THE WELLBEING OF CARERS OF PEOPLE WITH SEVERE AND ENDURING EATING DISORDERS (SEED).

Stephen James Linacre

Submitted in accordance with the requirements for the degree of

Doctor of Clinical Psychology (D. Clin. Psychol.)

The University of Leeds

Academic Unit of Psychiatry and Behavioural Sciences

School of Medicine

September 2011

The candidate confirms that the work submitted is his own and that appropriate credit has been given where reference has been made to the work of others

ACKNOWLEDGEMENTS

I would like to thank Professor Andrew Hill for his patience, calming attitude and optimism that I could do this. This would have not been possible without his support. I would like to thank all the members of carer support groups who have participated in this research and thank them for being welcoming and encouraging when I visited them and informing me that this was a worthwhile project. I would like to thank Dr Gemma Traviss for her input and support around the statistical analyses. I would also like to thank Dr Suzanne Heywood-Everett for assisting in the development of this research and offering support from a clinical perspective.

I feel that it is also extremely important to thank my friends and parents for their encouragement to continue when aspects of the research have been difficult. Their patience to listen to my problems even when they did not know what they meant was invaluable. I would like to thank B-eat (the national eating disorders charity) for their support, but especially Lawrence Brown and Louise Dunne for their ongoing contact and providing opportunities to reach participants. I also must thank the Max Hamilton Fund for providing me with extra funding for me to complete this research.

There will be many people I will have missed off this thank you list, but my sincere appreciation goes to everyone that has provided help and support no matter how small. I would however, personally like to thank the DClinPsychol administration team (Debby, Jen and Lydia) for their support and belief that I would get to the end successfully.

ABSTRACT

Introduction: Research on carers of people with eating disorders (ED) is limited and on carers of people with severe and enduring eating disorders (SEED) almost nonexistent. Nearly 40% of carers of people with ED experience clinical level mental health difficulties. The current aims investigated wellbeing in carers of people with ED and specifically, carers of people with SEED; investigated gender differences; and compared data with wellbeing studies investigating carers of people with other long-term conditions. The Stress Process Model (SPM) (Pearlin, Mullan, Semple, & Skaff, 1990) was used to better understand predictors of wellbeing.

Method: Carers (28 male, 76 female) were recruited from ED carer support groups. Carers were stratified using duration (since diagnosis) of their recipient's ED (0-2 years, 2-6 years, over 6 years). The "over 6 years" category was classified as SEED. Comparison data were drawn from carers of people with dementia, brain injury, ED and psychosis. Standardised questionnaires measured wellbeing (SF-36), experiences of caregiving (ECI), perceived caregiver competence (MoCC), sense of personal mastery (MoPM) and expressive support (MoES).

Results: Carers of people with SEED were not significantly different on reported wellbeing to the whole sample of carers of people with ED. However, carers of people with ED reported significantly less wellbeing than community norms, carers of people with brain injury and dementia. Perceived dependency, carer gender and sense of personal mastery accounted for 29% of the variance in mental wellbeing scores. Differences in reported positive experiences of caregiving were identified.

Discussion: The mental wellbeing of carers of people with SEED and ED appears poorer than carers of other conditions. Further research on carers of people with SEED is needed. The SPM is a helpful framework to use. Clinical implications include ensuring that perception of dependency and the positive experiences of caregiving are addressed in workshops and support groups.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS

SEED	Severe and Enduring Eating Disorders
ED	Eating Disorders
ECI	Experience of Caregiving Inventory
SF-36	Short Form Health Survey 36
AN	Anorexia Nervosa
BN	Bulimia Nervosa
SPM	Stress Process Model
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders version 4
ICD-10	International Statistical Classification of Diseases and Related Health Problems
OCD	Obsessive Compulsive Disorder

INTRODUCTION

Why Carers of People with Eating Disorders?

Eating disorders (ED) are serious psychological and physical health conditions (Klump, Bulik, Kaye, Treasure, & Tyson, 2009). They impact on the individual patient and the carers around them. Research on carers of people with ED has been somewhat neglected (Winn et al., 2007). In particular, research on carers of people with severe and enduring eating disorders (SEED) is almost nonexistent (Robinson, 2009). Carers' wellbeing is important to help a patient recover and feel safe. The guidelines for ED (NICE, 2004) stipulates that "community based services are preferred to inpatient treatment where this can be managed". Furthermore, the National Service Framework for mental health (DoH, 2000) states that the needs of carers should be taken into account. This continues to be highlighted in the recent publication "No Health without Mental Health" (DoH, 2011). It states that services should "put them, and their families and carers, at the centre of their care" (p16). Mental health difficulties such as ED can have a significant impact on an individual's psychological, social and physical wellbeing thereby creating obstacles to independent living and they place demands that require increasing support from others.

This thesis's primary aim is to investigate the psychological wellbeing of carers of people with SEED. This will include comparison of the present study outcomes with existing data on carer wellbeing from studies investigating carers of people living with other long-term health conditions. It is expected that carers of people with SEED will have significantly less wellbeing when compared to carers of other patient groups. The research will use the Stress Process Model

(SPM) (Pearlin, Mullan, Semple, & Skaff, 1990) to better understand determinants and predictors of carer wellbeing. Variables that represent the domains of the SPM (e.g. context of care, primary stressors, secondary stressors, resources) will be analysed to identify which variables have significant effects on negative carer wellbeing. Previous research on caregivers has suggested that all "resources" identified in the SPM might be associated with caregiver wellbeing in a positive way. The current research will be specifically interested in carers' sense of personal mastery and self rated caregiver competence as these could have implications for services. The research thus far on carers of people with ED has predominantly been atheoretical rather than model driven (Dimitropoulos, Carter, Schachter, & Woodside, 2008). This research will aim to contribute to the understanding of the carer role in ED and SEED populations and identify the impact on carer wellbeing. It is hoped that the use of the SPM will identify factors that consequently could highlight potential interventions that may assist carers.

What is SEED?

SEED is a contemporary term used in clinical settings to identify people with ED who experience the condition in a severe and enduring form. According to Steinhausen (2002), 20% of people presenting with anorexia nervosa (AN) can go on to develop this into a chronic debilitating form. Arkell and Robinson (2008) reported that the research literature has not been able to develop a way of separating a chronic form of ED from a more acute form. It is still acknowledged that SEED is yet to be fully defined (Long, Fitzgerald, & Hollin, 2011). Nevertheless, Arkell and Robinson (2008) used the criteria for SEED as over ten years since diagnosis and that clients met the ICD-10 diagnostic criteria continuously apart from temporary weight restoration due to hospital admissions. Uher et al. (2003) reported that 80-90% of patients recover from an ED after a median duration of 6 years. Therefore it could be argued that a classification of SEED could be anything which exceeds this (Tierney & Fox, 2009).

Fichter, Quadflieg and Hedlund (2006) conducted a longitudinal approach to studying patients with chronic ED. Nearly 30% of their large sample met DSM-IV diagnostic categories for ED 12 years after initial contact. Another long term follow up study by Wentz, Gillberg, Anckarsater, Gillberg and Rastam (2009) indicated that 12% of their sample continued to have a diagnosable ED after 18 years. Furthermore, even if a clear ED diagnosis could not be met, 39% of their sample continued to have some difficulties with food or weight and met another psychiatric diagnosis (e.g. OCD, depression) 18 years after the onset of AN. These studies emphasised that ED can be severe and enduring in a significant proportion of people. Arkell and Robinson (2008) suggested that people with SEED may need more rehabilitative treatment approaches. This raises the question about the experiences and wellbeing of caregivers of people with SEED.

Tierney and Fox (2009) conducted a Delphi study to explore practitioners’ views of chronic AN. They found that practitioners did not agree on the duration of illness or the number of treatment attempts, which would define chronicity. In light of this, in the current research, participants (who are carers) will be stratified using the duration of their care recipient’s illness.

Grange, Lock, Loeb and Nicholls (2010) have highlighted that there is still limited research in ED on how best to understand caregiver distress, especially in patients who remain seriously ill. The current research will aim to clarify whether carers of people with SEED have more caregiver burden (perceived negative experiences), less mental wellbeing and a reduced sense of personal mastery.

Severe and Enduring in Other Disorders?

According to Childs and Griffiths (2003,202) up to 15,000 people in England experience severe and enduring mental health problems. However, across the UK there seems to be little agreement regarding definition (Slade, Powell, & Strathdee, 1997). Ruggeri, Leese, Thornicroft, Bisoffi and Tansella, (2000) defined severe and enduring mental illness (SEMI) if clients met two criteria. The duration of service contact must exceed two years and a score below 50 on the Global Assessment of Functioning Scale (Spitzer, Gibbon, Williams, & Endicott, 1996) must be obtained. Some researchers have stated that SEMI must include psychosis whereas others are less specific.

Dementia is a degenerative and progressive condition. There are several subtypes of dementia but symptoms do get worse and ultimately result in death. Xie, Brayne and Matthews (2008) reported that life expectancy following diagnosis ranges from three to nine years. It therefore seems appropriate for it to be classified as severe and enduring.

Another condition that could be termed “severe and enduring” is that of acquired brain injury (ABI). Reekum, Bolago, Finlayson, Garner and Links

(1996) have shown that there is a high prevalence of severe mental health conditions following an ABI. Yates (2003) reported that a great sense of loss can impede the adjustment process following an ABI which can reduce the person's quality of life. The need to be dependent on other people for help with daily activities can be a likely outcome, and physical limitations may also be a factor. These issues can be similar to people with SEED.

When existing data from the literature was selected to compare with the current research results, the above conditions were considered.

THE NATURE OF CAREGIVING

Caring for someone with a chronic health condition is a time consuming, energy draining and emotional activity. Unpaid carers, who tend to be family members, have many demands placed on them. Jones (2009, S22) reported that carers of people with early psychosis continue to "feel marginalised and invisible to services". Health services have only recently started to acknowledge the impact that chronic mental health conditions have on informal carers, despite the National Service Framework for Mental Health highlighting it as a need over 10 years ago (Thornicroft, 2000).

Who are the Carers?

It is important that caregiving is defined. Schulz et al. (1997) have suggested that the caregiver literature has used varying definitions. Wives who care for a spouse suffering from Alzheimer's disease may assist with activities (e.g. cook meals, clean the home) that may have been part of their role before the onset of Alzheimer’s disease. Likewise, parents who care for a child with type 1 diabetes by educating them about food and healthy eating may also have done this as part of their role as a parent. Schulz and Quittner (1998, 107) therefore suggested that a carer should be defined as someone who provides “extraordinary care and exceeds the bounds of what is normative or usual”. A more operationalised definition has been offered by Perlick, Hohenstein, Clarkin, Kaczynski and Rosenheck (2005) who suggested that a caregiver can be anyone who fulfils at least three of the following: (1) a parent, partner or other relative; (2) maintains frequent contact with the patient; (3) provides significant financial support; (4) has most frequently been collateral in the patient’s treatment and is aware of the severity of the condition; (5) is a person known to staff from the service who can be contacted in an emergency regarding the patient’s care.

Informal caregivers are usually family members (Zarit & Edwards, 2008). Research on female caregivers has been conducted widely; however male primary caregivers have been less often investigated. Chambers, Ryan and Connor (2001) have suggested that this may be because more females than males adopt a caring role. Research has suggested that females make up to 80% of the total caregiver population (Yin, Zhou, & Bashford, 2002). Other research however; has suggested that this may be changing as societal roles change, perhaps due to evidence that gender roles have become more flexible over time (Gerson, 2002). According to Juratovac (2009), male caregivers may represent up to 40% of the caregiving population. This discrepancy between the two studies may be due to the date when these findings were obtained. Juratovac

(2009) suggested that males are increasingly accepting of the roles involved with caregiving.

The above research evidence has been drawn mainly from studies on the care of older adults, identifying carers as spouse or adult children. Goodman, Zarit and Steiner (1997) suggested that reciprocity has an influence on caregiving, whereby care is provided to pay back the care received earlier in life. Societal norms and obligations may exert a factor on caregiver stress. In conditions such as ED and schizophrenia, the primary caregiver is more likely to be a parent or spouse (Foldemo, Gullberg, Ek, & Bogren, 2005; Nielsen & Bara´-Carril, 2005). The care recipient may be an adult; yet societal norms such as "you must care for your children" or "marriage vows" may add to caregiver stress. Societal norms develop over time and are specific to a community group as what is deemed acceptable to be a member of that community. Such statements above, could increase feelings of guilt in individual carers and be expected by others that they must provide effective caregiving.

The average duration of an episode of AN is 6 years (Herzog, Deter, Fiehn, & Petzold, 1997) and the typical onset of AN is during adolescence. In AN, the primary caregiver is likely to be the mother and as time progresses, "developmental inappropriateness" can occur as mothers care for dependent adult children (Treasure et al., 2001). The relationship appears to be a factor on how carers perceive burden and the associated distress (Kyriacou, Treasure, & Schmidt, 2008a).

