterprise. This is of enormous benefit to both the scientist investigating caregiving and the practitioner treating caregivers. Despite these obvious benefits theory is not always given its deserved prominence in much of this literature. Ultimately the use of theory is conducive to the scientific goal of the accumulation of knowledge.

The absence of an explicit theoretical model may make research findings vague and the development of a cumulative body of knowledge on the subject is impeded. Failing to provide an adequate theoretical framework than provides testable hypotheses creates fundamental difficulties with defining the parameters of investigation and detracts enormously from the quality of this important research. Many of the conflicting and counter-intuitive results reported in this field, it has been argued, may be attributable to the weak theoretical base to this work (Braithwaite, 1996; Orbell, 1996; Pearlin et al., 1990).

A number of distinctly different explanatory models pervade in this literature attempting to delineate why physical or psychological health might suffer as a result of caregiving. The choice of a particular theoretical model in this research is crucial for two main reasons. Firstly it outlines the parameters in which the research will attempt to describe and explain the caregiver health. Secondly, if the data support the selected theoretical model, it will guide the researchers suggested or implemented interventions aimed at reducing strain.

1.4.3. What theories have been used?

When psychological theory is used in studies examining caregiver health and well-being, it is often some adaptation of the basic stress-coping model which

has been clearly outlined by Elliot and Eisdorfer (1982) in the basic x-y-z stress model. This is not a formal model of the stress- health process but a simple conceptual illustration of how variables can be theoretically organized. This model is illustrated in figure 1.3. The model has three primary elements. X represents potential activators, Y represents individual's reaction to activators and Z represents consequences to the reactions. Mediators are believed to be the filters and modifiers that act on each stage of the x-y-z sequence to produce individual variation. This basic conceptualization is implicit in the research design and analysis of many studies of informal caregiving and the basic formulation fits with most theoretical approaches to stress and health.

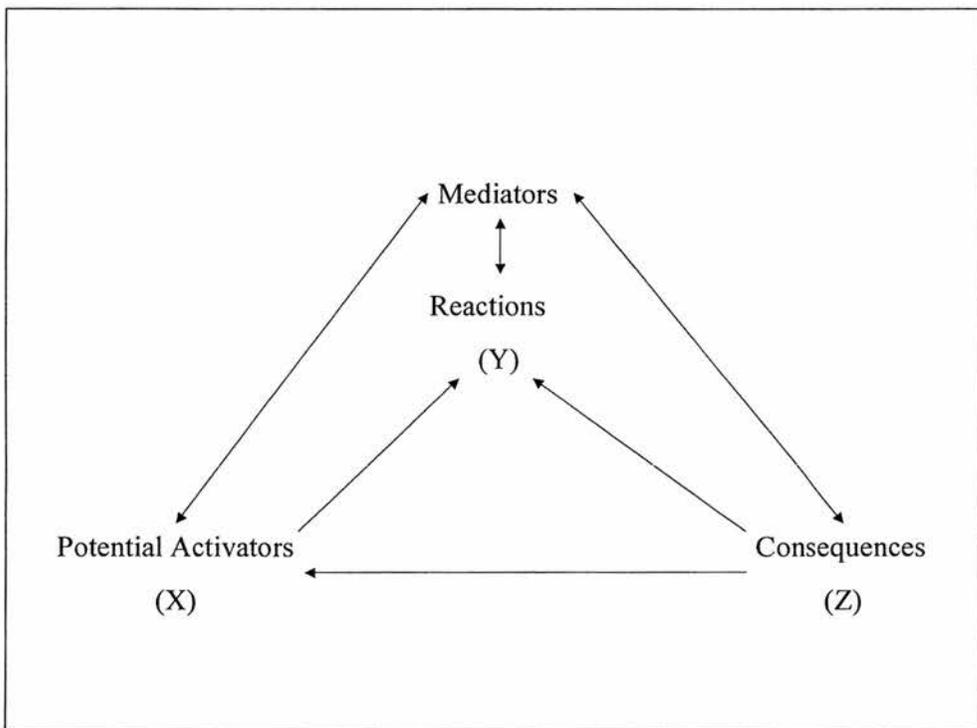


Figure 1.3

The basic x-y-z stress model (Elliot & Eisdorfer, 1982, taken from Schulz, 2000).

Of the more specific theoretical models of caregiver health that have been proposed, they could be usefully differentiated into three main categories: those that focus on caregiver's 'environment' as the fundamental agent of health, those

that focus on caregiver's interpretation or 'appraisal' of their situation as the key agent of strain and those that focus on the biological processes associated with strain. It is important to note that these approaches are not mutually exclusive. It is clear that the role of environmental, social-cognitive variables and biological processes in the stress processes is generally not disputed, however the relative importance of each may depend on the researchers' theoretical leanings e.g. Lazarus and Folkman (1984) inspired approaches emphasise appraisal processes and coping strategies. The difference in emphasis may appear slight, perhaps even inconsequential, but this can, indeed, have profound effects for the trajectory of a research program, particularly the formulation of interventions to improve caregiver health. The approaches differ mainly in their degree of emphasis. Many theoretical formulations in the caregiver literature take cognizance of all these perspectives of the stress processes (Vitaliano et al., 2003; Pearlin et al., 1990; Pruchno et al., 1989b). Moreover, some of the concepts may be couched in either terms of appraisal or environment. Psychological 'control' (Skinner, 1996) for example, is a concept that transcends both appraisal and environment approaches. Self-efficacy in Bandura's (1977) Social Cognitive Theory (SCT) and control in Karasek's (Karasek & Theorell, 1990) Demand-Control-Support (DCS) model are intrinsically and extrinsically determined respectively. The most commonly used models will be discussed in the following sections.

1.4.3.1. Lazarus and Folkman's cognitive transactional theory of stress

Lazarus and Folkman's cognitive transactional theory of stress (Lazarus, 1999; Lazarus & Folkman, 1984) has been one of the foremost formal theories of stress that has been explicitly referred to and used in caregiving studies. The key focus of this model is on an individual's appraisals of environmental demands. The approach is encapsulated in the often-quoted and now classic definition of stress and coping (Lazarus & Folkman, 1984), which states that psychological stress is:

'a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her resources and endangering his or her well-being'.

And that coping is the,

'constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.'

Two types of interdependent appraisal are identified in this approach. Primary appraising occurs when an environmental demand is evaluated as benign, a harm, a loss, a threat or a challenge whereas secondary appraising occurs when coping options are considered. These two appraisal processes determine whether and which coping strategies are used e.g. problem-focused coping versus emotion-focused coping.

While this framework has provided the foundation to several influential studies in this field of research (Vitaliano et al., 1991; Haley et al., 1987; Schulz et al., 1988) some authors argue that the 'stress process model' has not generated an unequivocal body of research relating to informal caregiving (Kneebone & Martin, 2003).

Figure 1.4 shows a Lazarus inspired model of the caregiving process (Chappell et al., 2002; Yates et al., 1999). Figure 1.4 clearly shows the all-important role of 'appraisal processes' assumed by this approach in determining caregiver endpoints such as health and well-being. It is beyond the scope of this review, and indeed irrelevant to the current argument, to describe this approach in detail, for a comprehensive exposition of the development of this theory, see Lazarus (1993) or (Lazarus, 1999).

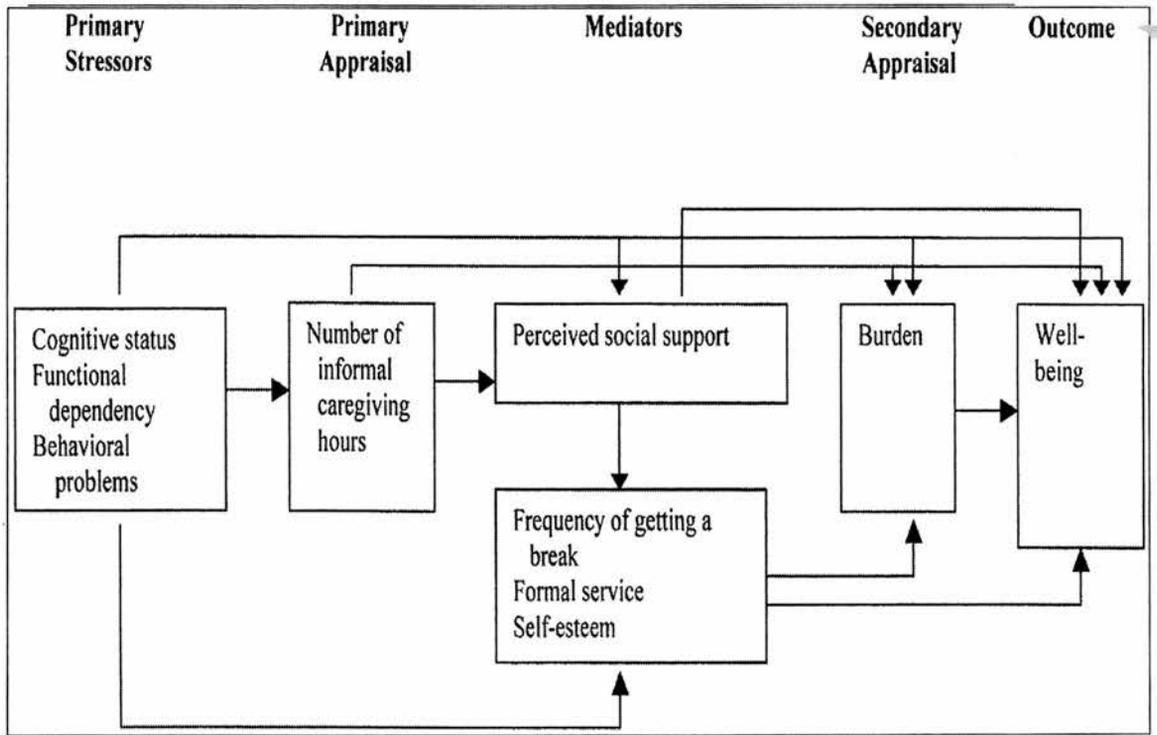


Figure 1.4

Stress and coping model of caregiver burden and well-being

(based on Yates 1999, image from Chappell and Reid 2002)

Kneebone & Martin (2003) recently critically reviewed dementia caregiver research based on Lazarus and Folkman's (Lazarus & Folkman, 1984) stress and coping model, particularly studies that have examined 'ways of coping'. They concluded that the ability of this type of research to inform the clinician is limited, due to the failure of most of these studies to consider stressor specificity in coping measurement and the preponderance of cross-sectional studies, which cannot inform us with any degree of certainty, which coping strategies work best and at what time point of the illness trajectory they should be employed. Kneebone & Martin argue that a body of clinically useful findings relating to caregiving, have not emerged after almost 20 years of research using this model, however it is important to note this may not be a problem of the model in itself, but in how researchers have attempted to test it. For example cross-sectional research is a particularly limited approach to examining coping.

The approach of Lazarus and Folkman (Lazarus 1999; Lazarus & Folkman, 1984) is indeed an important contribution that has greatly enhanced our understanding of how individual's coping strategies influence emotional outcomes. However the application of this approach to studying other health outcomes may be limited. Indeed Lazarus expressed some misgivings about attempts to show psychosocial influences on health at all (Lazarus, 1999; Lazarus, 1992). However given that there is a particular interest in understanding caregiver physical health, as it is generally agreed that caregiving puts one at increased risk for physical illness, this model may not be optimal one for this line of research. Recent prospective studies in the caregiver literature have demonstrated that there is a strong case for the caregiving-health relationship (Vitaliano et al., 2002; Schulz et al., 1999; Shaw et al., 1997). It is important to note that the conclusion is not that the stress & coping approach should be discarded, rather there may be more appropriate theoretical models for the study of caregiver health and well-being.

A broader limitation of these types of approaches that focus on appraisal stems from a growing body of empirical evidence demonstrating that affective or emotional responses may not have cognitive antecedents that are accessible to individuals. Cognitive approaches argue that the experience of stress involves mostly explicit or computational processing of information, which are by their definition amenable to change. However, a large body of evidence exists indicating that a considerable part of human strain reactions, particularly affective responses, happen at a level outside of our awareness (Murphy & Zajonc, 1993; Chartrand & Bargh, 1999), therefore appraisal may have a more limited role than once thought. This mirrors changes in other areas of health psychology where researchers are consistently finding that social cognition models can only explain moderate amounts of variation in psychological phenomena e.g. The theory of planned behaviour (Armitage & Conner, 2001). These findings diminish the presumed potency of explicit social-cognitive processes in strain reactions, assumed by cognitivist researchers.

1.4.3.2. Integrative models of stress .

Recently some theorists have developed integrative models of the stress-health process (Cohen, Kessler & Gordon, 1995), which have been articulated in terms of informal caregiving (Martire & Schulz, 2001). This integrative approach is outlined in figure 1.5 incorporating environmental, appraisal and biological approaches. The pathway from caregiving demands to negative physiological, affective, behavioural or cognitive responses (line a). in Figure 1.5 reflects this possibility that appraisal may not always be a key process. The line b in Figure 1.5 illustrates one of the many possible feedback loops that may also occur in the stress process. The line b in figure 1.5 shows that negative physiological, affective, behavioural or cognitive responses can influence the appraisal of demands and adaptive capacities. There is a good deal of empirical support for this type of prediction (Watson et al., 1989). There are many other possible feedback loops that may occur in the model presented in Figure 1.5, however full explication is beyond the scope of this chapter.

1.4.3.3. Vitaliano's model- Exposure X Vulnerability/Resources

Some theorists have attempted to refine the complexity of the models of stress such as those outlined in Figure 1.6 and to integrate the findings from the broader stress-health literature. Vitaliano's model in figure 1.6 represents one such attempt (Vitaliano et al., 2003; Vitaliano et al., 1991). This is arguably a more parsimonious, yet inclusive and elegant model of caregiver health and illness, which may generate less ambiguous predictions. This may be a more promising model of caregiver health than Figure 1.4 for promoting the development of a cumulative body of work on caregiver health. This model also incorporates concepts from broader mind-body research. For example the concept of an exposure times vulnerability interaction, which may refer to biological, psychological or social individual differences in vulnerability. However Vitaliano's model has not yet been subjected to a systematic body of research.

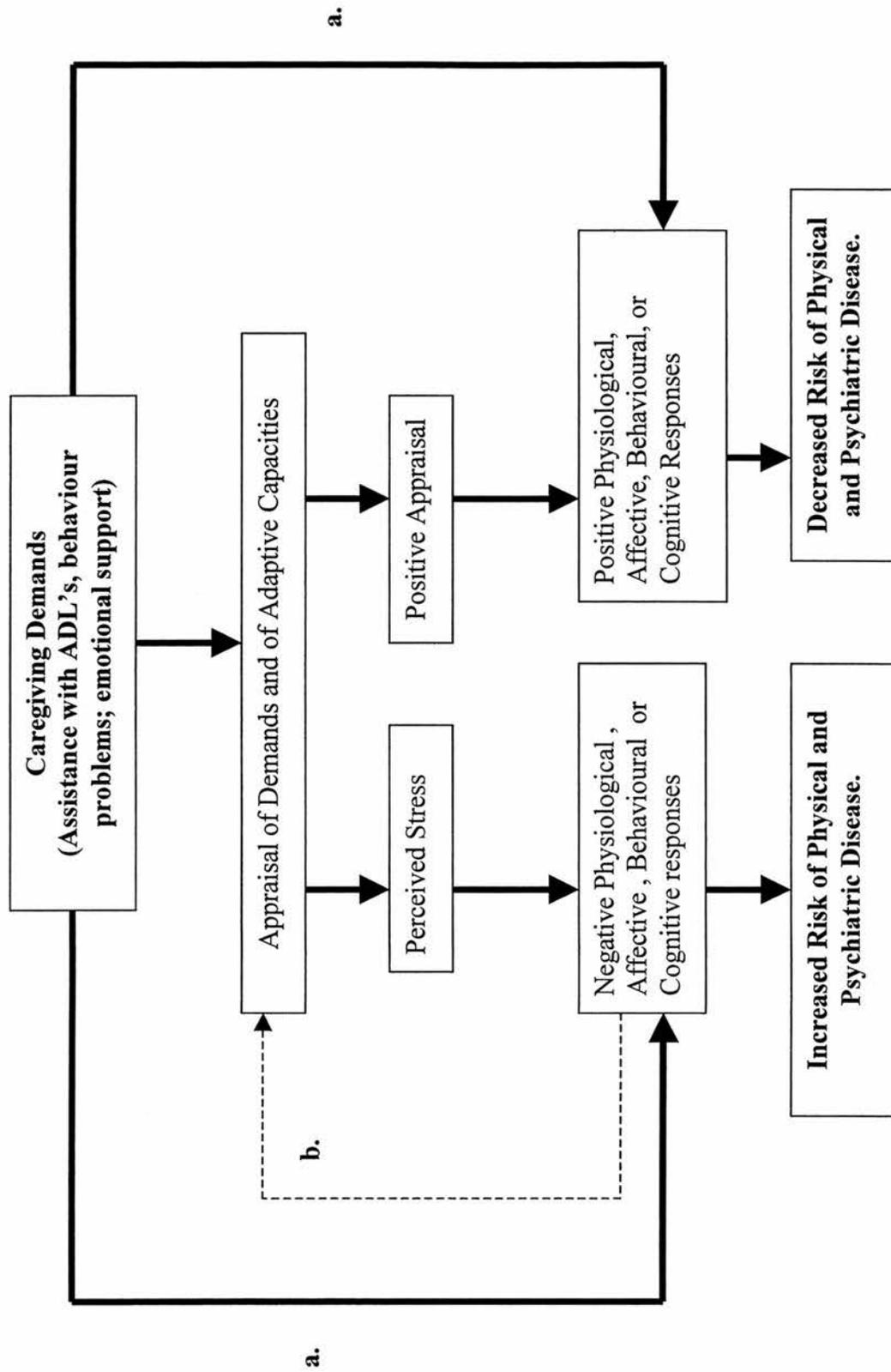


Figure 1.5.

A integrative environmental, psychological and appraisal model of the stress-health process applied to caregiving. (Illustration adapted from from Martire & Schulz, 2001 and Cohen, Kessler and Gordon, 1995)

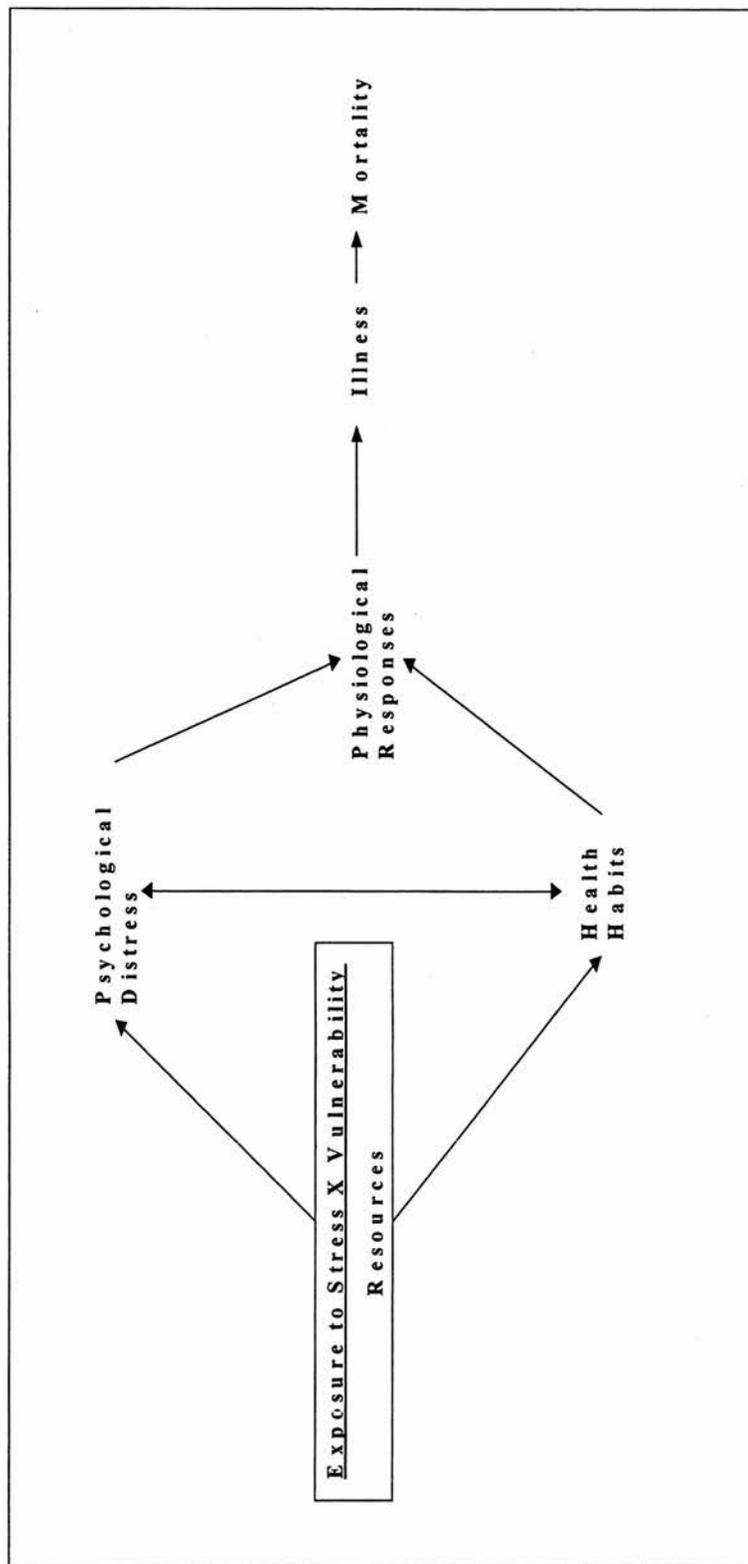


Figure 1.6
Vitaliano's theoretical model of stress and health/illness (Vitaliano et. al, 2004).

1.4.4. *Caregiving and the social environment- a population approach*

Consideration of the quality of the caregiver's social environment may offer a more useful approach to cognitively oriented accounts of caregiver strain for a number of reasons. This type of approach may have more promise than individually-focused accounts particularly in terms of intervention on a wide scale. Individual approaches such as the cognitive transactional models have their roots in a tradition of research influenced by clinical psychology, however this individual approach may not be appropriate in caregiving populations, particularly as many if not most caregivers cope quite well and few have clinically significant levels of psychopathology, therefore few may require individual attention. Furthermore individual treatments are much less likely to be implemented on a wide scale. A public health approach to informal caregiving may be more fruitful in terms of understanding and improving conditions for caregivers.

There is an increasing appreciation of the relationship between social environment and health (Marmot & Siegrist, 2004; Seeman & Crimmins, 2001; Taylor & Seeman, 1999). More environmentally orientated models of stress, such as Hobfall's (1989, 2001) *conservation of resources* (COR) model, broaden the conceptualization of the stress process to include objective environmental contingencies as predictive variables. This approach does, indeed, overlap somewhat with the Lazarus and Folkman's (1984) conceptualization, however a number of important distinctions exist. For example, Schwarzer (2001) contends that the unique and original contribution of the largely disregarded COR model is in its claim that 'lack of resource gain' is an important predictor of strain reactions. Lack of resource gain clearly has links to the concept of 'reward', which is a fundamental concept in psychology however this construct is lacking from many theoretical formulations of the stress-health process. This neglected concept may be important to caregiver researchers given the recent interest in the concept of 'gain' in the caregiving experience (Foley, Tung, & Mutran, 2002; Kramer, 1997).

1.4.5. *Job strain models of stress and health*

In contrast to the caregiver stress literature, the work stress or 'job strain' literature has converged on a more limited set of key theoretical concepts. Two models of job strain have gained particular prominence in recent years. Karasek's Demand-Control (DC) model (Karasek and Theorell, 1990) and Siegrist's Effort-Reward Imbalance (ERI) model (Siegrist, 1996) have been examined in a number of methodological rigorous population studies, including the Whitehall studies in the UK (Stansfeld, Bosma, Hemingway, & Marmot, 1998; Bosma, Peter, Siegrist, & Marmot, 1998) and in several other countries (Van Vegchel, De Jonge, Meijer, & Hamers, 2001; Schnall et al., 1990; Alfredsson, Karasek, & Theorell, 1982). The job strain models have inspired a vast literature predicting physical, psychological and behavioural endpoints in various occupations (Van der Doef & Maes, 1999; Van Der Doef & Maes, 1998).

While stress is a major preoccupation of both occupational psychology and informal caregiving research, there are few examples of the well-established and validated theories from occupational literature being applied to the caregiving literature. These types of models (Siegrist, 1996; Karasek & Theorell, 1990; Baker, 1985) may provide a useful alternative to general theories of stress such as Lazarus & Folkman (Lazarus & Folkman, 1984) in examining the impact of caregiving and in generating hypotheses, as they provide parsimonious and perhaps more easily manageable frameworks in which to study this phenomenon. Indeed, recent work using Siegrist's Effort-Reward Imbalance Model of Job Strain suggests that these models may have a value in informal contexts beyond working life (Von dem Knesebeck & Siegrist, 2003). Conceptualising informal caregiving as an occupational stressor (Orbell et al., 1993) allows sensible organisation of many of the variables that are thought to be key to the understanding of caregiver outcomes. Many of the central constructs in these models have obvious pertinence to caregiving scenario e.g. Demands (Gaugler, Davey, Pearlin, & Zarit, 2000; Nieboer et al., 1998), Reward (Danigelis & Fengler, 1990; Riedel, Fredman, & Langenberg, 1998), Control (Griffin, Fuhrer, Stansfeld, & Marmot, 2002; Miller, Campbell, Farran, Kaufman, & Davis, 1995) and social Support (Haley et al., 1987; Miller

et al., 2001) . These models may be particularly useful for a public health approach to informal caregiving, which will be discussed in more detail in subsequent sections.

1.4.5.1. The Demand-Control Model

This elegant and economical two-dimensional model argues that the characteristics of a given occupation or the ‘psychosocial work environment’, rather than characteristics of the worker, are the most fundamental agents of job strain. The model is illustrated diagrammatically in figure 1.7. The two principle variables determining strain outcomes are the physical and psychological *Demands* of a job and the *Control* over fulfilling these job Demands. High Demands and Low Control are associated with greater risk of strain reactions and subsequent physical disease or psychological morbidity. See quadrant 1 of figure 1.7. The second prediction made by this model argues that in the presence of Control, active learning and motivation to develop new behaviour patterns will ensue. See quadrant 2 figure 1.7. This, the model predicts, will decrease the risk of strain reactions. Control was originally referred to as decision latitude and defined as, ‘the working individual’s potential control over his tasks and his conduct during the working day’. This was further differentiated into two separate components skill discretion and decision authority i.e. control over behaviour, which are now more often measured as separate constructs. The other two quadrants 3 and 4 refer to work conditions that are low strain and passive. No adverse outcomes are expected for low strain or passive jobs, however a gradual atrophying of learned skills and abilities may occur in this type of job (Karasek & Theorell, 1990). Empirical tests of this part of the model have been lacking and most research interest has focused on quadrant 1 with a smaller number of studies examining the prediction made in quadrant 2.

Initially, Karasek argued that it was the interaction between Demand and Control that predicted affective and behavioural outcomes, however subsequent studies failed to provide consistent support for this interactive prediction (Van der Doef & Maes, 1999), particularly for psychological outcomes. The alternative interpretation of the model argues that there are two

main effects of Demand and Control on job strain outcomes and also a possible interaction with Control moderating the effect of high job Demand. Reviews have suggested that both main effects and interactive predictions should be tested for (Van Der Doef & Maes, 1998). Despite some disagreement over the main thrust of the model i.e. main vs. interactive effects of Demand and Control, and some argument about the poor match between the theoretical constructs and the actual measures that have been used in studies (de Jonge, Mulder, & Nijhuis, 1999; Wall, Jackson, Mullarkey, & Parker, 1996) the model continues to dominate the job strain literature and inspire an impressive body of research. The predictive utility of this model of job strain for physical and psychological health outcomes has been extensively validated in a range of population studies (Kivimaki et al., 2002; Hemingway & Marmot, 1999; Johnson & Hall, 1988; Theorell & Karasek, 1996).

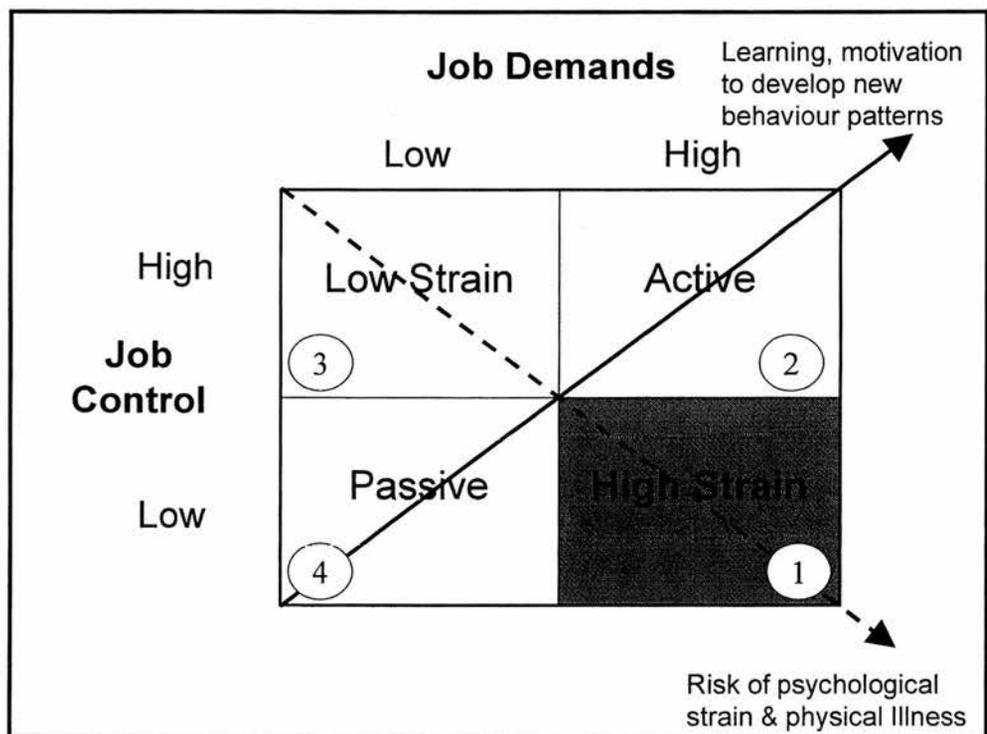


Figure 1.7.

The Demand-Control model of job strain (Karasek, 1979).

Social support has been a more recent addition to the model (Karasek & Theorell, 1990; Johnson et al., 1988), making the currently accepted model 3-Dimensional (See figure 1.8). As illustrated in the model the most toxic or pathogenic work conditions are those where workers have high Demands, low job Control and low levels of social Support. Like Control, social Support is thought to moderate/buffer the effects of high job Demands.

The original formulation of Karasek's theory (1979), without the social support dimension, has been applied in an isolated caregiver study by Orbell & Gillies (1993). The authors found moderate support for the model's predictions. Given the efficacy of the model in this instance, it is surprising that further research was not carried out. A test of the revised DCS model in a caregiving context would reveal the cross contextual validity of Karasek's predictions and would offer a fresh approach to this fragmented literature.

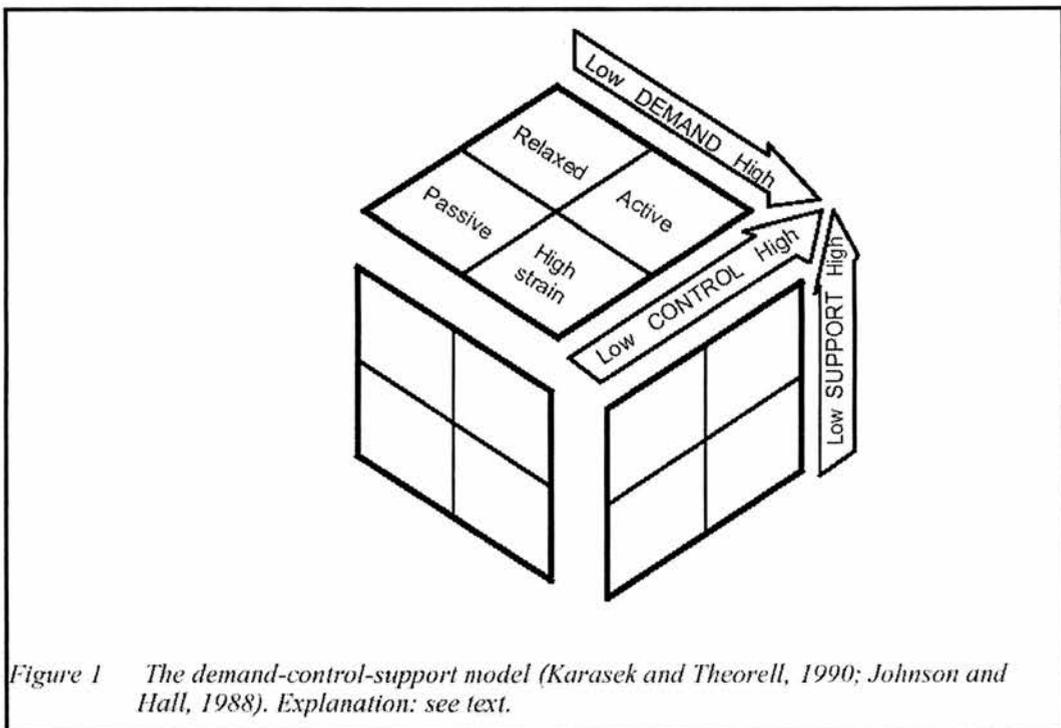


Figure 1.8

The Demand-Control- Support (DCS) Model (Karasek and Theorell, 1990)

1.4.5.2. The Effort-Reward Imbalance Model

In very basic terms the Effort-Reward-Imbalance model postulates that a lack of reciprocity between ‘cost’ and ‘gains’ of work results in strain reactions at emotional and physiological levels (Siegrist, 1996). The model is illustrated diagrammatically in figure 1.9. As outlined in the figure the model’s emphasis is on the trade-off between ‘intrinsic and extrinsic effort’ and ‘reward’. Intrinsic effort is defined as the personal need or desire for control or ‘over-commitment’ in the occupational setting, while extrinsic effort is determined by situational conditions. Extrinsic effort is virtually indistinguishable from ‘Demand’ as conceptualized in Demand-Control model. Rewards are distributed by three transmitter systems: money, esteem, and career opportunities. The model postulates that diminished reciprocity elicits sustained strain reactions at emotional and physiological levels. Several studies have demonstrated that individuals, who score higher on measures of effort-reward imbalance, are at increased risk for physical and psychological health problems (Bosma et al., 1998; Siegrist, 1996).

Comparable imbalance between effort and reward is often evident in the experience of caregiving. For example, the combination of having a demanding role as a caregiver, meeting the care recipient’s every whim, while not receiving support, acknowledgement or other compensation from the care recipient, one’s family, neighbours, or even society constitutes high cost/low gain conditions. The ERI model would predict that such conditions are conducive to strain reactions and ultimately poor physical and psychological health.

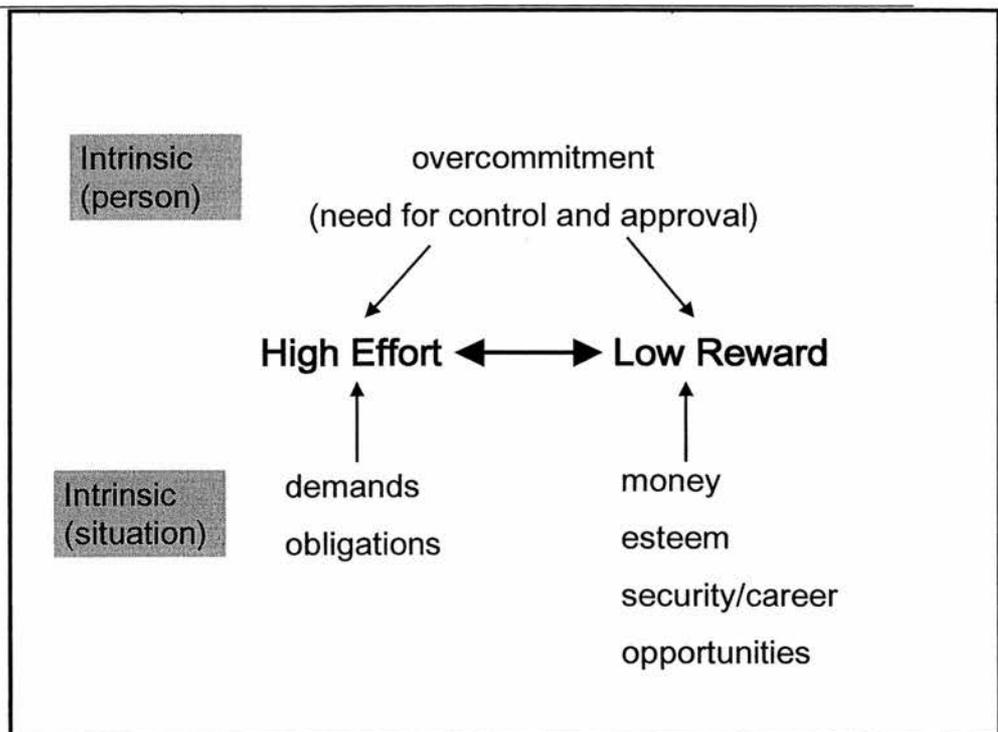


Figure 1.9

The Effort-Reward Imbalance Model (Siegrist, 1996)

This concept of reciprocity or ‘social exchange’, which is at the core of the ERI model, has received a great deal of attention in social psychology (Buunk & Hoorens, 1992) and several caregiver studies have examined variations of the constructs relating to impaired reciprocity in caregiving situations (Pearlin et al., 1990; Danigelis et al., 1990). All social relationships have effort and reward i.e. reciprocity. In normally functioning social relationships cooperative behaviour, however, is likely to be sustained only when there is either direct or indirect reciprocity, in which benevolence to one individual increases the chances of receiving help directly in return or indirectly from others. In a caregiving situation there is often a perceived imbalance or ‘inequity’ (Kuijer, Buunk, Ybema, and Wobbes, 2002) in the relationship between the caregiver and the care recipient. Restoration of the pre illness/disability levels of reciprocity in such relationships is often unattainable, yet caregivers cannot or chose not to terminate these relationships. The ERI may have some potential in studying caregiver health inequalities given its

obvious overlap with these approaches and its growing empirical support in predicting a range of health outcomes.