Kin relationship

In the general carers literature, the kin relationship and quality of the relationship between the caregiver and the care recipient can make a difference in how the caregiver perceives the caregiving duties (Yee & Schulz, 2000). For example, in the older adult literature, husbands caring for their wives often reported less emotional distress than vice versa (Bookwala & Schulz, 2000). Spouses and parents tend to be the main caregivers in people with ED. Although it is generally assumed that men are less emotional than women, Barrett, Robin, Pietromonaco and Eyssell (1998) have suggested that this view should not necessarily be held. It may be the case that men manage their emotional experience in regards to caregiving in a different way. Gender differences in wellbeing of carers are discussed later.

An epidemiological study using the 2001 census found that there were 5.9 million people in the UK providing informal care (Doran, Drever, & Whitehead, 2003). Only 56% of these people were in good health compared to 70% of people not providing care.

Carer Wellbeing

Research on carer wellbeing has been extensive over the last twenty years, the majority of studies indicating negative consequences of caregiving on wellbeing (Whitlatch, Feinberg, & Sebesta, 1997). A few studies however; have reported little or no effect on carer wellbeing (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Vitaliano, Zhang, & Scanlan, 2003). Robison et al (2009) explained their results by suggesting that people in better health may take on the caregiving role more readily. Their sample did not capture those carers who may have stopped caregiving due to psychological or physical distress. Furthermore, as their sample self identified themselves as “carers”, they suggested that in future research, a clear and restrictive definition of “carer” is required.

Wellbeing is a multidimensional concept and it incorporates physical, social and psychological aspects (Sartorius, Okasha, & Maj, 2005). The effects of caregiving have been linked to poorer physical health (Vitaliano et al., 2005). In carers of people with dementia “immunological competence” is decreased when compared to matched controls (Kiecolt-Glaser et al., 1987). Moreover, carers who have pre-existing health conditions (e.g. hypertension) are likely to have exacerbated symptoms when compared to non-carers (Schulz & Williamson, 1997). Caregiving has also been linked to poorer social wellbeing. O'Reilly, Finnan, Allwright, Smith and Ben-Shlomo (1996) found that the carers’ level of social contact decreased as the need to care for their spouse increased. Wellbeing may also have financial implications. Carers are often required to stop employment or reduce their working hours (Sadik & Wilcock, 2003).

According to Hirst (2005), there is an existing wealth of studies which identify that providing unpaid care to the elderly increases the rate of psychological distress in comparison to population norms. The psychological distress of younger caregivers of people with chronic health conditions has also been evidenced (Bolden & Wicks, 2009). This study found over 50% of carers of patients with chronic liver disease had clinical levels of depression. The authors identified that the main predictors of depression in carers were subjective burden, lack of caregiver rewards, ethnicity, employment and decreased income. Some of these factors are more modifiable than others. For example, ethnicity is a fixed characteristic, yet subjective burden and caregiver rewards can be improved through interventions designed to help caregivers cope (Cuijpers, 1999).

Multiple perspectives on carers' wellbeing have been investigated in order to increase understanding of the caregiving situation. Robinson and Austin (1998) investigated the match between the views of primary caregivers and the views of supportive others' perceptions of the primary caregivers' health. They compared self rated views on health of 75 wives who cared for their "mentally impaired" husband with the views of 75 supportive others. The husbands who were "mentally impaired" were mainly suffering from Alzheimer's disease, though some experienced other forms of dementia. The authors found that the supportive others and the primary caregivers' ratings of the primary caregivers health were similar. A further study by Son et al. (2007) conducted in the USA used three indicators of health (self-reported health; negative health behaviours; usage of health services). Increased use of health services and negative changes in health behaviours have been observed in carers experiencing high levels of burden (Vitaliano et al., 2003). Son et al. (2007) found that caregivers of people with greater numbers of behaviour problems rated their health more poorly, took poorer care of themselves and spent more money on their health care.

One methodological factor pointed out by Schulz et al. (1997) is that caregivers in a majority of studies are recruited through advertisements or service agencies. They suggested that these recruitment strategies yield selection biasing towards those who are more likely to be distressed. The current research will aim to recruit from such agencies i.e. carer groups. It will therefore be important to remember that such samples may not be representative of carers as a whole.

Despite the above limitations, self report measures of wellbeing have been reported to be valid (Oswald & Wu, 2010). These authors demonstrated that subjective reports of wellbeing closely reflect objective measures of wellbeing. The few studies that look at carers' wellbeing of people with ED have tended to use this format (Kyriacou et al., 2008a). One such study suggested that a portion of carers of people with ED experience their own mental health difficulties (Whitney, Haigh, Weinman, & Treasure, 2007). This study involved the distribution of questionnaires to 173 primary carers (parents or spouse) on a volunteer database. They were defined as carers only if the care recipient had a diagnosed ED. Secondary caregivers (e.g. siblings) were excluded and only one carer was used when more than one carer was within the same family. This left a participant total of 115. It was found that almost 40% of their sample reported significant psychological distress. The main factors predictive of their distress were the perceived dependency of the patient, the stigma associated with ED and the perceived level of burden. The duration of the ED was associated with more negative appraisals of caregiving. Some of these carers believed they had more of the responsibility of care and control of the ED than their care recipient. This study indicated that caring for someone with an ED can have negative health implications on the caregiver.

Ravi, Forsberg, Fitzpatrick and Lock (2009) investigated whether a relationship exists between parental self reported psychopathology and symptom severity in adolescents with AN. Parental scores on the SCL-90R clearly showed that the parents of adolescents with AN were significantly more psychologically distressed than a community sample of parents. However, the research did not find a direct association between severity and duration of AN with parental psychopathology, but they did find that parents experienced more hostility as the severity and duration of AN increased. Steinglass (1998) has suggested that having a child with a serious mental health condition over an extended period of time is likely to increase psychopathology in parents themselves. Further studies are required to establish this finding in ED and more specifically in carers of people with SEED.

Measuring Wellbeing

The psychological wellbeing of carers has been the primary measure of wellbeing. However; some researchers have measured psychological wellbeing only as the number of reported depressive or anxiety symptoms (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Standardised measures used for research or clinical populations e.g. CES-D (Radloff, 1977), BDI (Beck, Steer, & Brown, 1996) or SCL-90R (Derogatis, 1983) have been popular. Other studies have used versions of the General Health Questionnaire (GHQ) (Goldberg & Williams, 1988) to measure psychological distress. It has been pointed out that most of these measures only grasp the “narrowest sense” of a carer’s mental health (Harvey et al., 2008). Although the SCL-90R does assess various symptoms of psychopathology, it is very clinical in nature. Harvey et al. recommended that studies investigate wellbeing more widely, with the use of measures that assess multiple dimensions. Factors such as physical and social functioning need to be considered when measuring carers' psychological wellbeing. They proposed that an instrument like the Short Form Health Survey 36 (SF36) (Ware, Snow, Kosinski, & Gandek, 1993) could be used to tap into the construct termed "quality of life". Research data on carers' wellbeing using the SF-36 is available which has provided a comparison for the SF-36 data collected in the current study. Furthermore, community norms have been available.

Carer studies using the SF-36

Argimon, Limon, Vila and Cabezas (2004) investigated the wellbeing of carers of people with dementia and compared this with an age and gender matched community sample. The results showed that female carers had a reduced quality of life and their scores were significantly different in six of the eight subscales when compared to their community sample. In contrast, the samples of male carers were not significantly different to the community sample in seven of the eight subscales. The exception was the "Physical Functioning" subscale where male carers reported better physical functioning than the matched community sample. The authors explained these findings by arguing that caring for someone requires an adequate level of physical functioning. As with most research investigating carers, only a small sample of male carers was obtained, limiting the robustness of these findings. Furthermore, as more females take on a caring role, it may be that women are more willing to disclose negative feelings and health difficulties (Kroenke & Spitzer, 1998).

McPherson, Pentland and McNaughton (2000) investigated the wellbeing of carers of people with brain injury and compared this to community norms and people with a longstanding illness. Carers gave lower scores (less wellbeing) than community norms in four of the subscales ("Physical Role", "Social Functioning", "Emotional Role" and "Mental Health") and gave lower scores than people with a long standing illness in three of the eight subscales ("Physical Role", "Emotional Role" and "Mental Health"). This study investigated carers following 15-18 months after their care recipient was discharged from inpatient rehabilitation, suggesting that the impact on carer wellbeing can be longer standing than an initial adjustment. McPherson et al (2000) also found differences in wellbeing between carers dependent on the relationship they had with the care recipient. Spouse carers tended to report less wellbeing than did parent carers, especially on the "Emotional Role" subscale. This was explained by the authors in that there is a greater role shift for spouses than parents who have typically taken the caring role during the whole of the care recipients' life time.

De La Rie, Van furth, De Koning, Noordenbos and Donker (2005) is the only study investigating carers of people with ED that has used the SF-36 to measure carer wellbeing. They found that carers of people with ED had scores that were significantly different in six of the subscales, when compared to community norms. This study was conducted in the Netherlands and Dutch norms were used. Compared to these norms, carers of people with ED scored significantly lower (poorer perceived wellbeing) on the "Vitality", "Social Functioning", "Emotional Role" and "Mental Health" subscales. This study also included a qualitative element and reported that a lesser quality of life was associated with higher subjective burden of care. The authors acknowledged that the carers used were from a self help organisation which may have indicated that their sample had more difficulty in coping than carers in general. However, it may have also been that these carers had learnt more adaptive coping strategies and reported better wellbeing than carers in general. They used a small sample of 40 carers and it was acknowledged that larger samples of carers of people with ED are needed. Their study relied on the fact that a person was attending a support group. It did not specify whether the care recipient had a formal ED diagnosis, nor did it ask about the duration of the ED or the time the carer had been in their role (Martín et al., 2011). Given that there is now recognition that SEED is possibly a different entity to shorter forms of ED (Robinson, 2009), studies on carers need to ask these questions. The results of the current research will aim to address some of these limitations.

Gutiérrez-Maldonado, Caqueo-Urízar and Kavanagh (2005) is another study that has investigated wellbeing, but in carers of people with schizophrenia. This study used the SF-36 but reported norm referenced scores rather than actual scores. This meant that it was not possible to use it as a comparison study with the current results. Gutiérrez-Maldonado et al. (2005) found that the scores for the "Emotional Role", "Vitality" and "Mental Health" subscales were particularly low. Furthermore, they reported that female carers presented with a poorer state of health. Despite this study being conducted in Chile, the authors acknowledged that their results were consistent with research findings in more developed countries.

In each of the above four studies, two of the subscales of the SF-36 (notably the "Emotional Role" and "Physical Role") have particularly large standard deviations. Argimon et al. (2004) have suggested that these scores in part may be explained by "ceiling" and "floor" effects due to these subscales only having a few response categories (i.e. Yes/No). The current research used other measures in the research pack to further investigate some of these areas (e.g. current mental health status and coping style).

The wellbeing of carers is a complex construct. Some of the issues relating to carer wellbeing have been highlighted. A model that was developed to better understand this construct will now be presented. It will be used to structure and further develop the literature review and provide further justification for the current research hypotheses.

A Model Framework

A psychological model that has been used to conceptualise caregivers' wellbeing is the SPM (Pearlin, Mullan, Semple, & Skaff, 1990). This model identifies three main concepts that need to be considered when investigating the wellbeing of carers. Firstly, Zarit and Edwards (2008) proposed that "stress proliferation" is important, whereby stress from caring overflows into other aspects of the carers' life. For example, the carer may need to reduce their hours of employment to care, thus potentially increasing the stress level regarding financial matters. The SPM refers to these as "Secondary Stressors" whereas "Primary Stressors" are associated to the activities of caregiving more directly e.g. feeding the care recipient.

A second concept is "stress containment", whereby a carer may use "resources" to limit his/her experience of stress. The model suggests that "resources" may be psychological, social or economic. Mastery and social support were two "resources" that have been investigated in this research. Both of these "resources" were chosen as previous studies have identified them as important in carer wellbeing (Ergh, Rapport, Coleman, & Hanks, 2002; Li, Seltzer, & Greenberg, 1999). A further concept states that caring should be conceptualised as a career. The ability to adapt to a caregiving situation may be seen as a developmental process. The SPM includes the carer career under "Outcomes".

The concept of a carer's career has been investigated within the older adult literature (Gaugler & Teaster, 2007). Three stages have been identified (role entry; process into an institution; bereavement) (Pearlin & Aneshensel, 1994). These stages could be applied to any caring role that involves a recipient who may require hospitalisation or could be at risk of death. Carers of people with chronic conditions are more likely to be further into their caring career than carers of people with more acute conditions. In ED, carers are likely to experience different stages of caring e.g. care and support needed when a person is in denial of the ED will differ to the care and support needed when a person recognises they have a problem. Likewise, carers of people with ED may need to adjust their care if their care recipient is in hospital compared to when they are in the community.

The SPM has previously been used in research on carers of various conditions e.g. dementia (Hooker et al., 2002); dementia and lung cancer (Haley, LaMonde, Han, Burton, & Schonwetter, 2003); brain injury (Chronister & Chan, 2006); multiple sclerosis (O'Brien, Wineman, & Nealon, 1995). In research on caregiving of people with ED however; the SPM has previously only been used once to predict family functioning in carers of AN (Dimitropoulos et al., 2008).

The model is illustrated below.

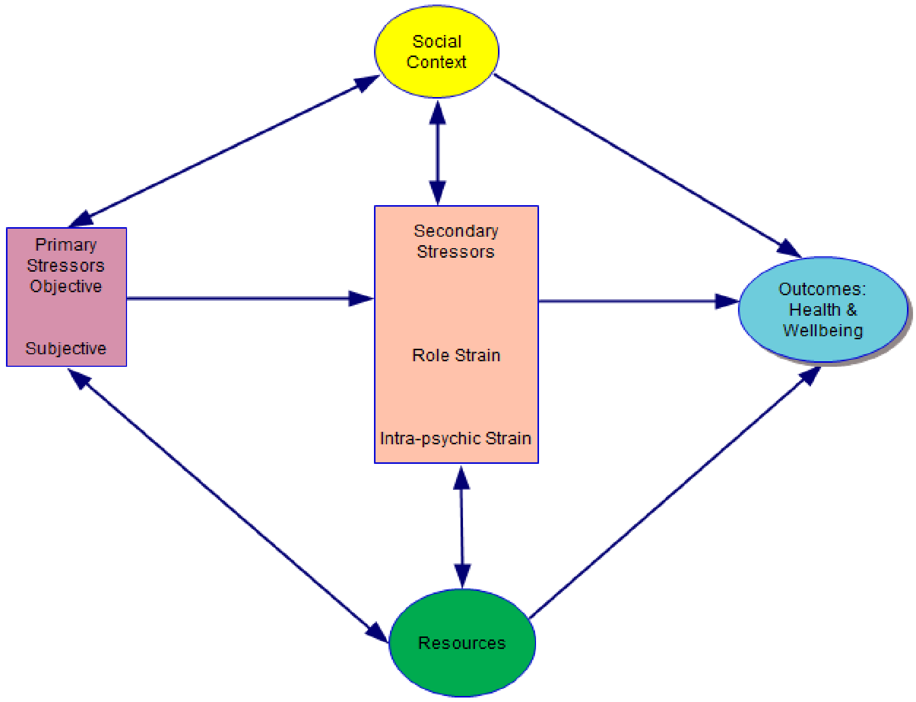


Figure 1: The Stress Process Model Adapted from Pearlin et al., 1990

The current research has investigated specific areas of the caregiving experience, namely the impact of caregiving duration and condition (e.g. severe and enduring) on caregivers' wellbeing. This relates to factors identified in the "social context" aspect of the SPM. It has also investigated the impact of "resources" identified in the SPM, namely a sense of personal mastery on carers' perceived wellbeing. Some researchers have queried whether "resources" may act as a mediator on carer wellbeing (Goode, Haley, Roth, & Ford, 1998; Gaugler et al., 2009). The SPM may be a useful way to understand carers of people with SEED.

The use of the SPM as a framework to present the literature is the most commonly used model in caregiver research and is the most varied in its application (Yates, Tennstedt, & Chang, 1999). It has been used to better understand carers of people with various conditions (e.g. dementia, cancer). It is a flexible framework that acknowledges the multiple factors and individual differences involved in caregiver stress and wellbeing; the influence of time and adaptation; possible mediators and contextual circumstances.

The Social Context

The social context involves; who is the caregiver, what relationship is held between carer and recipient and where the caregiving takes place. Some of these factors have already been discussed. It also includes the gender of the carer and the amount of contact which are discussed below.

Gender of carer

Pinquart and Sorensen (2006) conducted a meta-analysis on how gender differences influence caregivers' stress, health and coping. They found that gender differences in psychological health, physical health and caregiving stressors were evident but small in magnitude. Their review identified that female caregivers reported higher levels of behaviour problems in care recipients, higher levels of burden, depression, lower levels of subjective well being and physical health compared to male caregivers. These were above what was expected from the gender differences found within the general population. Pinquart and Sorensen (2006) concluded that higher levels of caregiving stressors (subjective burden) and lower levels of social resources account for some of the gender differences found in the literature. The remaining differences have been attributed to stressors and resources that are non-specific to caregiving (Pinquart & Sorensen, 2001). For example, women tend to live longer and are more likely to be widowed.

Some of the limitations of the Pinquart and Sorensen's review were that some variables such as care recipient gender and the employment/caring conflicts were not considered. They also suggested that further research is necessary to differentiate how men and women are affected by caregiving stressors and resources. They suggested that the quality of the relationship with the care recipient may cause more stress for women than for men.

Further consideration of the above findings indicated that women tended to be more willing to disclose negative feelings and health difficulties (Kroenke & Spitzer, 1998). Research has consistently shown that women will report more adverse bodily sensations than men (Barsky, Peekna, & Borus, 2001). Reasons for this difference have been attributed to many factors including differences in symptom labelling, socialisation processes and opportunities to report. In terms of caregiving, it may be that men are using more successful coping strategies. However; Pinquart and Sorensen's (2006) meta-analysis pointed out that observed gender differences in caregiver stress and wellbeing may be subject to social change. This is because differences are smaller in more recent studies and with those involving younger caregivers.

In the ED literature, there are some findings on family members and gender differences. Strober, Freeman, Lampert, Diamond and Kaye's (2000) family study found a higher rate of psychological problems in first degree relatives of ED patients. This study suggested that systemic and cognitive appraisal coping factors are likely to be important. Another study by Kyriacou, Treasure and Schmidt (2008b) investigated the experiences of mothers and fathers caring for their offspring with AN. Over 50% of the carer sample scored at, or above the clinical threshold for anxiety. More specifically, mothers were more likely to report psychological distress in regards to interpersonal and self-related strains. This finding has been replicated within a Chinese culture (Ma, 2010). Kyriacou et al. (2008b) suggested that as most of their sample of mothers did not work full time, this may act as a protective factor for the ability of fathers to cope.

Male carers are generally underrepresented in research, and it would be useful to identify if differences do exist. One qualitative study (Whitney et al., 2005), observed that fathers of children with AN used more cognitive and avoidant coping strategies compared to mothers who were more emotional. It may be that stereotypical roles like “fathers must remain strong and provide” and "mothers will provide the care and nurturing" may influence how the family system operates.

The family is an important factor in the recovery from an ED (Treasure, Gavan, Todd, & Schmidt, 2003). Based on previous research, the current study would expect to show that female carers would show higher levels of distress compared to male carers. As there are no studies on gender differences in carers of people with SEED it would also be useful to obtain data from carers of both sexes to support or refute the claim that gender differences exist.

Level of contact

Research on the living arrangements or amount of contact between caregiver and recipient has been shown to be associated with increased distress. For example, in the older adult literature it has been shown that co-residence with a care recipient can be a negative factor on caregivers' psychological wellbeing (Zarit & Edwards, 2008). Increased proximity has been linked to increased levels of caregiver burden, which in turn is associated with higher levels of psychological distress (Colvez, Joël, Ponton-Sanchez, & Royer, 2002). In mental health issues such as depression, caregivers who live with the care recipient are more likely to feel psychological distress themselves (Benazon & Coyne).

If living with a care recipient is stressful, it could be assumed that living apart may be beneficial. However, it has also been suggested that institutionalisation of a care recipient with dementia can lead the caregiver to have feelings of failure and depression (Schulz et al., 2003). The sparse research findings on carers of people with ED have suggested that carers perceive more psychological distress when they have more frequent contact with the ED patient (Graap et al., 2008b; Winn et al., 2007). The current research has taken into account the level of contact that the patient has with the carer.

Primary Stressors – Objective and Subjective

Primary stressors are events that are directly related to the condition or by the assistance provided to the care recipient, for example bathing and feeding of a dementia patient. The SPM by Pearlin et al. (1990) would initially identify these as “primary objective stressors”. The literature on carers of older adults on “primary objective stressors” has indicated only small associations with caregiver psychological wellbeing (Zarit & Edwards, 2008). However, primary stressors may also evoke an emotional response that adds a subjective component. The emotional impact of primary stressors on the caregiver is referred to as the “primary subjective stressor”. The caregivers’ perception and appraisal of the event as stressful is associated with less psychological wellbeing (Son et al., 2007). Essentially, “primary objective stressors” are what carers do and “primary subjective stressors” are what they think/feel about what they do.

Care recipients who have emotional and behavioural problems are perceived to be more stressful by the caregiver (Pinquart & Sorensen, 2003). This finding is consistent in carers supporting people with various types of condition e.g. brain injury (Riley, 2007), Alzheimer’s disease (Asada, Kinoshita, & Kakuma, 2000) and ED (Whitney et al., 2007). In brain injury research, a personality change has also been found to be a strong predictor of carer stress and depression (Mitchley, Gray, & Pentland, 1996). Furthermore, carers become more distressed when they perceive the care recipient being able to control their behaviour (Bolton et al., 2003), or they believe that the care recipient's behaviour was motivated by hostile intentions (Dopke & Milner, 2000). The nature of mental health problems such as schizophrenia and ED are likely to present the carer with more emotional and behavioural problems than someone with primarily a physical health condition. Carers of people with ED may experience the above situations frequently. Furthermore, such attributions can impact on the emotional wellbeing and cohesiveness of the family (Treasure et al., 2003).

The SPM can be related to carers of people with ED. Activities like additional preparation of low calorie meals, excessive supermarket shopping following binges, or assisting the recipient with physical care could be classified as "Primary Objective Stressors". When an emotional factor is added, (e.g. a carer responding to a distressed care recipient who had just binged; or watching the weight of the care recipient decline to life threatening levels), this may increase perceived stress in the caregiver.

Burden

"Stressors" as referred to in the SPM, and the term "burden" seem to be intrinsically linked. Subjective burden (similar concept to primary subjective stressors) has been described as the extent to which carers perceive themselves as carrying a heavy load, the emotional cost, and their attitude towards caring for the individual. Objective burden (similar concept to secondary stressors) has been described as the extent of disruptions the caring impacts on the carer's life e.g. not working, having to change family routines. Carer burden is consistently linked to high levels of psychological distress in carers of dementia (Gallagher-

Thompson, Haley, & Czaja, 2000) and schizophrenia (Møller, Gudde, Folden, & Linaker, 2009).

The research on carer burden of people with ED has been much less investigated (Graap et al., 2008b). The first study on carer burden in the ED literature found that carers of people with AN reported higher levels of subjective and objective burden when compared to carers of people with bulimia nervosa (BN) (Santonastaso, Saccon, & Favaro, 1997). Despite this early study, burden in carers of people with ED has not been further investigated until more recently. Graap et al. (2008a) reported that objective burden only accounted for 7% variance of the experience of burden. This suggests that the psychological "subjective" component of burden may be more associated with carers' patterns of appraisal, perception and attribution, which corresponds with the SPM. Burden and psychological distress has not yet been assessed in carers of people with SEED (Robinson, 2009).

Measuring Burden

A measure that has been used to assess burden is the Experience of Caregiving Inventory (ECI) (Szmukler et al., 1996). It has been used in studies of carers of people with mental health problems (e.g. Kyriacou et al., 2008b; Møller et al., 2009; Treasure et al., 2001; Winn et al., 2007). Data from Treasure et al, (2001) was used to compare burden with the data obtained in the current study. Harvey et al. (2008) conducted an independent review of many instruments used in carer research. They highlighted that 26 of the 64 instruments reviewed were suitable for carer research. The ECI met many of their criteria (importance of construct to carers; carer involvement in measure development; acceptability to carers; appropriateness for carers; reliability; validity; interpretability and feasibility). The ECI was not specifically designed to fit the domains of the SPM, however some subscales are more closely linked to primary stressors or objective burden (i.e. directly related to the illness) than others. These subscales are "Difficult behaviours", "Negative symptoms" and "Problems with services".

Secondary Stressors

Aneshensel, Pearlin and Mullan (1995) have operationalised secondary subjective stressors into three indicators. These are; "role overload" identified by a feeling of being depleted emotionally or physically; "role captivity" identified by a feeling of entrapment by responsibilities; and a feeling of "loss in a relationship". In all caregiving situations these indicators are possible, but in conditions that involve emotional and behavioural change or are progressive, chronic or degenerative, they are more likely.