1.4.6. Why might the job strain models be useful in caregiving health research?

In Braithwaite's (Braithwaite, 1996) paper her title is framed as a question, 'Between stressors and outcomes: Can we simplify process variables?' In the past long lists of variables were entered into regression analysis predicting caregiver outcomes. The job strain models use a smaller set of variables that are more rigorously specified in terms of variable definitions, directionality of effects, and interaction mechanisms. The present thesis examines whether the Demand-Control model and Effort-Reward Imbalance model can be used to examine caregiver health and well-being. Many of the previously uncovered strain producing variables, one could argue, could be couched in terms of Demand, Control, or Reward, as they are understood in these two models. Despite the obvious advantages of these models, they have received scant attention in caregiver strain research. There are several attractive features to the two work strain models over and above previous formulations of caregiver strain. Firstly, both models have a simple formulation. Both have been well-validated and can be measured relatively simply and inexpensively. The Karasek model in particular has a rich literature spanning over 20 years. A wide range of outcomes including objective behavioural data such as absenteeism and job change are comparable to caregiver outcome measures such as decision to continue caring or decision to institutionalize care recipient. Finally, a theoretically-informed intervention literature using both the ERI and DCS models is beginning to emerge (Siegrist, 2001). This could help inform caregiver intervention studies based on these frameworks.

In order to argue for the acceptance of a new scientific theory there are a number of criteria that must be met by the new theory. Five of the principle criteria are set out in table 1.3. In order to evaluate the potential of the job strain models these criteria will be revisited in the final discussion chapter.

Table 1.3**Criteria for acceptance of a new theory** (Popper, 1959).

-
1. Previously accepted theories (PAT) gave an acceptable explanation of something, the new theory must give the same results.
 2. New theories explain something that the PAT either got wrong or, more commonly, did not apply.
 3. The new theories should make predictions that are later verified.
 4. Elegance - Aesthetic quality - simple, powerful includes universal symmetries. That is simple, easy-to-remember or apply formulation, expressed as some symmetry of nature, be powerful enough to used in many applications
 5. Provide a deeper insight or link to another branch of knowledge
-

1.4.7. Conclusions

Caregiver health research has clear scientific and social justifications. However, it continues to fail to consider theory as an important foundation on which research should be built. Where researchers have endeavored to develop comprehensive theoretical models the caregiver stress process is often over-complicated and no clear guidance for intervention is provided. As a result, a mixed bag of results, with regard to identifying predictors of strain and attempts to reduce it, continues to be unearthed.

Work strain research has received vast quantities of resources, both financial and intellectual in order to attempt to solve the toxic effects of particular occupational settings. Large-scale population studies have allowed the testing and validation of a number of explanatory models. This research effort has thrown up some useful theoretical constructs. As Braithwaite (1996 p52) has argued about caregiver research, variables should be reduced 'to a limited set of key concepts', as this provides 'economies in a field where potential variables are numerous and the time of the research subjects is precious.' These formulations from the job strain literature may potentially achieve this, and ultimately guide interventions to reduce negative outcomes, not only for the caregiver but also the health service. The proposed studies will

therefore attempt to test the efficacy of these two job strain models in predicting psychological health outcomes in a caregiving context. Firstly in a sample of informal caregivers caring for Stroke patients and in more detail in a sample of caregivers caring for Congestive Heart Failure patients.

1.5. Illness populations studied in the caregiver literature

While many clinical populations have been studied in relation to informal caregiving the bulk of the literature has focused on a limited number of conditions namely, Alzheimer's Disease and related disorders (ADRD), cancer, heart disease (mostly post myocardial infarction spouses e.g. Coyne & Smith, 1991), stroke and a smaller literature on chronic mental illness (Biegel, Sales & Schulz, 1991). ADRD, Cancer, Stroke and Congestive Heart Failure will be considered in the following sections to illustrate the attention that attention that these range of conditions have received in the caregiver literature.

1.5.1. Alzheimer's Disease and related disorders (ADRD)

The majority of caregiver health studies, particularly a number of 'classics' that are often cited in this literature, have been concerned with caregivers of patients with dementing illnesses such as Alzheimer's Disease (Lawton et al., 1991; Haley et al., 1987; Zarit et al., 1980). Indeed, most would agree that individuals in this scenario often have to adapt to the most difficult and challenging demands that caregivers could be faced with. The decline in both functional and cognitive abilities that accompany the progression of these illnesses often results in patients requiring full time assistance and monitoring. Indeed the empirical evidence suggests that this type of caregiving has a much greater impact than non-dementia caregiving and that findings from ADRD caregiving populations may not extrapolate to other caregiving populations (Ory et al., 1999). Many researchers have argued, each illness type offers distinct caregiving demands (Martine & Schulz, 2001), and for this reason studies that target specific illnesses are warranted. This provides a much-needed illumination of the caregiving experience for particular illnesses.

1.5.2. Cancer and Stroke

There is a significant and growing literature examining informal caregiving in cancer and stroke populations. The extent of this research is surprisingly limited by comparison to the ADRD literature. The cancer and stroke research has however reached the critical mass necessary for reviews of studies examining caregiving in this clinical condition to be carried out and several have recently appeared in the cancer (Haley, 2003; Nijboer et al., 1998) and stroke (Han & Haley, 1999; Low, Payne, & Roderick, 1999) literature. These studies have identified caregiving issues that may be specific to the clinical condition e.g. the unique difficulty of chemotherapy in cancer and residual disability following stroke.

1.5.3. Congestive Heart Failure

One illness in particular that is conspicuous by its relative absence from the caregiver literature is Congestive Heart Failure (CHF). In very basic terms CHF is a medical condition where the heart muscle is not sufficiently strong enough to pump blood around the body. It is an incurable illness, with the exception of a heart transplant, which has a diverse range of symptoms that most often leads to significant limitations in functional status. Treatment regimens for CHF are extremely complex and this complexity is reflected in the high rates of re-hospitalisation in this population (Rich, 2002). With the exception of lung cancer heart failure is as 'malignant' as many common types of cancer, yet it is rarely identified as an important health issue in the public domain (Stewart, Macintyre, Hole, Capewell, & McMurray, 2001). This caregiver population has been chosen for special attention in the present thesis for a number of reasons.

Firstly this condition is showing increasing prevalence and incidence in both the UK and the US (McMurray & Stewart, 2002; McMurray & Stewart, 2000). CHF is now regarded as a major and escalating public health problem, which is and will continue to be a huge drain on health-care resources (Berry, Murdoch & McMurray, 2001). Secondly, there is a great deal of variability in the care needs of these patients, therefore this should provide for a good test of the proposed theoretical models of caregiver health. Finally, in managing heart

failure successfully the involvement of a key support person is often the variable that enables patients to remain in the community, outside of hospitals and long-term care facilities (Murberg et al., 2001; Coyne et al., 2001; Krumholz et al., 1998). This support person, who is often the spouse, is vital in not only managing the medical regimen but also in sustaining the patients quality of life. The few studies that have examined the impact of CHF on other family members have found that the various roles and obligations involved in providing this care can be exhausting and stressful (Karmilovich, 1994). To date the literature examining informal caregiving and CHF not been reviewed.

1.5.4. Conclusion

The caregiving literature has been dominated by a limited number of clinical conditions that do not represent the main causes of disability in the developed world (Murray and Lopez, 1996). Therefore this literature may have limited use in understanding caregiving on a wider scale. Congestive Heart Failure (CHF) may reach epidemic proportions in developed counties over the next 20 years (Stewart et al., 2001), yet few studies have addressed caregiving and CHF. In an attempt to set the existing literature on informal caregiving and CHF in context a narrative review and analysis of the studies that have examined issues surrounding informal caregiving and CHF will be conducted in the next chapter.

Chapter 2

2 Informal Caregiving and Congestive Heart Failure. Review and Analysis.

Overview of Chapter 2

While informal caregiving is an important and burgeoning field of research there are a number of clinical conditions that have received limited attention. One such condition that is rapidly increasing in incidence and prevalence is Congestive Heart Failure (CHF). This chapter provides a narrative review and analysis of the studies that have examined informal caregiving in Congestive Heart Failure. The review identified 17 papers that examined the role and/or impact of informal caregiving for CHF patients. Demands specific to CHF caregiving were identified e.g. monitoring complex medical and self-care regimen, disturbed sleep and frequent hospitalisation of patients. Relatively high levels of emotional distress were identified in CHF caregivers. Few studies explicitly investigated the role of informal carers in the management of CHF. Studies were limited in number, scope and quality. We outline the implications for policy and make several recommendations for future research.

Abstract

Background: There is increasing evidence that discharge planning and post-discharge support for CHF patients can contribute greatly to the medical management of heart failure (CHF) in the community and that the quality of the CHF patient's close personal relationships can influence outcome in CHF. However there has been little research on the impact of CHF on informal caregivers or the role of informal caregivers in the management of the condition. In this paper we provide a review and analysis of studies that have explicitly investigated these issues in the informal caregivers of CHF patients.

Results of the Review: 17 papers were identified that examined the role and/or impact of informal caregiving for CHF patients. Our main findings were: Demands specific to CHF caregiving were identified e.g. monitoring complex medical and self-care regimen, disturbed sleep and frequent hospitalisation of patients. Relatively high levels of emotional distress were identified in CHF caregivers. Few studies explicitly investigated the role of informal carers in the management of CHF. Studies were limited in number, scope and quality.

Conclusion :- Caring for a family member with CHF can affect the well-being of those responsible for care, which may have consequences for the CHF patient's health. Further studies are needed to clarify these issues and to examine the role of informal caregivers in the management of CHF in the community.

Note: An abbreviated version of this Chapter is in press and is to appear in the European Journal of Heart Failure (See Appendix G).

2.1 What is Congestive Heart Failure?

Congestive Heart Failure is a syndrome characterised by a collection of symptoms including the retention of excessive fluid, often leading to swelling of the legs and ankles and congestion in the lungs. This is a consequence of the hearts inability to keep up with its workload in maintaining adequate blood supply to the lungs and the rest of the body. Heart failure is a chronic condition that can be treated with medications, diet and other lifestyle changes, and in some cases, surgery. Patients are classified into one of four categories based on their symptoms. These four categories are outlined in table 2.1. CHF is increasing in incidence and prevalence and it is placing a increasing large burden on society given the expensive nature of the treatment and management of this condition (McMurray & Stewart, 2002). It is particularly problematic in older adults and is the number one reason for admission for this group in both the US (Rich, 1997) and the UK (Stewart, MacIntyre, Capewell, & McMurray, 2003).

Patients with Congestive Heart Failure (CHF) are, by definition functionally impaired. Individuals with highly symptomatic CHF experience marked to severe limitation of physical activity (Miller et al., 2004; De Geest et al., 2003). Given that 1-2% of the general population in developed countries have CHF (Cowie et al., 1997), and that this figure is expected to rise (Stewart et al., 2003), CHF is fast becoming a leading cause of disability among older adults in many industrialised nations with consequent burden on health services.

Table 2.1:
New York Heart Association (NYHA) Classification System for Heart Failure (American Heart Association, 2004).

<i>Class</i>	<i>% of patients in this category</i>	<i>Symptoms</i>
<i>Class I (Mild)</i>	35%	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnea (shortness of breath).
<i>Class II (Mild)</i>	35%	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnea.
<i>Class III (Moderate)</i>	25%	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea.
<i>Class IV (Severe)</i>	5%	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

Comprehensive discharge planning and discharge support for CHF patients is increasingly being viewed as an important means of reducing this burden of care (Phillips et al., 2004; Stewart, Blue, Walker, Morrison, & McMurray, 2002). For example home-based nurse interventions have shown promising results in several studies and there is growing support for the widespread application of this type of post-discharge care. However research into discharge planning and discharge support for CHF patients has surprisingly proceeded for the most part, without the inclusion of the informal caregivers of CHF patients into research designs. While most clinicians are aware that CHF is associated with a worse quality of life than most forms of cancer and other chronic diseases (Juenger et al., 2002) and that caregiver support is extremely important, the available research literature does not explicitly reflect the important role that carers may have in managing the illness.

The following review firstly characterises the demands that the informal caregivers of CHF patients often face. Secondly the reasons why informal caregivers warrant the attention of CHF researchers are outlined and finally a review and analysis of the studies that have looked at informal caregiving in CHF is provided.

2.1.1 *Has CHF been neglected in the caregiver literature?*

The clear neglect of the CHF and other non-dementing illnesses is evident in figure 2.1. This shows the number of articles returned in a Web of Science search for the terms ‘caregiver’ or ‘spouse’ and each of ‘dementia’, ‘cancer’, ‘stroke’ and ‘heart failure.’ When this is compared with figure 2.2, which shows the disability adjusted life years (DALY’s) that are attributable to four comparable categories of illness (CVD refers to cardiovascular disease and IHD ischaemic heart disease), it is clear that CHF and other non-dementing illnesses are clearly under-represented in the caregiver literature in light of their contribution of these conditions to DALY’s in developed regions.

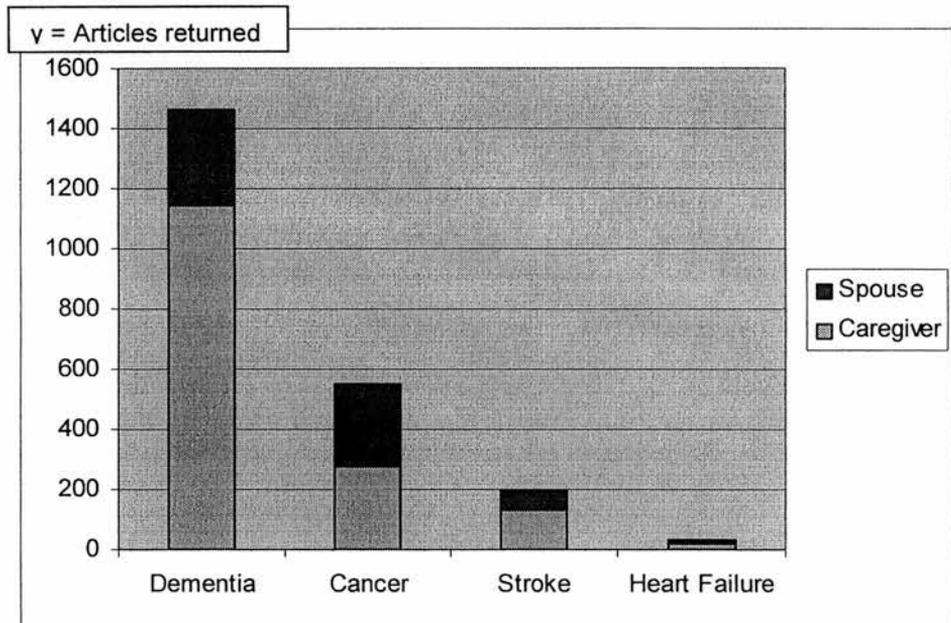


Figure 2.1
A web of science search using ‘spouse’ and ‘caregiver’ as key words with 4 clinical conditions (8th of July 2004).

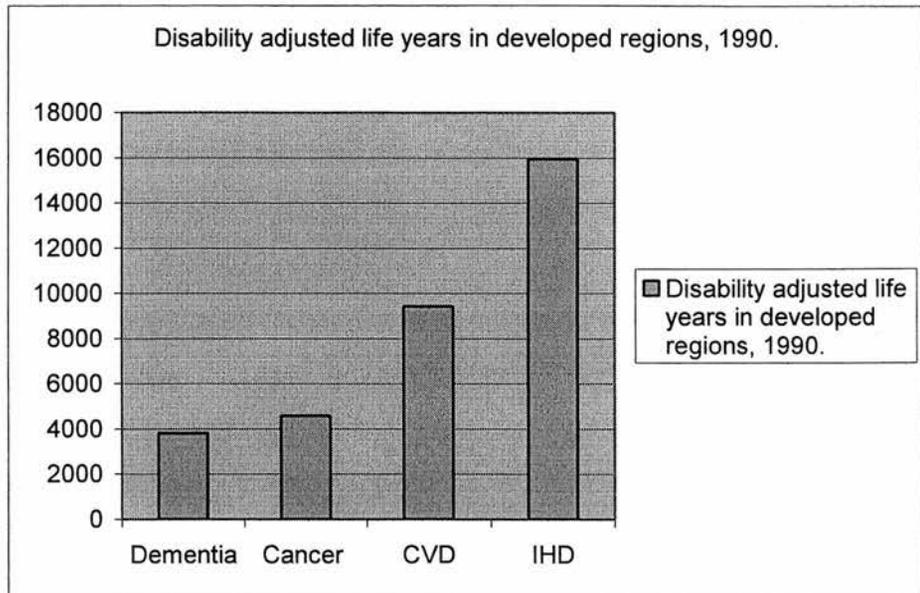


Figure 2.2
Disability adjusted life years that were attributable to 4 illness categories in developed regions, 1990. (Data from Murray and Lopez, 1996).

2.1.2 What are the caregiving demands of CHF patients?

Due to the considerable levels of disability in general ambulation and managing the household that can be attributed to CHF (Guccione et al., 1994), individuals with moderate to severe CHF are often reliant on family or friends for assistance with instrumental activities of daily living (IADL's e.g. shopping, house keeping) and sometimes even activities of daily living (ADL's e.g. bathing or dressing) (De Geest et al., 2003). Family members caring for an individual with CHF may also often have to endure and attend to a range of problems, which are outlined in table 2.2. The combination of these factors has the potential to severely impact upon individuals providing informal care for CHF patients.

Table 2.2
Caregiving Demands in Congestive Heart Failure.

<i>CHF related symptom, limitation or behaviour</i>	<i>Potential to burden</i>	
	<i>Spouse/partner caregiver</i>	<i>Non-spousal caregiver</i>
- Limitations in physical activity (Guccione et al., 1994)	Yes	Yes
- Fluctuating symptoms (Jaarsma, Stromberg, Martensson, & Dracup, 2003)	Yes	Yes
- Complex medical and self-care regimen e.g dietary restrictions – low sodium content and controlled water intake (Jaarsma et al., 2003)*	Yes	Yes
- CHF related depression (Freedland et al., 2003; Faris, Purcell, Henein, Coats, 2002) *	Yes	Yes
- Caregiver restricted social life (Martensson, Dracup, & Fridlund, 2001)	Yes	Yes
- Frequent hospitalisations (Cowie et al., 2002)*	Yes	Yes
- Changes in sexual activity (Jaarsma, Dracup, Walden, & Stevenson, 1996)*	Yes	No
- Worry associated with an ICD** or other technological medical device (Tagney, James & Albarran, 2003)	Yes	Yes
- Disturbed sleep patterns caused by CHF-related sleep apnea and the use of diuretics in the patient. e.g. daytime sleepiness and interrupted sleep (Brostrom, Stromberg, Dahlstrom, & Fridlund, 2003)*,	Yes	No

* denotes demands that may be specific to CHF. ** Implantable Cardioverter Defibrillator.

2.1.3 *Why is informal care important in CHF?*

2.1.3.1 Benefit to the CHF patient

The availability of a supportive spouse or other family relative is likely to be of benefit to the CHF patient in improving overall quality of life of the patient and in assisting the medical management of the condition (D'Alto, Pacileo, & Calabro, 2003). Indeed, a growing body of evidence has found associations between key social relationships and prognosis in CHF. The mechanisms whereby such support promotes health, however still remains

elusive. Murberg and Bru (Murberg & Bru, 2001) found that social isolation, after controlling for depressive symptoms, heart failure severity, functional status and age is a significant predictor of patient mortality. Another recent study (Krumholz et al., 1998) found that among elderly female patients hospitalised with clinical heart failure, the absence of emotional support, measured before admission, is a strong, independent predictor of the occurrence of fatal and nonfatal cardiovascular events in the year after admission. Coyne et al. (2001) found that when marital quality and NYHA class are considered jointly, they both make independent, statistically significant contributions to the prediction of patient mortality. It appears that the presence of informal supports has a positive effect on CHF prognosis and that social isolation, particularly single marital status appears to be associated with poorer outcomes (Chin & Goldman, 1997). The beneficial effects of social support on CHF prognosis found in these studies, however may come at a psychological and physical cost to the individuals providing the support.

2.1.3.2 Detriment to the informal caregiver

Research across a variety of clinical conditions has consistently found that providing care to a functionally dependent family member or friend contributes to psychiatric and physical morbidity in informal caregivers (Pinquart & Sorensen, 2003b; Vitaliano, Zhang, & Scanlan, 2003; Schulz, O'Brien, Bookwala, & Fleissner, 1995), however arguably more significantly from a public health perspective are findings by Schulz & Beach (1999), who have recently shown that informal caregiving is an independent risk factor for mortality. After adjusting for sociodemographic factors, prevalent disease, and subclinical cardiovascular disease, individuals who were providing care and experiencing caregiver strain had mortality risks that were higher than noncaregiving controls (relative risk [RR], 1.63; 95% confidence interval [CI], 1.00-2.65). These findings give research examining the role and impact of informal caregiving in all illness categories an added urgency.

2.1.4 *Why should CHF informal caregivers be studied?*

It is clear that the illness groups that have been most heavily studied in the caregiver literature e.g. Alzheimer's and dementia related diseases (Pinquart & Sorensen, 2003b), stroke (Han & Haley, 1999) and cancer (Haley, 2003) are associated with demands on the caregiver that one would not necessarily expect in CHF e.g. cognitive decline, behaviour problems, pain and nausea etc, however this should not preclude the specific study of individuals providing informal care for CHF patients, as this illness poses several unique challenges for family caregivers, as outlined in table 2.2. As Biegel and Schulz (1999) have argued each patient population poses distinct caregiving challenges and researchers should attempt to separate the disease specific from the general aspects of caregiving.

Despite the increasing incidence and prevalence of CHF (McMurray & Stewart, 2002) and the potentially high caregiving demands, particularly in moderate to severe CHF, there are few comprehensive studies that have systematically examined the physical and psychological impact of CHF on informal caregivers or that have examined the role of informal caregivers in managing the disease as illustrated in figure 2.1. This relative neglect of CHF informal caregivers is in stark contrast to other leading causes of morbidity and mortality such as stroke and cancer, both of which have an extensive caregiving literature (Han & Haley, 1999; Haley, 2003; Nijboer et al., 1998). This relative neglect may be explained by the fact that CHF is an 'emerging' health issue in comparison to Stroke and Cancer and as a result, both the biomedical and the psychosocial aspects of CHF research are in their infancy by comparison.

Given the magnitude of the problem of CHF and its relative disregard in the caregiving literature, an up to date review of the state of knowledge about informal caregiving in CHF is therefore needed. The purpose of this paper is, to provide a review and analysis of published studies that have examined informal caregiving in CHF. We have developed five specific aims for this review (i) evaluating the effects of CHF on caregivers' well-being (ii) evaluating the role of informal caregivers in the management of CHF (iii) outlining policy and practice implications of current studies. (iv) outlining the limitations of current research (v) identifying future avenues of research relating to caregiving in CHF.

2.2 Methods of Search Strategy

A literature search for relevant articles was conducted on three databases (PsychINFO, Medline and Web of Science) for the period 1993- 2003 using the following key words: Heart failure, cardiac failure, carer, caregiver, partner, spouse and family. Articles were selected using the criteria listed in table 2.3 The search criteria were deliberately inclusive because of the neglect of this topic in the literature.

Table 2.3

Inclusion criteria of articles selected for review

-
- (1) Articles must be written in English.
 - (2) Articles must be published in peer reviewed journals
 - (3) Articles must be research studies or review papers.
 - (4) Articles must involve informal caregivers i.e. voluntary assistance from family or friends as opposed to paid help from social services.
 - (5) Articles that focused on more generalised chronic disease and palliative care, rather than caregiving in heart failure were excluded.
 - (6) Reference sections of selected articles were also searched for relevant articles.
-

2.3 Results of Search Strategy

17 studies were identified. 14 studies that used quantitative methodology are summarised by study population characteristics (both patients and caregivers), research design, outcome-measures used and key results in Table 2.4. The 3 studies that used qualitative methods are discussed in section 4.1. The findings from all 17 studies are discussed in light of the review aims and previous findings in other chronic conditions.

Table 2.4

Summary of quantitative CHF caregiving studies.

NYHA = New York Heart Association; LVEF = Left Ventricular Ejection Fraction; BDI = Beck Depression Inventory; SF-12 or 36 = Short Form 12 or 36; HRQL = Health Related Quality of Life; HSCL-25 = 25 item Hopkins Symptom Checklist; PAIS = Psychosocial Adjustment to Illness Scale; CES-D = Center for Epidemiological Studies-Depression Scale; PSS = Perceived Stress Scale; MISSB = Modified Inventory of Socially Supportive Behaviours Scale.

1 st Author & Year [ref. No.]	Study Population (1) number of participants (2) Carer definition (3) Sociodemographic details (Carer) (4) Sociodemographic details (Patient)	Study Design	Characteristics of patients (a) % NYHA class III or IV (b) Mean (SD) % LVEF.	Outcome (i) psychological health (ii) carer burden (iii) physical health (iv) social health (v) miscellaneous (i) nil (ii) nil; (iii) nil (iv) nil (v) patient survival.	Key Results
Rohrbaugh 2004	(1) 191 (2) Patient's spouses (3) Mean age 52 (Range 29-75); 74% female. (4) Mean age 53 (29-78); 74% male.	Prospective; longitudinal; quantitative.	(a) 42% (b) 21.6 (7.3)	(i) nil (ii) nil; (iii) nil (iv) nil (v) patient survival.	Spouse's confidence rating in managing patients CHF was a significant predictor of CHF patient survival over the next 4 years. This effect was independent of patient self-efficacy for managing CHF.
Schwarz & Dunphy 2003	(1) 75 (2) Family members who provided support to CHF patient with activities of daily living.; 51% were spouses. (3) Mean age 63 (SD: 15), 73% female. (4) Not provided	Cross-sectional; quantitative.	(c) not provided (d) not provided	(i) CES-D, PSS; (ii) nil; (iii) nil (iv) MISSB (v) salivary cortisol	Stress and social support accounted for 50% of the variance in depressive symptomatology. Social support did not moderate the effect of stress on depressive symptoms. Cortisol measure did not relate to self-report measures of stress or depression.
Martensson 2003	(1) 48 (2) 100% were spouses (3) Mean age 57 (SD: 10); 100% female (4): Mean age 61 (SD: 9); 100% male	Cross-sectional comparison of patients and spouses; quantitative.	(a) 65% (b) .26 (9)	(i) BDI; SF-12; (ii) nil (iii) SF-12 (iv) nil (v) nil	Spouses were significantly less depressed than CHF patients. Spouse depression and HRQL did not significantly influence patient depression. Spouse depression was positively related to better patient functional status.

Schwarz & Eilman 2003	<p>(1) 156 family members that lived in same city and provided the majority of help to CHF patients.</p> <p>(3) Mean age 65 (SD: 15); 74% female</p> <p>(4) Mean age 77 (SD: 6); 50% male</p>	Cross-sectional, Longitudinal; Quantitative.	(a) not given (b) not given	(i) CES-D (ii) Geriatric Center Caregiving Appraisal Scale. (iii) nil (iv) Socially Supportive behaviours scale. (v) PSS.	Depressive symptoms and perceived stress were low, informal social support and caregiving satisfaction were high. The interaction of caregiver stress and depression was a significant predictor of CHF patient readmission. High levels of caregiver stress and depression were associated with increased risk for patient readmission.
Rohrbaugh 2002	<p>(1) 128</p> <p>(2) 100% were spouses.</p> <p>(3) Mean age 52 (SD: 11). 38% female.</p> <p>(4) Mean age 53 (SD: 10). 62% male.</p>	Cross-sectional; Quantitative.	(a) 31% (b) .22 (7)	(i) HSCL-25; Goldberg's emotional stability (ii) nil; (iii) nil; (iv) Marital quality (v) Emotion focused coping	40% of spouses were in the distressed range for HSCL. Spousal distress correlated with marital quality.
Evangelista 2002	<p>(1) 103</p> <p>(2) Living in the same household as the patient; the primary caregiver for > 1 month.</p> <p>(3) Mean age 60 (SD: 18). 70% female</p> <p>(4) Mean age 58 (SD: 12). 33% female.</p>	Cross-sectional; Quantitative.	(a) 61% (b) .26 (6)	(i) SF-12; (ii) nil; (iii) SF-12; (iv) nil, (v) nil	Caregivers had better emotional well-being than CHF patients. Emotional well-being of caregivers is associated with patient well-being.
Coyne 2001	<p>(1) 189</p> <p>(2) Spouses</p> <p>(3) Mean age 52 (Range 29-75) 79% female.</p> <p>(4) Mean age 53 (29-78) 31% female</p>	Longitudinal, Quantitative	(a) 75% (b) .22 (7)	(i) nil ; (ii) nil (iii) nil; (iv) nil; (v) Marital quality.	A composite measure of marital quality predicted CHF patient 4-year survival. When marital quality and NYHA class are considered jointly, they both make independent, statistically significant contributions to the prediction of patient mortality.

Walden 2001	(1) 74 (1) Significant others, identified as the patients' primary caregivers. (2) Not provided (3) Mean age 52	Cross-sectional, Quantitative.	(a) 100% (b).22 (6)	(i) nil; (ii) nil, (iii) nil, (iv) Heart Failure Needs Questionnaire for Caregivers	Educational and counselling needs were the same for patients and spouses. The most important were 'hope for a good quality of life', to receive honest explanations and to receive information about steps to take in an emergency.
Scott 2000	(1) 18 (2) Primary family caregivers (3) Mean age 63 (SD: 12), 89 % female (4) Mean age 69 (SD: 9) 85% male	Cross-sectional, Quantitative	(a) not given (b) not given.	(i) nil; (ii) Caregiver Reaction Assessment (iii) The Quality of life Index nil; (iv) Caregiver preparation appraisal.	Insufficient preparation to care and caregiving tasks significantly contributed to negative aspects of care provision. The esteem and mental health of the caregiver significantly enhanced HRQoL among caregivers.
Bull 2000a	(1) 130 (2) Family caregivers (3) Mean age 59 (SD: 14) (4) Mean age 73 (SD: 9)	Prospective, longitudinal; quantitative.	(a) not given (b) not given	(i) SF-36; (ii) Response to Caregiving Scale; (iii) SF-36; (iv) SF-36; (v) Client Satisfaction Questionnaire.	Family caregivers who reported more involvement in discharge planning had significantly higher scores on satisfaction, feelings of preparedness, perceptions of care continuity, acceptance of the caregiving role and self-reported health, than those who reported little or no involvement in discharge planning.
Bull 2000b	(1) 134 (2) Family caregivers (3) Mean age: 59 (SD: 14), 73% female (4) Mean age: 73 (9) (51% male)	Cross-sectional, quantitative.	(a) not given (b) not given	(i) SF-36; (ii) Perceptions of difficulty managing care; (iii) SF-36; (iv) SF-36; (v) Client Satisfaction; Health Locus of control; Continuity of care scale.	Continuity of care and extent to which caregivers felt prepared to manage care following hospitalisation were the best predictors of family caregiver's satisfaction with discharge planning.

Bull 2000c	<p>(1) 180 (2) Family caregivers (3) Mean age:59 (SD: 15), 73% female (4) Mean age 74 (SD: 9)</p>	A before- and- after non- equivalent control group design; Quantitative.	(a) not given (b) not given	(i) SF-36; (ii) Perceptions of difficulty managing care; (iii) SF-36; (iv) SF-36; (v) Client Satisfaction, Continuity of care scale.	Caregivers who participated in a professional-patient partnership model of discharge planning (intervention) reported receiving more information about care management and having a more positive reaction to caregiving 2 weeks postdischarge than the control cohort.
Westlake 1999	<p>(5) 63 (6) Spouses or sexual partners. (7) Mean Age 55 (SD: 11). 74% female (8) Mean Age 56 (SD: 9). 69% male.</p>	Cross-sectional. Quantitative and qualitative.	(a) not provided (b) must be <40%	(i) (ii) nil (iii) PAIS (iv) PAIS (v) Informational needs.	The most important sexual relationship issue of spouses was related to decreased frequency in sexual relations. Instruction relating to the sexual activity of CHF patients and partners should be provided by hospital staff.
Karmilovich 1994	<p>(1) 41 (2) 100 % were spouses. (3) 57 (Range 38-74), 73% female. (4) 44% were between 51 and 60 years of age.</p>	Cross-sectional Quantitative	(a) 100% (b).21 (7)	(i) Derogatis BSI (ii) Caregiver Demand Scale. 2 subscales Physical Caregiving Scale and Role Alterations Scale. (iii) nil (iv) nil (v)	Significant relationship between the number and perceived difficulty of helping behaviours performed and levels of stress. Females identified items relating to social participation and the relationship with the spouse as most burdensome. Men reported items relating to supervision and responsibility as most difficult to manage.

2.4 Discussion

2.4.1 *CHF caregiving and caregiver well-being*

2.4.1.1 Prevalence of emotional distress

Only four studies in the present review included standardised and psychometrically validated measures of emotional distress (Schwarz & Elman, 2003; Martensson, Dracup, Canary, & Fridlund, 2003; Rohrbaugh et al., 2002). The largest of these studies found that 21% of the sample (N=156) scored >16 on the Center for Epidemiological Studies Depression-Scale (CES-D), indicating depressive symptomatology (Schwarz & Elman, 2003). The mean CES-D score for their sample was 11.4 (SD 8.8), which is comparable to a recent meta-analysis which found that the mean CES-D score for 57 caregiver studies using this measure was 11.5 (SD 2.9) (Pinquart & Sorensen, 2003b). This finding suggests that CHF caregivers may have at least comparable levels of emotional distress to those patients caring for patients with other chronic conditions that are known to detrimentally affect informal caregivers. The relatively small samples of these studies, as with other caregiver studies, may have been subject to sampling bias, with caregivers with very mild and very severe levels of caregiving-related emotional distress underrepresented (Schulz et al., 1997).

Measures of emotional distress such as depression and anxiety are important outcomes in the wider caregiver literature and most studies have shown that informal caregiving is associated with increased levels of emotional distress (Pinquart & Sorensen, 2003b; Schulz et al., 1995).

2.4.1.2 Predictors of caregiver well-being

Several predictors of CHF caregiver well-being were identified in this review. Two studies found that gender was important with female caregivers having lower levels of emotional well-being (Rohrbaugh et al., 2002; Evangelista et al., 2002). Female caregivers also reported more difficulty in performing helping behaviours to CHF patients in one study (Karmilovich, 1994). In the reviewed studies of CHF caregivers neither age of caregiver nor relationship to patient, however were related to indices of caregiver strain or burden.

In other illness populations female caregivers have been found to be consistently more distressed (Yee & Schulz, 2000; Lutzky & Knight, 1994; Lutzky

& Knight, 1994). The two other well-established demographic predictors of caregiver outcomes are relationship to patient and age of caregiver (Pinquart & Sorensen, 2003b). Having a closer relationship to the care recipient and being younger are both associated with poorer mental health outcomes for caregivers. For example spousal caregivers and younger caregivers have generally been found to report greater caregiving strain than non-spousal caregivers (Cantor, 1983). These patterns were not examined in the identified studies.

CHF patient symptoms have not been consistently related to caregiver well-being. This is in contrast to other caregiver populations e.g. Alzheimer's disease (Pinquart & Sorensen, 2003a) and stroke (Schulz, Tompkins, & Rau, 1988). Rohrbaugh et al. (2002) found that NYHA class was not related to spousal emotional distress, while Martensson et al. (2003) found that, perhaps counter intuitively, higher functional status, as defined by NYHA class was related to poorer mental health. This recent finding was in a small sample (N=48), however it may well be that a higher functioning patient has the potential cause more problems for informal caregivers. For example, it has been argued that burden in Alzheimer's (AD) caregivers does not follow a linear trajectory with functional/behavioural impairment, but peaks in the middle phases of AD when behavioural disturbances are most problematic (Pruchno & Resch, 1989b). It may well be that informal caregivers are most distressed in the mild to moderate stages of CHF. Patients may have difficulty accepting the seriousness of the illness in the mild to moderate stages, but may become resigned to it in the more advanced stages when symptoms and activity limitations increase.

However in a meta-analysis of the wider informal caregiving literature, Pinquart & Sorensen (2003a) have found that higher levels of burden are generally related to higher levels of impairment in the care recipient. Indeed, it seems likely that patients who are experiencing more symptoms are more likely to require more assistance; therefore more demand on the caregiver and the greater the potential for poor outcomes. However this issue remains unclear with regard to CHF caregivers. Further research is needed to resolve this apparent paradox.

Bull and colleagues (Bull, Hansen, & Gross, 2000a; Bull, Hansen, & Gross, 2000b; Bull, Hansen, & Gross, 2000c) found that CHF family caregivers that were offered more involvement in discharge planning had higher scores on satisfaction, feelings of preparedness and were more accepting of their caregiving role than

family caregivers who were not offered involvement in discharge planning. In follow-up of this data caregivers who reported more involvement in discharge planning also reported better health.

Social support to informal caregivers has been consistently found to predict better outcomes for informal caregivers (Miller et al., 2001; Haley et al., 1996), however the one study that did examine social support in CHF caregiving did not find the predicted moderating effect of social support on depression (Schwarz & Dunphy, 2003). Caregiver personality factors have also been shown to relate to caregiver outcomes (Bookwala & Schulz, 1998; Hooker et al., 1994), however the reviewed studies did not examine these type of predictors.

2.4.1.3 Caregiver Health

Self-reported health was measured using the Short Form-12 or the Short Form-36 (SF scales) in six studies (Martensson et al., 2003; Schwarz & Elman, 2003; Evangelista et al., 2002; Bull et al., 2000a; Bull et al., 2000b; Bull et al., 2000c). The mean Mental Health Scores (MHC) using the SF scales were 51 (SD: 8) for Evangelista *et al's* (Evangelista et al., 2002) study and 46 (SD:7) for Martensson *et al's* study (2003), indicating approximately normal mental health, as the maximum score is 100 and means for population studies in this age group are around 51 (SD:10.2) (Ware, Kosinski, & Dewey, 2000). However, as with measures of emotional distress, a lack of matched non-caregiving comparison group data in these studies prevent firm conclusions to be drawn about whether MHC scores were significantly different in CHF caregivers. Martensson's *et al's* study (Martensson et al., 2003) was the only study that provided a mean score for Physical Component Summary (PCS) of the SF-12, for their entire caregiver sample (PCS mean for CHF spouses was 40.2, SD: 4.4). This score is slightly lower than US population norms for women in this age group (PCS mean for women between 55-64 years is 46.3, SD: 11) (Ware et al., 2000), indicating poorer health.

2.4.1.4 Caregiver appraisal

Caregiving specific measures of burden/strain or satisfaction have been widely used in other chronic conditions and have proven reliability and validity (Braithwaite, 2000; Vitaliano, Young, & Russo, 1991). Such measures provide an

index of the perceived affective, cognitive, somatic and behavioural consequences that arise as a result of informal caregiving. Only Schwarz and Elman's study (Schwarz & Elman, 2003) included this type of measure in their study design. They found that caregiving satisfaction was not related to hospital readmission of CHF patients.

These types of measures are particularly sensitive to affective changes relating to informal caregiving and they may detect effects that generic measures of emotional distress or well-being fail to. Given the value of this type of measure in Schulz and Beach's study (Schulz & Beach, 1999) predicting mortality, it is recommended that such measures be included in future CHF caregiver studies. Comparing longitudinal burden or strain measures between caregiving groups would also provide valuable insights into when along the illness trajectory is caregiving most difficult. This might suggest an optimal time for caregiver interventions. For example, interventions for caregivers might be of no discernible immediate benefit when the care recipient is NYHA class I, whereas strong immediate effects may be found when the care recipient is NYHA class III.

2.4.1.5 Qualitative findings

A number of research studies using qualitative methods were found (Martensson et al., 2001; Brostrom et al., 2003; Mahoney, 2001). Several interesting findings emerged from these studies. Brostrom et. al's study examined the influence of CHF related sleeping disorders on the social support provided by CHF patient's spouses. In this study respondents indicated that spousal support of the CHF patient may be negatively influenced by sleep disturbances as a result of the patients' symptoms of CHF and anxiety in relation to the disease.

Martensson et. al's study aimed to describe situations experienced by the spouses of patients with CHF that could potentially effect their ability to provide support to the patient. Firstly when the spouse experienced involvement with others, e.g. when the spouse got help from friends or family, appreciation from the patient or was included in the care of the patient, caring experiences were viewed as positive. However, caring experiences were viewed as negative when the spouse felt like an outsider. For example, when the spouse could not participate in usual social activities as a result of the physical or psychological consequences of CHF

on the patient or when the spouse did not receive support or recognition from friends family or the health care system.

Finally, Mahoney's study used narratives from CHF patients and family members to characterise the interruptions, confusion and efforts to adapt that caregivers experience while caring for CHF patients.

2.4.1.6 Use of theory

As we have previously discussed in Chapter 1 many of the studies were reported without any reference to explicit theoretical models explaining the outcomes of interest e.g. emotional distress. Using explicit theoretical models would allow the development of a cumulative body of research on informal caregiving. This could inform preventative interventions to enhance caregiver health and reduce the health inequalities that are associated with caregiving (Schulz & Beach, 1999).

2.4.2 *The role of informal caregivers in the management of CHF*

It has been estimated that up to two thirds of CHF hospitalisations are preventable with poor compliance to medical regimens and failure to seek help for escalating symptoms being primary reasons (Michalsen, Konig, & Thimme, 1998; Vinson, Rich, Sperry, Shah, & 1990). Surprisingly, there appears to be little research examining the role of informal caregivers in the management of CHF, despite the recognition in several papers that informal supports have the potential to assist tertiary prevention in CHF (Jaarsma et al., 2003; D'Alto et al., 2003), particularly in relation to compliance enhancement, facilitating self-care and seeking treatment for worsening symptoms. This implicit recognition of the important effect that CHF patient's informal carers may have in managing the disease has not been adequately met with explicit efforts to incorporate these individuals into CHF research.

Two studies examined the educational needs of informal caregivers of CHF patients. Walden et al.'s (2001) study found that both patients and their caregivers wanted more information on several aspects relating to the condition including issues relating to quality of life, honest explanations about the condition and information about what to do in dealing with an emergency. Westlake, Dracup, Walden, & Fonarow (1999) focused specifically on the concerns of patients and

spouses relating to sexuality. They found that both patients and caregivers in their sample reported a moderate to high need to receive specific information about sexual activity. Other studies have shown that there is often a lack of knowledge or misconceptions among patients about CHF (Horowitz, Rein, & Leventhal, 2004; Cline, Bjorck-Linne, Israelsson, Willenheimer, & Erhardt, 1999). These studies examining the educational needs of informal caregivers recognise that family members may have an important role to play in the management of CHF.

A recent study of CHF patient's spouses showed that spouses confidence in the patient's ability to manage their condition predicted survival over and above the patient's own confidence, higher spouse confidence was associated with longer survival (Rohrbaugh et al., 2004). This study shows that the beliefs of close family may have an independent effect on outcome in CHF and that successful adaptation to heart failure may involve more than the CHF patients personal agency. Therefore close family members may indeed have an important role to play in the management of CHF.

2.4.3 *Policy and practice implications of current studies.*

2.4.3.1 Caregiver distress

The reviewed studies have several implications for policy and practice. Firstly, the relatively high levels of distress and poor mental health identified in the caregivers of CHF patients (Martensson et al., 2003; Schwarz & Elman, 2003; Rohrbaugh et al., 2002; Evangelista et al., 2002). This would suggest that attention should be given to the well-being of the patient's family in managing CHF. Two separate lines of inquiry suggest that depression and anxiety are worth further investigation in the informal caregivers of CHF patients. CHF has been consistently associated with higher levels of emotional distress in patients (Freedland et al., 2003; Faris et al., 2002) and there is a compelling body of evidence looking at dyadic coping, i.e. couples, patient-spouse or patient-caregiver, which suggests that emotional distress is more common in caregivers if the patients are distressed (Bookwala & Schulz, 1998). There is also a related body of work demonstrating spousal similarity in psychological distress (Benazon & Coyne, 2000; Dufort, Kovess, & Boivin, 1994). Together these findings would suggest that further investigation of the extent, causes and consequences of emotional distress in the informal caregivers of CHF

patients is warranted, due to the reciprocal influence of emotional distress in patient/caregiver dyads. Finally, Schwarz and Elman's (2003) finding that the interaction of caregiver stress and depression was associated with increased risk of CHF patient readmission is also worth further consideration. Caregivers who have high levels of stress and depression may be less able to fulfil their caregiver role, which could potentially increase the chance of patient readmission.

2.4.3.2 Specific caregiver and patient education

Westlake et al.'s (1999) and Walden et al.'s (2001) studies suggest that there are currently deficits in the information that patients and their family receive about living with CHF, which may effect the successful management of the condition and impair patient and caregiver quality of life. Specifically routine information should be given to CHF patients and their family members about living with and managing CHF, and in particular details about the safety of sexual activity should be provided.

2.4.3.3 Involving caregivers in healthcare

The findings from Bull et al's studies (Bull et al., 2000a, b and c) would suggest that empowering caregivers by involving them in patient care may have the potential to ameliorate the negative consequences of caregiving and increase the willingness of family members to provide support for a care needing relative. Martensson et al's (2001) qualitative study also found that caregiver involvement in care was associated with a more positive view of caring. These findings would suggest that health care professional should endeavour to recognise the impact of the illness on close family members and include them in the management of CHF patients whenever possible.

Rohrbaugh's data (2004) provide powerful evidence that clinicians and policy-makers should look beyond the patient when think about devising CHF therapies and management regimens. A number of home-based nurse interventions have begun to do this by including caregivers in self-care management programs. For example in one study (Stewart, Pearson, & Horowitz, 1998) caregiver vigilance of the CHF patient's condition was encouraged. However the full potential of caregivers as a mode of treatment in CHF has not been fully investigated to the extent that it has in other clinical conditions.

One recent RCT in the stroke caregiver literature found that an intervention that targeted caregivers by training them to provide care reduced health care costs, caregiver burden and perhaps more importantly improved patient psychosocial outcomes (Kalra et al., 2004). Perhaps the family members of CHF patient's could be trained to care more effectively, which could have possible benefits for caregivers e.g. increased self-efficacy, CHF patients e.g. symptom control and reduce health care costs.

However such interventions would have to be offset against any potential adverse effects of increasing family member's responsibility for the CHF patient's health. There is some evidence that increasing family members responsibility for patient care is associated with negative outcomes particularly emotional distress. For example, Dracup et al (Dracup, Guzy, Taylor, & Barry, 1986) has shown that cardiopulmonary resuscitation (CPR) training with a social support intervention can benefit family members of patients with heart conditions, however in other formats CPR training was associated with greater emotional distress for patients than control conditions. The effects of these types of intervention need to be assessed in both patients and family members.

2.4.4 Limitations of current research

2.4.4.1 Study Design

As table 2.4 clearly demonstrates the majority of study designs were quantitative cross-sectional studies. Prospective longitudinal and randomised controlled trials (RCT's) study designs examining CHF caregiver outcomes are required in order to clarify several issues. It is increasingly recognised that there is an economic imperative to promote community based care of CHF patients (Phillips et al., 2004; Stewart et al., 2002). Given the importance of informal caregivers in the management of CHF patients in the community, clinical trials should assess the impact of interventions on patient's primary support persons. No RCT's examining CHF caregiver outcomes were found. Increasingly in the Alzheimer's caregiver literature RCT designs have been employed to examine the effect of interventions designed to improve caregiver outcomes (Gitlin et al., 2003; Sorensen, Pinguart, & Duberstein, 2002; Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Marriott, Donaldson, TARRIER, & Burns, 2000). These studies have

had moderate effects on caregiver outcomes. At present these type of studies are lacking in the CHF literature.

2.4.4.2 Representative samples

There was great variability in how CHF caregivers were sampled and defined. In a number of studies caregivers were not operationalised, as such. Defining caregivers loosely has been singled out as a possible confound of the wider literature and has the potential to call into question the meaningfulness of research findings (Vitaliano et al., 1997; Malonebeach & Zarit, 1991). A number of studies recruited only spousal caregivers, which has the benefit of controlling for the effect of relationship to patient, but perhaps biases the sample, as many CHF patients are elderly and single. Married individuals tend to have better health than unmarried or widowed patients (Kiecolt-Glaser & Newton, 2001). Not all studies provided socio-demographic details of their caregiver samples. This is important when comparing studies or explaining anomalous findings.

The clinical characteristics and socio-demographics of the care-recipient should also be recorded in caregiver studies. This provides valuable information when evaluating how representative samples are. Some samples were clearly caring for a more functionally limited patient sample than others. The distribution of the care-recipient sample across the 4 NYHA categories is clearly a useful piece of information, as this classification is based on CHF patient symptoms. The percentage of patients in class III and IV in particular, i.e. those most likely to be care-needing, given this limitation based classification, is clearly a useful piece of information. However, only 9 of 17 studies included enough clinical detail in order to establish this. In addition mean and standard deviation scores for left ventricular ejection fraction (LVEF's) are also a useful index of the severity of CHF in patient samples. These are routinely provided in studies examining CHF patients. This allows comparisons across studies. Only 7 of 17 studies included means and standard deviation for patient LVEF. Other clinical and socio-demographic characteristics that could shed light on caregiver outcomes include, patient neurohormonal assays, catecholamine assays, types of treatment that patient is receiving (both pharmacological and non-pharmacological), etiology of heart failure, patient's VO_2 max, patient quality of life, patient anxiety or depression, time since diagnoses of CHF, patient age, availability of home-help for patients,

patient co-morbidities, patient 6-minute walk distance and patient socio-economic status.

2.4.4.3 Weakness of measures

The use of heterogeneous measures in these studies also prevents the development of a cumulative body of knowledge on the subject. A number of studies used measurement instruments that have not received extensive validation and the psychometric properties of some self-report measures were not recorded (Karmilovich, 1994). This calls into question the reliability and validity of such measures. Future studies should endeavour to use measurement instruments that have proven reliability and validity and that can be meaningfully compared to other caregiving studies in different illness categories.

Reliability of measures of functional ability in CHF patients that are obtained from caregiver self-reports may be questionable (Karmilovich, 1994). Several studies have shown that caregivers personality characteristics can influence reports of patient impairment e.g. caregivers high in neuroticism report significantly more impairment in patients than patients themselves (Bookwala & Schulz, 1998). Both self-report and objective measures should be used when measuring caregiver stressors.

While self-rated health measures such as the Short-Form 36 have proven reliability and validity (Ware et al., 2000; Hemingway, Stafford, Stansfeld, Shipley, & Marmot, 1997) as outcome measures, increasingly, in the caregiver literature biomedical indices of health status are also measured; including various measures of immune function (Kiecolt-Glaser et al., 1991), blood pressure (Cacioppo et al., 2000), infectious illness episodes (Dyck, Short, & Vitaliano, 1999), physician visits (Kiecolt-Glaser et al., 1991) and mortality (Schulz & Beach, 1999). The inclusion of such objective measures in study designs provides a more compelling case for the health effects of caregiving stressors and indeed the positive effects of interventions aimed to reduce negative consequences of caregiving. Future studies should attempt to measure such objective outcome measures of health.

2.4.4.4 Sample size and statistical power

The sample size of the reviewed quantitative studies ranged from 18-191 (mean: 109; SD: 58) Only one (Schwarz & Elman, 2003) of the 13 quantitative studies reported statistical power for testing the stated hypothesis. This raises concern about the ability of the studies to answer research questions.

2.4.5 *Future avenues of research relating to caregiving in CHF*

There is indeed a dearth of literature examining the impact of informal caregiving in CHF. However the body of work reviewed points to several worthwhile avenues of research relating to caregiving in CHF.

2.4.5.1 Caregiver strain and CHF severity

Further longitudinal examination of the relationship between CHF illness severity and caregiver distress are recommended as two plausible contradictory hypotheses can be generated from previous literature. High functioning CHF patients may be associated with higher levels of reported caregiver strain or distress (Martensson et al., 2003) than poorly functioning CHF patients, perhaps because these individuals may have more variable and unpredictable care needs and may be less likely to comply with medical advice and engage in healthful self-care behaviour due to the mild nature of their symptoms. Indeed, in the MI literature one study (Mayou, Foster, & Williamson, 1978) found that wives of MI patients who had returned to work within two months showed more strain than wives whose husbands were still at home. On other hand poorly functioning CHF patients may also be associated with higher levels of strain or distress due to the higher levels of dependency associated with the later stages of the disease . Longitudinal study of patient and caregiver variables would resolve this issue and provide valuable information for interventions to improve patient and caregiver outcomes.

2.4.5.2 Enhancing adherence to medical regimens and health behaviour advice.

Several studies have argued that non-adherence is common in elderly heart failure patients (Cline et al., 1999). Rich et. al (1996) found that patients living with another person tended to be more adherent to their medication regimen

than patients living alone. Informal caregivers, particularly close family members, are ideally placed to enhance compliance to medical advice. Indeed health professionals caring for patients with CHF could look at informal caregivers as part of the non-pharmacologic armoury in treating and managing CHF. It has been argued that interventions that target both patients and their informal caregivers are more likely to enhance compliance with complex medical regimens than targeting patients alone (D'Alto et al., 2003). Further compliance research particularly home based interventions, incorporating informal caregivers into research designs are needed.

2.4.5.3 Assessing the impact of interventions for patients on their caregivers

Randomised controlled trials of drugs, exercise or self-management programs in CHF patients do not routinely include measures of caregiver well-being in evaluating outcome. Given the increasing evidence that caregiver and care-recipient well-being and quality of life appear to be related, assessment of the impact of trials on caregivers is warranted. Indeed significant positive effects of patient interventions on caregiver outcomes provide further supportive evidence for the implementation of particular interventions.

There is also increasing technology being used in the treatment of certain types of heart failure which may have an impact on the family or significant others. The Implantable Cardio-Verter Defibrillator or ICD is one such device that is increasingly being used to treat certain types of ventricular arrhythmia that can accompany heart failure. A number of studies have shown that this type of technology can have a significant impact on the patient's spouse and family (Marx, Bollmann, Dunbar, Jenkins, & Hawthorne, 2001; Dougherty, 1995). The 'collateral health effects' (Christakis, 2004) of these technologies also need to be assessed in their evaluation.

2.4.5.4 Education of patients and caregivers

It has been suggested in a number of studies that counselling and education of patients is an essential part of the non-drug management of CHF, as it may enhance long-term adherence to CHF management strategies (D'Alto et al., 2003; Gibbs, Jackson, & Lip, 2000; Braithwaite, 2000). A recent study by

Horowitz et al (Horowitz et al., 2004) suggested that there may be a great deal of confusion among patients surrounding CHF and its management. Patient's beliefs about the illness may not correspond to the medical model of the illness. For example some patients in their study had an acute model of CHF whereas the medical understanding is a chronic one. Such misconceptions and divergent beliefs may have implications for the self-management of the illness. However, none of the reviewed studies examined the effect of knowledge or beliefs on patient or caregiver outcomes. This type of study is necessary before it could be argued that counselling or education for CHF caregivers is beneficial. It may be that comprehensive education or counselling programs have little or no effect on important outcomes, or possibly even a negative effect for family caregivers. Indeed it is likely that extensive information may have the potential to create emotional distress, such as anxiety or depression in patients and family members. For example should the sobering mortality rates of CHF be explained to patients and family members? Research should establish what type and what level of information has the potential to improve physiological, cognitive, emotional and behavioural outcomes for patients and their caregivers.

2.4.5.5 Identifying pathogenic caregiver behaviour.

There is also empirical support that social relationships may in exceptional circumstances have deleterious effect on the health of the care-recipient (Williamson & Shaffer, 2001; Newsom & Schulz, 1998). While informal caregivers have the potential to improve patient outcomes in CHF, it is also worth remembering that individuals close to the CHF patient may also have the potential to detrimentally affect patient outcomes. For example 'over-protectiveness' of myocardial infarction patients by their spouses has been shown to be associated with increased patient anxiety and depression (Clarke, Walker, & Cuddy, 1996). Future studies should also endeavour to understand the CHF patient's reactions to being helped by family or friends.

2.4.5.6 Informal Caregivers - Whose responsibility : specialist, GP or nurse?

The idea of a care triad between the physician, the patient and the patient's closest family member has been discussed and advocated for a number of years in

the field of geriatrics (Silliman et al., 1996; Silliman, 1989). However there is little discussion on the relative role of specialists, GP's or nurses in facing the problem of caregiving. Elucidation of each of these group's roles may be particularly important in CHF, where patients and caregivers may come into contact with each type of health care provider on a regular basis. Further research needs to identify and clarify the role of the various health care specialists in addressing the problems faced by informal caregivers.

2.4.5.7 The economic value of informal caregiving in CHF

As CHF is an expensive condition to treat the economic value of informal care in managing CHF may be considerable. The economic cost to families of providing informal care may be much greater than previously thought (Stommel, Given, & Given, 1993). Recent estimates have shown that the value of informal care for ill and disabled adults may be equal if not greater than national health care budgets (Arno, Levine, & Memmott, 1999). Obviously health services cannot replace the care provided by informal carers, but they could provide more effective ways to support and empower the family caregivers of CHF patients, which may have the potential to improve outcomes for the carer, the patient and reduce health care costs.

2.5 Conclusions

While it is obvious that the CHF patient will be the main focus of health care professionals endeavours in CHF treatment, the reciprocal effects of the disease on close family members and patients are key to understanding the progress of the disease. It is surprising that there are so few studies examining issues surrounding informal caregiving in CHF, given the extent of the problem and the potentially high demands that family members may face, particularly in the advanced stages of the condition. This is particularly striking in light of several recent studies demonstrating the benefits of home-based care for CHF patients and the vast literature examining informal caregiving in other clinical conditions.

Many of the studies reviewed here were weak in conceptualisation and methodological rigor. In order to optimise the management of CHF patients, further longitudinal studies examining the informal caregivers of CHF patients are required. The availability of social support is an important prognostic indicator of

outcomes and has the potential to improve outcomes in CHF by enhancing tertiary prevention. Burdensome CHF caregiving may be an important predictor of ill health, which has consequences not just for the caregiver but also for the CHF patient, who is often dependent on the good health of close family or friends in order to remain in the community.

Chapter 3

3 Can the Demand Control Model of Job Strain be extended to examine the emotional well-being of informal caregivers?

Overview

As discussed in Chapter 1 there have been limited attempts in developing theoretical models in the research examining the health of informal caregivers. In this Chapter a preliminary analysis using the Demand-Control model of Job Strain is conducted. While the focus of the thesis is on Congestive Heart Failure, in this analysis we provide a preliminary analysis of the Demand-Control in a pre-existing data set of Stroke caregivers. In this chapter a brief background to the literature on Stroke caregiving is provided and the rationale for the present research question, the theoretical model, measurement of the model variables and statistical analysis is discussed.

Chapter 3 Abstract

Background: The Demand-Control model was used to predict emotional distress in a pre-existing data set of informal caregivers to Stroke patients.

Method: Data was gathered from 138 informal caregivers/patient dyads at two time points. The dependent variables were the caregiver's anxiety and depression (HADS). The predictor variables were caregiver Demand (stroke survivor's assessment of their physical and psychosocial functional limitations) and Control (caregiver's perceived control over stroke survivor's recovery). Hierarchical multiple regression was the primary method of analysis.

Results: In cross-sectional analysis of Time 1 and Time 2 data, main effects for Demand and/or Control were detected for anxiety and depression. The interaction between Demand and Control as predicted by the model was not found. Contrary to prediction, in longitudinal analysis of change, it was found that decreasing Control along with increasing Demand was associated with reduced distress.

Conclusion: The model was moderately successful in predicting emotional distress. The relative importance of caregiver Demand and Control in predicting outcomes changed over time in this data. Attempts to replicate these findings are recommended.

Note: An abbreviated version of this Chapter is in press and is to appear in the Journal of Psychosomatic Research (See Appendix G).

3.1 Introduction

3.1.1 *Stroke caregiving and emotional well-being*

Research has consistently shown that providing informal care for a stroke survivor can have a significant negative impact on the emotional well-being of informal caregivers (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 1998; Anderson, Linto, & Stewart-Wynne, 1995; Schulz, Tompkins, & Rau, 1988). Various outcome measures such as caregiver burden/strain, self-reported health and emotional distress have been shown to be influenced by a wide range of clinical, demographic and psychosocial variables e.g. gender and age of the caregiver (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001), caregivers health (Bugge, Alexander, & Hagen, 1999), patient affect (Blake & Lincoln, 2000), satisfaction with social support, self efficacy and coping strategies (van den Heuvel et al., 2001), caregiver 'view of the future' (Forsberg-Warleby, Moller, & Blomstrand, 2002) and patient cognitive decline following stroke (Thommessen, Wyller, Bautz-Holter, & Laake, 2001). Mediating and moderating mechanisms for these variables have been suggested and tested. However an unwieldy and seemingly unrelated array of factors relating to caregivers physical and mental health have been unearthed and these may be of limited use to policy makers and clinicians, aiming to alleviate the problems faced by stroke caregivers. Two recent reviews highlighted the lack of consensus in the literature regarding the most salient determinants of stroke caregiver outcomes such as emotional distress (Han & Haley, 1999; Low et al., 1999).

Several critiques of the wider caregiving literature have suggested possible reasons for the apparent lack of consensus in this research, including differing measurement strategies, poor operationalisation of key variables, weak study design and inadequate sampling techniques (Schulz et al., 1997; Barer & Johnson, 1990; Pearlin et al., 1990). Perhaps more fundamental is the widespread lack of concern for theoretical development that pervades this literature (Vitaliano, Zhang, & Scanlan, 2003). Issues surrounding conceptualisation and theory have received a limited amount of attention,

particularly in relation to informal caregiving in stroke. In this paper we address the issue of theory and measurement of caregiver stressors.

3.1.2 Theory driven research

As already discussed in Chapter 1, using cogent models that aim to tap the universals of providing informal care to chronically ill or disabled relatives has been lacking in the caregiver literature despite its many advantages. In this chapter the Demand-Control model of Job Strain (Karasek & Theorell, 1990) is used to generate hypotheses about anxiety and depression in a sample of informal caregivers. The Demand-Control model as applied to informal caregiving is outlined in figure 3.1.

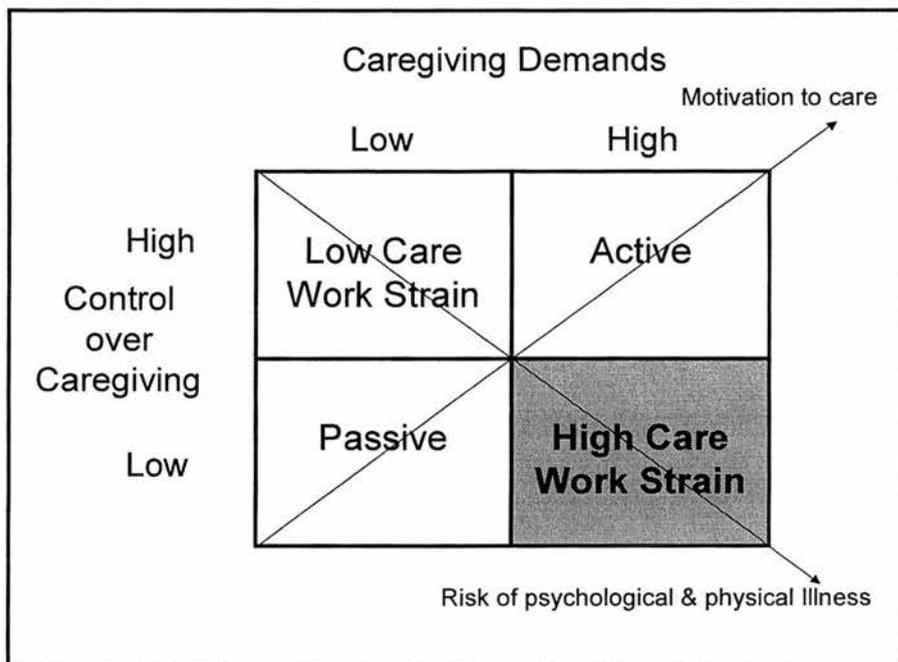


Figure 3.1. The Demand-Control Model applied to Caregiving

3.1.3 Measurement of Caregiver Stressors

Another widely cited criticism of these types of studies that attempt to assess the impact of informal caregiving, and indeed all of the stress and health literature that relies on pen and paper tests, is the measurement problems associated with using self-report measures to predict self-report measures from

the same participant (Watson & Pennebaker, 1989). It is argued that relationships between independent and dependent variables tend to be spuriously inflated due to the influence of common method variance e.g. negative affectivity when both stressor and health variables are measured through self-report from the same individual. It has been recommended that differing types of measurement should be used when possible to overcome this problem of affective bias or other types of common method variance e.g. social desirability.

In the present study the act of caregiving is specifically conceptualised as assisting the recovery of the stroke survivor. The 'Demand' variable is conceptualised as, the patient's assessment of their own physical and psychosocial functional limitations, using the modified Functional Limitations Profile (FLP) (Pollard & Johnston, 2001; Pollard & Johnston, 1999). The Demands of the 'work environment' in stroke caregiving, it is suggested, are largely determined by the physical and psychosocial behavioural limitations of the stroke survivor. The FLP taps these limitations in a straightforward descriptive fashion. This is in contrast to other measures of caregiver Demand, which may be more prone to subjective bias. For example, Bookwala and Schulz (1998) show that caregiver personality variables can bias assessments of caregiver stressors. Caregivers who were high in neuroticism and low in mastery reported higher levels of behavioural and functional limitations in care-recipients. The FLP also incorporates a more complete range of the Demand concepts of the Job Strain model which are often over-looked when testing the model in the work stress literature e.g. the physical, psychological, social and emotional Demands of given occupations (de Jonge, Mulder, & Nijhuis, 1999). This patient generated Demand variable overcomes the "nuisance" variable of negative affect (NA), as outlined by Watson and Pennebaker (Watson & Pennebaker, 1989), and it reflects an arguably more objective measure of caregiver Demand than any similar variable obtained from the caregiver. In addition Mora, et. al (2002) have found that trait NA does not bias elderly adults' reports of their own symptoms and that both NA and self assessed health (SAH) reflect independent sources of common sense

and self-knowledge, and each contributes valid information about the elderly individuals' perceptions of their somatic states.

The 'Control' variable in this study asks specifically about the caregivers perceived ability to control the stroke survivor's recovery. This addresses the problem of stressor specificity, which some authors have argued is too-often neglected (Kneebone & Martin, 2003). While this argument related to research based on Lazarus and Folkman (Lazarus & Folkman, 1984) framework, particularly 'ways of coping' styled measures, the Job Strain literature also argues for Control measures that are specific to the occupation being studied (De Jonge et al., 1999; De Jonge, Dollard, Dormann, Le Blanc, & Houtman, 2000; Wall, Jackson, Mullarkey, & Parker, 1996). It has been argued that studies that have failed to find an effect for Control, often have Control measures that do not relate specifically to the occupation under investigation or contain the complex construct of *Decision Latitude*, which some authors claim is actually more than one construct (de Jonge et al., 1999; Wall et al., 1996; Wall et al., 1996).

3.1.4 *The Present Study*

This present study offers several improvements to previous investigations of the impact of stroke caregiving. In particular, the study offers a conceptual and theoretical clarity that previous stroke caregiving studies have often lacked. Explicit predictions regarding emotional outcomes are derived from a model that has been hitherto virtually unexplored in relation to informal caregiving, despite extensive validation using both psychological and physiological outcomes in work stress studies.

A prospective longitudinal design has been employed, allowing changes in predictor (Demand and Control) and dependent (anxiety and depression) variables to be tracked over time. The data collection points in this study are also clearly defined in terms of the recovery trajectory. This is often not the case and rarely has caregiver data been gathered so soon following stroke. This allows us to say what is happening to the caregiver and at what point of the recovery trajectory. Many previous studies have not allowed such clear statements to be made.

3.1.5 *Study research question and hypotheses.*

The current study aimed to answer the following research question: Can Karasek's Demand-Control model explain variance in caregiver emotional distress (anxiety and depression) in the informal carers of stroke patients? In order to do this 3 hypotheses were generated. These were tested cross-sectionally at 2 time points and prospective longitudinally, in which case the predictions refer to change in Demand, Control, anxiety and depression between Time 1 and Time 2. Age and gender of the caregiver, and caregiver relationship to patient (spouse v non spouse) were controlled for, as these socio-demographic demographic variables have well-established relationships to caregiver emotional outcomes (Pinquart & Sorensen, 2003a; Cantor, 1983).

1. Caregiving in high Demand conditions will be associated with increased caregiver anxiety and depression.
2. Increased caregiver Control over assisting recovery following stroke will be associated with decreased anxiety and depression.
3. Higher Perceived Control over assisting the patient's recovery following stroke will moderate the effects of high Demand on anxiety and depression.

3.2 **Methods**

3.2.1 *Design*

The study included cross-sectional analysis at two time points and a prospective longitudinal analysis of change. Caregiver measures were recorded at 2 time-points: at 2 weeks (Time 1), and at 8 Weeks (Time 2) following the patient's discharge from hospital. Both the patient and their caregiver were interviewed separately in their own homes. This study was part of a larger randomised controlled trial evaluating a workbook-based intervention that was aimed to assist recovery for stroke patients and their partners. This intervention did not affect caregiver depression, anxiety (See table 3.1), Demand, ANCOVA $F(1, 133) = 0.09, p=0.76$, or Control, ANCOVA $F(1,133) = 0.00, p=0.99$.

Table 3.1.

A randomised controlled trial of a workbook-based intervention for stroke patients and carers: Effects on carer's emotional distress.

Measure	Time	Control	Intervention	df	F	P
		Mean (SD)	Mean (SD)			
Depression	1	4.9 (3.9)	5.3 (3.7)	(1,135)	.02	.89
	2	4.8 (4.1)	5.1 (4.3)			
Anxiety	1	7.3 (4.2)	7.5 (4.7)	(1, 135)	.06	.82
	2	7.0 (4.5)	7.1 (4.7)			

* $P < 0.05$. F values refer to ANCOVA using time 1 scores as a covariate.

3.2.2 Participants

All patients discharged from a large teaching hospital in Dundee, Scotland following acute stroke and their carers, between February 1998 and May 2000, were invited to participate. 327 patients were invited to participate. Caregivers were identified by asking the stroke patient 'who is the individual most involved in your care at home?', while they were recovering in hospital. 203 patients and 172 caregivers were recruited, however data for caregiver/patient dyads was only available for $n=138$. This sub-sample was used as measures from both patient and caregiver were used to test the model. There were no significant differences between this sub-sample and the main sample in the main study measures or intervention effects. Details of this patient and caregiver sample are presented in table 3.2. Patient cognitive impairment was assessed using a combined Information and Orientation section of the Clifton Assessment Procedures for the Elderly (CAPE) (Pattie & Gilleard, 1979) and the Mental Status Questionnaire (Wilson & Brass, 1973) giving a total of 14 items (due to tests sharing 8 items). Respondents were excluded from recruitment if they scored less than 8/14, a score indicating moderate impairment.

Table 3.2**Patient and Caregiver characteristics (N=138).**

Patient characteristic	Mean (SD) or % [range]
Age	67.9 (12.3) [17-91]
Gender % female	76%
Deprivation category (See note)	
1-2 (least deprived)	23%
3-5	45%
6-7 (most deprived)	32%
Side of motor deficit (% left)	47%
Previous stroke (% yes)	15%
Mental status questionnaire	7.2 (4.0)
Barthel Index at Time 1	17.9 (3.3) [3-20]
Co-morbidities (% yes)	84%
Caregiver characteristics	
Age	61.3 (14) [21-88]
Gender % female	76%
Relationship to patient	
Spouse	79%
Child	11%
Caregiver self-rated health	
Excellent- Very Good	34%
Good	39%
Fair-Poor	27%

Note: Deprivation category is measured using the Carstairs Depcat Scale (1 least deprived to 7 most deprived). (McLoone, 2004)

3.2.3 Measures

Descriptive statistics, including means, standard deviations, ranges, Cronbach's alpha's and zero-order correlation for all measures are presented in table 3.5.

Demand was measured using the modified Functional Limitations Profile (Pollard & Johnston, 2001; Pollard & Johnston, 1999). This is the UK version of the Sickness Impact Profile (Patrick & Peach, 1989). It is a behaviourally based measure of sickness-related dysfunction. The version used in this study excluded the 'work' category of the FLP. It contained 127 items covering ambulation, bodycare, alertness, mobility, sleep, social, emotion, eating, household, recreation and communication limitations that the patient may be experiencing. Statements are read about specific behaviours and patients are asked if they describe them or not; they are then asked if they believe the limitation in behaviour is due to their stroke. The modifications to the FLP were made as a result of several problems in the scale design including the scoring method of this instrument and the ordering of items. Preliminary evaluation of this modified instrument has suggested sound internal reliability, criterion validity and sensitivity to change in a number of illness populations (Pollard & Johnston, 1999). There is a possible range of 0-100. The complete measure and scoring are shown in appendix B.i.

Control was measured using a situational Control measure developed by the authors called the perceived control over recovery scale for caregivers. This 8-item measure asked the caregivers how much Control they felt they had over the stroke survivor's recovery. It demonstrated adequate internal reliability at both time points and test-retest at Time 1 and Time 2 was $r = 0.69$, $p < 0.01$. The measure correlated positively with patient recovery locus of control at Time 2 $r = .18$, $p < 0.05$ providing some evidence of convergent validity (Partridge & Johnston, 1989). The complete measure and scoring are shown in appendix B.ii.

Anxiety and Depression: The Hospital Anxiety and Depression Scale was used to assess caregiver distress (Zigmond & Snaith, 1983). This 14-item questionnaire aims to exclude somatic items, which are likely to be derived from physical illness. It provides a measure of both anxiety and depression in two sub-scales, 7 items in each scale with 4-point response alternatives, ranging from 0 to 3. There is a possible range, therefore, of 0-21. The scores are described as "normal" if they range between 0-7, as "possible distress" if they fall between 8-10 and "probable distress" if between 11-21 (see table 3.3).

Total scores for anxiety and depression are calculated by adding the scores obtained for each item. Several reviews have established the psychometric properties of this measure (Bjelland, Dahl, Haug, & Neckelmann, 2002; Johnston, Pollard, & Hennessey, 2000; Herrmann, 1997). The complete measure and scoring are shown in appendix B.iii.