Secondary stressors are areas of the caregivers' life that are disrupted due to caregiving responsibilities. Caregivers usually hold multiple roles (e.g. mother, wife, daughter, employee, friend & carer) that can lead to role strain. It is common that family conflict can occur when one member of the family has a mental health condition (Scharlach, Li, & Dalvi, 2006). Families can start to accommodate their behaviour to the symptoms of the illness (Treasure et al., 2008). For example, a carer of a person with social phobia could cut out their leisure activities to run shopping errands to enable the person to continue to function. This behaviour, from the carer's perspective, may help the recipient in the short term as observably it reduces current distress. In the long term however, it may exacerbate the person's symptoms and concurrently increase the non related caring demands on the carer. For example, it may reduce time spent with friends and other family members or force time to be taken off from work.

Caregiving and work conflict is related to role overload and negative wellbeing (Edwards, Zarit, Stephens, & Townsend, 2002). The current research has not investigated "secondary stressors" specifically, but has used subscales from the ECI to acknowledge the importance of "secondary stressors" which can significantly contribute to carer wellbeing.

Intrapsychic strain

This refers to the way that some carers become so immersed in their caregiving role that an erosion of self concept can occur. This can impact on carers' mental health. Furthermore, intrapsychic strain has also been linked to higher mortality rates when compared to age and gender matched controls (Schulz & Beach, 1999). Caring for someone can elicit strong emotional reactions including guilt, shame, fear, despair and anger (Chambers et al., 2001). Research has suggested that caregiving can have both positive and negative consequences (Hunt, 2003). For example, it was suggested that carers can experience a conflict in emotions (Hall, 1990). Warmth and love may contrast with fear of the future and the despair of loss. Carers of people with physical and mental health conditions consistently report strong emotions related to the act of caring (Highet, McNair, Davenport, & Hickie, 2004; Krishnasamy & Plant, 2004).

Carers of patients with mental health problems in particular, may experience feelings of shame and guilt that can be exaggerated by stigma in the community. Crisp, Gelder, Rix, Meltzer and Rowlands (2000) identified that ED are at the top end of the blame spectrum for stigma. Beliefs and stigma are likely to increase the psychological impact on carers of people with ED. Dimitropoulos et al. (2008) felt that the SPM did not consider stigma as a factor that could be important to carers' psychological wellbeing. When they tested an adapted version of the SPM with carers of AN, they found that stigma was an important predictor of caregiver outcomes (e.g. psychological distress). Stigma directed towards the family (courtesy stigma) was much more of a factor than stigma directed towards the care recipient. Stigma has been measured using the "Stigma" subscale on the ECI (Szmukler et al., 1996). Previous research has indicated that high levels of courtesy stigma can cause family members to isolate themselves thus reducing available coping resources such as social support (Corrigan & Miller, 2004). The impact of "resources" will be discussed below.

Positives of caregiving

Morano (2003) claimed that researchers have mainly focused on the negative aspects of caregiving, although some studies in the general caregiver literature have started to realise the importance of positive experiences of caregiving on wellbeing. Areas include carer self-esteem (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999); uplifts of caregiving (Kinney, Stephens, Ann, Franks, & Norris, 1995); satisfaction (Kramer, 1997); finding a meaning (Ayres, 2000); and personal gain (Rapp & Chao, 2000). Baronet (2003) investigated carers' positive and negative appraisals of people suffering from schizophrenia or bipolar disorder. It was found that younger carers when compared with older carers had increased satisfaction from caregiving activities.

The quality of the relationship between caregiver and care recipient was improved.

Two studies on carers of people with ED have reported some positive aspects of caregiving. Highet, Thompson and King (2005, 329) conducted a qualitative study that identified positives such as “a sense of being useful to the sufferer”; and increased personal qualities such as “an understanding of others with problems”. Treasure et al. (2001) used a mixed methodology that incorporated validated questionnaire measures and a free writing task. They used the Experience of Caregiving Inventory (ECI), developed in a study of carers of adults with psychosis by Szmukler et al., (1996). The measure was designed from analyses of 626 caregiver responses about their experiences. It has become a popular measure in caregiving research and has eight negative subscales and two positive subscales (see methods section for more information about the ECI). Treasure et al (2001) found that carers of people with ED reported feelings of loss nearly twice the level compared to carers of people with psychosis. There were no differences between the carer groups on the ECI positive subscales (positive personal outcomes; good aspects of the relationship). However, the free writing task suggested that positives were involved in successful caregiving, e.g. closer family bonds. The thematic analysis identified numerous positive feelings towards the care recipient such as acceptance, hope, support and love. Some of these positive aspects may be different in carers of people with SEED. Although positive aspects of caring was not the primary focus of this research, the use of the two positive subscales on the ECI (Szmukler et al., 1996) have provided some data around this concept.

Social support.

Another “resource” that has been investigated in carer wellbeing studies is social support. There is a dynamic relationship between a stressor, a resource and an outcome. Resources are not static and over time they may increase or become depleted. The general assumption that social support is a buffer to stress has been established in the general literature (Cohen, 2004), yet research on the association between social support and caregiver distress has produced inconsistent results (Miller et al., 2001). Zarit and Edwards (2008) stated that social support can be categorised into two main factors: “instrumental support” and “emotional support”. Miller et al. (2001) utilised data from four previous carer studies and used replication analysis to identify differences and commonalities between the carer groups on distress and social support. Less “emotional support” was associated with higher levels of distress in two of the four samples. However, their findings regarding “instrumental support” on carer distress were less clear and in one sample, increased “instrumental support” was associated with higher levels of distress. It was suggested that different types of social support can potentially impact the wellbeing of carers, but further clarity is needed around the measurement of these constructs.

In the ED literature, the effect of social support on carers has been reported in qualitative studies. Honey and Halse (2006) found that carers of people with ED valued being able to talk to friends and colleagues about their caregiving responsibilities. Even when no practical advice could be offered, the carers reported feeling better by having someone listen to them. However, Coomber and King (2011) found that social support did not predict or mediate psychological distress in carers of people with ED. They found that maladaptive coping strategies (discussed below) were predictive of burden and psychological distress.

Again, this is not a main focus of this research. However, it is important to acknowledge the impact that social support could have on carer wellbeing. Anecdotal reports from liaison with carer support groups for people with ED suggest that more social activities and increased social-emotional support is needed. The current study has used a basic measure of the social support accessed by carers, the "Expressive support" scale (Pearlin et al., 1990).

Coping strategies

Three broad categories of coping strategies have been identified in the carer literature: problem focussed, cognitive focussed and emotion focussed (Zarit & Edwards, 2008). As the SPM would predict it is important to understand the coping mechanisms used by carers as there is an association between coping and psychological wellbeing. Oyebode (2003) pointed out that emotion focussed coping results in poorer adaptation to the caring role.

The current study has not measured the coping strategies employed by carers; however a proxy overall question on coping strategies has been included on the CIQ (q13). A more thorough qualitative investigation of coping strategies used by carers of people with ED has been investigated previously (Coomber & King, 2011; Honey & Halse, 2006). These authors recommended that further standardised measures on coping strategies specific to carers of people with ED (and consequently carers of people with SEED) needs to be developed before a thorough investigation of coping strategies can be conducted.

Mastery.

A "resource" factor that has been investigated within the carer literature and is one of the main focuses of the current research, is the concept of mastery or control. People have beliefs about their capabilities to produce levels of performance that exercise influence over events that affect their lives. Bandura (1997) termed this concept "self efficacy". A sense of self efficacy in caregiving is likely to increase confidence in being able to cope (Gilliam & Steffen, 2006). In some respects, self efficacy and mastery appear to be synonymous terms. However, Gecas (1989) has suggested that mastery is a more global construct in life, whereas self efficacy is more specific to competence on particular areas or tasks. A three year longitudinal study with carers of people with dementia found that a global sense of mastery had a direct effect on reducing ratings of depression over time (Aneshensel et al., 1995). It also was related to a reduced sense of role captivity and an increased perceived competence as a caregiver. Li et al. (1999) also found that daughters of people with dementia who had higher levels of mastery were more likely to use problem focussed coping strategies and showed lower levels of depression, in comparison to daughters who reported lower levels of mastery.

Research has demonstrated that carers of people with dementia can cope better with the stresses of caregiving by having an increased sense of personal mastery (Mausbach et al., 2006). In a meta-analysis it was identified that skill based interventions for carers can reduce the likelihood of carers developing mental health difficulties (Brodaty, Green, & Koschera, 2003). Mausbach et al.

(2006) suggested that these interventions could increase the carers' sense of mastery.

People with a low sense of mastery are more likely to dwell on personal weaknesses and the negative consequences of failure, increasing the possibility of poor mental health. In a caregiving situation this may lead to avoidance or to over reliance on others for support. Interventions aimed to help caregivers enhance their caregiving skills and their sense of mastery concurrently may be the most beneficial to the carer and care recipient.

The literature on carers of people with ED and their global sense of mastery or self efficacy is extremely limited. There appears to be no research that measures mastery or self efficacy in caregivers of people with ED. Only one study has looked at carers of people with ED with the SPM framework and the possible positive effects of mastery on caregivers wellbeing was not analysed (Dimitropoulos et al., 2008). A qualitative study on carers' experiences of caring for a family member with an ED has indicated a need for services to enhance carer self efficacy. It was reported that "providing clear guidelines to follow and regular feedback .... it gave them confidence in what they were doing" (Honey et al., 2008, 46).

The SPM proposed that a sense of mastery is a "resource" that carers may draw on. It may also act as a mediator between primary and secondary stressors and negative carer wellbeing (Gaugler et al., 2009). In the current study, the personal sense of mastery and self perceived caregiver competence was assessed with two brief valid and reliable measures used previously to test the SPM (Given et al., 1992; Pearlin et al., 1990).

Caregiving career

A sense of mastery has also been closely linked to the caregiving career (Skaff, Pearlin, & Mullan, 1996). The "caregiving career" has been conceptualised as a variety of stages/transitions throughout the caregiving process from the acquisition of the role to the end of caregiving due to death, recovery or movement away. Skaff et al's (1996) longitudinal study found that carers' sense of mastery declined the longer that they cared for their relative, that their sense of mastery remained unchanged if the care recipient was placed in a care facility and if caring ended (in this population most likely because of death of the care recipient) the carer's sense of mastery increased. They concluded that being released from the burden of caregiving can improve a sense of personal mastery. Interventions aimed to improve a sense of personal mastery may be a protective factor on caregiver wellbeing.

Much of the research on caregiving has suggested that people caring for family members with chronic health conditions go through transitions of caring (Gaugler et al., 2008). Shah, Wadoo and Latoo (2010) have pointed out that caring for someone with a mental health problem is not a static process as the care recipient's needs change.

Early conceptualisations of caregiving proposed a "wear and tear" analogy (Pearlin, Menaghan, Lieberman, & Mullan, 1981), whereby the longer a carer was in their role, the more likely negative outcomes would be apparent. For example, in carers of people with brain injury the time since injury has been shown to predict levels of stress (Chronister & Chan, 2006). In literature relating to the care of older adults however, Montgomery and Williams (2001) suggested that the duration of care is rarely an independent predictor of caregivers' wellbeing. Research has suggested that carers have an ability to tolerate distress and adapt to meet the demands of chronic caregiving. Longitudinal studies have demonstrated an adaptation effect (Gaugler, Kane, Kane, & Newcomer, 2005). Some carer studies even reported improved psychological wellbeing over time (Whitlatch et al., 1997), which supports an adaptation model of caregiving (Pavalko & Woodbury, 2000). It could be that some carers improve their competence (and wellbeing) over time due to the practice they obtain. However, as caregiving is not a static process and the needs of care recipients constantly change, carer wellbeing could be affected if they do not adapt accordingly.

Research has identified that the first transition for carers is entry into the caring role. Gaugler, Zarit and Pearlin (2003) found that psychological wellbeing of the carer was associated with how abruptly a caregiver begins their role. This may have parallels to carers of people with ED. As an eating disorder develops, the person may attempt to hide their difficulties, e.g., wear oversized clothes or make excuses about mealtimes. Carers may take time to recognise that something is seriously wrong or use coping strategies such as denial. Treasure, Smith and Crane (2007) used animal metaphors to describe how carers of people with ED react to the caring situation, denial being an “ostrich”. According to Robinson (2009, 80) some fathers of daughters with ED can distance themselves from what they may perceive as “women issues”. If carers are informed, have good communication skills and can adapt to the needs of their loved ones quickly, carers are more likely to adopt a more successful caring role.

The second transition that has been identified as impacting carers’ wellbeing is when the care recipient moves into an institution. Zarit and Edwards (2008) have suggested that hospital placements involve a restructuring of the caring role. Schulz et al. (2004) found that placing a family relative with dementia into institutional care can cause the carer increased psychological distress. This has parallels with all chronic conditions that may require hospitalisation. People with SEED may have repeated admissions to hospital (Robinson, 2009).

People with ED may often be ambivalent about treatment. In extremely severe cases of ED a patient may be forced treatment under the Mental Health Act. This may evoke feelings of guilt and anxiety in the caregiver. It may be that a carer's sense of mastery is disintegrated by the fact that they were unable to help when their care recipient entered hospital. Feelings of "I'm a bad carer" may be instigated. Some primary stressors may be reduced from the carer being placed in hospital and it may be more possible to utilise an "out of sight out of mind" approach. Nevertheless, increased stressors; such as "feeling in the dark" from hospital staff; travelling distances to hospital placements (which for ED can be substantial); and feeling a loss of contact; may arise. Qualitative studies in carers of people with ED have shown that hospitalisation can evoke strong feelings. Dimitropoulos, Klopfer, Lazar and Schacter (2009) reported that siblings had feelings of helplessness and loneliness when their sister was admitted.

The final transition identified in the carer literature is the cessation of caring (Zarit & Edwards, 2008). This may be the death of the care recipient in older adult populations (and approximately up to 15% of cases of people with SEED (Arkell & Robinson, 2008)). Gaugler and Teaster (2007) have suggested that there is great variability in the adaptation to loss or bereavement. In ED populations it is more likely to be the decision of the care recipient to move away from the long term primary caregiver.

Moen, Robison and Fields (1994) have suggested that in the care of the elderly, the average duration of a spell of caregiving lasts two years or less. Bibou-Nakou, Dikaiou and Bairactaris (1997) used this criterion in their study examining the relationship between level of burden and psychological distress amongst carers of people with schizophrenia.

The current study has not closely monitored carer careers and transitions, however, it is important to be aware that the stage of caring may impact carers' wellbeing. The current research has obtained data on the amount of time the carer has been in their role and will also ask about the residential situation (e.g. some care recipients may be in hospital).

Comparison Groups of Carer Distress

Schulz and Quittner (1998) reported that research on the comparison of carer groups has been limited. The literature often remains focussed on particular illnesses or conditions. Schulz and Quittner (1998) acknowledged that a level of disability is difficult to hold constant and the context varies, but if similar measurement tools and some level of matching occurs then such studies should be attempted. A few researchers have attempted this approach.

The carers of people with dementia have been compared to carers of people with more physical health conditions such as cancer (Clipp & George, 1993) or physical difficulties associated with old age (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). The carers of dementia patients who experienced more emotional and behavioural problems reported more subjective stress and more negative wellbeing. Furthermore, clinical depression is lower amongst carers of physically impaired recipients compared to cognitively impaired recipients (Pinquart & Sorensen, 2007; Tennstedt, Cafferata, & Sullivan, 1992).

In the ED literature, there are only two studies known where the psychological distress of carers has been compared to carers of people with other conditions. Treasure et al. (2001) compared the experiences of caring for someone with AN with the experiences of caring for someone with psychosis. Both groups of carers had care recipients who met the diagnostic DSM-IV criteria for AN or psychosis. They found that levels of distress (measured by GHQ12 scores) of carers of people with AN were significantly higher than carers of people with psychosis. In addition, carers of people with AN reported experiencing significantly more difficulties in their carer role which led to negative emotions such as guilt and shame. Graap et al. (2008a) also highlighted that the level of contact with the patient differed significantly between the psychosis carer comparison group and the AN carer group. They suggested that this would have an impact on the perceived level of burden and the consequent level of psychological distress in carers. They used carers of severely ill AN patients which may be synonymous with SEED. They suggested that this might not be representative of all ED carers' experiences as AN has the highest mortality rate in all psychiatric conditions (Harris & Barraclough, 1998). This point is valid in that some carers do not care for people who are severely physically ill with ED. However, carers of people with SEED are still a subgroup of carers that need to be considered.

To attempt to rectify some of the difficulties in the Treasure et al. (2001) study, Graap et al. (2008a) compared carers of people with AN, BN or schizophrenia. They used the GHQ12 (Goldberg & Williams, 1988), the Burden Inventory (Zarit, Orr, & Zarit, 1985) and an adapted semi-structured research interview called the Carers' Needs Assessment (CNA), originally designed for carers of dementia patients (Wancata et al., 2005). The sample included 30 carers of patients suffering from schizophrenia and 32 carers of patients suffering from ED. Unlike Treasure et al. (2001) they did not find any differences in the amount of face to face contact with the patient in relation to the carers' reported psychological distress. It seemed that carers of AN and schizophrenia patients reported significantly more psychological distress than carers of BN patients. Another paper using the same data focused on carers of AN and BN patients (Graap et al., 2008b). They suggested that the difference in reported psychological distress in carers may have been due to the perceived level of burden. The use of the CNA semi structured interview highlighted that carers of AN patients may feel more responsible for the health of their "loved one" as the threat is more overt than in BN. AN in comparison to BN, is a much more visually apparent disorder and has a higher number of deaths.

Carers are generally willing to accept offers of support to help them manage the psychological impact of caring for someone with an ED (Surgenor, Rau, Snell, & Fear, 2000). Some healthcare professionals have started to highlight the need to support carers of people with ED (Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008a). It is acknowledged that there is an interactive relationship between psychological wellbeing of carers and the patient's duration, severity and outcome of their condition, as suggested in the literature on family/carer treatments for schizophrenia (Pilling et al., 2002).

The subjective impact on each individual carer is an important factor when clinicians assess the carer's needs. Some carers will be coping, others may be experiencing distress. According to the SPM the outcome (carer wellbeing), will be influenced by the subjective impact of the primary stressor, the resources available, the social context and secondary stressors.

The current research aimed to identify whether there were any differences between carers of other conditions and those who care for people with SEED by comparing the current results with existing data.

Conclusions and Basis for the Current Research

The current research will address some of the gaps highlighted by Zabala, Macdonald and Treasure (2009), who identified that the distress and burden experienced by carers of people with ED has been relatively neglected in the literature. Furthermore, research on carers of people with SEED has not been conducted (Robinson, 2009). It is therefore important that further information about this group of carers is obtained. Research has indicated that the duration of an illness can influence caregivers' coping mechanisms. Gibbons, Horn, Powell and Gibbons (1984) found that length of illness was directly associated with psychological distress, yet later research has not consistently confirmed this finding. The current study's main aims were to investigate wellbeing and the perceived burden of carers of people with SEED. The psychological wellbeing and perceived levels of burden in carers of people with SEED was compared with carers of people with less long-standing eating disorders, and people with other severe and enduring mental health conditions using data obtained in previous studies. It was expected that carers of people with SEED would have particularly impaired wellbeing.

A secondary aim was to assess some of the components of the SPM and identify which variables have a significant effect on wellbeing in carers of people with an eating disorder and specifically with SEED. A focus was on sense of personal mastery and self rated caregiver competence and whether these scores had a positive association with levels of carer wellbeing. Previous research has identified that carers who reported a greater sense of personal mastery reported higher levels of wellbeing (Li et al., 1999; Mausbach et al., 2006).

MAIN HYPOTHESES

1. That self reported wellbeing in carers of people with ED would be less than community norms.
2. That female carers would have significantly less wellbeing than male carers.
3. That carers of people with SEED would have significantly less wellbeing when compared to existing data on wellbeing of carers of other patient groups.
4. Those variables representing domains in the SPM would be associated with carer wellbeing. Specifically, it was hypothesised that variables relating to “resources”, particularly “personal sense of mastery” and “self competence in caregiving” would be significant predictors of carer wellbeing.

METHODS

Participants

Carers were recruited through a number of carer support groups based in England (see Appendix A). Carer support groups were contacted directly and no direct contact was made with individual NHS patients. Service user involvement and engagement was important in this research and therefore attendance at carer support groups was crucial to obtaining participants. If potential participants did not attend a carer support group when the investigator made a scheduled visit, carers on the groups' circulation lists were also invited to participate. It was acknowledged that some carers at groups may have been living with people presenting with ED symptoms for months or years before a diagnosis had been given. Likewise, some care recipients may have not yet received a formal diagnosis. In this study however, all participants were caring for care recipients who had received a formal ED diagnosis.

In all, 21 carer support groups were contacted and 287 research packs were distributed. One hundred and five research packs were returned but one was omitted from the analyses due to a diagnosis not being stated. This equated to a return rate of 36%. Participants were members of a carer support group and fulfilled the carer definition as stipulated by Perlick et al. (2005).

Of these 104 participants, 34 were classified as carers of people with SEED. The carers of people with ED were stratified into groups of severity based on the time they have been caring for someone with ED (0 to 2 years, 2 to 6 years, over 6 years). Over 6 years is the minimum number of years that researchers have classified as SEED (Wentz et al., 2009). In the current study participants were classified as carers of a person with SEED if they selected "over 6 years" to indicate their length of time in providing care, and if this was consistent with the reported time since diagnosis of an ED in their care recipient.

Comparison literature

Comparative carer group data was obtained through a search of the carer wellbeing literature. The comparison carer groups included were carers of people with dementia, carers of people with brain injury, carers of people with psychosis and other data assessing carers of people with ED, as reviewed above. These data were in Journal publications that had assessed carer wellbeing using the SF-36. It was judged that these carer groups were caring for people with conditions of a comparable nature to carers of people with SEED.

Carers of people with dementia are likely to care for someone with both emotional and physical health difficulties; this may occur when caring for a person with SEED. People with dementia may experience repeated admissions into institutional care for "respite"; this can occur in people with SEED. Dementia is progressive and worsens over time and therefore fulfils the concept of it being a severe and enduring condition.

Caring for a person with brain injury may involve a loss of the relationship that was held prior to the injury and may involve a higher level of dependency, which can be similar in some people with SEED. Brain injury may affect a person's personality and daily functioning, which may also be affected in people with SEED. Additionally, carers and people with brain injury are more likely (than carers and people with dementia) to be similar in age with carers and people with SEED.

Psychosis and particularly schizophrenia, are terms classified as severe mental illnesses (Barrowclough, 2005). According to Arkell and Robinson (2008) the condition of SEED should be classified similarly in terms of global impairment. In both ED and psychosis groups the majority of carers are likely to be a parent or spouse. Furthermore, carers of people with psychosis have been previously included in research into carers of people with ED (Graap et al., 2008a; Treasure et al., 2001). Although it was not possible to compare wellbeing between carers of people with psychosis and carers of people with SEED due to the use of different measures, the current study was able to compare the groups on the carers' experiences of caregiving.

Measures

The Short Form Health Survey (SF36) version 1 (Ware et al., 1993)

This questionnaire (see Appendix B) measures overall wellbeing and consists of eight subscales: "Physical Functioning" (10 items), "Physical Role" (4 items), "Bodily Pain" (2 items), "General Health" (5 items), "Vitality" (4 items), "Social Functioning" (2 items), "Emotional Role" (3 items), and "Mental Health" (5 items). These subscales can be calculated into two summary scales – "Mental Summary" and "Physical Summary".

The "Physical Functioning" subscale assesses the ability to perform activities without restrictions imposed by the person's current health. The "Physical Role" subscale measures difficulties with daily activities as a result of physical health problems. The "Bodily Pain" subscale measures the perceived intensity of pain or discomfort. The "General Health" subscale measures the person's perception of overall health. The "Vitality" subscale measures the person’s perceived energy levels and fatigue. The “Social Functioning” subscale measures the person’s perceived limitations in social activities. The “Emotional Role” subscale measures difficulties with daily activities as a result of emotional problems and the “Mental Health” subscale measures the person’s level of psychological distress. Higher scores on these scales suggest fewer problems in these respective areas.

Actual scores and norm referenced scores can be calculated on the subscales; however the summary scales are always norm referenced with a score of 50 being the norm. Ware Jr (1999) has pointed out that subscale scores should not be mixed (actual and norm referenced) when reporting. The current research used actual scores for the subscales. The whole measure has been found to have good internal consistency when used in research on caregivers. The subscales range from Cronbach alpha coefficient 0.72 to 0.92 (Machnicki et al., 2009).