3.2.4 Procedure

All patients who were admitted to Ninewells Hospital in Dundee, Scotland for stroke were identified. Within 48 hours of hospital admission following stroke, standard clinical measures were administered by a nurse and confirmed by CT scan where appropriate. While patients were in hospital, following stabilisation of their condition, they were approached by a researcher, who explained the aims and details of the study. If they agreed to participate, they were asked to sign an informed consent form at that time. Caregivers were identified at this point and contact details were sought in order to invite them to participate. The first interview took place later, within 2 weeks of hospital discharge (Time 1). Time 2 was conducted 8 weeks after discharge. If patients failed the cognitive screening test, they were not required to complete the measures and carers were invited to continue in the study. Duration of interviews was between 45 minutes and two hours, depending on the breaks requested by participants.

3.2.5 Statistical analyses

Descriptive statistics and analysis of variance were used to examine and describe the data. Relationships between variables were explored using Pearson's correlations. Hierarchical multiple regression analyses were used to test the efficacy of the model. Post-hoc power analysis showed that the analysis at Time 1 (N =138) and Time 2 (N=106) had over 90% power, to detect a medium effect size (Cohen's $f^2 = .15$) on depression and anxiety using 3 predictor variables and an alpha level of .05. There were no significant differences between caregivers who dropped out after Time 1 in age ($t = -0.48$, $p = 0.64$), gender (Chi-square = 0.26, $p = 0.61$) or relationship to patient i.e. spouse or non-spouse (Chi-square = 0.90, $p = 0.34$).

3.2.6 Ethics

Prior to the commencement of the study an ethical proposal was submitted to the Tayside research Ethics Committee. Ethical approval was granted by the Committee following a review of our protocol and measures.

3.3 Results

3.3.1 Levels of anxiety and depression over time

Table 3.3 shows the breakdown of normal (0-7 on HADS), possible (8-10) and probable (11-21) anxiety and depression in this sample of caregivers at Time 1 and Time 2. At Time 1 48% of the sample and at Time 2, 40% of the sample were in possible/probable range for anxiety. 23% and 22% of the sample were in the possible/probable range for depression at Time 1 and 2, respectively. It is important to note that these may not be the same caregivers in each of the normal, possible and probable depression and anxiety categories at both time points.

Table 3.3

Levels of caregiver emotional distress (HADS scores)

	Normal (0-7)		Possible (8-10)		Probable (11-21)	
	Anxiety	Depression	Anxiety	Depression	Anxiety	Depression
	%	%	%	%	%	%
Time 1	52	77	28	12	20	11
Time 2	60	78	22	12	18	10

3.3.2 Changes in Demand, Control, depression and anxiety over time.

Table 3.4 displays the mean scores for the Demand, Control and outcome (HADS anxiety and depression) variables over time. Repeated measures ANOVA's were performed to test for within-subject change over time. The dependent variables (HADS anxiety and depression) did not change significantly over time. However there was a statistically significant reduction in both Demand and Control over time.

Table 3.4
Caregiver measures over time. Repeated measures ANOVA's.

<i>Measure</i>	<i>Time 1</i>		<i>Time 2</i>		<i>F</i>
	M	SD	M	SD	
Dependent Variables					
Depression HADS	5.1	3.8	5.0	4.2	F=0.17
Anxiety HADS	7.4	4.4	7.1	4.6	F=2.01
Independent Variables					
Demand	51.2	19.3	48.4	21.6	F=4.4*
Control	29.2	7.6	27.6	8.1	F=8.36**

* $P < 0.05$ ** $P < 0.01$

3.3.3 Descriptive statistics and zero-order correlations.

Table 3.5 presents the descriptive statistics and the intercorrelations for the study variables. Gender, age and relationship to patient (spouse or non-spouse) were used as control variables. An examination of zero-order correlations in table 3.5 shows that Demand and Control were related to anxiety and depression as the model would predict i.e. Higher Demand is associated with higher anxiety and depression and Lower Control is associated with higher anxiety and depression. Females were reporting more anxiety at both time points. Age and relationship to stroke patient were positively related to control i.e. older caregivers and spouses had higher levels of control. Spouses had higher levels of depression.

Table 3.5
Descriptive Statistics and Zero-Order Correlations for key study variables – Cross-sectional analysis.

Variable	Range	M (SD)	Cronbach's α	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Age	21-88	61.3 (14.0)		1.00										
2. Gender	0-1	----		.07	1.00									
3. Relationship	0-1			.59**	.04	1.00								
<u>Time1</u>														
4. Demand	0-86	51.2 (19.3)	0.86	.03	-.02	-.05	1.00							
5. Control	8-40	27.2 (7.6)	0.91	.21*	.11	.21*	-.29**	1.00						
6. Anxiety	0-20	7.4 (4.4)	0.80	-.15	.19*	-.02	.19*	-.18*	1.00					
7. Depression	0-16	5.1 (3.8)	0.79	.09	.08	.16	.23**	-.29**	.65**	1.00				
<u>Time2</u>														
8. Demand	0-82	48.4 (21.6)	0.89	.01	-.02	-.08	.71**	-.18*	.20*	.29**	1.00			
9. Control	8-40	27.6 (8.1)	0.91	.17	-.02	.22*	-.29**	.69**	-.32**	-.31**	-.24**	1.00		
10. Anxiety	0-20	7.1 (4.6)	0.83	-.12	.23**	-.04	.06	-.18*	.81**	.55**	.06	-.33**	1.00	
11. Depression	0-18	5.0 (4.2)	0.80	.11	.08	.18*	.20*	-.23**	.54**	.76**	.19*	-.32**	.66**	1.00

* P<0.05, ** P<0.01, Relationship = spouse is 1, non-spouse is 0. Gender = male is 0, female is 1.

3.3.4 Hierarchical Multiple Regression

The numbers of respondents varied across different analyses due to missing data. An alpha level of 0.05 was used for all statistical tests. A cross-sectional hierarchical multiple regression (MR) analysis of Time 1 and Time 2 is followed by a longitudinal MR analysis controlling for baseline scores, using residualized change scores for independent and dependent variables. Residual scores were used to test if change in Demand and Control predicted changes in emotional distress. For both dependent (Depression and Anxiety) and independent (Demand and Control) variables, the values of Time 2 measures were adjusted for values at Time 1. A residual greater than zero would reflect greater anxiety, depression, Demand or Control than expected on the basis of the initial scores, a residual less than zero would reflect less anxiety, depression, Demand or Control than expected on the basis of initial scores. A residual value of zero would reflect no change in independent and dependent variables

In order to test the predictions of the model cross-sectionally a hierarchical multiple regression was performed. In the 1st step caregiver age, gender (female =1, male = 0) and relationship to patient (spouse =1, non-spouse =0) were entered as independent variables. In the second step Demand, Control and a Demand multiplied by Control variable, to test for interaction, were entered as independent variables and multiple regressions were performed for depression and anxiety. Independent variables (Demand and Control) were centred prior to forming the interaction variable (Demand multiplied by Control) and performing the analysis as suggested by Cohen, et. al (Cohen, Cohen, West, & Aiken, 2003). Centering is achieved by subtracting the mean value for each predictor from individual scores. This centering procedure was used to decrease the likelihood of multi-collinearity between the interaction term and its components Cohen et. al (Cohen et al., 2003).

Predicting anxiety and depression cross-sectionally (Time 1).

The overall model for anxiety was not significant cross-sectionally at time 1, adjusted $R^2 = .07$, $F(6, 118) = 2.62$, $p > 0.05$, after controlling for

caregivers age, gender and relationship to patient. Younger caregivers were significantly more anxious, $\beta = -.22$, when gender and relationship to patient were controlled for. Details of the regression are presented in table 3.6.

The overall model for depression was statistically significant cross-sectionally at time 1, adjusted $R^2 = .13$, $F(6,118) = 4.04$, $p < 0.05$, after controlling for caregivers age, gender and relationship to patient. Details of the regression are presented in table 3.6. High Demand and low Control were associated with higher depression. The interaction of Demand and Control did not account for a statistically significant amount of variance.

Predicting anxiety and depression cross-sectionally (Time 2).

The overall model for anxiety was statistically significant cross-sectionally at time 2, adjusted $R^2 = .14$, $F(6,119) = 4.31$, $p < 0.05$, after controlling for caregivers age, gender and relationship to patient. Details of the regression are presented in table 3.6. Of the predictor variables entered Control was accounting for most of the variance in anxiety, lower Control was associated with higher anxiety. Demand and the interaction of Demand and Control were not statistically significant.

The overall model for depression was statistically significant cross-sectionally at time 2, R^2 change = .15, $F(6,119) = 4.63$, $p < 0.05$, after controlling for caregivers age, gender and relationship to patient. Details of the regression are presented in table 3.6. Again of the predictors entered Control was accounting for most of the variance, Lower Control was associated with higher depression. Demand and the interaction of Demand and Control were not statistically significant.

Table 3.6
Hierarchical multiple regression of the Demand-Control Model at Time 1
and Time 2 on HADS Anxiety and Depression (n=138).

Step and Variable	HADS anxiety β	HADS depression β
Time 1		
<i>Step 1 Control variables</i>		
Age	-.22*	-.02
Gender	.17	.02
Type of caregiver (spouse or non-spousal)	.12	.19
R ²	.06	.03
F	2.53	1.38
<i>Step 2 Demand-Control Model</i>		
Demand	.17	.20*
Control	-.13	-.27**
Demand X Control	-.07	-.10
R ² change	.06	.14**
F	2.63	4.04**
Time 2		
<i>Step 1 Control variables</i>		
Age	-.17	-.01
Gender	.22*	.04.
Type of caregiver (spouse or non-spousal)	.06	.21
R ²	.07*	.04
F	2.85*	1.82
<i>Step 2 Demand-Control Model</i>		
Demand	-.04	.14
Control	-.34**	-.33**
Demand X Control	.05	.02
R ² change	.11**	.15**
F	4.31**	4.63**

* P<0.05, ** P<0.01. Relationship = spouse is 1, non-spouse is 0. Gender = male is 0, female is 1.

Predicting change between Time 1 and Time 2 in anxiety and depression.

In order to test the model longitudinally a multiple regression using residualised change scores was used. Residualised anxiety and depression were entered as the dependent variables and residualised Demand, Control and a Demand multiplied by Control variable, to test for interaction, were entered as the independent variables into the regression model. Initial anxiety accounted for 66% of the variance in anxiety at Time 2, and initial depression accounted for 58% of the variance in depression at Time 2. Initial Demand accounted for 51% of the variance in Demand at Time 2 and initial perceptions of Control accounted for 47% of the variance in Control at Time 2. Table 3.7 presents the descriptive statistics and the intercorrelations for the residualised change score variables. An examination of zero-order correlations in table 3.7 shows that residualised Demand and Control do not relate strongly to residualised anxiety and depression as the model would predict. Residualised anxiety and depression, however did have a strong relationship suggesting that changes in depression were related to changes in anxiety.

Table 3.7.

Descriptive Statistics and Zero-Order Correlations for key study variables- Longitudinal Change Score Analysis.

Variable	M (SD)	1.	2.	3.	4.	5.	6.	7.
1. Age	61.3 (14.0)	1.00						
2. Gender	-----	.07	1.00					
3. Relationship	-----	.59**	.04	1.00				
4. Residualised Demand	0 (15.17)	-.02	-.01	-.06	1.00			
5. Residualised Control	0 (5.91)	.02	-.11	.10	-.09	1.00		
6. Residualised Anxiety	0 (2.67)	-.01	.12	-.04	-.08	-.14	1.00	
7. Residualised Depression	0 (2.71)	.06	.02	.08	-.10	-.17	.52**	1.00

* $P < 0.05$, ** $P < 0.01$. Relationship = spouse is 1, non-spouse is 0. Gender = male is 0, female is 1.

After controlling for caregivers age, gender and relationship to patient, the overall model was not statistically significant for anxiety, Adjusted $R^2 = .05$, $F(6, 116) = 2.00$, $p > 0.05$; but it was for depression, adjusted $R^2 = .09$, $F(6, 116) = 3.09$, $p < 0.05$. In both analyses the interaction of Demand and Control emerged as the only statistically significant factor in the model. Details of these analyses are presented in table 3.8.

Table 3.8

Hierarchical multiple regression of the Demand-Control Model on HADS Anxiety and Depression using residualised change scores# .

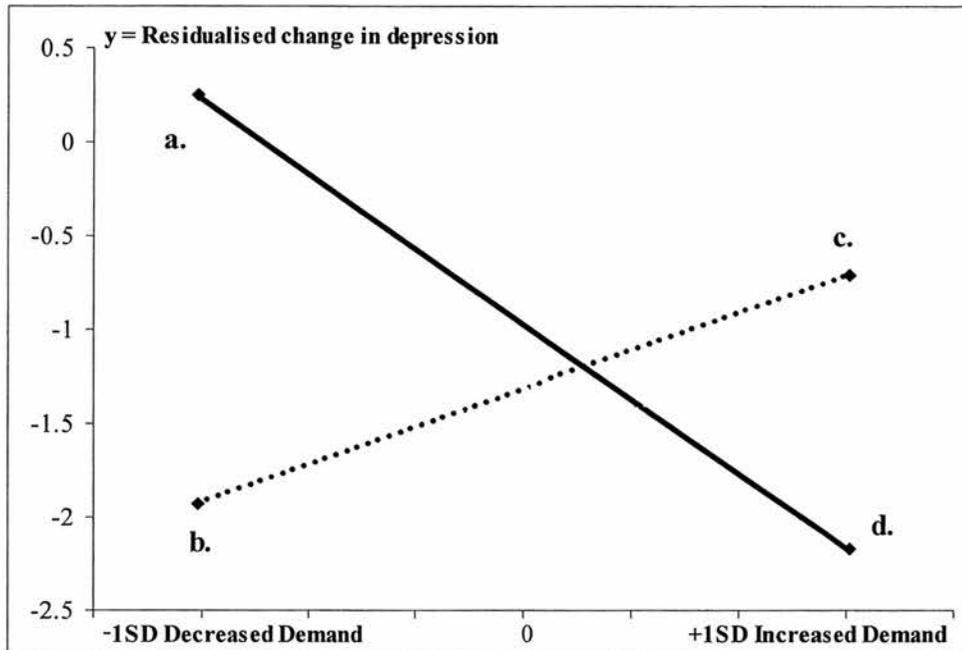
Step and Variable	HADS anxiety# β	HADS depression# β
<i>Step 1 Control variables</i>		
Age	-.02 (.01)	.01 (.05)
Gender	.15 (.14)	.04 (.02)
Type of caregiver (spouse or non-spousal)	-.01 (-.04)	.11 (.08)
R^2	.02 (.00)	.02 (-.01)
F	0.93 (0.86)	0.63 (0.55)
<i>Step 2 Demand-Control Model</i>		
Demand#	-.09 (.02)	-.10 (-.05)
Control#	-.04 (.04)	-.06 (.02)
Demand X Control#	.24** (.00)	.31** (.12)
R^2 change	.07* (-.02)	.12** (.02)
F	2.00 (0.22)	3.09**(0.57)

* $P < 0.05$, ** $P < 0.01$. . Relationship = spouse is 1, non-spouse is 0. Gender = male is 0, female is 1.

The bold type indicates the regression analysis when the outlying point is removed.

In order to investigate the form of the interaction between Demand and Control on depression, a decomposition analysis was carried out, as described

by Cohen et. al (2003). That is the slope of perceived Control on emotional distress (depression and anxiety) at high and low levels of Demand (+1 and -1 SD above/below the mean, respectively) was examined using unstandardised regression coefficients to determine whether the detected interaction reflected the hypothesised moderation effect of control on the relationship between Demand and depression. Figure 3.2 shows that contrary to prediction, the greatest decrease in depression was in caregivers who experienced an increase in Demand, and a decrease in perceived Control over assisting recovery over the 8 weeks.



<i>Increased Control (+1SD)</i>	
<i>Decreased Control (-1SD)</i> _____	
a.	<i>Decreased Demand, decreased Control.</i>
b.	<i>Decreased Demand, increased Control.</i>
c.	<i>Increased Demand, increased Control</i>
d.	<i>Increased Demand, decreased Control</i>

Figure 3.2

Relationship between Demand and Depression for increased and decreased levels of Control (Residualised scores).

An analysis of the residual scatterplot of this solution revealed that a single outlier was largely responsible for the detected interaction. This data point was an individual who had a decrease of -2.3 standard deviation units in Demand, a decrease of -3.9 standard deviation units in Control and an increase of 4.6 standard deviation units in depression between Time 1 and 2. The

figures in bold in table 3.8 show the regression analysis when this outlying case is deleted. Neither significant main effects nor interactions emerged when this data point was deleted.

3.4 Discussion

3.4.1 Cross-sectional - depression and anxiety

Cross-sectional analyses were generally supportive of the Demand-Control model. Both Demand and Control were equally important in predicting depression at Time 1, demonstrating the two main effects of Demand and Control of the model (Karasek & Theorell, 1990) on depression and supporting hypotheses 1 and 2. Results for anxiety at Time 1 were in the predicted direction but failed to achieve statistical significance. This was largely due to the strong effect of age of caregiver in predicting anxiety. The finding that younger caregivers are at increased risk for emotional distress supports previous research (van den Heuvel et al., 2001; Schulz et al., 1988). The Time 2 cross-sectional analysis at 8-weeks, revealed that caregiver perceptions of Control over assisting recovery were more important in predicting both anxiety and depression than caregiver Demand, which was no longer detected as a statistically significant predictor of emotional distress. Caregivers with higher perceptions of Control over assisting recovery at this time point were less depressed and anxious. This supports hypothesis 2.

At both time points it was main effects for either Demand or Control or both that were revealed, rather than any interactive or 'buffering' effect that is sometimes uncovered (Van Der Doef & Maes, 1998). However, the change in the predictive power for Demand and Control between Time 1 and Time 2 is not easily explained. Perhaps at the outset of the 'occupation' of caregiving (Time 1, 2 weeks following discharge) the Demands of the job are the most potent factors in explaining emotional distress, whereas at Time 2 (8 weeks following discharge), given time to observe either a decline or improvement in the stroke survivor's physical and psychosocial functioning (i.e. changes in the work Demands), perceptions of controllability over assisting recovery may be more powerful in influencing emotional distress. In the early phases of stroke

caregiving it may be that controllability is not certain and therefore not important, whereas in the weeks following stroke, changes in functional status tend to occur, mostly improvement but also decline, and consequently perceptions of Control change accordingly. In this sample there were statistically significant decreases in Demand between Time 1 and Time 2, with an overall reduction in functional limitations of the sample at Time 2. This overall reduction in Demand over time may explain why it became less important in predicting distress at Time 2.

3.4.2 Longitudinal analysis of change - depression and anxiety

As well as Demand and Control predicting emotional distress at one point in time, the model (Karasek & Theorell, 1990) also suggests that changes in Demand and Control should relate to changes in indicators of Strain i.e. depression and anxiety. A multiple regression analysis using residualised change predictor (Demand and Control) and dependent (Anxiety and depression) variables was performed to test the efficacy of the model in predicting change. This produced an altogether different pattern of results compared to the cross-sectional analysis. Main effects for Demand and Control were not found for depression or anxiety, however interactions of Demand and Control were detected for both dependent variables. On further investigation of these interactions, the interactions predicting depression and anxiety turned out to be the exact opposite of the strain hypothesis of the model, with *decreases* in caregiver perceptions of Control over recovery *reducing* the effects of increased Demands and vice versa. The Demand-Control model (Karasek & Theorell, 1990) in contrast argues that increased job Control moderates i.e. reduces the effects of increased job Demands. However interpretation of this finding should be treated with caution given the potential unreliability of the regression solution. When the one outlying data point was removed the interaction effect disappeared and main effects did not emerge. The finding is interesting nonetheless and it is consistent with the 'goodness-of-fit hypothesis' about appraisals of controllability (Park, Folkman, & Bostrom, 2001). This hypothesis argues that better adjustment is achieved when coping efforts match the controllability of the situation.

Another possible explanation for the detected interactions in the residualised change analysis might lie in models of depression that are derived from attribution theory such as the learned helplessness theory of depression (Abramson, Seligman, & Teasdale, 1978). Figure 3.2 shows that increases in Demand and increases in caregiver perceptions of Control over the patient's recovery is associated with increase in depression. These may be caregivers who see the patient declining and attribute control over recovery to themselves. According to learned helplessness theory internal explanations for uncontrollable events are associated with personal helplessness and leads to increased depression (Abramson et al., 1978). This might also explain why stronger effects for the interaction of Demand and Control were found for depression rather than anxiety.

The study findings have implications for interventions designed to reduce negative outcomes for those caring for stroke survivors, and indeed other illness groups. While increasing perception of Control over recovery in stroke survivors may produce significant improvements in a number of important patient outcome measures (Johnston, Morrison, MacWalter, & Partridge, 1999), this approach should be carefully considered before using the same strategies in the informal caregivers of stroke patients. It may be that control-enhancing interventions aimed to reduce negative outcomes for stroke caregivers should take cognisance of the controllability of the caregiving stressors that they wish to address. Certain stressors are clearly controllable, for example managing one's time more effectively, while others are clearly less so, this includes the physical and psychosocial recovery of the patient. Caregiver interventions should perhaps focus more on teaching caregivers how to deal with controllable caregiver stressors rather than less controllable stressors such as the recovery of the care recipient. Nevertheless since the belief that you can affect the patient's recovery is associated with less depression, training caregivers in ways that they may assist the patient's recovery, may be beneficial to both patients and particularly the caregivers, in terms of reducing emotional distress. However given a deteriorating patient, the benefits of such an intervention may be negligible.

3.4.3 *Levels of depression and anxiety*

In our sample between 40% and 48% of caregivers had scores above 8 for anxiety and between 22% and 23% had scores above 8 on depression on the hospital anxiety and depression scale (HADS). Levels of anxiety and depression in particular, were lower than previous findings by Anderson et. al (Anderson et al., 1995), but quite similar to findings by Dennis et al (Dennis et al., 1998). Using a score of 8 as the cut-off for possible morbidity on the HADS, Anderson et. al found that 58% of stroke caregivers had possible anxiety and 50 % had possible depression, while Dennis et al found that 37% of their sample had similar levels of anxiety (HADS>8) and 17% had similar levels of depression (HADS>8). It is not exactly clear why the levels of depression in particular are much higher in Anderson et al's study, however their results are based on a one year follow-up of caregivers that were caring for patients, who were possibly experiencing more functional limitations. These caregivers would have been caring for a longer period than the present sample, hence more caregiver Demand and greater duration of exposure to Demand, which might explain the discrepancy between the two studies in depression i.e. strain outcomes. As our scores for HADS anxiety and depression fall between those of Anderson et. al (Anderson et al., 1995) and Dennis et. al (Dennis et al., 1998) studies, we can conclude that our sample is representative of stroke caregivers in terms of levels of emotional distress.

The levels of anxiety in the Stroke caregiver sample were greater than general population controls as reported by Herrmann (1997). Between 18 and 20% of the Stroke caregiver sample were reporting anxiety scores > 10. Herrmann (1997) reported that 7% of a general population sample reported anxiety scores >10. Depression scores were also higher than the general population scores reported by Herrmann (1997). Between 22 and 23% were reporting depression scores >8 in the caregiver sample whereas Herrmann (1997) reports that 5% of a general population sample reported depression scores >8. The levels of anxiety and depression in Stroke caregivers were similar to a large sample of cardiological patients (n=5579) where 19% scored

greater than 10 on HADS anxiety and 17% scored greater than 8 on HADS depression (Hermann, 1997).

3.4.4 Study Limitations

There are a number of limitations to the present study, which should be acknowledged. First of all, the Control measure used in this study is not exactly the Control or 'decision latitude' construct as specified by Karasek. Decision latitude is an operationalization of the concept of Control and refers to a workers control over their behaviour. In our study the Control measure asks about Control over outcome i.e. the patient's recovery rather than Control over caregiver behaviour, per se. However it was felt that the items still reflected Control over the task of assisting recovery, which was how we specifically operationalised the care work of the stroke caregivers in this study. In addition specificity of Control measures has been generally recommended in reviews of the literature (Van der Doef & Maes, 1998; 1999).

This study would have also been enhanced if dependent measures of positive emotional states were available. Several researchers have argued for the inclusion of indices of both positive and negative emotional states in studies investigating the impact of caregiving e.g. Caregiver Satisfaction or measures of Well-Being (Beach, Schulz, Yee, & Jackson, 2000; Lawton et al., 1991; Kramer, 1997). It may be that the absence of positive emotional states in informal caregivers is as equally important as the presence of negative emotional states (Billings, Folkman, Acree, & Moskowitz, 2000; Folkman & Moskowitz, 2000). Predicting these positive outcomes may be analogous to Karasek's second prediction about motivation to work i.e. learning and motivation increase as Control increases (See 'Active' quadrant of figure 3.1.

3.5 Conclusion

This study has found preliminary support for the application of an occupational theory of stress to the study of informal caregiving. The Demand-Control Model and other models of Job Strain, may offer useful new model for unifying the various predictors of caregiver health outcomes. Further longitudinal and intervention studies using these types of models to guide

research questions, design and analyses are recommended.

Chapter 4

4. Using the Demand Control Model and the Effort-Reward Imbalance Model to predict Caregiver Strain in Congestive Heart Failure.

Overview

Chapter 3 showed that the Demand – Control (D-C) Model of Job strain (Karasek & Theorell, 1990) can be used to predict emotional distress in the informal caregivers of stroke patients. In this chapter we attempt to extend this work by using the D-C model and another related model of job strain, the Effort-Reward Imbalance (ERI) Model (Siegrist, 1996), to predict Caregiver Strain in a sample of caregivers caring for individuals with Congestive Heart Failure. Our dependent variable in this study is the Care Work Strain Scale (Orbell, Hopkins, & Gillies, 1993), which represents a more proximal measure of the subjective caregiving experience than the generic emotional distress measure used in Chapter 3. These caregiving specific outcome measures, sometimes referred to as ‘burden’ or ‘strain’ measures, have validity and reliability and they are commonly used as outcome variables in this field (Thornton & Travis, 2003; Dyck, Short, & Vitaliano, 1999; Vitaliano, Young, & Russo, 1991).

We also develop on the study reported in Chapter 3 in a number of other ways. Firstly we attempt to improve on the measurement of the models constructs, in particular by making measurement of the predictor variables more objective. This is important given that the Demand-Control Model in particular has an environmental or ‘stimulus’ orientation rather than a cognitive or appraisal approach to the analysis of stress. Secondly we use a sample of individuals caring for patients with stable Congestive Heart Failure, which has a very differing clinical trajectory than Stroke. This will allow the generalisability of the application of job strain models to informal caregiving to be assessed. As discussed in Chapter 2, CHF caregivers have received a limited amount of attention despite the increasing incidence and prevalence of the condition and the substantial demands that may be associated with CHF. The current study will address this issue.

Chapter 4 Abstract

Background: In order to develop the job strain approach to informal caregiving we used both the Demand-Control model and the Effort-Reward Imbalance (ERI) Model of job strain to predict Care Work Strain in sample of caregivers caring for Congestive Heart Failure (CHF) patients.

Method: Data was gathered from 60 caregiver/patient dyads at two time points. The dependent variable was Care Work Strain, a measure of the subjective burden of caregiving. The independent variables were: (1) Demand/Effort, which was measured using the six –minute walk test of the care-recipient (CR) and the CR’s assessment of their own functional limitations, as measured by the Functional Limitations Profile (2) Control over caregiving, which was measured using a perceived Control over caregiving measure (3) Reward was measured using an adapted version of the ERI questionnaire. Hierarchical multiple regression analysis was used as the primary method of analysis .

Results: Main effects for Control and Reward were found in cross-sectional analysis. Lower Control and Reward were associated with higher care Work Strain. There was some support for the interactive prediction between Demand and Control in cross-sectional analysis. Higher Control moderated the effect of high Demand on Care Work Strain.

Conclusion: In this study we found further support for the application of models of job strain to examine caregiver health outcomes. There may be some unexploited potential in these models in examining a range of caregiver health outcomes. Further work on the development of measures of caregiver Demand, Control and Reward should be a priority of this approach.

4.1. Introduction

It is clear that being an informal caregiver and reporting caregiving strain is associated with poorer health (Schulz & Beach, 1999). However despite extensive study our understanding of how informal caregiving influences health is limited (Vitaliano, Zhang, & Scanlan, 2003). There are several reasons for this, including weak study design, wide variation in measurement and poor operationalisation of key variables, all of which have been recognised for some time (Malonebeach & Zarit, 1991; Barer & Johnson, 1990). However two crucial issues that have received limited attention is the role of theory in this research, as we have discussed in Chapters 1 and 3, and the study of informal caregivers who care for older adults, who are cognitively intact.

In a recent meta-analysis of the literature that has examined caregiver health, Vitaliano et al. (2003) argued strongly in favour of development of theoretical models of how caregiving might influence health, and in extending the caregiver literature to clinical conditions other than Alzheimer's Disease and Related Disorders (ADRDs), which has dominated much of this research (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Studies addressing theory and non-dementia caregivers are therefore necessary in order to move the field forward.

4.1.1. Theory

As we have discussed in Chapter 1, in contrast to the informal caregiving literature, there has been remarkable progress in other disciplines in psychology that have examined stress-health relationship, particularly the study of work and health outcomes (Kivimaki et al., 2002; Steenland et al., 2000; Theorell & Karasek, 1996). The study of how one's occupation, or more specifically the organisation of one's psychosocial working environment, can influence health has achieved a great deal more elucidation than how informal caregiving relationships can influence health. This may, in part, be due to ongoing efforts to test, develop and refine explicit theoretical models of stress in the occupational literature (Dunham 2000; Cooper, 1998).

Two theories of occupational stress have received considerable attention and empirical support in recent years. Karasek's Demand-Control (DC) Model (Karasek & Theorell, 1990) and Siegrist's Effort-Reward Imbalance (ERI) Model (Siegrist, 1996) have been the most prominent theories of stress in occupational literature. The two theories have had considerable success in predicting both physical, particularly cardiovascular disease, and psychological health outcomes in a range of study designs (Steptoe, Siegrist, Kirschbaum, & Marmot, 2004; de Lange, Taris, Kompier, Houtman, & Bongers, 2003; Van der Doef & Maes, 1999; Van Der Doef & Maes, 1998; Bosma, Peter, Siegrist, & Marmot, 1998).

In addition to the empirical support for the models there are at least four other reasons why these models may be worth further investigation in relation to caregiver health.

1. Firstly the models are unusually parsimonious and elegant in comparison to other models of 'stress', particularly those used in studies of caregiver burden and well-being e.g. (Chappell & Reid, 2002; Yates, Tennstedt, & Chang, 1999), which incorporate a wide range of variables with sometimes unspecified relationships.
2. Both models make clear a priori predictions about main effects and interactions concerning the model variables and outcome i.e. strain and learning.
3. Thirdly they use concepts that transcend several levels of psychological research into stress and behaviour e.g. Control and Reward, therefore they provide links to other branches of knowledge within psychology and possibly even beyond to biology. These are all desired attributes of any scientific theory (Popper, 1959) suggesting that the models may be powerful enough to have wide ranging application in studies concerning the chronic stress process. Indeed a recent study shows that the ERI model can be successfully applied in non-work situations (Von dem Knesebeck & Siegrist, 2003) while there is also some earlier evidence that the Demand-Control model can be applied to informal caregiving (Orbell & Gillies, 1993).
4. Finally the variables that the models refer to are potentially amenable to change, particularly Control and Reward through the reorganisation of

formal and informal support for caregivers. Potentially this could reduce negative outcomes for caregivers.

The two theories are described and reviewed in Chapter 1 however in the interest of clarity a brief reiteration will be provided. The Demand-Control model (Karasek & Theorell, 1990) postulates that job strain results from the joint effects of high job Demands and low job Control. The Effort-Reward Imbalance Model (Siegrist, 1996) focuses on the “costs” and “gains” at work with job strain resulting from an imbalance between the two. The application of this model to caregiving, as we are examining it in this study, is illustrated in Figure 4.1. In this study we only use the extrinsic component of the model. The personal component of the model was not examined in this study.

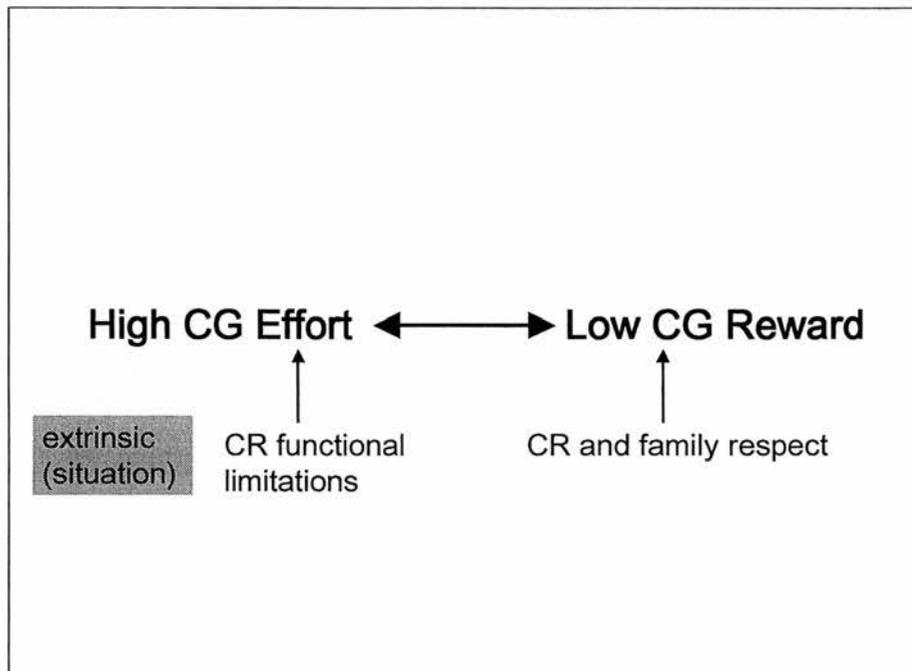


Figure 4.1.

The Effort-Reward Imbalance Model as applied to caregiving.

4.1.2. Alzheimer's Disease and Related Disorders (ADRD).

The preponderance of caregiver studies using ADRD samples and the neglect of common cardiovascular conditions is at odds with the disability attributed to these two classes of illness in epidemiological studies (Guccione

et al., 1994). In addition to this ADRD caregiving has its own unique difficulties and lacks others that are associated with other common clinical conditions. As we have discussed in chapter 2 Congestive Heart Failure has received limited attention with respect to informal caregiving, despite its rapidly increasing prevalence and incidence in older adults and the fact that it may be associated with considerable and unique caregiving demands. Therefore, further studies of caregiving in this condition are clearly warranted.

4.1.3. The Present Study

In this study we provide further analysis of the Demand-Control Model and a preliminary analysis of the Effort-Reward Imbalance Model using a range of self-report and objective behavioural measures in a sample of informal caregivers caring for friends or family members with Congestive Heart Failure (CHF).

4.1.4. Research question and hypotheses:

Can the Demand-Control Model and the Effort-Reward Imbalance Model explain variance in caregiver strain in CHF caregivers?

In order to do this 5 a priori hypotheses were generated. These were tested cross-sectionally at 2 time points and prospective longitudinally, in which case the predictions refer to change in independent and dependent variables between Time 1 and Time 2.

1. Caregiving in high Demand/Effort conditions will be associated with increased caregiver strain. (Main effect)
2. Higher caregiver Perceived Control over caregiving will be associated with decreased caregiver strain. (Main effect)
3. Higher Perceived Control over caregiving will moderate the effects of high Demand on caregiver strain. (Interaction effect)
4. Caregiving in low Reward conditions will be associated with increased caregiver strain. (Main effect)
5. Caregiving in effort-reward imbalance conditions will be associated with increased caregiver strain. (Interaction effect)

4.2. Method

4.2.1. Design

The study included cross-sectional analysis at two time points and prospective longitudinal analysis of change. Caregiver measures were recorded at two time points. Time 1 was at recruitment and Time 2 was 3 months after Time 1. Both the patient and the caregiver were interviewed separately in their own homes whenever possible, otherwise data was collected by self-report questionnaire. The study was part of a larger randomised controlled trial evaluating an exercise intervention that aimed to increase walking ability in CHF patients. This intervention did not affect patient walking ability (ANCOVA $F(1,47) = 1.44, p = 0.24$).

4.2.2. Participants

The caregivers of patients aged 70 years or older with stable congestive heart failure (CHF) on optimal medical therapy were recruited through 2 Medicine for the Elderly Day Hospitals and through the Ninewells Heart Failure Clinic by a medically qualified Clinical Research Fellow employed by the Department of Ageing and Health in Ninewells Hospital, Dundee. The patients were also being simultaneously recruited for a randomised trial of exercise training in older people with heart failure, further details of which are outlined in Chapter 4. The exercise study recruited 82 suitable CHF patients, 60 of these patients had informal caregivers that were willing to take part, giving a 73% response rate. 11 of the patients didn't have a caregiver, 9 caregivers declined participation (all female: 5 spouses, 3 daughters, 1 sister), 1 caregiver was too ill at time of recruitment and 1 caregiver could not be specified into any of these categories. Caregivers were identified by asking the patients, 'who in the family usually provides help at home?' Socio-demographic and clinical characteristics of CHF patients and caregivers are presented in table 4.1.

Table 4.1

Socio-demographic and clinical characteristics of CHF patients and their informal caregivers.