The Experience of Caregiving Inventory (ECI) (Szmukler et al., 1996)

This measure has been referred to in the literature review above and is shown in Appendix C. Consent from the author was obtained to use it within this research. It is a 66 item questionnaire that captures eight negative subscales; *difficult behaviours* (e.g. him/her being moody, irritable etc); *negative symptoms* (e.g. him/her being withdrawn etc); *stigma* (e.g. experiencing stigma of having a mentally ill relative etc); *problems with services* (e.g. how to deal with mental health professionals etc); *effects on the family* (e.g. how he/she gets on with other family members etc); *loss* (e.g. his/her lost opportunities etc); *dependency* (e.g. being unable to do things you would like etc); *need for backup* (e.g. having to support him/her etc). There is also two positive subscales; *positive personal* *outcomes* (e.g. I have become more understanding of people with problems etc); *good aspects of the relationship with the patient* (e.g. he/she is good company etc) about the carer's experiences. Respondents select a rating on a five point Likert scale from "never" to "nearly always". Subscale scores and total negative and total positive scores can be obtained by adding up the corresponding subscales. Higher scores on the negative scales indicate greater negative perceptions of caregiving whereas higher scores on the positive scales indicate greater positive perceptions of caregiving. This measure has been used with a variety of carers of mental health conditions. Each subscale has been reported to have satisfactory reliability (Cronbach alpha coefficient between 0.74 and 0.91) and the total scale (all 66 items) has also shown good reliability (Cronbach alpha = 0.93)(Sepulveda, Whitney, Hankins, & Treasure, 2008b).

A couple of limitations of this measure are identified. There is an uneven focus on positive and negative experiences of caregiving. More positive aspects of caregiving such as resilience, hope and optimism are not assessed which could balance up the predominantly negative stance. An item on the *loss* subscale asks the carer if they have thought about how he/she (their care recipient) thinks a lot about death. Carers cannot truly know what people are thinking and this item should be reworded to ask whether he/she (their care recipient) talks a lot about death.

Measure of Personal Mastery (MoPM) (Pearlin & Schooler, 1978)

This is a questionnaire (see Appendix D) that measures a *sense of personal mastery*; defined as a person's feeling of control they have over aspects of their life. Mastery is a global construct and this measure does not directly relate to caregiving, however previous research suggests that this is important to carers' wellbeing (Yates et al., 1999). The scale consists of seven items that relate to their overall control of their life (e.g. *my future mostly depends on me*). Two items are reverse scored. Responses are coded on a four point scale from strongly disagree to strongly agree. Total scores range from 7 (high sense of mastery) to 28 (low sense of mastery). The scale has shown satisfactory internal consistency in a variety of studies. Cronbach alpha = 0.78, in Jang, Borenstein-Graves, Haley, Small and Mortimer (2003) and Cronbach alpha = 0.77 in Marshall and Lang (1990).

Measure of Caregiving Competence (MoCC) (Pearlin et al., 1990)

This is a brief questionnaire (see Appendix E) designed to assess the caregivers self competence in providing care. It consists of four items that asks the carer to rate their perceived performance of caregiving. The four items are measured on a four-point Likert scale (total scores range from 0 to 12). A higher score indicates a higher sense of self competence. This is not a comprehensive measure and later researchers have designed more complex tools e.g. Steffen, McKibbin, Zeiss, Gallagher-Thompson and Bandura (2002). It was decided that a simple measure would be satisfactory for this aspect of the study as the use of more complex tools (such as Steffen et al, 2002) could overburden participants. Furthermore, researchers continue to use the MoCC when assessing caregiving competence in relation to the SPM (Hepburn et al., 2005; Rodriguez & Crowther, 2006). Cronbach's alpha of 0.74 was reported indicating satisfactory, and statistically acceptable, internal consistency (Pearlin et al., 1990).

Measure of Expressive Support (MoES) (Pearlin et al., 1990)

This is a questionnaire (see Appendix F) with eight items asking carers to express how much they agree or disagree with statements related to support they feel they have from other people. Participants indicate on a 4 point Likert scale and scores range from 8 to 32, with higher scores representing a perception of increased support. One item is reversed as it asks the question from a negative reference. Like the other measures designed by Pearlin and associates, it has continued to be used in caregiver research e.g. Hayslip, Han and Anderson (2008); and Rose-Rego, Strauss and Smyth (1998). Adequate internal consistency was reported by the measure developers (Cronbach alpha = 0.87) and this has been repeated by independent researchers (Cronbach alpa = 0.89;)(Rose-Rego et al., 1998).

Caregiver Information Questionnaire (CIQ)

A questionnaire (see Appendix G) was designed to gain the following information; age and gender of carer, age and gender of care recipient, relationship of carer to care recipient, care recipients' diagnosis, time since diagnosis, length of time in caring role since diagnosis, carer and care recipient's living arrangements, estimated daily amount of contact time with care recipient, the carer's perceived coping style, and asks whether the carer has a mental health diagnosis. These questions were selected after considering previous research that has identified that these factors can have a potential influence on carer wellbeing.

Procedure

The principle investigator contacted ED carer support group facilitators by email or telephone. Information about the research was sent to the facilitators who were asked to raise it with their carer members. If the support group was involved with the NHS, appropriate R&D procedures were carried out prior to this. If the carer support group was affiliated with a private company or a charity, the principle investigator enquired about the need for local R&D assessment. All group facilitators or service managers were given copies of the NHS ethics approval letter. Once the group facilitators had discussed the research with their members, it was decided how best to proceed. Some carer support groups that had low numbers were sent research packs in the post. Contact details were made clear so that potential participants could contact the principle investigator regarding any questions.

Most carer support groups agreed for the principle investigator to visit their group and discuss the research with them. When the carer support groups were visited it was conveyed that the wellbeing of carers is very important in helping a patient recover from or best manage a severe and enduring illness. It was explained that the research aims were to better identify the needs of carers of people with ED and to highlight differences and similarities between carer groups so that health professionals can be more specific and effective in the support and information they offer. A PowerPoint presentation was conducted (see Appendix H) and the opportunity was given for all potential participants to ask questions. Appendix A shows the groups that received presentations and the groups that were contacted by email and post. It also shows the number of participants secured from each group.

Research packs contained six questionnaires, an information sheet and consent form, a leaflet on available support and a freepost envelope. These were given to interested carers following the presentation or were left with the group facilitator if they felt that other group members who were not present, may be interested. The participant information sheet (see Appendix I) explained the nature of the research and included information on confidentiality and the participants' right to withdraw. The care recipients were not contacted as the aim of the study was to obtain the carers' perspectives. Therefore no clinical data were accessed.

Completed research packs were returned to the University of Leeds and once opened, were stored confidentially as stipulated in the ethics application.

Ethical considerations

This research underwent scrutiny by the NHS Leeds Central Research Ethics Committee and was authorised in June 2010 (REC reference 10/H1313/54). Several R&D departments were contacted and authorised this study when it was necessary before contact with carers support groups were made.

Choice of Methodology

Different methodologies were considered when developing this study. However, qualitative studies regarding the wellbeing of carers of people with ED has previously been conducted (e.g. Honey et al., 2008; Highet, Thompson and

King 2005). There are wellbeing measures available that have good psychometric properties. Zabala et al (2009) highlighted the need to compare wellbeing in carers of different clinical groups. A quantitative approach was deemed the most appropriate method to achieve this.

Data Analysis

Descriptive statistics were performed. Data were visually reviewed using histograms and exploration tests (Levene’s test for homogeneity of variance and Kolmogorov-Smirnov for normal distribution) were conducted to determine that parametric analyses were suitable. Although some variables did not meet these assumptions, most of the primary variables were acceptable. It was acknowledged by the authors of the SF-36 (Ware, Kosinski, & Keller, 1994) that some of the subscales (those with fewer levels) are susceptible to floor and ceiling effects resulting in skewed data. As the current sample of participants was restricted to carers of people with eating disorders, normality on some of the wellbeing subscale scores was not expected.

Data for the number of contact hours did not meet the assumptions of parametric tests; therefore the Kruskal-Wallis test was conducted to check whether there was a difference between the groups defined by length of care.

The first part of the inferential analyses involved comparison of carer wellbeing defined by the SF-36 with community norms. Independent *t* tests were conducted to analyse the differences between subtest scores found in the current research and those expected in a community population. This aimed to address hypothesis one.

Analyses were then focused on determining whether there was a difference in scores between the lengths of time caring for someone with an eating disorder. MANOVAs were conducted, firstly on the subtests of the SF-36 and then on the two summary scales of the SF-36. As four carers did not complete all the questions on the SF-36, the MANOVA analyses were based on 100 responses. This would highlight whether the length of time caring for someone with an eating disorder significantly affected aspects of wellbeing.

As gender differences in carers has been shown repeatedly to have an effect in carer wellbeing studies, predominantly favouring male carers to have better wellbeing, analyses were conducted using MANOVAs. As with the length of care, subtest analysis and summary scale analysis was conducted separately. This aimed to address hypothesis two.

The current data were then analysed by comparing data obtained from carer group outcomes in other published studies. Wellbeing scores (measured by the SF-36) in studies looking at carers of people with dementia, brain injury and ED were used. Independent *t* tests were used to compare means. This aimed to address hypothesis three.

The other measures used in this study (ECI, MoCC, MoPM, MoES) were then analysed. Firstly, the ECI analyses took a similar method to the SF-36 analyses except that it was not possible to compare with any community norms. MANOVAs were conducted on the subtests and on the total summary scales, firstly using length of care as the fixed factor and then using gender as the fixed factor. A comparison of the current ECI scores with another published study (Treasure et al., 2001) was made using independent *t* tests.

As the other measures only produced a total score, analyses between carer gender and the mean scores, and length of care and mean scores were conducted using one way ANOVAs. For each measure the participant numbers in the 0-2 years and the over 6 years (SEED) groups varied slightly due to missing data.

The second part of the analyses involved developing linear regression models to help explain the factors associated with carer wellbeing. This was done to assess whether any of the variables identified in the SPM were predictive of the data provided by carers of people with ED and how much of the variance was explained by these variables. This addressed hypothesis four. Exploratory analyses were conducted for each predictor variable entered into the models to ensure the outputs were robust. Three regression models were developed. First, all the main dependent variables and known factors (from previous research) that could be associated with wellbeing were analysed. Secondly, the subscales of the ECI were entered, and thirdly those predictor variables that were considered most influential were entered into a model. Previous research using the SPM has indicated that all the "resources" in the model may have a helpful effect on carer wellbeing, whether directly or as a mediator (Au et al., 2009; Gaugler et al., 2009).

RESULTS

Characteristics of carers and their recipients

The demographic data obtained from the CIQ are summarized in Table 1. Frequencies can be seen for the whole sample as well as by reported length of care (<2 years, 2-6 years, >6 years).

Length of care **N(% of sample)**	**0- 2 years** **35 (33.3%)**	**2-6 years** **35 (33.3%)**	**Over 6 years** **34(32.4%)**	**Whole sample** **104**
Carer Sex Ratio (m/f)	7/28	6/29	15/19	28/76
Carer Age groups	**35**	**35**	**34**	**104**
18-30	2	4	0	6
31-40	4	1	2	7
41-50	19	10	5	34
51-60	9	16	18	43
61-70	1	4	9	14
Recipient Sex Ratio (m/f)	3/32	5/30	3/31	11/93
Recipient Age groups	**35**	**35**	**34**	**104**
Under 18	12	8	0	20
18-30	23	23	24	70
31-40	0	3	6	9
41-50	0	1	1	2
51-60	0	0	2	2
61-70	0	0	1	1
Relationship	**35**	**35**	**34**	**104**
Parent	32	30	27	89
Sibling	1	2	0	3
Spouse	0	1	6	7
Friend	1	0	0	1
Other	1	2	1	4
Diagnosis	**35**	**35**	**34**	**104**
Anorexia	28	27	21	76
Bulimia	5	4	5	14
Anorexia and Bulimia	0	2	7	9
Other ED	1	2	1	4
No stated diagnosis	1	0	0	1
Median diagnosis date	December 2009	October 2007	May 2001	March 2008
Live together	**35**	**35**	**34**	**104**
Yes	26	23	16	65
No	9	12	18	39

Table 1 Demographics of carers and recipients of care

The majority of carers were female (73%) and cared for someone with a diagnosis of AN (73%). Furthermore, 86% of carers were a parent of the care recipient. This is consistent with the age group stated by carers as 88% were 41 years or older. Sixty three percent of the carers stated that they lived with their recipient.

The care recipients were also predominantly female (89%). Sixty eight percent of the care recipients were aged between 18 to 30 years.

When the respondents were grouped by length of care there was a significant association between length of care and carer gender (χ^2 (2, N=104) = 7.66, p = 0.02), with proportionately more male carers in the over 6 years group (SEED). This imbalance was clarified by a chi-square analysis. There was a significant association between carer gender and classification as carers of SEED (χ^2 (1, N=104) = 6.35, p = 0.01). There was no significant association between length of care and living together (χ^2 (2, N=104) = 5.69, p = 0.06).

Table 2 presents the frequencies for other carer variables obtained from the CIQ. Carers predominantly reported behavioural coping strategies such as going for a walk (47%) or cognitive strategies such as thinking of happier times (38%). Sixteen percent of care recipients were reported to be in hospital at the time of questionnaire completion. In terms of existing psychiatric diagnosis, 13% of the carer sample reported this.