Variable		
Age of caregiver (years), mean (SD)	63.4 (14.6)	Range 39-87
School leaving age mean (SD)	15.6 (1.3)	Range 14-18
Deprivation category mean (SD)	3.7 (2.1)	1-7
	Number (N=60)	%
Gender of caregiver		
Female	39	65%
Caregiver marital status		
Married	41	70%
Single	7	12%
Separated/divorced	7	12%
Widow/widower	3	5%
Caregiver's relationship to patient		
Spouse	24	40%
Child	26	43%
Other	10	17%
Age of Patient	80.5 (5.0)	Range
School leaving age mean (SD)	14.2 (1.2)	11-18
	Number (N=82)	%
Gender of Patient		
Female	36	44
Patient marital status		
Married	32	39
Single	4	5
Separated/divorced	2	2
Widow/widower	42	51
Living arrangements)		
Independent, own home	46	56
Home help, own home	13	15
Independent in sheltered housing	11	13
Home help, sheltered housing	9	11
Lives with relative	3	4
NYHA functional class		
II	46	56
III	36	44
LVEF impairment		
Mild LV impairment	28	34
Moderate LV impairment	26	32
Poor LV function	28	34

4.2.3. Measures

Descriptive statistics, including means, standard deviations, ranges, Cronbach's alphas and zero-order correlations are presented in table 4.3.

Dependent Variable

Caregiver strain was measured using the Care Work Strain Scale, a subscale of the Impact of Informal Caring Scale (Orbell et al., 1993). This 13-item measure has a 7-point response scale from strongly agree to strongly disagree giving a range of 13-91. The reliability and validity of this measure have been established (Orbell et al., 1993). The scale showed criterion validity in the present sample, as it correlated significantly with the overall score on the Hospital Anxiety and Depression scale, Pearson's $r=0.53$, $p<0.001$ at Time 1, Pearson's $r=0.71$, $p<0.001$ at Time 2. Other psychometric properties are outlined in Table 4.3. The complete measure and scoring are shown in appendix D.i.

Predictor variables

The Demand variable of the D-C model and the Effort variable of the ERI model were conceptualised as the functional limitations of the care-recipient. Given the conceptual and often empirical overlap between the two variables in the job strain literature, the same measures were used for Demand and Effort. This was measured in two different ways:

(1) Self-report by patient:

The modified Functional Limitations Profile (Pollard & Johnston, 2001; Pollard & Johnston, 1999) was used to assess physical and psychosocial limitation. This is the same measure as used in Chapter 3. The complete measure and scoring are shown in appendix B.i. The scale showed criterion validity in the present sample, as it correlated significantly with the 6 Minute walk test, Pearson's $r=-.53$, $p<0.001$ at Time 1, Pearson's $r=-.68$, $p<0.001$ at Time 2.

(2) Observed performance of patient

The six-minute walk test is a reliable and valid measure physical function in frail, elderly and disabled people (Demers, Mckelvie, Negassa, & Yusuf, 2001; Guyatt et al., 1985). It has been selected as a practical measure relevant to the day to day functioning of elderly patients. Participants are asked to attempt walk between two fixed points at a fast comfortable pace and the distance covered in six minutes, or less if the patient is unable to last 6 minutes, is recorded. This provides a valid measure of what patients can do. The correlation between Time 1 and 2 was 0.9, $p < 0.01$, demonstrating satisfactory reliability.

Control- self-report by caregiver

Control was measured using a self-report measure developed by Orbell (Orbell & Gillies, 1993). The Control measure was operationalised as the extent to which caregivers felt that they had a choice or discretion over, whether to provide assistance with daily activities. It was measured by asking caregivers 'To what extent do you feel relied upon to perform this task?' (1 Not at all- 5 Always Relied upon). This question was asked for each of the activities of daily living (ADL's) and the instrumental activities of daily living (IADL's) that caregivers reported providing assistance with. In order to avoid confounding Control with Demand/ Effort, computed sums were divided by the total number of ADL and IADL's that caregivers help with. Control scores therefore ranged from 0-5. 0 was assigned to caregivers who did not provide any assistance with ADL's or IADL's. The correlation between Time 1 and 2 was 0.88, $p < 0.01$, demonstrating satisfactory reliability. There was some evidence of criterion validity for this scale as it correlated significantly with the availability of formal home help for the CHF patient (1=no home help, 2= home help for the patient) Kendall's tau = - 0.24, $p < 0.05$. The complete measure and scoring are shown in appendix D.ii. Note that the effort rating scale outlined in D. iii was not used in this analysis due to its confounded relationship with the dependent variable in this analysis i.e. Care Work Strain.

Reward- self-report by caregiver

Reward was measured using a 7-item scale developed by the authors. The items and scale were based on those of the original ERI questionnaire developed by Siegrist (Siegrist et al., 2004). The items are outlined in table 4.2. Only item 2, 3 and 4 were used in the present analysis as items 1, 5, 6 and 7 had consistent non-response. Caregivers were asked if they agreed or disagreed with each statement. If caregivers agreed they got a score of 5 for the item. If they disagreed with the statement they were asked to indicate how distressed they were by the situation. There were four options for this: Not at all distressed, somewhat distressed, I am distressed, I am very distressed. These responses scored 4, 3, 2, and 1 respectively giving a range of 3 to 15 for the scale. The scale correlated moderately Pearson's $r=0.39$, $p < 0.01$, with the Care Work Satisfaction scale of the Impact of Informal Caring Scale (Orbell et al., 1993) demonstrating convergent validity. The correlation between Time 1 and 2 was 0.71, $p < 0.01$, demonstrating satisfactory reliability. The complete measure and scoring are shown in appendix D.iii.

Table 4.2

Items used to measure caregiver Reward. Adapted from original ERI questionnaire.

Reward Scale Items
1. I receive the respect that I deserve from my friends/neighbours for caregiving
2. I receive the respect that I deserve from my family for caregiving
3. I receive the respect that I deserve from the person that I am caring for
4. I experience adequate support from others with caregiving.
5. I receive the respect that I deserve from society for caregiving
6. Considering all my efforts in caregiving for this person, I receive the appreciation that I deserve.
7. Considering all my efforts in caregiving for this person, I receive adequate compensation for caregiving.

4.2.4. *Procedure*

After obtaining informed consent caregivers were interviewed independently in the care-recipient's or their own homes, or by self-report questionnaire when this was not possible, at Time 1 (baseline) and Time 2 (3 months).

4.2.5. *Ethics*

Prior to the commencement of the study an ethical proposal was submitted to the Tayside Research Ethics Committee (21st December 2001). This document contained all the relevant details of the proposed study. Ethical approval was granted on the 30th January 2002. A copy of ethical approval is included in Appendix F.

4.2.6. *Statistical analysis*

Descriptive statistics were used to examine and describe the data. Relationships between variables were explored using Pearson's and Kendall's tau for non-normally distributed data. Hierarchical multiple regression analyses were used to test the efficacy of the model. Histograms and residual plots were used to detect any univariate or multivariate outliers. Normal probability plots and residual scatterplots were examined for any deviations from normality.

4.3. Results

Table 4.3 contains the descriptive statistics and the inter-correlations for the study variables. An examination of the zero-order correlations in Table 4.3 shows that all the significant correlations between Control, Reward and Care Work Strain scale are in the direction that the theory would predict. Lower Control and Lower Reward are associated with significantly Higher levels of Care Work Strain. However there were weak relationships between the measures of Demand and Care Work Strain at both Time points. There were no significant changes from Time 1 and Time 2 in any of the predictor or dependent variables.

Hierarchical Multiple Regression

The numbers of respondents varied across different analyses due to missing data. An alpha level of 0.05 was used for all statistical tests. In order to test the predictions of the two models a cross-sectional hierarchical multiple regression analysis of Time 1 and Time 2 data is followed by analysis of change. In the 1st step caregiver age, gender (female =1, male =0) and relationship to patient (spouse =1, non-spouse =0) were entered as independent variables. Age gender and relationship to patient were controlled for as these socio-demographic variables have well-established relationships to caregiver emotional outcomes (Pinquart & Sorensen, 2003a; Cantor, 1983). In the second step Demand, Control and a Demand multiplied by Control variable, to test for interaction were entered as independent variables and Care Work Strain was entered as the dependent variable. Where interactions between two continuous independent variables are assessed the variables were centred prior to forming the interaction variable as suggested by Cohen (Cohen, Cohen, West, & Aiken, 2003). Centring is achieved by subtracting the mean value for each predictor from individual scores. This centring procedure was used to decrease the likelihood of multi-collinearity between the interaction term and its components.

Table 4.3
Descriptive Statistics and Zero-Order Correlations for key study variables – Cross-sectional analysis.

Variable	Mean	(SD)	Actual Alpha [^]	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.
Time 1																
1. Care Work Strain	33.72	17.94	13-90	0.97	1.00											
2. Age	63.28	14.50	39-87	-----	.00	1.00										
3. Gender	-----	-----	0-1	-----	.36**	.33**	1.00									
4. Relationship	-----	-----	0-1	-----	.07	.79**	.39**	1.00								
5. Demand (CR self-report)	65.45	13.70	29-92	0.77	.05	.15	.05	.09	1.00							
6. Demand (CR walking)	251.88	108.93	63-600	-----	-.25	.11	-.07	.24	-.53**	1.00						
7. Control (CG self-report)	3.60	1.22	0-5	-----	.44**	.43**	.53**	.46**	.08	.01	1.00					
8. Reward (CG self-report)	14.55	1.30	9-15	.64	-.51**	.29*	-.13	.11	.04	.05	-.14	1.00				
Time 2																
9. Care Work Strain	37.37	21.64	13-87	0.97	.84**	.13	.25	.18	.05	-.17	.41**	-.40	1.00			
10. Demand (CR self-report)	65.30	12.11	20-81	0.69	.20	.11	.16	.03	.68**	-.60**	.18	-.08	.09	1.00		
11. Demand (CR walking)	240.17	102.25	53-494	-----	-.21	.05	-.08	.17	-.52**	.92**	.01	.07	-.16	-.68**	1.00	
12. Control (CG self-report)	3.58	1.44	0-5	-----	.40**	.40**	.51**	.44**	.09	.07	.88**	-.08	.41**	.13	.09	1.00
13. Reward (CG self-report)	14.53	1.01	11-15	.46	-.46**	.32*	.10	.19	.15	.12	-.08	.71**	-.38**	.10	.00	1.00

* P<0.05, ** P<0.01. Relationship = spouse is 1, non-spouse is 0. Gender = 0 is male, 1 is female.

Table 4.4
Hierarchical Multiple Regression Analyses using the Demand-Control Model to predict Care Work Strain at Time 1 and 2.

Step and Variable	Care Work Strain Time 1		Care Work Strain Time 2	
	Model 1.	Model 2.	Model 1.	Model 2.
<i>Step 1 Control variables</i>				
Age	-.16	-----	-.03	-----
Gender	.40**	-----	.22	-----
Type of caregiver (spouse or non-spousal)	.04	-----	.12	-----
R ²	.10*	-----	.00	-----
F	3.13*	-----	1.10	-----
<i>Step 2 Demand-Control Model</i>				
Demand	-.00	-.09	.07	-.16
Control	.42**	.40**	.44*	.33
Demand X Control ^a	.17	-.23	.26	-.32*
R ² change	.15*	.19**	.16	.24*
F	3.57**	4.48**	1.96	2.83*

P < 0.05*, P < 0.01**, Model 1 = Care-Recipient Self-Report Demand, Model 2 = Care Recipient Objective Demand.

^a Both variables centred before forming interaction term.

Table 4.5
Hierarchical Multiple Regression Analyses using the Effort-Reward Imbalance Model to predict Care Work Strain at Time 1 and 2.

Step and Variable	Care Work Strain Time 1		Care Work Strain Time 2	
	Model 1.	Model 2.	Model 1.	Model 2.
<i>Step 1 Control variables</i>				
Age	-.16	-----	-.03	-----
Gender	.40	-----	.22	-----
Type of caregiver (spouse or non-spousal)	.04	-----	.12	-----
R ²	.09	-----	.00	-----
F	2.73	-----	1.06	-----
<i>Step 2 Effort-Reward Imbalance Model</i>				
Effort	.06	-.26	.08	-.17
Reward	-.49**	-.45**	-.49**	-.49**
Effort X Reward ^a	-.03	.10	-.09	.11
R ² change	.21**	.26**	.21*	.23*
F	4.00**	4.98**	2.45*	2.74*

P < 0.05*, P < 0.01**, Model 1 = Care Recipient Self-Report Effort, Model 2 = Care Recipient Objective Effort.

^a Both variables centred before forming interaction term.

Table 4.6
Hierarchical Multiple Regression Analyses using change in Control and Reward to predict Time 2 Care Work Strain Scores.

Step and Variable	Care Work Strain Time 2 D-C model	Step and Variable	Care Work Strain Time 2 ERI model
<i>Step 1 Control variables</i>			
Care Work Strain Time 1	.81**	Care Work Strain Time 1	.85**
Control Time 1	.06	Reward Time 1	.03
R ²	.69**	R ²	.69**
F	51.34**	F	43.69**
<i>Step 2</i>			
Control Time 2	.13	Reward Time 2	-.02
R ² change	.00	R ² change	.00
F	0.51	F	0.01

P < 0.05*, P < 0.01**

4.3.1. *Predicting Care Work Strain (Time 1)*

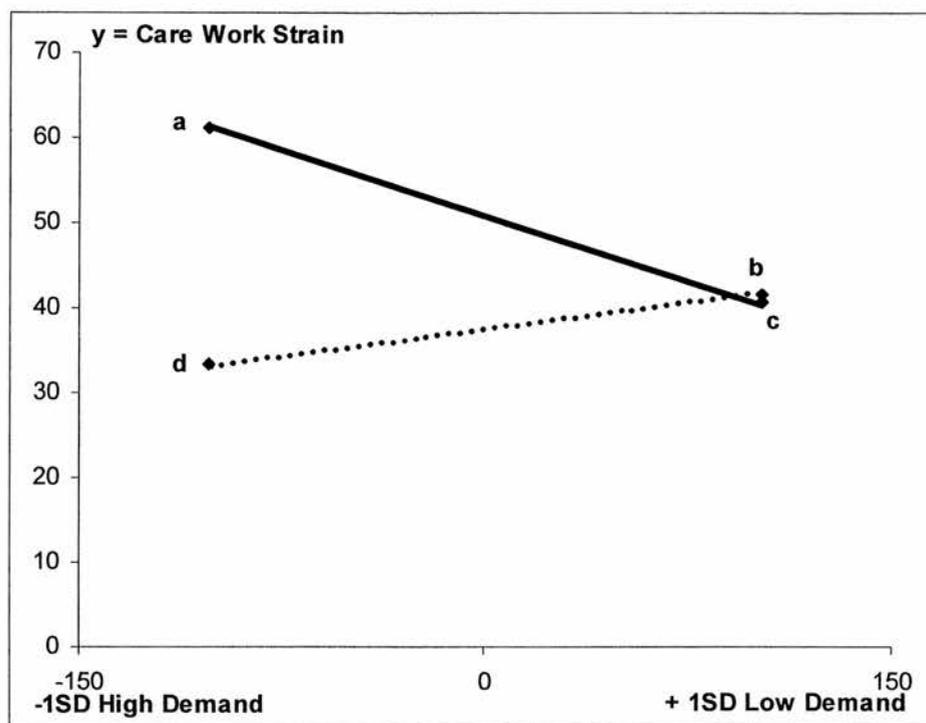
Demand-Control Model: The overall (omnibus) test for the Demand-Control model using the care-recipient functional limitations measure of Demand and the caregiver self-reported Control measure was statistically significant, adjusted $R^2 = .21$, $F(6,51) = 3.57$, $p < 0.05$, after controlling for caregivers age, gender and relationship to patient. As can be seen from the standardised Beta weights in table 4.4, Control explained most of this variance. Lower Control was associated with higher Care Work Strain. The interaction of Demand and Control did not add to the predictive power of the model beyond the main effects. The overall test for the Demand-Control Model using the objective measure of Demand was also statistically significant, adjusted $R^2 = .27$, $F(6, 51) = 4.48$, $p < 0.05$, after controlling for caregivers age, gender and relationship to patient. Once again in this analysis Control had the greatest contribution to this model as shown in table 4.4. Lower Control was associated with higher Care Work Strain. The interaction of Demand and Control did not enhance the predictive power of the model.

Effort-Reward Imbalance Model: The overall (omnibus) test for the Effort-Reward Imbalance Model using the care-recipient functional limitations measure of Effort and the caregiver self-reported Reward measure was statistically significant, adjusted $R^2 = .27$, $F(6,44) = 3.98$, $p < 0.05$, after controlling for caregivers age, gender and relationship to patient. As the standardised beta weights show in Table 4.5, Reward explained most of the variance in this model. Higher Reward was associated with Lower Care Work Strain. The interaction of Effort and Reward was did not contribute significantly to the model.

The overall test for the Effort-Reward Imbalance Model using the objective measures of Effort was statistically significant, adjusted $R^2 = .32$, $F(6, 44) = 4.98$, $p < 0.05$, after controlling for caregivers age, gender and relationship to patient. Once again Reward explained most of the variance in this model. Neither Effort or the interaction between Effort and Reward contributed significant amounts of variance to this model. The details are shown in Table 4.5. Lower Reward was associated Higher Care Work Strain.

4.3.2. *Predicting Care Work Strain (Time 2)*

Demand-Control Model: The overall (omnibus) test for the Demand-Control model using the care-recipient functional limitations measure of Demand and the caregiver self-reported Control measure was not statistically significant, adjusted $R^2 = .12$, $F(6,38) = 1.96$, $p > 0.05$, after controlling for caregivers age, gender and relationship to patient. As can be seen from the standardised Beta weights in table 4.4, Control explained most of the variance in this model. Lower Control was associated with higher Care Work Strain. The interaction of Demand and Control did not add to the predictive power of the model beyond the main effects. At time 2 the overall test for the Demand-Control Model using the objective measures was statistically significant, adjusted $R^2 = .20$, $F(6,38) = 2.83$, $p < 0.05$, after controlling for caregivers age, gender and relationship to patient. In this analysis the interaction of Demand and Control emerged as the strongest predictor in the model. Details are provided in table 4.4. In order to investigate the form of the interaction between Demand and Control on Care Work Strain, a decomposition analysis was carried out as described by Cohen et al (Cohen et al., 2003). Figure 4.2 shows this plotted interaction. High Control appeared to moderate the effect of high Demand on Care Work Strain. Point a represents high Demand and Low Control. This is associated with the highest level of care work strain.



- a. High Demand, Low Control
- b. Low Demand, High Control
- c. Low Demand, Low Control
- d. High Demand, High Control

High Control (-1SD)

Low Control(+1SD) —————

- tive Control scores = High Control.

+ tive Demand = Low Demand.

Figure 4.2 Relationship between Demand and Care Work Strain for High and Low Levels of Control.

Effort Reward Imbalance Model: The overall (omnibus) test for the Effort-Reward Imbalance Model using the care-recipient functional limitations measure of Effort and the caregiver self-reported Reward measure was statistically significant, adjusted $R^2 = .17$, $F(6, 38) = 2.45$, $p < 0.05$. As the standardised beta weights show in Table 4.5, Reward was accounting for most of this variance. Lower Reward was associated Higher Care Work Strain. Adding the interaction of Effort and Reward did not improve the predictive power of the model. The overall test for the Effort-Reward Imbalance Model using the objective measures of Effort was also statistically significant, adjusted $R^2 = .19$, $F(6, 38) = 2.73$, $p < 0.05$. In this model Reward was

contributing most of the explained variance. Lower Reward was associated Higher Care Work Strain.

4.3.3 Predicting change between Time 1 and Time 2

In order to test the models longitudinally a hierarchical multiple regression was performed. Given the robustness of the main effects for Control and Reward on Care Work Strain we tested if change in these predictors could account for additional variance in Time 2 Care Work Strain after controlling for Time 1 levels of Care Work Strain, Control and Reward. Time 1 scores in Care Work Strain, Control and Reward were entered in the first step of the model followed by Time 2 scores in Control and Reward in the second step. Table 4.6 shows that neither Time 2 levels of Control or Reward explained any additional variance in Time 2 Care Work Strain beyond that explained by Time 1 levels of Care Work Strain or Time 1 levels of Control or Reward.

4.4. Discussion

4.4.1. Findings

In this study further support for the application of the Demand-Control model to informal caregiving was found in another clinical condition, which differs considerably from the Stroke population that we examined in Chapter 3. Preliminary support for the Effort-Reward Imbalance Model in predicting caregiver strain outcomes was also established.

Bivariate associations between Demand/Effort (objective measure only), Control, Reward and Care Work Strain were in the predicted directions lending support to hypotheses 1 i.e. the main effect of high Demand/Effort on Care Work Strain, 2 The main effect of Control on Care Work Strain and 4 the main effect of Reward on Care Work Strain. In our multivariate cross-sectional analysis where we controlled for caregiver age, gender and relationship to the patient we found no support for hypotheses 1 using two different types of measurement for Demand/Effort. We found consistent support for the two main effects predicted in hypotheses 2 and 4. There was some support for hypotheses 3, as the plotted interaction between Demand and Control at Time 2 was of the predicted form, with high Control moderating the effect of High

Demand on Care Work Strain. There was no support for the interaction between Effort and Reward. In the prospective longitudinal analysis of change we limited the analysis to Control and Reward, as they were the most robust predictors of Care Work Strain. Time 2 Control and Reward did not explain any additional variance in Time 2 Care Work Strain beyond that explained by Time 1 levels of Care Work Strain, Control and Reward.

The clearest pattern in the results is that Control and Reward emerged as the strongest predictors of Care Work Strain in these models. This finding for Control is in line with the Job Strain literature, where Control is consistently found to be a powerful predictor of physical and psychological health outcomes even when Demand is not (Bosma et al., 1997). In tests of the ERI model however, the interaction between Effort and Reward is usually found (de Jonge, Bosma, Peter, & Siegrist, 2000; Bosma et al., 1998). We also found that Demand/Effort, Control and Reward also appear to be orthogonal, as there were weak relationships between these variables at both Time points. This supports the independence of these constructs.

4.4.2. *Measurement*

In this study the objective measures of Demand i.e. the patient six-minute walk test was a better predictor of Care Work Strain than the caregiver self-reported measure of Demand. The predicted interaction of Demand and Control at Time 2 was also detected using this measure of Demand. There is some evidence that interactions are more likely to be detected using continuous variables such as the objective measure of Demand that we used than coarser self-report measures (Russell & Bobko, 1992). Most caregiver studies examining the relationship between care-recipient impairment or disability and caregiver strain outcomes use pen and paper measures of patient impairment or disability which are known to be problematic in that there is a great deal of variation depending on who scores them (Bookwala & Schulz, 1998) and they may lack the validity, reliability and sensitivity of behavioural/performance measures. The six-minute walk test in particular may be useful as the reliability, validity and sensitivity of this test have been well-established in a range of clinical and non-clinical conditions (Kervio, Carre, & Ville, 2003;

Steffen, Hacker, & Mollinger, 2002; O'Keeffe, Lye, Donnellan, & Carmichael, 1998). Other useful and easily administered behavioural/performance measures of functional ability that might more accurately capture the Demands that caregiver are faced with than pen and paper assessments include: the timed up and go test or TUG test (Podsiadlo, & Richardson, 1991), and observer assessed disability (Partridge & Johnston, 1989).

The poor predictive power of the patient derived measure of Demand (Functional Limitations Profile) is in contrast to the Time 1 analyses in Chapter 3, where this measure of Demand emerged as a significant predictor of caregiver emotional distress, however in the Time 2 analysis in Chapter 3, Control became the dominant predictor and Demand lost its predictive power. It may be that caregiver Demand, if operationalised as patient functional limitations, may only be a reliable predictor when the Demands are new. This was likely to be the case in the Time 1 analysis in Chapter 3, which was conducted 2 weeks following the patient's discharge from hospital. The Time 2 analyses in Chapter 3 and the analyses in this chapter were not examining caregivers facing relatively new Demands, as both groups of caregivers were likely to be caring in relatively stable Demand conditions i.e. there would have been few caregivers experiencing acute changes in Demand or Control over the previous 3 months.

4.4.3. Theoretical issues

The present study shows that the job strain approach seems to have some use in another caregiving population with very different clinical characteristics than stroke therefore we can assume that the job strain models may have some generalisability in explaining health outcomes such as burden or strain in a range of informal caregiving situations. This type of cross-disciplinary link may have the potential to move this field forward, particularly for researchers interested in the biological processes whereby caregiving exerts its influence on health as the models have been particularly influential in this type of research (Steptoe et al., 2004; Steptoe, Cropley, Griffith, & Kirschbaum, 2000).

Given that informal caregiving takes a biological toll on the body it seems logical that there may be a certain toxic organisation of family caregiving that may be associated with negative health effects in much the same way as the toxic organisation of work has been associated with poorer worker health. Although our dependent variable is not a physical health outcome as such it can be thought of as a proxy indicator. In Schulz & Beach's (1999) study it was the caregivers that were reporting strain that were at increased risk for mortality, therefore self-reported strain is an important outcome that is associated with health status.

4.4.4. Limitations

Our prospective longitudinal analysis was limited by the fact that little change occurred in both independent and dependent variables between Time 1 and Time 2. There were no significant changes in predictor or the dependent variables between Time 1 and Time 2. Therefore the likelihood of finding support for the models was minimal, particularly given the low statistical power of the analysis. A longer period of time or a larger sample may be required to detect statistically significant effects of change in the predictor variables on change in the dependent variables.

While the relationship between Reward and care work strain were in the predicted direction and encouraging for the model there were some problems with the measurement of the construct. Firstly the measure produced a highly negatively skewed distribution, skew statistic at time 1 was -3.5 and -2.4 at Time 2. This may be a social desirability effect i.e. the tendency for respondents to respond in a way that they believe is socially acceptable or in a way that shows respondents in a positive light. This problem of social desirability has been noted in caregiving research particularly among spouses (O'Rourke et al. 1996). In addition internal consistency was well below conventional norms, however this was also related to the fact that only 3 items were used to measure the construct. Smaller numbers of items tend to produce lower internal consistency. Therefore much further work remains to be done with regard to the measurement of the Reward construct.

However this restricted distribution may not be a problem of the measure and may be explained by the fact that our sample of CHF patients were restricted in a number of ways. For example chair-bound patients and patients with cognitive deficit were excluded. In addition patients that choose to participate in an exercise intervention trials may not be entirely generalisable to the population of care-recipients. Perhaps there was a ceiling effect with Reward as the sample of CHF patients studied were the least difficult or 'Reward consuming' individuals to care for. It is conceivable that the measure may have performed better in a sample of caregivers caring for a more heterogeneous sample of care recipients e.g. patients at the extreme ends of dependency e.g. Alzheimer's and dementia related patients or severe traumatic brain injury where deficits in patient-caregiver reciprocity is potentially much more salient.

4.4.5. *Future Work*

The obvious next step would be to replicate these findings using a range of study designs, particularly using physiological markers of health such as cardiovascular measures, neurohormonal or immune assays as outcome measures. Future studies should also endeavour to improve on the validity, reliability and sensitivity of measurement of the model variables. Even though we have attempted to improve on the measurement of the model variables by including objective indicators of care-recipient physical impairment, there is room for improvement, particularly in relation to the measurement of caregiver Control and Reward, which appear to be the two most powerful variables in the model. Further work on establishing the psychometric properties of these measures is clearly warranted. In addition there may be additional components of these models that are worth including in studies. For example some studies have included a worker social support variable to the Demand-Control model (de Lange et al., 2003; Johnson & Hall, 1988), which has obvious relevance to the caregiving situation (Weitzner, Donovan, Jacobsen, & Haley, 2003). Some studies of the ERI model also include an additional explanatory personality variable called 'over-commitment' that may have relevance in the caregiving situation (Steptoe et al., 2004; Bosma et al., 1998).

4.4.6. *Implications*

Despite job stress being a clearly 'psychological' topic it has been mostly researchers in social epidemiology and public health that have advocated the two models of job strain examined in this chapter (Kivimaki et al., 2002; Bosma et al., 1998). Given the simplicity of these models it is perhaps understandable why these disciplines have adopted these approaches. The real potential of these models for informal caregiving may be in a public health or population approach towards informal caregiving. Given the extent of informal caregiving this may indeed be the way forward.

While both Control and Reward as they are measured here are both cognitive constructs, theoretically the models would argue that the environment should be the focus of intervention to reduce strain. Caregiver support services could be designed in ways that increase caregiver Control over caring and increase caregiver Reward. This does not necessarily mean that interventions informed by this theory are necessarily more expensive and intensive than interventions that target cognitions or coping strategies. Caregiver Control over their caregiving may be increased by making existing caregiver support services, such as respite, more accessible and transparent. Control in the home environment as opposed to the work environment has been recognised as an important predictor of health and well-being in a number of studies (Griffin, Fuhrer, Stansfeld, & Marmot, 2002; Christensen, Stephens, & Townsend, 1998) and this situational control may be influenced by the organisation of the caregiving situation in community settings. Reward can be increased by attempting to enhance what Siegrist (Siegrist, 1996) calls 'Esteem Reward'. Government recognition of the value of informal caregivers to society may go some way in achieving this (DoH, 1999). Ultimately interventions will change cognitive representations of Control and Reward however the job strain models would argue that the best means of doing this is by targeting the environment rather than targeting the cognitions themselves.

4.4.7. Conclusion

We found further support for the application of the Demand-Control Model to studies of health in informal caregiving and preliminary support for the Effort-Reward Imbalance Model in predicting care work strain in sample of informal caregivers caring for patients with stable CHF. These models may provide a useful framework for investigating caregiver health particularly at a population level.

Chapter 5

5. Does a change in caregiver Demand mediate the effect of a patient exercise intervention on Care Work Strain?

Overview

As we have discussed and demonstrated in chapter 2 and 4 providing care for a family member or friend with CHF is associated with considerable caregiver strain. Caregiver strain has been linked with a range of detrimental consequences for both caregivers and care-recipients. Therefore caregivers are often in need of additional outside support and guidance with caregiving. In this chapter we examine the effect of a care-recipient exercise intervention on caregiver strain. As a further test of the job strain models we examine whether an intensive exercise training intervention for CHF patients has an effect on Care Work Strain through a change in the job strain models predictor variables, with a focus on measures of caregiving Demand as this was the target of the care-recipient intervention.

Chapter 5 Abstract

Background: As a rigorous test of the job strain approach we examined the effect of a care-recipient exercise intervention that changed a measure of everyday activity i.e. an index of Demand/Effort in the job strain models, on Care Work Strain .

Method: 60 caregiver/patient dyads were randomised into 12 -week patient exercise intervention and control groups. Measures were taken pre-randomisation (Time 1), immediately post intervention Time 2 and three months later Time 3). The dependent variable was Care Work Strain, as per Chapter 4. Patient functional limitations were measured as per Chapter 4 and a measure of patient activity was also used in this analysis. This was obtained using a weeks data of from an automated accelerometer. Control and Reward were measured as per chapter 4.

Results: Contrary to prediction caregivers of patients in the exercise intervention had significantly higher levels of Care Work Strain at follow-up. Patients in the exercise group had significantly higher levels of activity as measured by accelrometry. There was no evidence that this change mediated the effect on Care Work Strain. There were no differences between the groups in Control or Reward at follow-up.

Conclusion: The unpredicted finding that caregivers of patients in the exercise group had higher levels of Care Work Strain at follow-up may be spurious. However there is too little contrary data to disregard the finding. We offer several possible mechanisms that may explain this finding.

5.1. Introduction

5.1.1. Caregiver interventions to improve health outcomes

In response to the negative health consequences that have been associated with informal caregiving there has been substantial interest in the development and evaluation of interventions that aim to reduce negative outcomes for caregivers (Gitlin et al., 2003; Schulz et al., 2002; Knight, Lutzky, & Macofskyurban, 1993). These interventions can have far reaching effects. One recent study showed that a skills and knowledge training intervention for stroke caregivers had positive effects for the care-recipients, the caregivers themselves and reduced treatment costs for the stroke patient over the following year (Kalra et al., 2004). Caregiver interventions may represent an important, under-researched and perhaps under-exploited mode of treatment in chronic illness.

Caregiver interventions can target one or more various entities e.g. the caregiver, the patient, the family or the home environment, and domains e.g. behaviour, emotion, cognition or symptoms (Schulz, 2000). This is illustrated in figure x . Interventions targeting one domain can have effects on multiple domains as is illustrated by the arrows in the figure 5.1.

Meta-analysis have confirmed that caregiver interventions can have positive effects on desired caregiver outcomes, however this work has been mainly limited to the caregivers of patients with dementia {Brodaty, Green, et al. 2003 #10830}(Sorensen, Pinquart, & Duberstein, 2002; Knight et al., 1993). In addition as with much of the non-intervention caregiver research intervention studies have made limited use of theoretical models of process in carrying out studies.

There may be scope to develop complex interventions targeting all these entities and domains in CHF populations, however in order to test the efficacy of theories of caregiver health it may be more prudent from a scientific point of view, to test individual domains in individual entities, particularly if there is data linking outcomes of interest with potentially changeable and measurable theoretical constructs. The argument for integrating theory, basic research and intervention in this way is increasingly being made (Pillemer, Sutor, & Wethington, 2003).

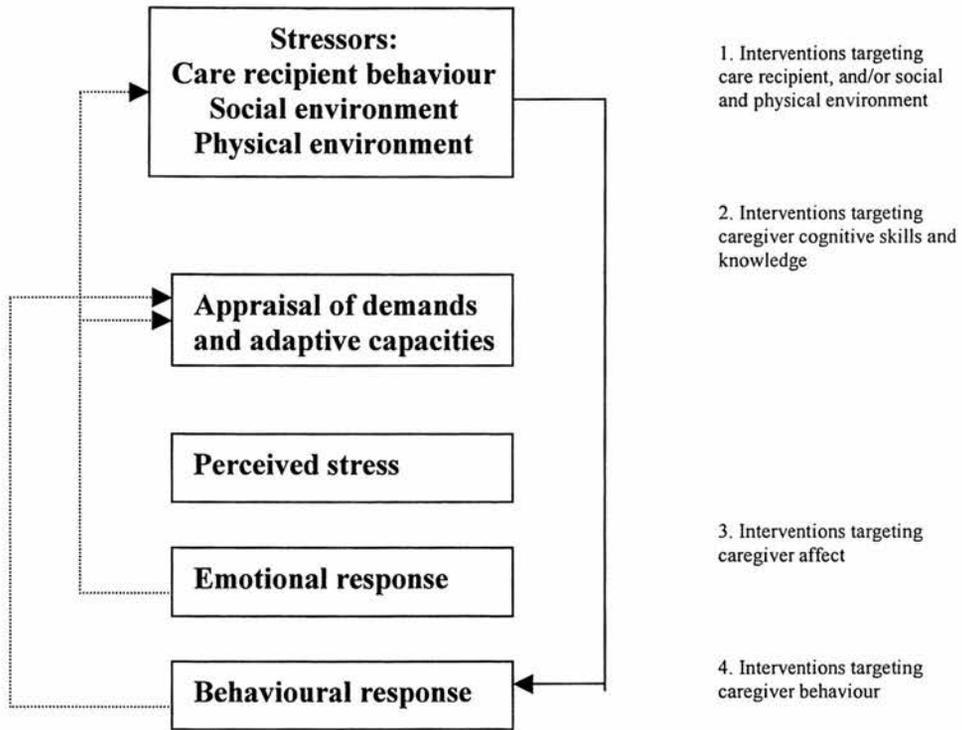


Figure 5.1

Improving caregiver health outcomes through intervention (pg 58 Schulz 2000).

Recent meta-analysis have suggested that care-recipient functional limitations are associated with poorer caregiver health outcomes e.g. burden and emotional distress. We also found some support for this relationship in Chapter 3. In terms of the Demand-Control model (Figure 5.2) of job strain, this equates with higher caregiver Demand being associated with higher strain outcomes. Therefore interventions that attempt to change this type of Demand should have some effect on measures of caregiver strain according to the Demand-Control Model (Karasek & Theorell, 1990) of Job Strain and the Effort-Reward Imbalance Model (Siegrist, 1996) as we have conceptualised them in this thesis.

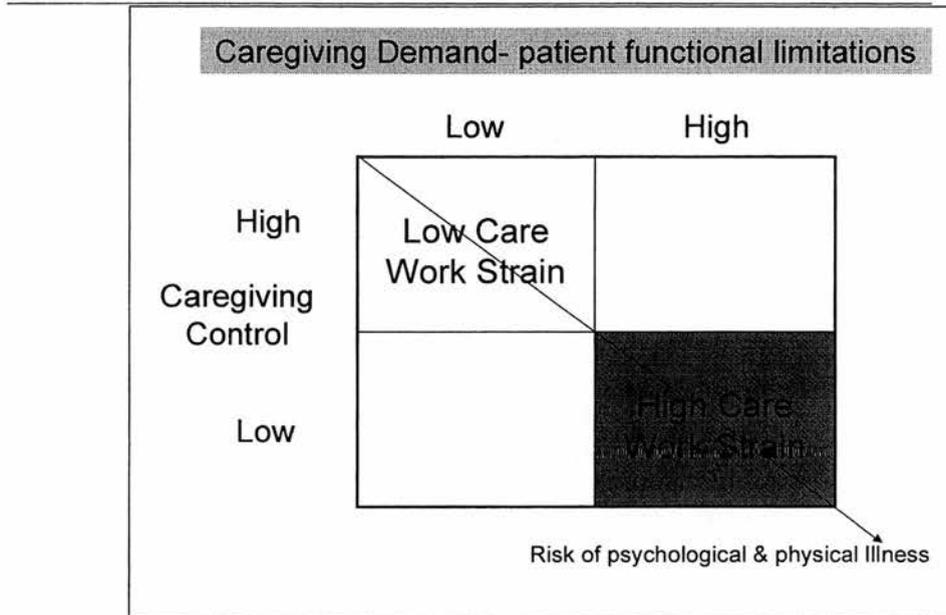


Figure 5.2
The Demand-Control Model applied to Caregiving.

5.1.2. Are changes in functional limitation associated with changes in caregiver strain?

A critical consequence of CHF is that the condition is associated with considerable disability in general ambulation (Guccione et al., 1994) and impaired exercise tolerance (Witham, Struthers, & Mcmurdo, 2003) due to dyspnoea and fatigue associated with the condition. However there is increasing evidence that CHF patients can benefit from exercise training (Piepoli, Davos, Francis, & Coats, 2004; Smart & Marwick, 2004). Significant improvements in patient functional limitation as a result of exercise training may have the potential to reduce caregiver strain, however measures of caregiver strain have not been examined in these patient exercise studies. Therefore we hypothesise that an intervention that changed functional ability in patients may have an effect on Care Work Strain. In this study we examined the effect of an exercise intervention that changed caregiver Demand i.e. patient functional limitation, on a measure of caregiver strain. In terms of our theoretical model we examine whether an experimental manipulation of caregiving Demand has an effect on Caregiver Strain.

5.1.3. *Research question and hypotheses*

We aimed to answer the following research question: Does an experimental manipulation of caregiver Demand/Extrinsic Effort have an effect on Care Work Strain?

We generated the following hypotheses:

1. Caregivers in the experimental condition (CHF patient exercise intervention) will have lower Care Work Strain than the control group.
2. This change in Care Work Strain will be mediated by the change in measures of caregiver Demand.

5.2. **Methods**

5.2.1. *Design*

The study design was a randomised controlled trial (RCT). A computer-generated randomisation list was used to perform randomisation. The exercise intervention lasted 12 weeks. Data was gathered at Time 1 (before exercise intervention), Time 2 (when hospital training phase of intervention is complete, 3 months after Time 1) and Time 3 (3 months following Time 2). The data collectors were blind to randomisation.

This RCT study was a separate study conducted by a separate research group with their own research aims and objectives and the trial analysis was not central to the present chapter. The only concern of the following analysis is to provide a further test of the Demand-Control model of Job Strain.

5.2.2. *Participants*

See Methods chapter 4 recruitment details and sample characteristics.

5.2.3. *Measures*

Descriptive statistics, including means, median, standard deviations, ranges, skewness values and cronbach's alpha's for the main study measures are presented in table 5.1.

Dependent variable.

Caregiver strain was measured using the Care Work Strain Scale, a subscale of the Impact of Informal Caring Scale (Orbell, Hopkins & Gillies, 1993). Further details are provided in methods section chapter 4.

Independent variables- Caregiver Demand

As with Chapter 3 and 4 Caregiver Demand was conceptualised as the functional limitation of the care-recipient, three different measures were available.

The six-minute walk test. Further details of this have been provided previously on page x in Chapter 4. The correlation between Time 1 and Time 3 score was 0.9, $p < 0.01$, demonstrating satisfactory reliability.

Activity monitor data was gathered over 7 day periods via a triaxial accelerometer. The RT3 Triaxial Activity recorder (Stayhealthy, Inc) was used to measure ambulatory activity over a week. The RT3 is the size of a pager and is worn on the waist. It continuously tracks activity through the use of piezo-electric accelerometer technology that measures motion in three dimensions and provides triaxial vector data in activity units, metabolic equivalent units (METs) or kilocalories. There is evidence that this is a reliable and valid measure of physical activity (Rowlands, Thomas, Eston, & Topping, 2004). The correlation between Time 1 and 2 was .44, $p < 0.05$ and the correlation between Time 1 and 3 was 0.42, $p < 0.05$.

The modified Functional Limitations Profile (Pollard & Johnston, 2001) was also used to measure patient disability (Pollard & Johnston, 1999). Further details of this measured are presented in Chapter 3. The correlation between Time 1 and 3 was 0.71, $p < 0.01$, demonstrating satisfactory reliability.

The effect of the intervention on the other variables of the job strain models were also examined. The caregiver Personal Control and caregiver Reward measures were described and discussed in chapter 4. The low degrees of freedom in this analysis of Control is due to the fact that many respondents did not provide responses for this measure at Time 3. This may be due to the format of the questionnaire, which may have been misunderstood in self-report format.

5.2.4. Procedure

After obtaining informed consent caregivers were interviewed independently in the patients or their own homes, or by-self report questionnaire when this was not possible, at Time 1 (baseline) and Time 2 (3 months). Where caregivers were interviewed, the interviewer was blind to treatment allocation. At Time 3 (6 months) all caregivers were sent the same questionnaire battery by mail for self-report completion.

A research nurse who also remained blind to treatment allocation carried out all of the caregiver Demand data collection i.e. The Six Minute Walk test, the Functional Limitation Profile and the Accelerometry data collection.

5.2.5. Exercise Intervention

The following details about the intervention are taken verbatim from a submitted publication outlining the details of the RCT of the exercise intervention for CHF patients. This study was concerned about the effects of the intervention on a range of patient physical and psychosocial outcomes.

An experienced physiotherapist delivered the exercise intervention, which was divided into supervised and home phases. In the supervised phase (0-3 months) participants attended exercise classes as outpatients in groups of 3-4, twice a week during the first three months. Between 17 and 20 sessions were offered during the 3- month period. Each session began with a warm-up and ended with a cool-down sequence of movements. Further segments of exercise were added in between these sequences, consisting of upper limb exercise, lower limb exercise, slow whole-body aerobic movements and quicker whole body aerobic movements. A new segment was added at each session until the whole 6 part programme was performed. The six-part programme took approximately 20 minutes to complete and was set to music. At this point, wrist and ankle weights were introduced in a similar sequential fashion until the six sessions were performed using 500g wrist weights and 1.1 kg ankle weights. Weights and participation were adjusted to each participants ability and progress. We encouraged participants to use the Borg rating of perceived exertion scale, aiming for a Borg level of between 11 and 13 (Borg, 1982). We advised participants who rated their perceived exertion as greater than 13 to rest or

reduce the level of activity during the exercise session. After performing the exercises, participants undertook a series of breathing exercises and a ten-minute relaxation session to finish the session. We encouraged spouses or other family members to attend any or all of the sessions. Participants kept a diary detailing their main daily activities over this three-month period; the physiotherapist reviewed the diary with the participant weekly and set new targets for daily walking activity.

In the second phase (3-6 months), we asked participants to continue performing the exercises at home two to three times per week with the aid of a video or audio cassette with demonstrations, instructions and music. There was no face to face contact with the physiotherapist during this period. Participants continued to keep a diary of their daily activities, which we used as a basis for weekly telephone liaison. During these telephone calls, the physiotherapist gave encouragement and agreed new targets for daily walking activity.

Participants in the control group received usual care. We gave standardised written information about the diagnosis and management of heart failure to participants in both groups. We told participants in the control group that exercise was not harmful for their condition and we did not ask the control group to restrict their activities in any way.

5.2.6. Statistical analysis

We examined differences between caregivers for whom we obtained Time 3 data and for those who were not included in the Time 3 analyses due to loss to follow-up (withdrawal from study etc.) using independent t-tests and chi square tests of association. Analysis of covariance was conducted to compare the exercise and control groups. The independent variable was the exercise or control conditions and the dependent variables were Care Work Strain and the 3 caregiver Demand measures (6-minute walk, Accelerometry and the Functional Limitations Profile) and caregiver Personal Control and Reward. Participants pre-intervention measures on the variable being examined was used as the covariate in each analysis. This tested whether there was a significant difference between the two groups at Time 2 allowing for Time 1 levels. Adjusted mean difference score were also calculated for intervention effects on the Care Work Strain measure and three measures of Caregiver Demand.

Data was analysed using SPSS version 11. 10% of Time 1, Time 2 and Time 3 forms were double entered and descriptive statistics were examined for each variable for accuracy of data entry. Missing values were replaced with the series mean provided 80% of the measure was completed e.g. in the 13 item Care Work Strain scale, at least 10 responses were required for substitution to be performed. Data was screened for normality and presence of univariate and multivariate outliers by examining descriptive statistics, z-scores, and histograms. As the accelerometer data had positive skew values at all 3 time points and skew values above +2 at Time 2 this data was square root transformed for ANCOVA analysis. As Reward was highly negatively skewed and transforms could not improve the distribution of the data therefore ANCOVA was not appropriate. The difference between intervention and control groups was assessed using a Chi-squared analysis. Differences were examined between the two groups for individuals that stayed the same or increased and those that decreased in Reward from Time 1 to Time 3.

Post-hoc power analysis showed that the caregiver analysis (N=60) had power = 0.86 to detect a large effect size (.40), power =0.47 to detect a medium effect size (.25), power =0.12 to detect a small effect size (.10). Power calculations based on F-test on means in ANOVA at alpha =0.05 (Faul & Erdfelder's 1992 G-power program).

5.2.7. *Ethics*

Ethics approval for this study was granted by the Tayside Committee on Medical Research Ethics. The approval letter is contained in appendix G.

5.3. Results

5.3.1. *Flow chart for the trial.*

Figure 5.3 shows the flow chart for the study. Of the 82 CHF patients randomised 60 had caregivers that were willing to participate.

5.3.2. *Attrition*

Table 5.2 compares caregivers who withdrew after Time 1 and caregivers who completed the study. There were no statistically significant differences between these two groups, although males were more likely to drop out of the study than females.

5.3.3. *Equivalence of groups at baseline*

Table 5.3 compares the exercise and control groups on socio-demographics and main study measures at Time 1. There were no significant differences (at $p < 0.05$) between caregivers in the Control (N=30) and the Exercise Intervention Groups (N=30) in socio-demographic, independent or outcome variables at Time 1 indicating that the two groups were well matched at baseline.

Descriptive statistics

The descriptive statistics for the entire sample at each of the three time points is outlined in table 5.1. Skew was a particular problem for the accelerometer data and the caregiver Reward measure. Internal consistency was well below conventional criteria for the caregiver Reward measure. This has already been discussed in Chapter 4. Table 5.4 shows the raw correlations between the measures of patient functional limitation. There were strong significant relationships between the six minute walk test and the Functional Limitations profile and weaker but statistically significant relationships between accelerometer data and the other measures of functional limitation. This table provides construct validity for all three measures of functional limitation. The raw means and standard deviations for exercise and control group at the three time points are provided in table 5.5.

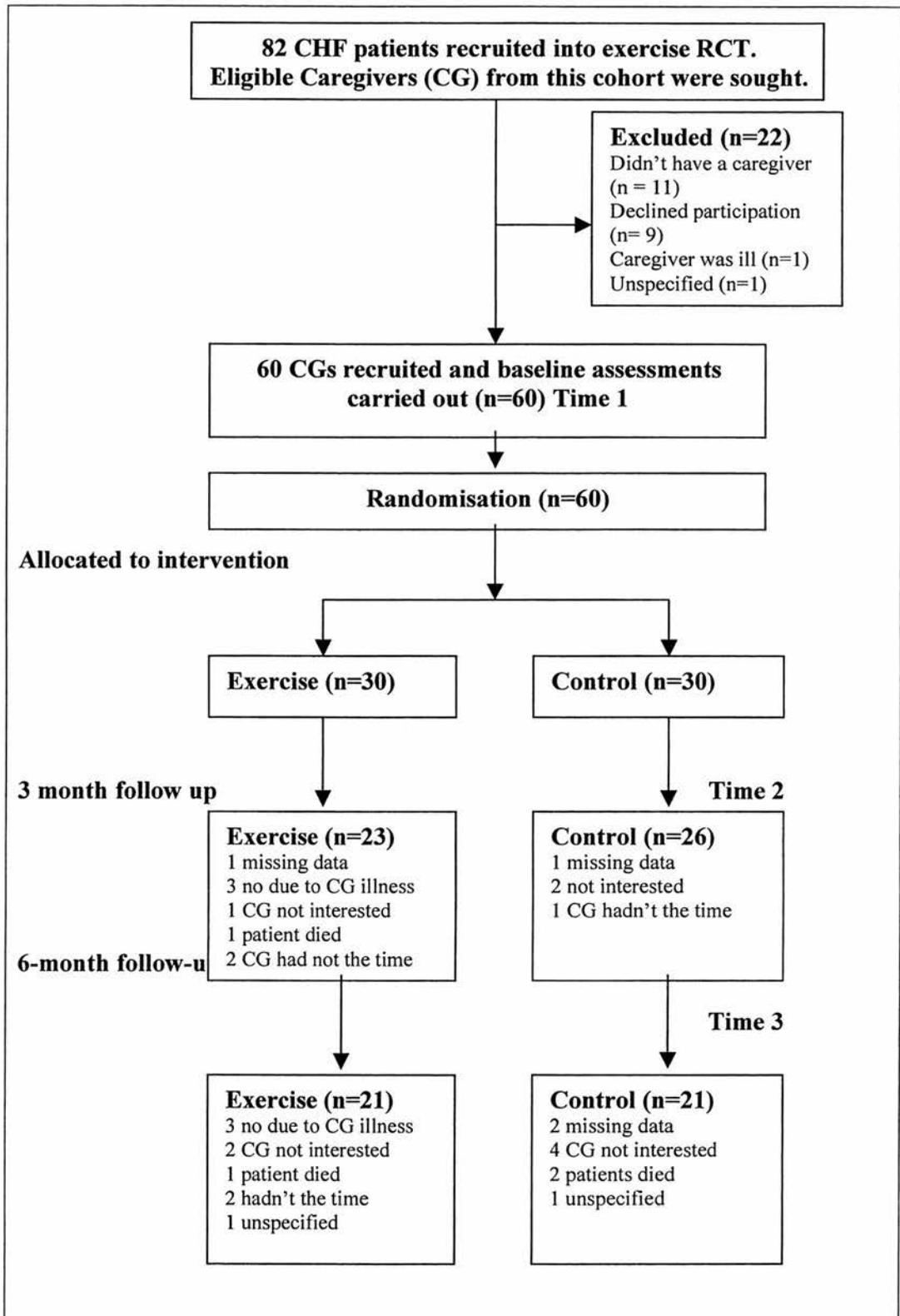


Figure 5.3

Flow of participants through the trial.

Table 5.1
Descriptive statistics for main study measures for entire sample. *Functional Limitations Profile

<u>Outcome variable</u>	<u>Time</u>	<u>Possible Range</u>	<u>Actual Range</u>	<u>Mean (SD)</u>	<u>Cronbach's</u>	<u>Skew</u>
Care Work Strain	1	13-91	13-90	33.7 (17.9)	0.97	1.1
	2	13-91	13-87	37.4 (21.6)	0.97	0.6
	3	13-91	13-79	36.7 (20.1)	0.97	0.4
<u>Independent variable</u>						
6 minute walk	1	—	63-600	251.9 (108.9)	N.a.	0.7
	2	—	53-494	241.2 (103.2)	N.a.	0.4
	3	—	48-440	249.9 (100.1)	N.a.	0.1
Accelerometer	1	—	22358-247293	90822 (50553)	N.a.	1.1
	2	—	16357-377618	93013 (62383)	N.a.	2.7
	3	—	25252-297051	102501 (69610)	N.a.	1.3
Patient FLP*	1	0-100	29-92	65.5 (13.7)	0.77	-0.9
	2	0-100	33-81	65.9 (10.8)	0.69	-1.0
	3	0-100	44-88	66.3 (10.8)	0.67	-0.1
Personal Control	1	0-5	0-5	3.6 (1.2)	N.a.	-1.5
	2	0-5	0-5	3.6 (1.4)	N.a.	-1.1
	3	0-5	0-5	3.0 (1.3)	N.a.	-0.7
Reward	1	3-15	9-15	14.6 (1.3)	0.64	-3.5
	2	3-15	11-15	14.5 (1.0)	0.46	-2.4
	3	3-15	8-15	14.10 (1.6)	0.59	-2.0

Table 5.2
Comparing those who completed the study with those who dropped out after Time 1.

	Withdrawn after T1 (N=18)	Completed Study (42)	P*
<u>Time 1 Measures</u>	<u>Mean (SD)</u>	<u>Mean (SD)</u>	
<i>Caregiver demographics</i>			
Caregiver age	67.3 (13.5)	61.6 (14.8)	.16
Caregiver school leaving age	15.1 (1.3)	15.7 (1.3)	.10
Caregiver deprivation category	3.6 (2.4)	3.8 (2.1)	.80
Group (control/intervention)	(9/9)	(21/21)	1.0
Gender (female/male)	(9/9)	(30/12)	.11
Spouse (yes/no)	(7/11)	(17/25)	.91
<i>Patient measures</i>			
6 minute walk test	269.9 (118.9)	244.1 (104.9)	.41
Accelerometer	103058 (68298)	85748 (41060)	.24
FLP	67.21 (15.5)	64.7 (13.0)	.52
HADS Depression	4.8 (2.9)	4.2 (2.3)	.39
HADS Anxiety	2.5 (2.3)	2.6 (3.1)	.91
<i>Caregiver measures</i>			
Care work strain	33.5 (20.1)	33.8 (17.2)	.95
HADS Depression	4.3 (3.0)	2.9 (2.9)	.13
HADS Anxiety	5.1 (3.8)	4.7 (3.3)	.70

* P values refer to t-tests or Chi-square tests.

Table 5.3**Baseline patient and caregiver characteristics for exercise and control groups**

<u>Patient variable (N=60)</u>	<u>Exercise (N=30)</u>	<u>Control (N=30)</u>	<u>P *</u>
<i>Patient demographics</i>			
Male	21	19	.58
Age in years M (SD)	79.7 (6)	80.8 (5)	.42
Married	15	11	.30
School leaving age M (SD)	14.4 (1.3)	14.1 (1.1)	.44
<i>Patient study measures</i>			
6 minute walk test M (SD)	256.0 (120)	247.7 (99)	.77
Patient FLP M (SD)	63.7 (16)	67.2 (11)	.32
Accelerometer M (SD)	91598 (50096)	90097 (51821)	.91
HADS anxiety M (SD)	3.1 (3)	2 (2)	.13
HADS depression M (SD)	4.1 (3)	4.6 (3)	.42
<i>Caregiver demographics</i>			
Male	13	8	.18
Age in years M (SD)	65.0 (15)	61.6 (14)	.36
Married	23	19	.26
School leaving age M (SD)	15.5 (2)	16.2 (2)	.23
Depcat score M (SD)	4.2 (2)	3.2 (2)	.11
Spouse of patient	14	10	.29
Lives with patient	15	13	.60
<i>Caregiver study measures</i>			
Care Work Strain M (SD)	34.4 (17)	33.1 (19)	.78
HADS anxiety M (SD)	5.5 (4)	4.1 (4)	.16
HADS depression M (SD)	3.8 (3)	2.8 (3)	.20
Control	3.6 (1.2)	3.6 (1.3)	.94
Reward	14.7 (1.2)	14.4 (1.4)	.56

* P values refer to t-tests or Chi-square tests.

Table 5.4
Correlations between the three measures of patient functional limitation.

Measure	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Trans. Accelerometer Time 1	1								
2. Trans. Accelerometer Time 2	.44**	1							
3. Trans. Accelerometer Time 3	.42**	.56**	1						
4. Six Minute Walk Time 1	.41**	.41**	.39**	1					
5. Six Minute Walk Time 2	.35**	.40**	.46**	.90**	1				
6. Six Minute Walk Time 3	.36**	.40**	.47**	.90**	.94**	1			
7. Patient FLP Time 1	-.38**	-.41**	-.52**	-.58**	-.58**	-.59**	1		
8. Patient FLP Time 2	-.24*	-.37**	-.37**	-.62**	-.66**	-.65**	.74**	1	
9. Patient FLP Time 3	-.33**	-.38**	-.45**	-.66**	-.66**	-.68**	.83**	.76**	1

Trans=Transformed, Patient FLP = Functional Limitations Profile, P<0.05 =*, P <0.01 = **

Table 5.5
Means and standard deviations for exercise and control groups at the 3 Time points. (N =60 Patient/caregiver sub-sample)

<u>Independent variable</u>	Intervention		Time 1 <u>M (SD)</u>		Time 2 <u>M (SD)</u>		Time 3 <u>M (SD)</u>	
	N		N		N		N	
6 minute walk	Control	30	247.7 (99)	28	233.4 (97)	23	251.0 (116)	
	Exercise	30	256.0 (120)	26	247.5 (109)	26	251.5 (113)	
Accelerometer	Control	30	90097 (51821)	28	99373 (68115)	22	83798 (57351)	
	Exercise	28	91598 (50096)	24	90947 (50787)	25	115858 (78344)	
Functional Limitations Profile	Control	30	67.2 (11)	28	66.3 (10)	23	66.3 (10)	
	Exercise	30	63.7 (16)	26	64.2 (14)	26	65.6 (14)	
Personal Control	Control	29	3.6 (1.3)	25	3.5 (1.6)	16	2.8 (1.5)	
	Exercise	29	3.6 (1.2)	22	3.6 (1.3)	15	3.3 (1.1)	
Reward	Control	26	14.7 (1.2)	23	14.8 (0.6)	22	14.2 (1.4)	
	Exercise	25	14.4 (1.4)	22	14.3 (1.3)	19	14.0 (1.9)	
<u>Dependent variable</u>								
Care Work Strain	Control	30	33.1 (19)	26	33.3 (25)	21	29.5 (18)	
	Exercise	30	34.4 (17)	23	41.9 (17)	21	43.9 (19)	

Table 5.6
Adjusted Means and ANCOVA p values for Control and Exercise groups (N= 60 Time 1, 49 Time 2 and 42 Time 3)

<u>Independent variable</u>	Baseline Time 1 <u>M (SD)</u>	Adjusted Time 2 Score		Adjusted Time 3 Score	
		<u>M (SE)</u>	<i>p</i>	<u>M (SE)</u>	<i>p</i>
6 minute walk	Control	247.7 (99)	234.5 (8)	247.6 (11)	0.77
	Exercise	253.7 (120)	248.8 (9)	251.9 (10)	
Accelerometer ($\sqrt{\text{transform}}$)	Control	289.0 (82)	294.6 (16)	278.2 (22)	0.11
	Exercise	292.6 (80)	293.8 (17)	327.5 (21)	
Functional Limitations Profile	Control	67.2 (11)	66.0 (1.7)	65.7 (1.6)	.60
	Exercise	63.7 (16)	65.6 (1.8)	66.9 (1.6)	
Personal Control	Control	3.6 (1.3)	3.7 (0.2)	2.9 (0.3)	.65
	Exercise	3.6 (1.2)	3.5 (0.2)	3.1 (0.3)	
<u>Dependent variable</u>					
Care Work Strain	Control	33.1 (19)	34.8 (2)	32.1 (3)	.045*
	Exercise	34.4 (17)	40.3 (2)	41.3 (3)	

5.3.4 Effects of exercise intervention on caregiver Demand variables

Table 5.6 reports the baseline means and standard deviations and the adjusted means and standard errors for Time 2 and Time 3 independent and dependent measures. The effects of the exercise intervention on each of the independent variables and the dependent variable (Care Work Strain) are examined using Analysis of Covariance (ANCOVA). The p values in the table refer to the F test in ANCOVA.

Six minute walk: There was not a significant difference between exercise and control conditions in walking distance at Time 2, after allowing for Time 1 walking distance, ANCOVA $F(1,44)=1.44$, $p=0.24$ or at Time 3, after allowing for Time 1 walking distance, ANCOVA $F=0.09$, $p=0.77$.

Accelerometer data: There was not a significant difference between exercise and control conditions in Accelerometry at Time 2, after allowing for Time 1 accelerometry ANCOVA $F(1,43)=0.00$, $p=0.97$ or at Time 3, after allowing for Time 1 accelerometry ANCOVA $F(1,35)=2.66$, $p=0.11$. In the full sample of patients participating in the trial ($N=82$) the difference between the groups achieved statistical significance in percentage change analysis ($p<0.05$).

Functional Limitations Profile (FLP): There was not a significant difference between exercise and control conditions in FLP scores at Time 2, after allowing for Time 1 FLP scores, ANCOVA $F(1,44)=0.02$, $p=0.89$ or at Time 3 after allowing for Time 1 FLP, ANCOVA $F(1,37)=0.28$, $p=0.60$.

Personal Control: There was not a significant difference between exercise and control conditions in Personal Control at Time 2, after allowing for Time 1 Personal Control ANCOVA $F(1,43)=0.20$, $p=0.52$ or at Time 3, after allowing for Time 1 Personal Control ANCOVA $F(1,27)=0.21$, $p=0.65$.

Reward: There were no significant differences exercise and control conditions in Reward. Participants in each group were classified according to whether Reward scores stayed the same/ increased or Reward decreased. This is shown in Table 5.7. Chi square analysis revealed that there were no differences between the groups in Reward, Chi Square = 0.33, $df=1$, $p=0.56$.

Table 5.7**Differences between exercise and control groups for Reward scores.**

	<i>Reward =or increased</i>	<i>Reward decreased</i>	<i>Total</i>
<i>Exercise</i>	11	7	18
<i>Control</i>	14	6	20
<i>Total</i>	25	13	38

5.3.5 *Effect of the exercise intervention on care work strain*

Care Work Strain: There was not a significant difference between exercise and control conditions in Care Work Strain scales at Time 2, after allowing for Time 1 Care Work Strain ANCOVA $F(1,46) = 2.73$, $p=0.11$, however there was a significant difference between exercise and control conditions at Time 3 after allowing for Time 1 Care Work Strain ANCOVA $F(1,39) = 4.29$, $p < 0.05$. Details are provided in table 5.6. The caregivers of patients in the exercise condition, contrary to prediction had significantly higher Care Work Strain Scores at Time 3 after controlling for Time 1 levels.

Table 5.8**Raw correlation between Care Work Strain and accelerometer.**

	1.	2.	3.	4.	5.	6.
1. Care Work Strain Time 1	1					
2. Care Work Strain Time 2	.84**	1				
3. Care Work Strain Time 3	.70**	.85**	1			
4. Transf accelerometer Time 1	-.18	-.10	-.07	1		
5. Transf accelerometer Time 2	-.14	-.11	-.16	.44**	1	
6. Transf accelerometer Time 3	.10	.17	.11	.42**	.56**	1

Transf= square root transformed

* $P < 0.05$, ** $P < 0.01$.

5.3.6 *Mediation analysis*

As the conditions were not met for doing a mediation analysis i.e. the relationship between the mediator and the dependent variable were weak and changed

direction at Time 3, as shown in table 5.8, this analysis is not presented here. The analysis is in the appendix E for illustrative purposes.

5.3.7 Levels of caregiver emotional distress

Table 5.9 shows the break down of normal (0-7), possible (8-10) and probable (11-21) anxiety and depression in this sample of caregivers at Time 1, Time 2 and Time 3. As can be clearly seen few CHF caregivers were in the probable range for anxiety and depression at each of the 3 time points.

Table 5.9
Levels of caregiver emotional distress (HADS) scores

	Normal (0-7)		Possible (8-10)		Probable (11-21)	
	Anxiety	Depression	Anxiety	Depression	Anxiety	Depression
	%	%	%	%	%	%
Time 1	82	86	9	12	9	2
Time 2	68	94	20	6	12	0
Time 3	65	88	20	10	15	2

The levels of anxiety in the CHF caregiver sample were greater than general population controls as reported by Herrmann (1997). Between 9 and 15% of the CHF caregiver sample were reporting anxiety scores > 10. Herrmann (1997) reported that 7% of a general population sample reported anxiety scores >10. Depression scores were also higher than the general population scores reported by Herrmann (1997). Between 6 and 14% were reporting depression scores >8 in the caregiver sample whereas Herrmann (1997) reports that 5% of a general population sample reported depression scores >8. The levels of anxiety and depression in CHF caregivers were considerably lower than a large sample of cardiological patients (n=5579) where 19% scored greater than 10 on HADS anxiety and 17% scored greater than 8 on HADS depression (Herrmann, 1997).

5.4 Discussion

5.4.1 Findings

Although the intervention did have a significant effect on Care Work Strain, this was contrary to prediction, failing to support hypothesis 1. Caregivers of CHF patients in the exercise group were reporting greater Care Work Strain at Time 3. A marginal effect on Caregiver Demand as measured by accelerometry was also detected. This was statistically significant in the larger patient sample (N=82) from which this sample is drawn. Therefore the exercise intervention was partially successful in increasing activity in CHF patients in the experimental condition. Patients in the exercise group had higher levels of everyday activity as measured by accelerometry. The change in Care Work Strain was not mediated by change in Caregiver Demand. Therefore we fail to reject the null hypothesis for hypothesis 2.

The exercise intervention did not have a strong effect on Caregiver Demand, as only one of the three measures of Demand changed significantly. Therefore the likelihood of detecting a significant mediating effect for Caregiver Demand on Care Work Strain may have been greatly reduced. In addition the reduced sample size available may have lacked the statistical power to detect a significant effect. Furthermore the relationship between the accelerometer Demand measure and Care Work Strain measure was the weakest of the three Demand measures.

The modest effect that the exercise intervention achieved on the three measures of caregiver Demand can be explained by a number of factors. However the most likely candidate was the heterogeneous nature of the patient group in terms of functional ability. This produced greater variation in the Demand measures than anticipated in the power analysis for this study. The standard deviation on the primary outcome measure for the exercise trial, the patient walk, was 108.9 metres at Time 1. In the power calculation for the study it was expected that a standard deviation of 50 metres would be obtained. Therefore the study had not adequate power to detect significant change due to the intervention in such a varied group of patients. In addition the intervention may not have been intense enough for many of the participants. Once again this was because of the heterogeneity of the sample.

The apparent detrimental effect of the patient exercise intervention on informal caregivers was surprising and may be a spurious finding, however it is worth considering a number of possible explanations. As our ANCOVA and chi-square analysis show this was not due to differences in Control or Reward.

It is not clear what the difference in everyday activity achieved in the intervention group means in terms of differences in care-recipient behaviour. The Functional Limitations Profile showed that there were no statistically significant differences in functional limitations between the two groups. The meaning of an increase in activity as measured by accelerometry in terms of changes in functional limitations has yet to be established. It may be that the care-recipients in the exercise group were more active, but no more functionally independent. This type of mild change in activity that has no real impact on the functional limitations of the patient may be more challenging for the caregiver and associated with poorer outcomes. However, we could not empirically demonstrate this relationship in the present study. It is clear that further validation of the accelerometry measure is required.

Recently Wiles et al. have described a post-rehabilitation disappointment effect in stroke patients who have high expectations of rehabilitation programs, but have responded poorly to such treatment (Wiles, Ashburn, Payne, & Murphy, 2004). It is conceivable that caregivers may also be influenced by the patient's poor response to treatment, particularly if their expectations are too high. The disappointment effect may indeed be pertinent in exercise programs for CHF patients where substantial numbers of motivated patients may have poor responses to the treatment. Perhaps more extensive pre-exercise counselling should be offered to ensure that patients and their caregivers will not have unrealistic expectations of exercise programs.

5.4.2 Previous literature

A recent meta-analysis examined the effectiveness of six types of caregiver interventions on six outcome variables in 78 studies (Sorensen et al., 2002). This analysis concluded that such interventions are effective, however there was a great deal of variation in the effects achieved by many of these interventions. In this analysis 6 studies were reviewed that targeted care recipient competence for intervention. The combined effect of these 6 studies did not have an effect on caregiver burden or

depression. This would appear to confirm the present finding that solely targeting care-recipient competence has limited efficacy in reducing caregiver strain/burden.

In Congestive Heart Failure there have been few attempts to develop interventions that aim to reduce caregiver strain/burden, however those that have show promising results (Hughes et al., 2000). Comprehensive discharge planning and home support for CHF patients and their caregivers have shown promising results (Phillips et al., 2004) for CHF patients. However most of these kinds of studies do not explicit outline what role the caregiver may have in assisting patient management.

In other clinical conditions there have been successful caregiver knowledge and skills training programmes, which have shown benefits for the caregiver and the care-recipient (Brodaty, Green, & Koschera, 2003). In one recent randomised controlled trial of this type of intervention in a stroke population there was also a reduction in treatment costs for the care-recipient over the following year (Patel, Knapp, Evans, Perez, & Kalra, 2004; Kalra et al., 2004).

5.4.3 Strengths and Limitations

This study is one of the few studies to examine caregiver outcomes in a patient exercise intervention in CHF. There is a great deal of data on the effects of exercise intervention on patients, but little study of how exercise programs impact on informal caregivers. There is little data to show that these interventions can have a positive or negative impact on informal caregivers.

The strong theoretical framework used in this study is a notable strength. Few caregiver intervention studies (Sorenson et al. 2002) have made use of theory despite its advantages. While we have advocated models of job strain in the present thesis other theories of stress and coping might be usefully applied to designing caregiver interventions such as Leventhal's self regulation model, which was recently used to investigate self-management in CHF (Horwitz, Rein & Leventhal, 2004).

The present study may have lacked the statistical power to detect a mediating effect for caregiver Demand particularly given the small effect of the intervention on measures of Caregiver Demand. A larger sample size and/or a longer time frame may be required to adequately test for such effects.

5.4.4 *Future Work*

A key focus of caregiver research has been the relationship between caregiver health outcomes and measures of care recipient functional limitation. It has been argued that this relationship may be particularly strong when cognitive deficits are not present in the care recipient (Pinquart & Sorensen, 2003a). As we have seen in this chapter measures of functional limitation are indeed related with each other, however there was considerable variation in the strength of these relationships and there were weak relationships with the measure of care work strain. Future work should endeavour to elucidate these relationships, as it appears to vary greatly depending on the measurement instruments used.

As few studies have examined the effect of exercise programs on both patients and their informal caregivers, it is not yet clear whether the negative effect found for caregivers in the exercise intervention group is a real effect. Future exercise studies should attempt to assess caregiver outcomes in order to clarify their effect on caregivers. One could hypothesise that intensive exercise interventions such as the one described in this study that have no effect on care-recipient functional limitations may be associated with poorer caregiver outcomes particularly if expectations of the intervention are high.

While understanding the effects of complex interventions such as exercise programs in both care-recipients and caregivers may be difficult, there have been a number of methods suggested recently to do this (Czaja, Schulz, Lee, & Belle, 2003). Of particular importance, as we have stressed throughout the thesis is the use of theory in design, measurement and analysis, as we have done in this chapter. Future studies should attempt to make full use of explicit theoretical models.

5.5 **Conclusion**

While we have found limited support for our theoretical model in this study, a number of considerations should be drawn from the present analysis. In developing interventions to improve caregiver health it is important to have some theoretical model underpinning the process whereby health may be improved. In terms of the present theoretical model of caregiver health, interventions should attempt to reduce caregiver Demand and increase caregiver Control over caregiving. In order to optimise

any caregiver interventions researchers should attempt to identify the process variables whereby interventions have their effect. As we have attempted to do in this chapter, process variables can be identified by using theoretical models. Many caregiver researchers are beginning to argue that theoretical and applied intervention research should not be separate endeavours (Pillemer et al., 2003). Although we have limited support for the theoretical model, the present chapter is one of the few attempts to move this work forward by achieving this necessary integration of intervention and theory.

Chapter 6

6. General Discussion

Chapter 6 presents an overview and a summary of the thesis findings. This is split into 5 sections. (1) Firstly the thesis findings are described and discussed in light of the research questions and (2) the study hypotheses. (3) The thesis findings are then compared with previous findings. (4) The strengths and limitations to the thesis studies are then described and discussed. (5) Finally the implications of the thesis findings for further research and policy are discussed.

6.1. Summary of thesis findings by research questions

6.1.1. Can models of job strain be used to investigate caregiver health and well-being?

The studies conducted in the thesis provide some support for the use of job strain models in the investigation of caregiver health and well-being. There was cross-sectional support for using the Demand-Control model and the Effort-Reward Imbalance Model in predicting anxiety, depression and care work strain. The most robust finding was a main effect for the Control variable of the Demand-Control model on emotional distress and care work strain. This was demonstrated in Chapter 3 and 4 using different conceptualizations and measurement instruments for the Control construct and different dependent variables i.e. anxiety, depression in Chapter 3 and care work strain in chapter 4. In addition these analyses were conducted in two independent populations of caregivers caring for individuals with two very different clinical conditions, Stroke (Chapter 3) and Congestive Heart Failure (Chapter 4). There was also cross-sectional support for a main effect for Reward on care work strain and some support for the interactive effect of Demand and Control on care work strain in chapter 4. However we did not find prospective longitudinal support for the two job strain models.

In terms of the 5 criteria set out in chapter 1 for the acceptance of new scientific theory, the job strain models may have the potential to meet some, if not all the criteria. The five criteria are set out again in table 6.1 with notes on how thesis findings relate to each of the criteria.

Table 6.1**Criteria for acceptance of a new theory and thesis findings.**

<i>Criteria</i>	<i>Thesis findings on job strain models</i>
1. Previously accepted theories (PAT) gave an acceptable explanation of something, new theories must give the same results.	The previously accepted theories of caregiver health and well-being could explain statistically significant amounts of variance in caregiver outcomes. The job strain models can explain comparable amounts of variance in caregiver outcomes.
2. New theory explains something that the PAT either got wrong or, more commonly, did not apply.	Few previous theories have applied the concepts of Demand, Control and Reward as they are conceptualised in the job strain models. These constructs have been shown to be predictive of illness in the context of work.
3. Makes a prediction that is later verified.	The theories made predictions that were verified in the thesis and further predictions that await verification.
4. Elegance - Aesthetic quality – simple and powerful. That is simple, easy-to-remember or apply formulation, expressed as some symmetry of nature, be powerful enough to used in many applications	The job strain models are particularly elegant in comparison to previously applied theories of caregiver health. There is evidence that they can be used in many applications e.g. occupational health research, Stroke and CHF caregiving health research. The D-C model makes predictions about both negative and positive health outcomes demonstrating some symmetry of nature.
5. Provide a deeper insight or link to another branch of knowledge	The job strain models may provide a link between two fields of stress-health research that have been conducted largely independent of each other and have continued as separate branches of knowledge about stress and health. Key constructs in one area of the stress-health relationship (work) may map on to another area (caregiving).