	0-2 years	**2-6 years**	**over 6 years**	**Whole sample**
Recipient in hospital	**35**	**35**	**34**	**104**
Yes	6	5	6	17
No	21	22	20	63
Missing Data	8	8	8	24
Coping Style	**35**	**35**	**34**	**104**
Doing	19	13	17	49
Thinking	13	17	10	40
Feeling	0	2	1	3
Missing Data	3	3	6	12
Carer Psychiatric Diagnosis	**35**	**35**	**34**	**104**
Yes	5	5	2	12
No	29	30	32	91
Missing Data	1	0	0	1
Contact in hours (SD)	**7.1 (6.7)**	**6.4 (6)**	**5.6 (6.5)**	**6.3 (6.4)**

Table 2 Frequencies of carer and recipient factors

Table 2 also displays the mean number of reported hours per day the carer had contact with the care recipient. It revealed that there was no significant difference between the three carer groups in the hours of contact they reported to have with their care recipients (*H*(2) = 1.1, p = 0.58.

Comparison of carer wellbeing with community norms

The wellbeing of the whole sample of carers was compared to the community norms provided by the SF-36 authors (Ware et al., 1994). Two carers (and on some subscales three carers) did not complete enough questions on a particular subtest to calculate a score, therefore the analyses involved 102 (or 101) carers. It can be seen in Table 3 that the perceived wellbeing scores of carers of people with ED was significantly lower on every subscale except Physical Functioning, when compared to community norms.

SF-36	***N***	**Current whole sample (SD)**	***N***	**Community norms (SD)**	**Statistic**
Physical Functioning	102	86.7 (17.7)	2474	84.2 (23.3)	*t*(2574) = 1.07, p= 0.28
Physical Role	101	68.1 (41.2)	2474	80.9 (34.0)	*t*(2573) = 3.68, p= <0.01*
Bodily Pain	102	69.8 (24.5)	2474	75.2 (23.7)	*t*(2574) = 2.25, p= 0.02*
General Health	102	66.1 (20.5)	2474	71.9 (20.3)	*t*(2574) = 2.83, p= <0.01*
Vitality	102	45.7 (20.9)	2474	60.9 (20.9)	*t*(2574) = 7.20, p= <0.01*
Social Functioning	102	65.8 (25.8)	2474	83.3 (22.7)	*t*(2574) = 7.59, p= <0.01*
Emotional Role	102	61.1 (42.0)	2474	81.3 (33.0)	*t*(2574) = 5.99, p= <0.01*
Mental Health	102	60.4 (16.7)	2474	74.7 (18.1)	*t*(2574) = 7.84, p= <0.01*
Physical Summary	101	50.3 (10.0)	2474	50.0 (10.0)	*t*(2573) = 0.30, p= 0.77
Mental Summary	101	40.0 (11.9)	2474	50.0 (10.0)	*t*(2573) = 9.77, p= <0.01*

Table 3 Wellbeing of carers compared with community norms (Ware et al., 1994)

*indicates significance at 0.05 level

All of the subscale scores (except Physical Functioning) indicated that carers reported a significantly less wellbeing than people in the community generally. The Mental Summary scale scores were significantly different indicating less mental wellbeing in carers. However, the Physical Summary scale scores were not significantly different between carers and community norms.

Carer wellbeing by length of care

To determine whether the length of time caring for someone with an eating disorder impacted on wellbeing, a MANOVA was conducted using the eight subscales of the SF-36 as the dependant variables and the length of care being the fixed factor. Table 4 displays the univariate analysis, alongside means and standard deviations for each variable. There was no significant effect of length of care on carer wellbeing defined by the eight subscales, *V* = 0.14, *F* (16, 182) = 0.83, p = 0.65. There was no evidence that longer-term carers had greater impaired wellbeing as defined by the SF-36.

SF-36 *N =*	**Whole** **100 (SD)**	**0-2 years** **33 (SD)**	**2-6 years** **33 (SD)**	**over 6 years** **34 (SD)**	**Statistic**
Physical Functioning	86.7 (17.7)	87.6 (18.6)	84 (20.9)	89.1 (12.8)	F=0.90, p=0.41
Physical Role	68.1 (41.2)	62.9 (44.3)	61.4 (42)	80.2 (36.3)	F=2.19, p=0.12
Bodily Pain	69.8 (24.5)	73.6 (27.8)	66.9 (24.7)	70.3 (20.3)	F=0.50, p=0.61
General Health	66.1 (20.5)	64.1 (20.9)	63.5 (22)	70.7 (18.6)	F=1.46, p=0.24
Vitality	45.7 (20.9)	42.1 (19.8)	43.5 (21.1)	50.6 (21.3)	F=1.80, p=0.17
Social Functioning	65.8 (25.8)	61.4 (25.1)	63.6 (25.6)	71.7 (26.5)	F=1.50, p=0.22
Emotional Role	61.1 (42)	58.6 (44.9)	51 (40.4)	72.6 (38.9)	F=2.65, p=0.08
Mental Health	60.4 (16.7)	59.2 (16.8)	58.5 (16.1)	63.1 (17.1)	F=0.87, p=0.42

Table 4 SF-36 subscales analyses by length of care

A further MANOVA was conducted using the two summary scales of the SF-36. Again, there was no significant effect of length of care on carer wellbeing defined by the two summary scales, *V* = 0.05, *F* (4, 194) = 1.29, p = 0.27. Although not significant it can be seen that the 2-6 year group reported poorest wellbeing on these two summary scales and the over 6 year group (SEED) reported the best wellbeing when comparing the three groups (Table 5).

SF-36 ***N* =**	**Whole** **100 (SD)**	**0-2 years** **33 (SD)**	**2-6 years** **33 (SD)**	**over 6 years** **34 (SD)**	**Statistic**
Physical Summary	50.5 (9.9)	50.5 (11.8)	49.2 (9.9)	51.7 (8.0)	F=0.50, p=0.61
Mental Summary	39.8 (11.8)	38.5 (12.7)	38.0 (10.3)	42.9 (12.1)	F=1.77, p=0.18

Table 5 SF-36 summary scales analyses by length of care

Carer wellbeing by gender

As gender has consistently been shown to be an important factor in carer wellbeing studies and to address hypothesis 2, analyses were conducted by gender. Table 6 displays the means, standard deviations and *t* test analyses of each subscale of the SF-36.

SF-36 ***N* =**	**Whole** **101 (SD)**	**Male** **28 (SD)**	**Female** **73 (SD)**	**Statistic**
Physical Functioning	86.5 (17.8)	91.1 (10.2)	84.8 (19.7)	F=2.56, p=0.11
Physical Role	68.1 (41.2)	76.8 (37.2)	64.7 (42.5)	F=1.74, p=0.19
Bodily Pain	70.1 (24.4)	71.1 (24.6)	69.8 (24.5)	F=0.06, p=0.81
General Health	65.9 (20.5)	67.5 (18.8)	65.3 (21.2)	F=0.24, p=0.63
Vitality	45.4 (20.8)	51.4 (18.9)	43.1 (21.2)	F=3.33, p=0.07
Social Functioning	65.7 (26)	72.3 (22.4)	63.2 (26.9)	F=2.55, p=0.11
Emotional Role	60.7 (42)	73.8 (34.4)	55.7 (43.8)	F=3.87, p=0.05*
Mental Health	60.3 (16.7)	64.9 (15.9)	58.5 (16.7)	F=2.98, p=0.09

Table 6 SF-36 subscales analyses by gender

*indicates significance at 0.05 level

A MANOVA revealed that there was no significant effect of carer gender on overall wellbeing, V = 0.09, F (8, 92) = 1.18, p = 0.32. Nor was there a significant effect of carer gender on carer wellbeing defined by the two summary scales, V = 0.04, F (2, 98) = 2.18, p = 0.12 (Table 7).

SF-36 ***N* =**	**Whole** **101**	**Male** **28**	**Female** **73**	**Statistic**
Physical Summary	50.3 (10)	51.1 (7.8)	50 (10.8)	F=0.25, p=0.62
Mental Summary	40 (11.9)	43.6 (10.6)	38.6 (12.2)	F=3.63, p=0.06

Table 7 SF-36 summary scales analyses by carer gender

Carers' wellbeing across health conditions.

Dementia

To address hypothesis 3, the current data were compared to wellbeing data generated by the SF-36 in other carer studies. Firstly, the data were compared with carers of people with dementia (Table 8). As Argimon et al. (2004) have only given SF-36 data by gender, it was not possible to compare a mixed gender group with a mixed gender group. As it has already been identified that there were no significant gender differences in the current data, the analyses conducted made two comparisons - female dementia carers with female eating disorder carers; female dementia carers with mixed carers of SEED.

The results in Table 8 identified that carers of people with ED reported that they had significantly better wellbeing in terms of physical functioning when compared to female carers of people with dementia. It also shows that female carers of people with ED reported significantly better wellbeing in bodily pain and general health when compared to female carers of people with dementia.

It shows that carers of people with SEED reported significantly less bodily pain, better physical functioning, better physical role and better general health than female carers of people with dementia. However, it should be noted that in the Argimon et al. (2004) study 54% of carers were over 65 years old, whereas in the current study 87% of carers were below 60 years old.

	Argimon, Limon, Vila, & Cabezas, (2004) – Carers of people with dementia.	**Current sample**		**Statistics**
			Gender mixed (m=15, f=19)	
SF-36 subscales	**Female (n=141) Mean (SD)**	**Female (n=73) Mean (SD)**	**Over 6 years (SEED) (n=34) Mean (SD)**	
Physical Functioning	73.8 (21.0)	84.8 (19.7)	89.1 (12.8)	1. _t_(212) = 3.71, p= <0.01* 2. _t_(173) = 4.06, p= <0.01*
Physical Role	65.4 (38.7)	64.7 (42.5)	80.2 (36.3)	1. _t_(212) = 0.12, p= 0.9 2. _t_(173) = 2.03, p= 0.04*
Bodily Pain	44.7 (33.2)	69.8 (24.5)	70.3 (20.3)	1. _t_(212) = 5.7, p= <0.01* 2. _t_(173) = 4.3, p= <0.01*
General Health	54.0 (24.9)	65.3 (21.2)	70.7 (18.6)	1. _t_(212) = 3.31, p= <0.01* 2. _t_(173) = 3.67, p= <0.01*
Vitality	49.3 (29.0)	43.1 (21.2)	50.6 (21.3)	1. _t_(212) = 1.62, p= 0.11 2. _t_(173) = 0.25, p= 0.81
Social Functioning	73.8 (35.5)	63.2 (26.9)	71.7 (26.5)	1. _t_(212) = 2.24, p= 0.03* 2. _t_(173) = 0.32, p= 0.75
Emotional Role	53.0 (42.6)	55.7 (43.8)	72.6 (38.9)	1. _t_(212) = 0.44, p= 0.66 2. _t_(173) = 2.45, p= 0.02*
Mental Health	51.3 (25.3)	58.5 (16.7)	63.1 (17.1)	1. _t_(212) = 2.2, p= 0.03* 2. _t_(173) = 2.58, p= 0.01*
Physical Summary	46.1 (10.0)	50.0 (10.8)	51.7 (8.0)	1. _t_(212) = 2.63, p= 0.01* 2. _t_(173) = 3.04, p= <0.01*
Mental Summary	38.3 (16.0)	38.6 (12.2)	42.9 (12.1)	1. _t_(212) = 0.14, p= 0.89 2. _t_(173) = 1.57, p= 0.12

Table 8 Wellbeing of carers of people with SEED and female carers of people with ED compared with carers of people with dementia

*indicates significance at 0.05 level

1. Female carers of people with dementia compared with female carers of people with ED

2. Female carers of people with dementia compared mixed gender carers of people with SEED (over 6 years)

As would be expected, the reported scores on the physical summary scale indicated significantly worse physical wellbeing for female carers of people with dementia. When looking at the psychological wellbeing subscales, differences in scores were less evident. Female carers of people with ED reported significantly poorer social functioning than female carers of people with dementia. They also reported significantly better mental health.

The carers of people with SEED reported significantly better wellbeing than the female carers of people with dementia on the emotional role and mental health subscales. However, the mental summary scale analyses found no significant differences between the groups on mental wellbeing. There were also no significant differences between the female carers of people with ED or the carers of people with SEED and the female carers of people with dementia on vitality scores.

Brain Injury

The current results of carer wellbeing were compared to carers of people with brain injury (McPherson et al., 2000). No summary scale scores of the SF-36 were reported but the subscale scores were available. The data were compared with the whole group of carers of people with ED and then with the carers of people with SEED (over 6 years). McPherson et al reported the modal age of their carer group to be between 40 and 50 years, 54% spouses and 36% parents. This more closely matched the current data than the comparison study with carers of people with dementia. The modal age of carers of people with ED was 51 to 60 years, 79% were parents and 18% spouses. Table 9 displays the comparisons between the two carer groups.