6.1.2. What is known about caregiving for CHF patients?

Chapter 2 reviewed and analysed studies that have examined informal caregiving in Congestive Heart Failure. This qualitative/narrative review revealed that there have been relatively few studies addressing issues surrounding informal caregiving in Congestive Heart Failure, despite the increasing incidence and prevalence of the condition. Individuals providing care for someone with CHF may face considerable challenges, many of which may be specific to the clinical condition e.g. frequent inpatient and outpatient health care, disturbed sleep and monitoring a complex self-management regimen (pharmacological, dietary and symptom monitoring). There is some evidence that informal caregivers of CHF patients may be at risk for poor health outcomes e.g. emotional distress (Schwarz & Elman, 2003).

6.1.3. What might be worth studying in relation to informal caregiving for CHF patients?

The review specified two main areas that researchers could usefully focus on:

The impact of CHF on informal caregivers

CHF is currently one of the most common clinical conditions in frail older adults and the estimates indicate that CHF is expected to increase in incidence and prevalence (Stewart, Macintyre, Capewell, & McMurray, 2003). A body of evidence already exists demonstrating a relationship between caregiving and patient outcome in CHF (Rohrbaugh et al., 2004; Coyne et al., 2001; Murberg & Bru, 2001; Krumholz et al., 1998), however much less is known about the relationship between CHF caregiving and caregiver outcomes. Given the unique and frequent difficulties associated with providing care for an individual with CHF, further investigation of the impact of the condition on informal caregivers is warranted. If caregiving in this condition is established to be particularly difficult, these studies could inform the development of interventions designed to reduce the negative effects of caregiving.

Recently a concept known as ‘collateral health effects’ has been proposed (Christakis, 2004). This refers to unintended effects of health care, which may be positive or negative, in others to whom health care recipients are connected e.g. the positive impact of giving a patient superior end of life care on the spouses health (Christakis & Iwashyna, 2003) or the negative impact of a medical device

such as an Implantable Cardioverter Defibrillator (ICD) on a patient's spouse or partner (Marx, Bollmann, Dunbar, Jenkins, & Hawthorne, 2001; Dougherty, 1995). These effects have been traditionally neglected in medical care and research. Conceptually 'collateral health effects' are in keeping with the systems approach to the caregiving dyad which was discussed in Chapter 1. This concept may have some potential in CHF research.

CHF may be associated with significant collateral health effects particularly as health professionals are applying increasingly complex non-pharmacological treatments for managing the condition e.g. exercise programs (Piepoli, Davos, Francis, & Coats, 2004), specialist home based nurse interventions (Stewart, Pearson, & Horowitz, 1998) and self-management programs (Wright et al., 2003). The impact of such interventions on spouses or other informal caregivers has not be adequately assessed in many studies. The unexpected effect of the exercise intervention in Chapter 5 may be an example of a collateral health effect.

The role of informal caregivers in managing the condition.

There may be scope for including informal caregivers in the community management of CHF. This may be particularly important as the health care of the chronically ill increasingly move towards home-based care in the community (Wilson, Wynn, & Parker, 2002). In a number of other clinical conditions of older adulthood caregivers have been given knowledge and skills training, which has had beneficial effects for the caregiver and/or the care-recipient (Kalra et al., 2004b; Hepburn, Tornatore, Center, & Ostwald, 2001; Teri, 1999; Robinson & Yates, 1994). As the self-management of CHF is relatively complex, and misconceptions about self-management of CHF may be common (Horowitz, Rein, & Leventhal, 2004), incorporating caregivers into self-management programs or home based nurse interventions (Stewart, Pearson, & Horowitz, 1998) may have the potential to enhance adherence with medical regimens. Adherence has been recognized as a particular problem in CHF patients (Cline, Bjorck-Linne, Israelsson, Willenheimer, & Erhardt, 1999) and research incorporating caregivers may represent one potential avenue for further research. This however would have to be offset against any potential negative impact that involvement in patient care may have on informal caregivers.

6.2. Support for study hypotheses in Chapter 3, 4 and 5.

The following section outlines the support for each of the hypotheses that we tested in chapter 3, 4 and 5.

6.2.1. Chapter 3

1. Caregiving in high Demand conditions will be associated with increased caregiver anxiety and depression. There was some support for this hypothesis in the Time 1 cross-sectional analysis. Higher Demand was associated with higher depression. There was no support in prospective longitudinal analysis of change.
2. Increased caregiver Control over assisting recovery following stroke will be associated with decreased anxiety and depression.

There was considerable support for this hypothesis at both Time 1 and Time 2 cross-sectional analysis. There was no support in prospective longitudinal analysis of change.

3. Higher Perceived Control over assisting the patient's recovery following stroke will moderate the effects of high Demand on anxiety and depression.

There was no support for this hypothesis in any of the analyses in Chapter 3.

6.2.2. Chapter 4

1. Caregiving in high Demand/Effort conditions will be associated with increased caregiver strain. (Main effect)

There was no support for this hypothesis in cross-sectional or prospective longitudinal analysis of change.

2. Higher caregiver Perceived Control over caregiving will be associated with decreased caregiver strain. (Main effect)

There was support for this hypothesis in cross-sectional analyses at both Time points. There was no support in prospective longitudinal analysis of change.

3. Higher Perceived Control over caregiving will moderate the effects of high Demand on caregiver strain. (Interaction effect)

There was some support for this hypothesis in cross-sectional analysis at Time 2. At higher levels of Demand, Higher Control had a moderating effect on Care Work Strain. There was no support in prospective longitudinal analysis of change.

4. Caregiving in low Reward conditions will be associated with increased caregiver strain. (Main effect)

There was support for this hypothesis in cross-sectional analyses at both Time points. There was no support in prospective longitudinal analysis of change.

5. Caregiving in effort-reward imbalance conditions will be associated with increased caregiver strain. (Interaction effect)

There was no support for this hypothesis in cross-sectional or prospective longitudinal analysis of change.

6.2.3. Chapter 5

1. Caregivers in the experimental condition (CHF patient exercise program) will have lower Care Work Strain than the control group.

There was no support for this hypothesis. Contrary to prediction caregivers in the experimental condition had significantly higher levels of Care Work Strain than the control group, after allowing for Time 1 scores.

2. This change in Care Work Strain will be mediated by the change in caregiver Demand.

There was no support for this hypothesis. The change in Demand did not mediate the effect of the exercise intervention on Care Work Strain.

6.3. Thesis findings and previous findings

Only one previous study explicitly tested the predictions made by the Demand-Control model to investigate caregiver health, (Orbell & Gillies, 1993). Main effects for Demand and the interaction of Demand and Control were found in this study. This is in contrast somewhat to the present studies, where we found main effects for Demand and/or Control and limited support for the interaction of Demand and Control. No studies have explicitly tested the predictions made by the Effort-Reward Imbalance model per-se, to predict caregiver health outcomes. Due to the limited attention to the complete models used in the present studies we compare our findings with previous findings by comparing the individual constructs in the two models that have been investigated in previous research.

6.3.1. Demand/Extrinsic Effort

In the thesis we conceptualized the Demand component of the model as the functional limitations of the care recipient. We deliberately avoided using caregiver reports of Demand as there is a lot of evidence that this type of variable

would be confounded with the type of dependent variables that we were examining e.g. self reported care work strain and emotional distress (Watson & Pennebaker, 1989).

We found some support for a small to moderate relationship between Demand and caregiver emotional distress and Care Work Strain. Previous studies have shown much conflicting evidence regarding the relationship between functional limitations and caregiver health and well-being outcomes. For example some studies have shown weak relationships between functional limitations and measure of caregiver strain or emotional distress (Pruchno & Resch, 1989; Zarit, Reever, & Bach-Peterson, 1980), while others have show strong associations. However a recent meta-analysis has argued that the relationship between impairment and strain outcomes are weaker mainly in convenience samples rather probability samples (Pinquart & Sorensen, 2003a). In this meta-analysis the weighted mean correlation between measures of burden and the physical impairment of the care recipient for 92 studies was 0.22 (.21-.23, 95% confidence interval). This is comparable to the relationship between the six-minute walk test and the measure of burden used in chapter 4 (Time 1 $r=-0.25$ and Time 2 $r=-0.21$). However the associations between the other measure of impairment, the functional limitations profile and burden was less reliable (Time 1 $r=0.05$ and Time 2 $r=0.20$).

The weighted mean correlation between the physical impairments of the care recipient and generic measures of depression in the meta-analysis was 0.14 (0.12-0.16, 95% confidence interval). The findings in Chapter 3 indicated a stronger relationship between the functional limitations profile and depression in chapter 3 study of stroke patients and caregivers (Time 1 $r=0.23$ and Time 2 $r=0.19$). However this finding may be explained by the nature of our care-recipient population. In further analysis of meta-analytic data set (Pinquart et al., 2003a), the relationship between functional impairment and depression was broken down by care receivers illness i.e. dementia patients, mixed patients and non-dementia patients. The weighted mean for non-dementia patients and caregiver depression was $r= 0.25$ (0.18-0.32, 95% confidence interval). As the patients in Chapter 3 were non-dementia patients our findings concur with the bulk of the comparable literature.

In our studies we were unable to show that change in caregiver Demand is associated with change in measures of emotional distress or Care Work Strain. Previous work has shown that caregivers facing high numbers of new Demands were more likely to experience increased levels of depression in the following six months compared with caregivers facing similar overall demands but few new demands for assistance following hospital discharge (Given, Given, Stommel, & Azzouz, 1999). The thesis studies may have lacked the statistical power to detect such effects in prospective longitudinal analysis. This may have been due to sample size or the limited change in study variables over the study time frames.

While there was a considerable range of caregiver Demand in the thesis studies, study exclusion criteria may have restricted this range somewhat. For example none of the care-recipients studied in the thesis had significant cognitive impairment nor were there any individuals that were unable to walk at all in the CHF studies. In addition care-recipient populations who choose to take part in exercise interventions or workbook interventions may not generalise to the population of care-recipients. For example the CHF patients in the thesis studies had low levels of emotional distress and some recent studies have shown that depression may be common in this clinical condition (Turvey, Schultz, Arndt, Wallace, & Herzog, 2002). It may be that the caregivers experiencing the most Demand and the poorest outcomes are difficult to recruit into research studies as this takes time that these caregivers may not have.

6.3.2. Personal Control

Control was broadly conceptualized in the thesis as caregiver personal Control over caregiving. In chapter 3 Control was conceptualized as Control over outcome i.e. the stroke patients recovery, and in chapter 4 Control was conceptualized as caregiver Control over their caregiving behaviour. The former definition relates more closely to 'skill-discretion' component of Control and the latter definition more closely matches the 'decision authority' component of Control that were specified in the original Demand-Control Model (Karasek & Theorell, 1990).

The studies described in Chapter 3 and 4 confirmed that these types of personal Control appear to be robust predictors of health outcomes in the informal caregivers of Stroke and CHF patients. The importance of personal Control for

caregiver health outcomes has been well established in a range of studies using both situational and person based measures of Control (Park, Folkman, & Bostrom, 2001; Atienza, Collins, & King, 2001; Miller, Campbell, Farran, Kaufman, & Davis, 1995). The present data confirm these findings. Indeed personal Control has been shown to be predictive of health outcomes in range of disciplines using a variety of methodologies in many different clinical and non-clinical populations, particularly research concerned with stress and health (Steptoe and Appels, 1989). Personal Control has been one of the foremost constructs in personality and social psychological research (Skinner, 1996) and theories that include some variation of this construct dominate a range of psychological research at several levels of analysis from behavioural neuroscience to human social cognition (Ajzen, 1991; Bandura, 1977).

6.3.3. The Interaction of Demand and Control

There is also some evidence of the interaction of Demand and Control in studies that have not explicitly examined Karasek's Demand-Control model (Karasek & Theorell, 1990). For example Miller et al (1995) showed that caregiver 'mastery', a trait variation of the Control construct, moderated the effects of stressors on depression. This concurs with the significant interaction found in Time 2 analyses of the Demand-Control predicting care work strain in chapter 4, where Control moderated the effect of high Demand on Care Work Strain.

6.3.4. Reward

Reward was conceptualized as caregiver 'Esteem-Reward' in Chapter 4 and 5. The other components of Reward specified by Siegrist (1996) may have limited applicability to informal caregiving. The poor performance of several items in the Reward questionnaire used in Chapter 4 and 5 indicates that Reward as applied to caregiving may be limited to the esteem Reward component. Generally Reward has not been well specified in the caregiver literature.

Reward and a host of related concepts and their converse such as gain, perceived inequity, reciprocity or 'social exchange' and benefit (as in 'cost-benefit'), have been long recognized as key constructs in psychological research and have received considerable support in the caregiver literature (Foley, Tung, &

Mutran, 2002; Ybema, Kuijer, Buunk, Dejong, & Sanderman, 2001; Hinrichsen, Hernandez, & Pollack, 1992; Danigelis & Fengler, 1990). In chapter 4 we found that higher caregiver Reward was associated with lower care work strain.

This supports several studies examining the relationship between informal caregiving and the Reward construct. For example there has been some support for considering caregiving as a process of mutual exchange (Horwitz, Reinhard, & Howellwhite, 1996). This is directly analogous to the Effort-Reward Imbalance approach to work, which is based on the norm of reciprocity implicit in all work contracts (Siegrist, 1996). Picot, Youngblut, & Zeller (1997) have developed a measure of caregiver Reward and some psychometric validation of this measure has been established. Stephens, Franks, & Townsend (1994) examined the influence of various role rewards including the caregiving role and found that caregiving Reward could explain significant amounts of variance in a measure of positive affect (Bradburn affect scale) after caregiver, wife and mother role stress were entered into a hierarchical regression equation. Riedel, Fredman, & Langenberg (1998) also found some benefit for the positive influence of Reward. Caregivers in their sample who reported receiving more Rewards from caregiving reported fewer difficulties. The role of perceived relationship inequity has also been examined in a number of studies as a predictor of health outcomes in couples facing cancer (Kuijer, Buunk, Ybema, & Wobbles, 2002; Ybema et al., 2001). These studies found that perceived inequity was associated with emotional distress. Inequity in social relationships is central to the concept of effort-reward reward imbalance (Siegrist, 1996), albeit in a more formal context than a marital dyad.

However the application of the Reward construct to studies examining caregiver health has been considerably more limited than those examining the role of personal Control and the full potential of this construct may remain under-exploited. Chapter 4 provides further support for the role of this construct in predicting care work strain.

6.3.5. *A negative effect of the exercise intervention on caregivers?*

The unexpected finding that care work strain was significantly greater in the caregivers of patients in the exercise group at follow-up was surprising. As we have discussed this finding may be potentially anomalous, however it is worth

considering why the exercise intervention may have had such an effect particularly given the paucity of studies that examine caregiver strain outcomes in care-recipient exercise studies, it may be too early to regard this as an unimportant unreliable finding. A number of plausible reasons why this may have occurred have been considered. These include a disappointment effect for the caregivers and/or patients as the intervention had little or no effect on the functional limitations of the patients. A recent paper by Wiles, Ashburn, Payne, & Murphy, (2004) discusses issues surrounding post-rehabilitation disappointment following stroke particularly when expectations of exercise programs might be high. This may be pertinent to the unexpected finding obtained in Chapter 5. Data was not collected on what patients or caregiver expectations were about participation in this program. In the stroke rehabilitation literature some have reported negative outcomes for patients following the termination of physiotherapy (Pound, Bury, Gompertz, & Ebrahim, 1994). Another related phenomenon that might be germane is the 'action effect'. This describes how outcomes achieved through action lead to greater regret than actions that have been forgone i.e. inactions (Gilovich & Medvec, 1995). Given the intensity and apparent motivation of the participants (over 75% of participants attended over 80% of sessions offered) in combination with the modest success of the intervention on nearly all outcomes measured, the action effect may indeed be relevant to this contrary finding.

In terms of the Demand-Control model there may have been an expectation among caregivers that Demand would decrease over time due to the intensive exercise intervention, however this did not reliably happen for the group of patients taking part in the exercise. The salience of the clinical condition may also have been increased for caregivers due to the frequent exposure of the care-recipients to the health care system in the experimental condition. This may have had the potential to increase the perception of caregiving Demand, which may provide some explanation of this finding.

6.4. Strengths and Limitations:

6.4.1. Measurement

There was some improvement in measurement in the thesis studies. In particular the use of multiple methods of assessing functional limitations of the care-recipients e.g. care-recipient self-reported Functional Limitations Profile

(Pollard & Johnston, 2001) and the six-minute walk test (Guyatt et al., 1985), has been a particular strength. Few studies examining caregiving have used such a heterogeneous range of measurement instruments in assessing patient impairment. This may be important as there is now a considerable body of evidence indicating that measurement of functional limitations differ significantly depending on who is providing the measure (Knapp & Hewison, 1999).

The measures of Control and Reward used in the thesis require further psychometric evaluation. Neither the Control measure used in Chapter 3 or the Reward measure used in Chapter 4 have been previously published. The Control measure used in Chapter 3 was designed according to the guidelines specified by Ajzen (1991) for designing questionnaires assessing the perceived behavioural control construct in the theory of planned behaviour. The Control measure in Chapter 4 was used in a previously published study that examined the Demand-Control model applied to informal caregiving (Orbell & Gillies, 1993). Conceptually this measure was closer to the Demand-Control model operationalisation of Control (Karasek & Theorell, 1990), particularly the decision authority component of job Control. However it is worth noting that the focus of being 'relied' upon that the measure used in Chapter 4 may not always associated with lower personal Control and consequent negative health outcomes in individuals that may want to take a proactive role in caregiving. Despite the potentially discrepant Control constructs that these measures may have been tapping e.g. the Control measure used in Chapter 3 was concerned with Control over outcome while the measure used in Chapter 4 was concerned with Control over caregiving behaviour, both measures related to emotional distress and Care Work Strain as the Demand-Control Model would predict. This may give us some additional confidence in the measures and the theoretical construct.

The Reward measure contained Reward items that were adapted from the items in Siegrist's ERI questionnaire (Siegrist et al., 2004). The wording was changed slightly to apply the items to informal caregiving. This measure did not perform well as it was highly skewed, Cronbach's alphas were well below conventional recommendations and items had to be dropped due to non-response. The non-response was interesting as it gives us some indication about the nature of Reward construct as it could be applied to informal caregiving. However the measure was significantly correlated with a measure of caregiver satisfaction

demonstrating convergent validity, and it predicted Care Work Strain in the Chapter 4 test of the Effort-Reward Imbalance Model. However it is clear that the validity and reliability of this measures requires further psychometric development.

It is important to note that there has been great variation in how both the personal Control and Reward constructs have been measured. For example personal Control has been measured as a personality variable such as ‘mastery’ (Christensen, Stephens, & Townsend, 1998) and as a situational Control variable (Atienza et al., 2001) in studies examining caregiving. Such wide interpretation of core constructs such as personal Control and Reward has the potential to produce a confusing body of findings and attempts to integrate findings may be hampered by heterogeneous conceptualization and measurement.

Ultimately the value of any model of caregiver strain may rest on the models success in encouraging the development of reliable measures of the constructs that are central to the model. Further theoretical and empirical consensus is required in order to make these concepts useful in research and intervention.

6.4.2. Study Design

A range of designs and analyses were employed in the thesis studies, including cross-sectional, prospective longitudinal and a randomized controlled trial design. Much of the caregiving literature has consisted of cross-sectional studies, which allow limited conclusion to be drawn from analysis of data. The best tests of the job strain models have been prospective longitudinal studies with large samples who were followed up over a number of years (De Lange, Taris, Kompier, Houtman, & Bongers, 2003; Bosma, Peter, Siegrist, & Marmot, 1998). In these studies a range of indicators of health were gathered at several time points. This type of study in a large sample of caregivers would provide a better test of the job strain models.

The design of the review and analysis of the studies that have examined informal caregiving in CHF in Chapter 2 was narrative in nature. The main reason for using this strategy was due to the small number and the heterogeneity of studies that have addressed this topic. In a recent quantitative review of the wider caregiving literature (Pinquart et al., 2003a) argue that integrating results in this

way may lead to different conclusions. Four main shortcomings of this approach were identified. Firstly all studies receive equal weight despite the fact that larger samples provide more reliable results. Secondly small and medium effect sizes may not be detected with small sample sizes. Thirdly, qualitative reviews often focus on a more limited number of studies than quantitative reviews. Finally narrative reviews cannot assess the significance and homogeneity of statistical effects and the influence of moderator variables (e.g. sampling method used or demographics) on observed caregiving effects. It is important to note the limitations of reviewing the literature in this way. However the narrative review approach was necessary in Chapter 2 given the small and diverse body of work examining informal caregiving and Congestive Heart Failure.

6.4.3. Theory

As we have extensively alluded to, a notable strength of the present studies is the explicit theoretical frameworks that have been used to generate hypotheses, research design and analyses. The parsimonious nature of the models is a particular strength and in keeping with the philosophical principle which is sometimes referred to as Occam's Razor. Occam's Razor or the principle of parsimony states that one should not increase, beyond what is necessary, the number of entities required to explain anything. If the Demand-Control Model and the Effort-Reward Imbalance model can explain equal amounts of variance to more complex models, then there may be an argument for limiting the number of variables that are required to investigate issues surrounding caregiver health. However if extension of the models e.g. the addition of caregiver social support, resulted in significantly more variance being accounted for then there would be good argument for revising the models.

In addition when two or more models are compared and found to make independent predictions of dependent variables of interest, attempts at theoretical integration should be considered. For example there is some debate as to whether the Demand-Control Model and the Effort Reward Imbalance Model could be integrated as the combination of both models make for better empirical prediction of some health outcomes (Peter, Siegrist, Hallqvist, Reuterwall, & Theorell, 2002). Further use of these models in caregiver studies is needed before an argument for or against such theoretical integration can be made.

In the thesis we tested a number of hypotheses derived from the Demand-Control model including main effects for Demand and Control. This has been referred to as the 'strain hypothesis' (Van Der Doef & Maes, 1998). We also examined whether Control had a moderating effect on the effects of high Demands on caregiver strain outcomes. This has been referred to as the 'buffer' hypothesis (Van Der Doef & Maes, 1998). Additionally we also tested whether change in Demand mediates the effect of an exercise intervention on Care Work Strain. As Baron and Kenny (Baron & Kenny, 1986) outline in their influential paper the distinction between moderating and mediating variables is often blurred. Although the mediation analysis in Chapter 5 failed to support the predictions made by the Demand-Control model, this is a novel way to test the predictions made by the model. While theoretically and conceptually the main effects of Demand and Control or the moderating effect of Control, it is often argued are the key tests of the model, mediation analysis of Demand and/or Control may be worth conducting given appropriate research design and research questions. This will provide a clearer picture of the nature of the relationship between the predictor variables in these models and health outcomes.

Despite our concentration on a limited number of theoretical approaches that can be used to examine caregiver health and well-being there are a number of other useful models that have received limited attention in the caregiving literature, but may have some unexploited potential to shed light on caregiver health and well-being. Leventhal's self-regulation model is one such model which has recently generated a large body of research (Hagger & Orbell, 2003) and has been applied in a limited number of studies examining informal caregiving (Figueiras & Weinman, 2003). This model focuses on the role of cognitive and emotional representations that are associated with a given illness. The caregiver's cognitive and emotional representations are believed to direct coping efforts. This approach may be useful in elucidating some caregiver health and well-being outcomes such as emotional distress. One particular focus using this approach in relation to caregiving has been the discrepancy between patient and caregiver or spouse representations as a predictor of adaptation to chronic illness (Heijmans, De Ridder, & Bensing, 1999). There has been some successful patient interventions using this approach (Petrie, Cameron, Ellis, Buick, & Weinman, 2002) and there may be potential for targeting dyads in this sort of intervention

given the potential potency of 'discrepant' illness representations in explaining caregiver outcomes (Heijmans, De Ridder, & Bensing, 1999).

However despite the current popularity of this model it is important to note that it may have limited potential, like the Lazarus and Folkman (1984) stress and coping model, for the public health approach that the thesis is advocating in informal caregiving.

6.5. Implications and Recommendations

6.5.1. Public health approach to caregiving

The models of job strain used in the thesis studies have an orientation toward a public health understanding of how the organization of human interaction can have an impact on the health of populations. This is in contrast to stress and coping models that have informed prevention and treatment interventions for individuals who may be at risk of poor health outcomes due to maladaptive coping patterns. Stress and coping models point to the individual coping strategies as being critical mediators of health outcomes particularly emotional distress. Interventions informed by this theoretical approach may be reliably effective, however if these interventions involve a lot of contact at an individual level, then there is little prospect of these intervention being applied to the caregiving population at large. For example this may be in excess of 6 million people in the UK. Health promotion on this scale may not be usefully informed by stress and coping models that inform individual therapies, although this approach may be optimal for clinical psychologists who are responsible for treating individuals in need of treatment. The approach of health psychology is geared more towards the group or population level approach of public health and the job strain models used in this thesis are consistent with this approach. In addition these models largely but not exclusively take the focus away from the individual caregiver as being source of the adaptive problem and the target for intervention and looks to environmental contingencies as the most important agents in the stress process.

The Demand-Control Model and the Effort-Reward Imbalance model on the other hand point to the organization of the inter-dependent systems within which the caregiving occurs e.g. the caregiver/care-recipient relationship, the wider family, formal health care. Potentially policy change may be more likely to

effect the major systems and forces in society in which individuals operate rather than the individuals themselves. A large body of work is now beginning to demonstrate that social positions, social connections are critical determinants of population health (Marmot and Siegrist, 2004).

The other distinction that may be drawn between job strain models and stress and coping approaches is that the latter have a more palliative model of caregiver stressors whereas the job strain models may be more orientated towards a prevention approach to caregiver stressors. Once again the spirit of a prevention approach is more in line with the public health approach to informal caregiving that we are advocating in this thesis.

6.5.2. Policy implications

Given the consensus surrounding the importance and robustness of both the Reward and Control constructs for health and behaviour and their accessibility to non-specialists, the appropriate enhancement of personal Control and Reward should be a key focus of policy to improve health outcomes for informal caregivers. Targeting personal Control and Reward contingencies may represent a simple heuristic for policy makers aiming to reduce the health inequalities that are associated with informal caregiving. It is important to note here that this can include both tangible, such as increased financial support, and ‘non-tangible’ Rewards such as enhancing the ‘esteem-reward’ of informal caregiving. This latter approach may be achieved by the changing of public attitudes toward informal caregiving and informal caregivers. This may be achieved by reorganization of formal support for caregivers and care-recipients.

6.5.3. Research implications

There were several methodological and conceptual difficulties that became apparent after the studies were undertaken. The most notable of which are discussed in the following sections.

6.5.3.1. Recruiting caregivers in CHF populations.

Unexpectedly significant numbers of patients did not have informal caregivers (11/82 or 13% of the CHF patients). This was surprising as all patients were over 70 years old with a mean age of 81, living in the community and had a diagnosis of at least NYHA Class II heart failure i.e. symptomatic with at least

some physical limitation. In addition, 9/82 (11%) declined participation in the study. A number of individuals may have declined participation as they said that they were not 'caregivers'. The word 'caregiver' may have become synonymous with dementia in common language, therefore a number of potentially suitable participants may have declined participation, as they felt that the patients concerned were independent of mind. In other words some individuals did not view a caregiving relationship as present, despite the fact that they may have provided assistance with activities of daily living or instrumental activities of daily living. It may be that the choice of words used in identifying appropriate participants may need to be reviewed in future studies particularly in populations that are cognitively intact and only mildly dependent on informal care.

6.5.3.2. The dyad as an entity for health researchers.

While researchers have acknowledged that caregiving may be best investigated in terms of the family system in which the caregiver is embedded (Patterson & Garwick, 1994) few empirical studies have adopted this approach, therefore there is little empirical support for the systems perspective in investigating chronic illness. This may be a difficulty of data collection and analysis rather than a belief that the approach is conceptually flawed. A compromise may be study of the caregiving dyad as a system (Lyons, Zarit, Sayer, & Whitlatch, 2002). While most people have a range of diverse interdependent relationships, many care-receiving frail older adults in particular, may have one single dyadic relationship that dominates a large part of their lives, most typically a spouse or partner and often an adult daughter. Such relationships can be conceptualized as a coherent entity that strives to establish a homeostatic equilibrium for the dyad. A dyadic approach may be conceptually and analytically more manageable than using the wider family as the unit of analysis in examining chronic illness and health. The health of individuals that exist in this sort of relationship cannot be fully elucidated without consideration of both individuals in the dyad. Future studies investigating adaptation to chronic illness in the community should attempt to consider the health of the dyad, particularly given the prevalence of dyads among older adults with chronic illness. This may be patient/spouse or patient/caregiver. Older frail adults often remain in the community by virtue of the fact that they have supportive interpersonal

relationships that enable them to remain independent of formal health care. The reciprocal nature of these relationships may have bi-directional effects on the health of individuals. This dyadic approach would allow a manageable 'systems-analysis' of caregiver health.

6.5.3.3.Using multiple methods to measure constructs

Future studies should attempt to measure variables with as diverse a range of measurement instruments as is logistically possible. This may help circumvent methodological and analytical problems such as common method variance (Podsakoff, Mackenzie, Lee, & Podsakoff, 2003). In addition this has the potential to enhance a researchers confidence in the validity, reliability and sensitivity of the construct that they are attempting to measure. This may be particularly important for measures where measurement error may be a particular issue such as care-recipient functional limitations (Knapp & Hewison, 1999).

6.5.3.4.Longitudinal studies

There was no longitudinal support for the models in the present studies, however this may have been due to a number of factors particularly those surrounding the issue of statistical power. While there was statistically significant change over time in the predictor variables in Chapter 3, there was no statistically significant change in the dependent variables. Perhaps a greater period of time is required before the change in predictors effects change in the dependent. The same issue applies for the data in Chapter 4, as there was limited change in predictor and dependent variables over time. Our analysis in Chapter 5 was also limited by the fact that interventions of this kind usually result in much larger effect sizes than found in Chapter 5 (Piepoli, Davos, Francis, & Coats, 2004). In CHF caregiving studies it is also very difficult to ascertain precisely when the caregiving started, given the insidious nature of the clinical condition, which may often have a very gradual onset. This poses a methodological problem as an accurate measure of exposure to caregiving Demand is difficult to establish in the case of an individual caring for someone with CHF. Other clinical conditions with more acute or definite onset may be more conducive to establishing the onset of exposure to Demand e.g. first time stroke populations (Forsberg-Warleby, Moller,

& Blomstrand, 2001) or other types of traumatic brain injury (Marsh, Kersel, Havill, & Sleigh, 1998).

Finally heterogeneity of care-recipient recovery is also desirable in longitudinal tests of the job strain models in informal caregiving. Some clinical conditions are associated with greater variation in recovery to pre-illness state than others. The course of recovery in particular clinical conditions may be constant from diagnosis e.g. stroke; relapsing e.g. cancer; or progressive e.g. Congestive Heart Failure. For example considerable recovery is often observed in Stroke (Johnston et al., 1999) and some types of cancer whereas this is less common in Congestive Heart Failure (Stewart, Macintyre, Hole, Capewell, & McMurray, 2001).

6.5.3.5. Theory based caregiver interventions

The increasing body of work concerned with developing and evaluating interventions (Sorensen, Pinquart, & Duberstein, 2002) has made limited use of theoretical models of process (Pillemer, Sutor, & Wethington, 2003). Future studies should use theory to inform study design and analysis of caregiver interventions. We have argued for the use of theory throughout the thesis, however this may be particularly important in intervention work where optimisation of interventions is a key goal. Finding out that a particular intervention brings about an improvement in some important outcome is of limited use if the mechanism whereby this happens remains unknown. Study of process is important in identifying potential mechanisms.

In light of the Demand-Control Model the present data would suggest that future caregiver research should focus on caregiver Personal Control over caregiving as a key construct in understanding the health impact of informal caregiving and in developing strategies to improve caregiver health outcomes. Intervention work should attempt to increase Personal Control over caregiving behaviour. The data also suggest that there is some potential for further examination of the role of caregiver Reward in predicting health outcomes and its potential in developing interventions to improve health outcomes.

6.5.3.6. Studying caregiving by clinical condition?

While there may be a good argument for studying caregiving populations by clinical condition due to the unique difficulties associated with particular conditions, the wisdom of this approach may be questionable in understanding caregiving for the oldest group of older adults e.g. the chronically ill over 85 years of age. These individuals often have multiple co-morbidities and cannot be easily assigned to one particular clinical category. There may be argument for studying caregivers by categories of behavioural, cognitive or emotional deficits rather than medically defined categories. Medical categories are often abstract classifications and the experience of illness may be indistinguishable from the patient's and the caregiver's perspective whether one has a diagnosis of chronic obstructive pulmonary disease from congestive heart failure. Therefore in the oldest old population there may be some potential in studying individuals by some behavioural category e.g. individuals that use walking aids, rather than some clinical category.

6.5.3.7. A paradigm shift in caregiver health research?

The ubiquity of the type of caregiving studied in this thesis i.e. caregiving for non-dementing frail older adults means that caregiving cannot be thought of as some sort of anomalous or abnormal situation that requires therapeutic intervention at the level of the individual caregiver. In certain cases particularly in Alzheimer's dementia and related disorders or 'ADRD' caregiving populations, this approach may be the most appropriate (Gitlin et al., 2003; Gallagher-Thompson & Steffen, 1994), however a public health approach may be more appropriate for addressing the health issues of the majority of caregivers. The vast majority of the literature on caregiving has been on dementia populations and as some authors have argued the findings from these studies may not extrapolate to non-dementing populations (Ory, Hoffman, Yce, Tennstedt, & Schulz, 1999). The Demand-Control model and the Effort-Reward Imbalance can be clearly thought of as psychological or psychosocial models of stress, however the public health implications of these models are more obvious than stress and coping models, and they may have some unexploited potential with regard to studying informal

caregiving at a population level. This may be particularly appropriate for caregiving in the more common clinical conditions of older adulthood.

A public health or population approach to understanding psychological and behavioural factors in health and illness is in keeping with current thinking within the wider discipline of health psychology. This paradigm shift away from the more clinical individualistic roots of the discipline of health psychology is increasingly being stated and this approach is viewed as the way forward for the discipline.

6.5.3.8. Testing other predictions made by the job strain models

Demand-Control Model: There are a number of other predictions made by the job strain models that have not been tested in this thesis, but that may have some analogous predictions in the case of informal caregiving. The Demand-Control model makes a prediction about learning and motivation to work (Karasek & Theorell, 1990). The prediction states that in the presence of high Demand and high Control workers will be more likely to experience motivation, learn new behaviours and skills (Taris, Kompier, De Lange, Schaufeli, & Schreurs, 2003) and less likely to be absent (Schechter, Green, Olsen, Kruse, & Cargo, 1997). This may be analogous to a number of outcomes that have been investigated in the caregiver literature such as motivation to care (Rapaport & Orbell, 2000), decision to institutionalise the care recipient or relinquishing the role as caregiver (Aneshensel, Pearlin, & Schuler, 1993; Pruchno, Michaels, & Potashnik, 1990) and caregiver satisfaction (Orbell Hopkins & Gillies, 1993). This hypothesis may be worth testing in informal caregiving.

Effort-Reward Imbalance Model: There may also be further hypotheses that can be derived the Effort-Reward Imbalance Model that could have some relevance for informal caregiving. For example Siegrist (Siegrist, 1996) has also typified a specific pattern of coping known as 'overcommitment'. Individuals exhibiting this pattern of coping may inaccurately assess cost-gain relations and be at greater risk of high effort-low reward contingencies (Steptoe, Siegrist, Kirschbaum, & Marmot, 2004). Testing this 'personal component' as opposed to the situational component of the ERI model may be worth examining in informal caregivers.

6.5.3.9. What about expert caregivers?

Recently patient self-management in chronic illness have been implemented in the form of a public health initiative known as the 'Expert Patients Programme' advocated by the department of health in the UK (Department of Health, 2001). The Expert Patients Programme is a self-management course that aims to provide people the confidence, skills and knowledge to manage their health conditions better and be more in control of their lives. There is a considerable empirical evidence base demonstrating that interventions that aim to improve patient self-management programmes can produce significant health benefits (Lorig, Ritter, Laurent, & Fries, 2004; Lorig et al., 1999). There may be some potential for extending this approach to informal caregivers. Increasing caregiver confidence, skills and knowledge about managing the patients clinical condition may have the potential to improve outcomes for both caregivers and patients. Indeed there is some recent evidence in support of such an approach (Kalra et al., 2004).

An expert carer approach fits particularly well with the theoretical models used in the thesis as it is conceivable that these programmes may have the potential to decrease caregiver Demand, increase caregiver Control and possibly increase caregiver Reward over caregiving. In particular an expert carer approach fits well with Karasek's integrated model (Karasek & Theorell, 1990) that includes both the strain and active learning hypothesis that was not examined in this thesis. Essentially the integrated model predicts that active learning has the potential to increase Control or 'Mastery' which in turn has the potential to attenuate the effects of accumulated strain. There may be considerable scope for evaluating an expert carer programme within this theoretical framework.

6.6. Conclusion

Many unresolved issues remain in the study of the health effects of informal caregiving. However this thesis has gone some way in clarifying a several key research issues. The first issue addressed by this thesis has been the relative neglect of congestive heart failure (CHF) populations in informal caregiving research. The thesis reviewed and analysed an important and underdeveloped body of knowledge concerning informal caregiving and CHF. Several general and specific areas of research that require urgent attention

concerning informal caregiving and CHF have been outlined. It is clear that there is much scope for further research in this condition.

The more central issue addressed by the thesis concerned the use of theory in caregiver health research. As two recent rigorous meta-analysis have confirmed that caregiving may be hazardous to one's physical and psychological health (Vitaliano, Zhang, & Scanlan, 2003; Pinguart & Sorensen, 2003b), the next important question is 'how does caregiving influence the physical and psychological health of informal caregivers?' In order to answer this question theoretical development is necessary. The present thesis provided some support for the use of theory from other disciplines, where significant progress has been made in elucidating the stress-health relationship. Research examining the relationship between work and health in general has been postulated as a likely candidate. Research examining work and health has advanced greatly in terms of establishing theoretical formulations and plausible mechanisms, whereby work may influence health. The studies conducted in the present thesis provide some support for using two prominent models from the job strain literature and some encouragement for a trans-disciplinary approach to studying caregiving and the stress-health relationship.

Despite the fact most people providing care cope quite well and are not in need of intensive clinical intervention, informal caregivers are at risk of health inequalities, therefore the health of informal caregivers remains an important area for further research. Individualistic models of stress and coping that have dominated this literature may be better suited to informing policy concerning the treatment of individuals in disciplines such as clinical psychology. However models of stress that are more applicable to a public health or population approach such as those presented in this thesis may be better suited to informing policy concerning the many millions of individuals that are now providing ongoing care for chronically ill older adults.

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Appendix A

Stroke Caregiver Information Sheet and Consent Form.

PARTNER/CARER INFORMATION SHEET for the STROKE WORKBOOK STUDY

What is the study called?

A randomised controlled trial of a workbook-based intervention for stroke patients: Effects on disability and distress in patients and partners

Who is running the study?

Dr RS MacWalter, Consultant Physician in General Medicine and Honorary Senior Lecturer in Medicine, Department of Medicine, Ninewells Hospital Dundee **and Professor Marie Johnston**, Professor of Psychology, University of St Andrews, and **Dr Valerie Morrison**, a psychologist, are in charge and special personnel, under their supervision have been appointed to run the study.

Why is the research desirable?

At present it is almost impossible to predict just how much disability and distress, if any, will be present in the weeks and months after stroke. It is possible that certain ways of thinking about the condition and its treatment can lead to a better outcome. We have devised a workbook containing topics of interest about your stroke, its effects and what you can do about it. We hope to show that completing the workbook can aid recovery by setting out some simple exercises, giving advice about living a more healthy lifestyle, and reducing feelings of depression. If this is the case, such workbooks may become part of the standard treatment helping future patients and their family and friends recover from stroke more fully and more quickly.

Why are you a suitable person to participate in this study?

Your relative has recently had a stroke and we hope, as you do, that he or she will recover quickly. We would like to know the way you feel about his or her condition and the rehabilitation process and perhaps have you both complete a workbook over the next month. Only half of the participants will be given the workbook. As with most studies, the allocation of this workbook is done randomly (like tossing a coin), so you will not know until you enter the study whether you get a workbook or not. This will not affect the normal treatment of your relative or friend in any way.

Sometimes a stroke can effect a person's ability to communicate, that is to speak and understand speech or to read and write. Also a person's thinking processes may be affected leading to problems with memory, concentration, planning things and

possibly confusion. If your relative has such problems, he or she will not be able to take an active part in the study. We would still like you to take part on your own. We also need your permission to use information from your relative's medical records in the study.

What are the procedures?

Step 1 Involves the completion of some simple, short **questionnaires** by you and your relative or friend. Trained personnel will see you just before or soon after his or her discharge from Ninewells Hospital and guide you through the questions. They will answer any questions you may have.

Step 2 If you are allocated a **workbook**, you will receive a visit at home within the next week when you and your relative will receive your workbook and some advice about how to use it. The researcher will visit again in a week and keep in contact through weekly telephone calls for the next four weeks. Again, you may ask questions at any time.

Step 3 You will be **visited** at your home in *six weeks* and then again in *six months* time to repeat the questionnaires whether or not you have been using the workbook. If you do not have a telephone or if you do not want the researcher to call at your home, alternative arrangements can be made.

Normal examinations by your doctor will also take place during the study and information will be gathered from your medical records. Your relative's GP will be notified if you choose to participate in the study.

All the information collected from you during the course of this study will be treated in the strictest confidence; no one outside the research team will have access to it. The Tayside medical Research Ethics Committee monitor all medical research in Tayside. They occasionally need to see patient information, but again this is in the strictest confidence.

What effects will be experienced at the time of the study or later?

Apart from having to talk about how you feel about your relative's condition and its treatment there will be no effects.

Are there any risks or side-effects?

There are no known risks or side effects.

Are there any expenses?

You should incur no expenses through participation in the study. The researcher will visit your home, so you do not have to make extra trips to the hospital. If, however, you prefer to come to the hospital this can be arranged and your transportation costs reimbursed.

Where can I get more information?

If you have any questions now or during the study you can contact The Researcher (to be appointed), on 01334-463055, Professor M. Johnston or Dr R.S. MacWalter.

What happens if you don't want to take part or decide you have had enough?

Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw at any time without having to give a reason and without this affecting your future medical care.

CONSENT FORM

I have read the information sheet and am willing to take part. I understand that I take part voluntarily and I can withdraw at any time.

NAME: _____ DoB: _____ SEX _____

PH. _____ ADDRESS _____

SIGNATURE: _____

Name of Relative

Appendix B

Stroke Caregiver Study Measures.

B. i THE FUNCTIONAL LIMITATIONS PROFILE (FLP)

The following statements are about your relative's current health and how the stroke may have

influenced their everyday life. Listen to each statement, **think of your relative today** and tell me if it describes them or not. If you agree or disagree you should tell me. I will then ask "Is this due to their health"- Please answer yes or no. *(Read down the list of items within each category. As soon as the carer agrees with a statement and attributes it to their relative's health, tick the box and move to the next category of items.)*

1. Ambulation

- | | | |
|--|-------|----------------|
| 1. I do not walk at all. | | (126) |
| 2. I get about in a wheelchair. | | (121) |
| 3. I do not use stairs at all. | | (106) |
| 4. I only walk with help from somebody else. | | (98) |
| 5. I get about only by using a walking frame, crutches, stick, walls, or hold on to furniture. | | (96) |
| 6. I only go up and down stairs with assistance from somebody else. | | (87) |
| 7. I only use stairs with a physical aid; for example, a handrail, stick or crutches. | | (82) |
| 8. I walk by myself but with some difficulty; for example, I limp, wobble, stumble or I have a stiff leg | | (71) |
| 9. I do not walk up or down hills. | | (64) |
| 10. I go up and down stairs more slowly; for example, one step at a time or I often have to stop | | (62) |
| 11. I walk shorter distances or often stop for a rest. | | (54) |
| 12. I walk more slowly. | | (39) |
| 13. I do not walk as well as I did before my stroke | | (not in flp) |

2. CFB-body care and movement items (124) The following statements describe how you move about, bath, go to the toilet, dress yourself **today**. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health**.

- | | | |
|--|-------|-------|
| 13. I am in a restricted position all the time. | | (124) |
| 14. I do not have control of my bowels. | | (124) |
| 15. I do not have control of my bladder. | | (122) |
| 16. I stay lying down most of the time. | | (120) |
| 17. I use a bedpan with help. | | (107) |
| 18. I do not bathe myself at all, but am bathed by someone else. | | (100) |
| 19. I do not get in and out of bed or chairs without the help of a person or mechanical aid. | | (100) |
| 20. I only stand up with someone's help. | | (93) |
| 21. I do not keep my balance. | | (93) |

22. I do not bathe myself completely; for example I need help with bathing.....(85)
23. I make difficult movements with help; for example getting in or out of the bath or car. (82)
24. I hold on to something to move myself around in bed. (82)
25. I only get dressed with someone's help. (82)
26. I get in or out of bed or chairs by grasping something for support or by using a stick or a walking frame. (79)
27. I spend most of the time partly dressed or in pyjamas. (75)
28. I do not fasten my clothing; for example I require assistance with buttons, zips or shoelaces. (68)
29. I only stand for short periods of time. (67)
30. I move my hands or fingers with some difficulty or limitation. (66)
31. I kneel, stoop or bend down only by holding on to something. (61)
32. I have trouble putting on my shoes, socks or stockings. (54)
33. I change position frequently. (51)
34. I am very clumsy. (47)
35. I dress myself, but do so very slowly. (43)

3. CFM-Mobility (114) These next statements describe how you get about the house and outside. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

36. I stay in bed most of the time. (114)
37. I stay in one room. (101)
38. I stay in bed more. (91)
39. I stay at home most of the time. (79)
40. I only get about in one building. (76)
41. I only go out if there is a lavatory nearby. (64)
42. I do not get about in the dark or in places that are not lit unless I have someone to help. (57)
43. I do not use public transport now. (52)
44. I do not go into town. (47)
45. I only stay away from home for short periods. (46)

4. CFH-Household management (90) The following statements describe your daily work, around the home. When you answer, think of yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

46. I do not do any of the daily household chores that I would usually do..... (90)
47. I do not do any of the shopping that I would usually do. (84)
48. I do not do any of the cleaning that I would usually do. (78)

49. I have difficulty using my hands; for example, turning taps, using kitchen gadgets, sewing or doing repairs. (78)
50. I do not do any of the maintenance or repair work that I would usually do in my garden. (75)
51. I do not do any of the clothes washing that I would usually do. (75)
52. I have given up taking care of personal or household business affairs; for example, paying bills, banking or doing household accounts. (69)
53. I do not do heavy work around the house. (59)
54. I only do housework or work around the house for short periods of time or I rest often. (50)
55. I do less of the daily household chores than I would usually do. (37)

5. CFR-Recreation (91) The following statements describe the activities you usually do in your spare time, for relaxation, entertainment or just to pass the time. Again, think of yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

56. I am not doing any of my usual inactive pastimes; for example, I do not watch TV, play cards, or read. (91)
57. I am not doing any of my usual physical recreation or more active pastimes (81)
58. I am cutting down on some of my usual inactive pastimes; for example, I watch TV less, play cards less, or read less (50)
59. I am doing more inactive pastimes instead of my other usual activities..... (43)
60. I am cutting down on some of my usual physical recreation or more active pastimes. (34)
61. I spend shorter periods of time on my hobbies and recreation. (32)
62. I go out less often to enjoy myself. (27)
63. I take part in fewer community activities. (25)

6. CFS-Social (109) These statements describe your contact with family and friends today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

64. I refuse contact with my family; for example, I turn away from them..... (109)
65. I frequently get angry with my family; for example, I hit them, scream or throw things at them. (103)
66. I isolate myself as much as I can from the rest of my family. (100)
67. I stay alone much of the time. (91)
68. I do not go out at all to visit people. (91)
69. I am disagreeable with my family; for example, I act spitefully or stubbornly. (86)
70. I make many demands on other people; for example, I insist that they do things for me or tell them how to do things. (76)

71. I avoid having visitors. (73)
72. I do not look after my children or family as well as I usually do. (66)
73. My sexual activity is decreased. (64)
74. I am often irritable with those around me; for example, I snap at people or criticize easily. (64)
75. I pay less attention to the children. (59)
76. I show less interest in other people's problems; for example, I don't listen when they tell me about their problems; I don't offer to help. (50)
77. I show less affection. (44)
78. I often express concern over what might be happening to my health..... (44)
79. I talk less with other people. (44)
80. I do not joke with members of my family as much as I usually do. (38)
81. I am cutting down the length of visits with friends. (31)
82. I go out less often to visit people. (31)
83. I take part in fewer social activities than I used to; for example, I go to fewer parties or social events. (25)

7. CFE-Emotion (141) The next statements describe your feelings and behaviour. Again think of yourself today.

84. I have attempted suicide. (141)
85. I talk hopelessly about the future. (96)
86. I say how bad or useless I am; for example, that I am a burden on others. (89)
87. I am irritable and impatient with myself; for example, I run myself down, I swear at myself, I blame myself for things that happen. (79)
88. I often moan and groan because of pain or discomfort. (67)
89. I keep rubbing or holding areas of my body that hurt or are uncomfortable. (59)
90. I laugh or cry suddenly. (58)
91. I get sudden frights. (56)
92. I behave nervously or restlessly. (48)

8. CFAL-Alertness (115) These statements describe your general alertness today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

93. I sometimes get confused; for example, I do not know where I am, who is around, or what day it is. (115)
94. I have more minor accidents; I drop things, I trip and fall, or I bump into things. (90)

95. I forget a lot; for example, things that happened recently, where I put things, or to keep appointments. (85)
96. I have difficulty reasoning and solving problems; for example, making plans, making decisions, or learning new things. (78)
97. I am confused and start to do more than one thing at a time. (74)
98. I have difficulty doing things which involve thought and concentration. (71)
99. I do not keep my attention on any activity for long. (52)
100. I react slowly to things that are said or done. (52)
101. I make more mistakes than usual. (49)
102. I do not finish things I start. (45)

9. CFSL-Sleep (111) These statements describe your sleep and rest activities today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

103. I sleep or doze most of the time, day and night. (111)
104. I spend much of the day lying down to rest. (96)
105. I sleep less at night; for example, I wake up easily, I don't fall asleep for a long time, or I keep waking (86)
106. I sit around half asleep. (84)
107. I sleep or doze more during the day. (80)
108. I lie down to rest more often during the day. (72)
109. I sit for much of the day. (62)

10. CFEAT-Eating (143) The following statements describe your eating and drinking habits. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

110. I eat no food at all except by tubes or intravenous infusion. (143)
111. I do not feed myself at all but have to be fed. (121)
112. I eat no food at all, but I take liquids. (113)
113. I feed myself with help from someone else. (95)
114. I feed myself but only with specially prepared food or special utensils..... (76)
115. I eat special or different food; for example, I follow a soft food, bland, low salt, low fat, or low sugar diet. (52)
116. I just pick or nibble at my food. (39)
117. I eat much less than usual. (34)
118. I drink less fluids. (33)

11. CFC-Communication (127) I am going to read out some statements about how much you talk to other people and write. Please think about yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

119. I communicate mostly by nodding my head, pointing, or using sign language, or other gestures. (127)

120. My speech is understood only by a few people who know me well. (94)

121. I am understood with difficulty. (89)

122. I don't write except to sign my name. (84)

123. I speak with difficulty; I get stuck for words, I stutter, stammer, or slur my words. (76)

124. I carry on a conversation only when very close to other people or looking directly at them. (59)

125. I often lose control of my voice when I talk; for example, my voice gets louder or softer or changes unexpectedly. (59)

126. I have trouble writing or typing. (50)

127. I do not speak clearly when I am under stress. (47)

Scoring for FLP:

Sum of scores for each section divided by 11.

B. ii THE PERCEIVED CONTROL OVER CAREGIVING SCALE

If 1 is Extremely Difficult and 5 is Not at all difficult

1. How difficult are you finding it to help your relative make a full recovery
1 2 3 4 5
2. How difficult are you finding it to help your relative make a good recovery
1 2 3 4 5
3. How difficult are you finding it to help your relative do what is necessary to recover
1 2 3 4 5
4. How difficult are you finding it to influence your relative's recovery
1 2 3 4 5

If 1 is No Control at all and 5 is Complete Control

1. How much control do you have over your relative making a full recovery
1 2 3 4 5
2. How much control do you have over your relative making a good recovery
1 2 3 4 5
3. How much control do you have over whether you influence your relative's recovery
1 2 3 4 5
4. How much control do you have over helping your relative to recover
1 2 3 4 5

Scoring for the perceived control over caregiving scale:

Sum of 8 responses

B. iii THE HOSPITAL ANXIETY AND DEPRESSION SCALE

First I would just like to thank you for taking part in this project. Now, I am going to ask you a series of questions about how you are feeling, and about what you think about things connected to your relative's recovery. This is not a test - there are no right or wrong answers. All strokes are different, so carers will be faced with different problems which may change as their relative reaches different stages in their recovery - so what's right for some people, won't be right for others. The main thing to remember is to say what **you are** feeling, and what **you** think about things, not what you think you **should** feel or think - remember, your answers are completely confidential. Try not to take too long in giving your answers - because what first comes to your mind is more likely to be what you really think. We will take a break about halfway. If you miss something, just ask me to repeat it. If you get tired, or want a break for any reason, just say. Shall we start?

Would you now tell me which comes closest to how you have been feeling in the past 7 days.

1. I feel tense or 'wound-up':

1. Most of the time 3
 2. A lot of the time 2
 3. Time to time, occasionally 1
 4. Not at all 0

2. I still enjoy the things I used to enjoy:

1. Definitely as much 0
 2. Not quite so much 1
 3. Only a little 2
 4. Hardly at all 3

3. I get a sort of frightened feeling as if something awful is about to happen:

1. Very definitely and quite badly 3
 2. Yes, but not too badly 2
 3. A little, but it doesn't worry me 1
 4. Not at all 0

4. I can laugh and see the funny side of things:

1. As much as I always could 0
 2. Not quite so much now 1
 3. Definitely not so much now 2
 4. Not at all 3

5. Worrying thoughts go through my mind:

1. A great deal of the time 3
 2. A lot of the time 2
 3. From time to time but not too often 1
 4. Only occasionally 0

6. I feel cheerful:

1. Not at all 3
 2. Not often 2
 3. Sometimes 1
 4. Most of the time 0

7. I can sit at ease and feel relaxed:

1. Definitely 0
 2. Usually 1
 3. Not often 2
 4. Not at all 3

8. I feel as if I am slowed down:

1. Nearly all the time 3
 2. Very often 2
 3. Sometimes 1
 4. Not at all 0

9. I get a sort of frightened feeling like 'butterflies' in the stomach:

1. Not at all 0
 2. Occasionally 1
 3. Quite often 2
 4. Very often 3

10. I have lost interest in my appearance:

1. Definitely 3
 2. I don't take so much care as I should 2
 3. I may not take quite as much care 1
 4. I take just as much care as ever 0

11. I feel restless as if I have to be on the move:

1. Very much indeed 3
 2. Quite a lot 2
 3. Not very much 1
 4. Not at all 0

12. I look forward with enjoyment to things:

1. As much as I ever did 0
 2. Rather less than I used to 1
 3. Definitely less than I used to 2
 4. Hardly at all 3

13. I get sudden feelings of panic:

1. Very often indeed 3
 2. Quite often 2
 3. Not very often 1
 4. Not at all 0

14. I can enjoy a good book or radio or TV programme:

1. Often 0
 2. Sometimes 1
 3. Not often 2
 4. Very seldom 3

Scoring for HADS:

Total anxiety = Sum of items 1,3, 5, 7, 9, 11, 13.

Total depression= Sum of 2, 4, 6, 8, 10, 12, 14.

Appendix C

Caregiver Information Sheet and Consent Form. CHF study.

Carer's Information Sheet

Psychological factors in patients with congestive heart failure and their carers.

We would like to invite you to participate in a research project. We are interested in your personal views on care giving and how you cope with it, as we believe it to be of potential importance. However, before you decide whether or not you wish to participate, we need to be sure that you understand firstly why we are doing it, and secondly what it would involve if you agreed. We are therefore providing you with the following information. Read it carefully and be sure to ask any questions you have, and, if you want, discuss it with outsiders. We will do our best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision. If you decide to participate, please sign the consent form on the final page.

THE BACKGROUND TO THE STUDY

- *What is the research about?*

Heart failure is associated with varying amounts of disability and providing assistance to someone with heart failure is not the same experience in all cases. It can range from being extremely demanding to being almost no different from the assistance that a perfectly healthy person would require. This study attempts to understand how providing help for heart failure affects those people that usually provide the help.

- *Who is sponsoring it, and are they paying the researcher or his/her department to do the research?* The University of St Andrews is sponsoring this study as part of a postgraduate student's research
- *Why have I been chosen as a possible participant in the research?* You have been invited to take part since some one you

either live with or who you assist has been diagnosed with heart failure. We have asked them to take part in this research and we are asking you also. This is because your views about their condition might be important in treatment.

- ***How many other people have been asked to consider participating?*** The study is being conducted at Ninewells Hospital and has the support of your doctor there. It estimated that approximately a hundred patients and carers will be asked to participate.

WHAT DOES THE STUDY ENTAIL?

- ***Will I have to come to the clinic?*** No. The study will involve completing some questionnaires and answering some questions on 3 occasions. The questions will mainly be about care giving for your relative/friend. The first time we will interview you will be either in your home or while you accompany your friend/relative for their check-up. The second time will be 3 months later. This time we will probably contact you by telephone, but if that is inconvenient then we will visit you at home. The final time will be 3 months after the 2nd interview. Completing the interview on the first occasion may take up to an hour and a half. The follow-up interviews should be somewhat shorter..
- ***What will I be asked to do at each visit?*** We will collect the information that we require from you by questionnaire or interview since it is only your opinions about care giving that we are interested in. We will also ask you questions about your health and how you are feeling.
- ***How long will my participation in the study last?*** 6 months.
- ***Is there any chance that the proposed research will be of benefit to me or the person I care for?*** This study will not be of

direct benefit to you. We hope that it will be of benefit to caregivers like yourself in the future.

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED IN THE STUDY?

- *How will my confidentiality be protected i.e. who will have access to the records generated and what steps will be taken to ensure that they will only be seen by those authorised to see them?* The information we are gathering is not particularly personal or sensitive; nevertheless your confidentiality will be protected. All the information will be stored without your name being attached and only the research team will have access to it.
- *Will my GP be told that I am taking part in this study, and the results of my participation?* No, since you are not taking part as a patient. The GP will be informed that your relative is taking part.
- *Will I be informed of the results of the study?* This study will take a number of years to complete, if you wish to know the main results then let us know and we will send you a brief report.

WHAT ARE MY RIGHTS?

- *How can I obtain more information if I wish?* Ask the person that gave you this sheet if you wish more information.
- *Can I discuss the study with friends and relatives, or my GP before deciding whether to take part?* Yes.
- *Can I refuse to take part or change my mind later even if I agree to take part now?* Yes.
- *If I do refuse to take part or change my mind later, will my relative still get the treatment his/her doctor thinks is right?* Yes.

Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your future medical care or your relationship with medical staff looking after your relative.

CONSENT FORM

I have read the information sheet and am willing to take part. I understand that I take part voluntarily and I can withdraw at any time.

NAME: _____ DoB: _____ SEX _____

PH. _____

ADDRESS _____

SIGNATURE: _____

DATE: _____

If you require further information about this study contact:

**Mr. Gerry Molloy, School of Psychology, University of St. Andrews,
01334 46(1983)**

Mobile 079 70693682

Appendix D

Congestive Heart Failure Study Measures



University of St. Andrews

Psychological factors in patients with congestive heart failure and their carers.

Please return this questionnaire to Mr. G. Molloy, School of Psychology, St. Andrews, Fife
KY16 9JU.

Name of Caregiver				
Address				
postcode				
Phone				
Name of Patient				
Gender	Male		Female	
Your school leaving age				
Details of further education, if any?				
Your relationship to patient.	Spouse	Other relative	Neighbour	Specify
Do you live with patient?	Co-resident		Lives apart	
Caregiver date of birth				
Employment status	Paid employment		No paid employment	
Marital Status	Married	Single	Sep./Dev.	Wid./Widr.
For how long have you been providing care?			Approximately how many hours per week?	
Today's date				
Name of interviewer				
Place of interview				
Interview duration	Start		End	
Time (0, 3 or 6 months) T1, T2 or T3				

Impact of Informal Caring Scale (Orbell, Hopkins and Gillies, 1993). D.i Care Work Strain Scale (Items 1-13)

The following questions refer to the care that you provide for your friend/relative and how it affects you. Again I would ask you to say what **you are** feeling, and what **you think** about things, not what you think you **should** feel or think - remember, your answers are completely confidential. Try not to take too long in giving your answers - because what first comes to your mind is more likely to be what you really think

Statement	Strongly Agree	Agree	Slightly Agree	Neutral	Slightly Disagree	Disagree	Strongly disagree
1. Because of my caring I don't have as much energy as I used to have	7	6	5	4	3	2	1
2. Because of my caring I am not getting enough sleep	7	6	5	4	3	2	1
3. Because of my caring I am physically tired	7	6	5	4	3	2	1
4. Because of my caring I take part less in social activities	7	6	5	4	3	2	1
5. Because of my caring I don't have enough time for myself	7	6	5	4	3	2	1
6. Because of my caring my health has suffered	7	6	5	4	3	2	1
7. I feel emotionally drained because of my caring	7	6	5	4	3	2	1
8. Because of my caring I don't keep in touch with my friends the way I used to.	7	6	5	4	3	2	1
9. I have too much to do to do everything well.	7	6	5	4	3	2	1
10. I have trouble with my nerves because of my caring	7	6	5	4	3	2	1
11. I feel like I am being pulled in different directions because of my caring	7	6	5	4	3	2	1
12. I feel trapped because of my caring	7	6	5	4	3	2	7
13. Because of my caring I feel like I have lost control of my life.	7	6	5	4	3	2	1

Statement	Strongly Agree	Agree	Slightly Agree	Neutral	Slightly Disagree	Disagree	Strongly disagree
14. Caring for this person makes me feel good about myself	7	6	5	4	3	2	1
15. The responsibility of caring gives me an important sense of satisfaction	7	6	5	4	3	2	1
16. Caring makes me feel valued	7	6	5	4	3	2	1
17. Caring for this person is a real source of pleasure to me.	7	6	5	4	3	2	1
18. I find my caring activities fulfilling/rewarding	7	6	5	4	3	2	1
19. Caring for this person makes me happy	7	6	5	4	3	2	1
20. My relationship with the person I care for is strained.	7	6	5	4	3	2	1
21. The person I care for lets me know how much s/he appreciates what I do	1	2	3	4	5	6	7
22. The person I care for doesn't appreciate what I do as much as I would like	7	6	5	4	3	2	1
23. I feel irritable/grouchy when I am around the person I care for	7	6	5	4	3	2	1
24. I wish I had a better relationship with the person I care for	7	6	5	4	3	2	1
25. Caring has made me closer to the person I care for	1	2	3	4	5	6	7
26. I feel that the person I care for asks for more help than s/he needs	7	6	5	4	3	2	1
27. Because of my caring my social life has got better	7	6	5	4	3	2	1

Statement	Strongly Agree	Agree	Slightly Agree	Neutral	Slightly Disagree	Disagree	Strongly disagree
28. Because of my caring I have more opportunities to be with my loved ones.	7	6	5	4	3	2	1
29. My life is better organized because of my caring	7	6	5	4	3	2	1
30. Because of my caring I am more 'alive' than I used to be	7	6	5	4	3	2	1
31. My caring means that my relationships with other family members are closer and richer.	7	6	5	4	3	2	1

Scoring for Care Work Strain Scale:

Sum of items 1-13

D.ii Demand and Control/Discretion Scale (Orbell and Gillies, 1993)

Do you provide assistance with any of the listed tasks (1-18)? If so, tick box and ask for an effort rating on the 5 point scale. For **Task discretion** ask the carer the extent to which they feel relied upon to perform each task on a 5 point scale from **1 Not at all – 5 Always relied upon**. Use aid in appendix.

Task		Very easy requires very little effort			Very difficult, requires a great deal of effort.		Task Discretion 1 2 3 4 5
		1	2	3	4	5	
1. Grooming	<input type="checkbox"/>	1	2	3	4	5	1. _____
2. Feeding	<input type="checkbox"/>	1	2	3	4	5	2. _____
3. Bathing	<input type="checkbox"/>	1	2	3	4	5	3. _____
4. Continence	<input type="checkbox"/>	1	2	3	4	5	4. _____
5. Ability to use the toilet	<input type="checkbox"/>	1	2	3	4	5	5. _____
6. Transfer (from chair to bed)		1	2	3	4	5	6. _____
7. Walking	<input type="checkbox"/>	1	2	3	4	5	7. _____
8. Using the stairs	<input type="checkbox"/>	1	2	3	4	5	8. _____
9. Communicating	<input type="checkbox"/>	1	2	3	4	5	9. _____
10. Preparing a meal	<input type="checkbox"/>	1	2	3	4	5	10. _____
11. Doing light housework	<input type="checkbox"/>	1	2	3	4	5	11. _____
12. Using transport	<input type="checkbox"/>	1	2	3	4	5	12. _____
13. Managing money	<input type="checkbox"/>	1	2	3	4	5	13. _____
14. Shopping	<input type="checkbox"/>	1	2	3	4	5	14. _____
15. Doing Laundry	<input type="checkbox"/>	1	2	3	4	5	15. _____
16. Taking medications	<input type="checkbox"/>	1	2	3	4	5	16. _____
17. Using the telephone	<input type="checkbox"/>	1	2	3	4	5	17. _____
18. Dressing	<input type="checkbox"/>	1	2	3	4	5	18. _____

Aid used in appendix:

Please indicate the extent to which you are relied upon to perform each task.

Not at all 1	Rarely 2	Sometimes 3	Often 4	Always 5
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Scoring for Control Scale. (Orbell and Gillies, 1993)

Task discretion ratings divided by number of tasks helped with. No assistance provided with any tasks = 0.

D.iii Reward Scale

For each of the following statements, please indicate first whether you agree or disagree with it. If there is an arrow behind your answer, please indicate how much you are generally distressed by this situation.

1. I receive the respect that I deserve from my friends/neighbours for caregiving

- Agree (5)
- Disagree (4) I am not at all distressed
- (3) I am somewhat distressed
- (2) I am distressed
- (1) I am very distressed

2. I receive the respect that I deserve from my family for caregiving

- Agree (5)
- Disagree (4) I am not at all distressed
- (3) I am somewhat distressed
- (2) I am distressed
- (1) I am very distressed

3. I receive the respect that I deserve from the person that I am caring for.

- Agree (5)
- Disagree (4) I am not at all distressed
- (3) I am somewhat distressed
- (2) I am distressed
- (1) I am very distressed

4. I experience adequate support from others with caregiving.

- Agree (5)
- Disagree (4) I am not at all distressed
- (3) I am somewhat distressed
- (2) I am distressed
- (1) I am very distressed

5. I receive the respect that I deserve from society for caregiving

- Agree (5)
- Disagree (4) I am not at all distressed
- (3) I am somewhat distressed
- (2) I am distressed
- (1) I am very distressed

6. Considering all my efforts in caregiving for this person, I receive the appreciation that I deserve.

- Agree (5)
- Disagree (4) I am not at all distressed
- (3) I am somewhat distressed
- (2) I am distressed
- (1) I am very distressed

7. Considering all my efforts in caregiving for this person, I receive adequate compensation for caregiving.

- Agree (5)
- Disagree (4) I am not at all distressed
- (3) I am somewhat distressed
- (2) I am distressed
- (1) I am very distressed

Scoring for Reward Scale:

Sum of 7 items.

Appendix E

Mediation Analysis Chapter 5

In the intervention analysis in Chapter 5 the intervention did not have a significant effect on any of the measures of caregiver Demand, however in an analysis of the entire sample of CHF patients (N=82) the effect of the intervention on one of the measures of Demand i.e. patient activity as measured by accelerometry was reliable, $p < 0.05$. As the Demand-Control model and some of our previous analysis supports a moderately consistent relationship between care-recipient functional limitation and Care Work Strain, we hypothesised that the most responsive measures of functional limitation in the exercise intervention i.e. accelerometry, may mediate the effect of the intervention on Care Work Strain. This measure of caregiver Demand was not used in the Chapter 4 test of the Demand-Control Model as this measure had the least well-established reliability, validity and sensitivity to change. The empirical relationship between accelerometer data and care work strain was admittedly weak as demonstrated in table 5.8. There were no significant relationships between accelerometer data and Care Work Strain at any time point therefore the mediation analysis presented here was theoretically driven rather than data driven and is for illustrative purposes.

Are changes in caregiver strain mediated by changes in caregiver Demand?

Testing for mediation: Baron & Kenny (1986) method

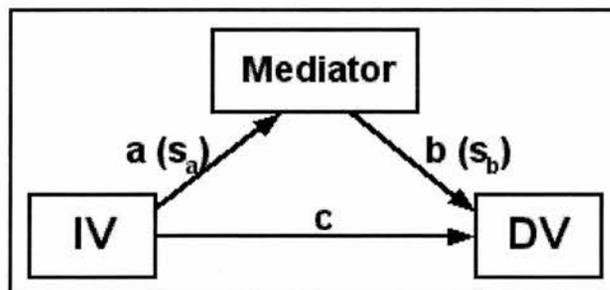


Figure x Testing for mediation using the Sobel test.

Where a, b and c are path coefficients. Variables in parentheses are standard errors of those path coefficients.

Description of mediation calculation

a = raw regression coefficient for the association between the IV and the mediator.

S_a = standard error of a

b = raw regression coefficient for the association between the mediator and the DV (when the IV is also a predictor of the DV).

S_b = standard error of b

Test for significant mediation effect : $z = \frac{a \cdot b}{\sqrt{S_{ab}}}$

where: S_a = standard error of a

S_b = standard error of b

$S_{ab} = (b^2 \cdot S_a^2 + a^2 \cdot S_b^2)$

There is a significant mediation effect if $z > 1.96$

As the intervention had a significant effect on Care Work Strain and a marginally significant effect on Demand (accelerometer) and we established relationships between functional limitations and caregiver emotional distress in chapter 3, we examined whether change in Demand mediated the effect of the randomisation on Care Work Strain using the above method. There was complete Demand (patient accelerometer) and Care Work Strain Measures for $N=38$ at Time 3. The dependent variable for equation 1 was residualised accelerometry (Time 1 predicting Time 3) and the dependent variable for equation 2 and 3 was residualised Care Work Strain (Time 1 predicting Time 3).

Testing whether the change in Demand (accelerometer Time 1- Time 3) mediated the relationship between the exercise intervention and change in Care Work Strain Time 3 (Care Work Strain Time 1-Time 3?).

Equation 1 Dependent variable: Demand (accelerometer Time 1- Time 3 residual).

Variable Entered	R^2	Adj. R^2	B	SE	$Beta$	df	F	p
Intervention	.06	.03	.51	.35	.23	1,36	2.09	.16

Equation 2 Care Work Strain (Time 1-Time 3 residual)

Variable Entered	R^2	Adj. R^2	B	SE	$Beta$	df	F	p
Intervention	.13	.10	.70	.30	.36	1,36	5.24	.03

Equation 3 Care Work Strain (Time 1-Time 3 residual)

Variable Entered	R^2	Adj. R^2	B	SE	$Beta$	df	F	p
Intervention			.71					
Demand	.13	.08	-.03	.15	-.03	2,35	2.57	.09

The 3 equations above show that the conditions are tentatively met for doing a mediation analysis to test whether change in caregiver Demand mediated the effect of change in Care Work Strain.

$$a = 0.51 \text{ (Equation 1)}$$

$$b = -0.03 \text{ (Equation 3)}$$

$$c^{\wedge} = 0.71 \text{ (Equation 3: Direct Effect)}$$

$$c = 0.70 \text{ (Equation 2: Total Effect)}$$

non-significant mediation effect.

$$a.b = c - c^{\wedge} = -0.01 \cong 0 \text{ (Mediated Effect)}$$

$$z = \frac{a.b}{\sqrt{S_{ab}}} = -0.20, p = 0.84$$

Caregiver Demand (as measured by accelerometry) did not mediate the effect of the exercise intervention on Care Work Strain as $z < 1.96$.

Note on the above mediation analysis

Strictly speaking the conditions for conducting a mediation analysis were not met in the above analysis. As can be seen in the figure E the relationship between the hypothesised mediator and Care Work Strain was weaker than is conventionally recommending for doing this analysis.

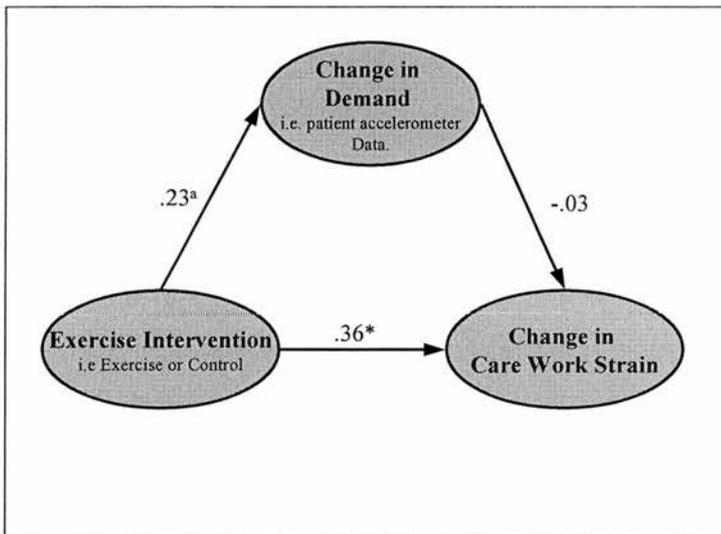


Figure E. Change in Demand as a mediator of the effect of an exercise intervention on Care Work Strain. All path coefficients are standardised.

N=38. * $P < 0.05$. ^a $P = 0.16$.

Appendix F

Ethics approval CHF study

Our Ref: 260/01

Tayside Committee on Medical Research Ethics

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NFB/FB

30 January 2002

Dear Professor Johnston

Ref: 260/01 Psychological factors in patients with congestive heart failure and their carers

Thank you for your letter of 11 January 2002 and I am sorry I have not been able to respond sooner, but I have been on holiday.

I know from Gerry Molloy that you are anxious to start and I am prepared to give final approval on behalf of the Ethics Committee, but nevertheless, there are still a couple of points that require to be clarified in the Patient Information Sheet. Under the heading 'What does the study entail?' the sentence that you have added in does not quite read correctly. Either the word 'how' is superfluous, or the last phrase is missing something. Although you did say that the word 'measures' lacked clarity, a comment with which I would agree, and that it had been omitted from the revised Patient Information Sheet, it is in fact still in this particular paragraph. Might I suggest, therefore, that in the appropriate sentence the phrase 'we will take measures' is simply omitted, and that two sentences further on rather than saying 'All the measures' this should read 'Everything will be carried out ...'

Perhaps you would be good enough to let me have another copy of the PIS taking these points into consideration. I have also received the Behaviour Problems Scale which was sent under cover of Gerry Molloy's letter of 8 January 2002.

Yours sincerely

Secretary