	McPherson, Pentland & McNaughton (2000) – Carers of people with brain injury	**Current sample Whole**	**Current sample – Over 6 years (SEED)**	**Statistics**
SF-36 subscales	**(n=70)** **Mixed gender split not specified**	**(n=101)** **73 female, 28 male** **Mean (SD)**	**(n=34)** **19 female, 15 male)** **Mean (SD)**	
Physical Functioning	83.1 (23.9)	86.5 (17.8)	89.1 (12.8)	1. *t*(169) = 1.07, p= 0.29 2. *t*(102) = 1.37, p= 0.17
Physical Role	71.8 (38.5)	68.1 (41.2)	80.2 (36.3)	1. *t*(169) = 0.59, p= 0.55 2. *t*(102) = 1.06, p= 0.29
Bodily Pain	80.1 (28.5)	70.1 (24.4)	70.3 (20.3)	1. *t*(169) = 2.46, p= 0.02* 2. *t*(102) = 1.79, p= 0.08
General Health	73.1 (22.9)	65.9 (20.5)	70.7 (18.6)	1. *t*(169) = 2.15, p= 0.03* 2. *t*(102) = 0.53, p= 0.60
Vitality	57.8 (23.7)	45.4 (20.8)	50.6 (21.3)	1. *t*(169) = 3.62, p=<0.01* 2. *t*(102) = 1.50, p= 0.14
Social Functioning	81.8 (25.3)	65.7 (26.0)	71.7 (26.5)	1. *t*(169) = 4.03, p=<0.01* 2. *t*(102) = 1.88, p= 0.06
Emotional Role	71.0 (38.7)	60.7 (42.0)	72.6 (38.9)	1. *t*(169) = 1.63, p= 0.11 2. *t*(102) = 0.20, p= 0.84
Mental Health	68.8 (21.0)	60.3 (16.7)	63.1 (17.1)	1. *t*(169) = 2.94, p=<0.01* 2. *t*(102) = 1.38, p= 0.17

Table 9 Wellbeing of the whole sample of carers and the carers of people with SEED compared with carers of people with brain injury.

*indicates significance at 0.05 level

1. Carers of people with brain injury compared with carers of people with ED

2. Carers of people with brain injury compared with carers of people with SEED (over 6 years)

The analyses identified that carers of people with ED reported significantly worse bodily pain, significantly poorer general health, vitality, social functioning and mental health when compared to carers of people with brain injury. It seems that they viewed their wellbeing to be poorer than the carers of people with brain injury. When carers of people with SEED were compared to carers of people with brain injury, it can be seen in Table 9 that there were no significant differences in wellbeing scores. The carers in the

McPherson et al study reported a mean time of care since injury as 17.6 months (SD 2.6), which is considerably shorter in duration than the carers of people with SEED and the whole group of carers of people with ED generally.

Eating Disorders

Only one study has used the SF-36 to measure carers' wellbeing when caring for people with ED (De La Rie et al., 2005). They did not report the overall summary scales so it was only possible to compare the eight individual subscales. They reported that their carers had a mean caring length of 3.5 years (SD 3.5) which was similar to the whole sample of current group of carers. The mean age of carers in the De La Rie study was 46 years (SD 10.7) which was also similar to the current sample. Table 10 displays the comparison analyses of data from the two studies.

When the current whole sample of carers was compared to De La Rie's sample of carers of people with ED, it can be seen that in six of the eight subtests there were no significant differences between the scores. Bodily pain was reported to be significantly worse in the carers in the current study. These carers also reported vitality to be significantly worse when compared to those scores found by De La Rie et al.

When comparing De La Rie's results with carers of people with SEED (over 6 years) it can be seen that in seven of the eight subtests there were no significant differences between the scores. However, carers in the current study reported significantly worse bodily pain.

	De La Rie et al., (2005) – Carers of people with an eating disorder.	**Current sample Whole**	**Current sample Over 6 years (SEED)**	**Statistics**
SF-36 subscales	**(n=40) 25 female, 15 male Mean (SD)**	**(n=101) 73 female, 28 male Mean (SD)**	**(n=34) 19 female, 015 male) Mean (SD)**	
Physical Functioning	90.4 (11.7)	86.5 (17.8)	89.1 (12.8)	1. *t*(139)= 1.28, p= 0.20 2. *t*(72) = 0.46, p= 0.65
Physical Role	75.6 (35.1)	68.1 (41.2)	80.2 (36.3)	1. *t*(139)= 0.31, p= 0.31 2. *t*(72) = 0.55, p= 0.58
Bodily Pain	82.8 (19.0)	70.1 (24.4)	70.3 (20.3)	1. *t*(139)= 2.95, p= <0.01* 2. *t*(72) = 2.73, p= <0.01*
General Health	72.4 (14.2)	65.9 (20.5)	70.7 (18.6)	1. *t*(139)= 1.84, p= 0.07 2. *t*(72) = 0.45, p= 0.66
Vitality	56.2 (17.0)	45.4 (20.8)	50.6 (21.3)	1. *t*(139)= 2.92, p= <0.01* 2. *t*(72) = 1.26, p= 0.21
Social Functioning	73.4 (20.3)	65.7 (26.0)	71.7 (26.5)	1. *t*(139)= 1.68, p= 0.10 2. *t*(72) = 0.31, p= 0.76
Emotional Role	56.4 (42.0)	60.7 (42.0)	72.6 (38.9)	1. *t*(139)= 0.55, p= 0.58 2. *t*(72) = 1.71, p= 0.09
Mental Health	61.6 (16.5)	60.3 (16.7)	63.1 (17.1)	1. *t*(139)= 0.42, p= 0.68 2. *t*(72) = 0.38, p= 0.70

Table 10 Wellbeing of female carers from the current whole sample and mixed gender carers of people with SEED, compared with the wellbeing of carers of people with ED found by De La Rie (2005).

*indicates significance at 0.05 level

1. Carers of people with ED in the De La Rie study compared with the current carers of people with ED

2. Carers of people with ED in the De La Rie study compared with the current carers of people with SEED

Analyses of caregiving experiences

Experience of caregiving by length of care

To determine whether length of care had an impact on the carers' experience of caregiving a MANOVA was conducted using the ten subscales of the ECI as the dependant variables and the length of care being the fixed factor. Table 11 displays the univariate analysis, alongside means and standard deviations for each variable. There was a significant effect of length of care on carers' experiences of caregiving as defined by the ten subscales, *V* = 0.35, *F* (20, 178) = 1.90, p = 0.02.

ECI ***N* =**	**Whole sample** **100** **Mean (SD)**	**0-2 years** **33** **Mean (SD)**	**2-6 years** **33** **Mean (SD)**	**Over 6 years** **34** **Mean (SD)**	**Statistic**
Difficult behaviours	14.6 (7.8)	15.0 (8.7)	15.2 (7.8)	13.5 (6.9)	F=0.50, p=0.61
Negative symptoms	12.4 (6.6)	13.4 (7.1)	13.6 (6.2)	10.3 (6.1)	F=2.70, p=0.07
Stigma	6.4 (4.0)	6.3 (3.7)	6.8 (3.9)	6.2 (4.5)	F=0.23, p=0.80
Problems with services	14.1 (7.4)	14.1 (7.3)	14.4 (7.2)	13.9 (8.0)	F=0.04, p=0.97
Effects on family	12.2 (6.3)	13.2 (7.1)	12.7 (5.2)	10.7 (6.5)	F=1.51, p=0.23
Need for back up	8.8 (5.3)	8.3 (5.7)	8.9 (4.8)	9.2 (5.5)	F=0.28, p=0.76
Dependency	11.2 (4.3)	12.3 (4.6)	10.8 (2.8)	10.5 (5.1)	F=1.75, p=0.18
Loss	13.1 (5.4)	12.7 (5.6)	13.6 (5.0)	13.2 (5.7)	F=0.20, p=0.82
Positive experiences	16.4 (5.4)	17.2 (5.7)	17.9 (4.3)	14.0 (5.5)	F=5.49, p=<0.01*
Good aspects of relationship	13.7 (4.1)	14.2 (4.2)	13.9 (3.3)	12.9 (4.6)	F=0.95, p=0.39

Table 11 Experiences of caregiving across carers with different lengths of caring (subscales).

*indicates significance at 0.05 level

Although the overall MANOVA was significant, only one subscale was found to distinguish the groups in the univariate analyses. Positive experiences scores were significantly lower in the carers of people with SEED (over 6 years). This shows that people who had cared for someone with an eating disorder for a longer period of time perceived themselves to have fewer positive experiences.

A MANOVA was conducted using the two summary scales of the ECI. There was no significant effect of length of care on carers' experiences of caregiving as defined by the two summary scales, *V* = 0.08, *F* (4, 194) = 1.95, p = 0.11.

Experience of caregiving by gender

To determine whether gender had an impact on the carers' experiences of caregiving MANOVAs were conducted, first on the 10 subscales of the ECI (Table 13) and then on the total summary scales of the ECI (Table 14). There was no significant effect of gender on carers' experiences of caregiving as defined by the ten subscales, V = 0.16, F (10, 89) = 1.75, p = 0.08. However, when inspecting the mean scores it can be seen that male carers reported fewer positive experiences of caregiving and thought that their care recipient was less dependent on them.

ECI ***N* =**	**Whole** **100** **Mean (SD)**	**Male** **27** **Mean (SD)**	**Female** **73** **Mean (SD)**	**Statistic**
Difficult behaviours	14.6 (7.8)	14.1 (6.2)	14.7 (8.3)	F=0.12, p=0.73
Negative symptoms	12.4 (6.6)	11.5 (5.6)	12.8 (7.0)	F=0.69, p=0.41
Stigma	6.4 (4.0)	5.4 (3.6)	6.8 (4.1)	F=2.61, p=0.11
Problems with services	14.1 (7.4)	14.4 (6.7)	14.0 (7.7)	F=0.05, p=0.83
Effects on family	12.2 (6.3)	11.9 (5.4)	12.3 (6.7)	F=0.09, p=0.77
Need for back up	8.8 (5.3)	8.2 (5.1)	9.0 (5.4)	F=0.44, p=0.51
Dependency	11.2 (4.3)	9.7 (3.7)	11.8 (4.4)	F=4.81, p=0.03*
Loss	13.1 (5.4)	12.3 (4.4)	13.5 (5.7)	F=0.96, p=0.33
Positive experiences	16.4 (5.4)	14.1 (6.4)	17.2 (4.8)	F=6.74, p=0.01*
Good aspects of relationship	13.7 (4.1)	12.5 (4.2)	14.1 (4.0)	F=3.27, p=0.07

Table 12 Experiences of caregiving by carer gender (subscales)

*indicates significance at 0.05 level

There was a significant effect of carer gender on carers' experiences of caregiving defined by the two total summary scales, *V* = 0.07, *F* (2, 97) = 3.41, p = 0.04.

ECI ***N* =**	**Whole** **100** **Mean (SD)**	**Male** **27** **Mean (SD)**	**Female** **73** **Mean (SD)**	**Statistic**
Total Positives	30.0 (8.5)	26.6 (9.2)	31.3 (8.0)	F=6.35, p=0.01*
Total Negative	92.8 (35.9)	87.4 (26.2)	94.8 (38.8)	F=0.84, p=0.36

Table 13 Experiences of caregiving by carer gender (summary scales)

*indicates significance at 0.05 level

It can be seen that the total positive scores were significantly different between gender. Male carers reported fewer positive aspects of caregiving. Furthermore, although not at a significant level it can be seen that male carers also reported slightly fewer negative aspects of caregiving.

Experience of caregiving across studies

As experiences of caregiving have been found to be significantly different across length of care, the following analyses compared data from other studies with the carers of people with SEED group (over 6 years). The data from Treasure et al. (2001) was used to compare the current scores with those of carers of people with psychosis and carers of people with AN. Table 15 shows the means, standard deviations and independent *t* test results.

	Current sample	**Treasure et al. (2001)**		**Statistic**
ECI ***N* = ( )**	**Over 6 years SEED (34)**	**Carers: Anorexia (71)**	**Carers: Psychosis (68)**	
Difficult behaviours	13.5 (6.9)	12.9 (7.4)	7.7 (6.4)	1. *t*(103) = 0.40, p= 0.69 2. *t*(100) = 4.20, p=<0.01* *
Negative symptoms	10.3 (6.1)	10.3 (6.4)	7.7 (6.5)	1. *t*(103) = 0.00, p= 1.00 2. *t*(100) = 1.94, p= 0.05
Stigma	6.2 (4.5)	5.3 (4.2)	3.5 (3.9)	1. *t*(103) = 1.00, p= 0.32 2. *t*(100) = 3.13, p=<0.01**
Problems with services	13.9 (8.0)	12.7 (7.7)	8.5 (6.2)	1. *t*(103) = 0.74, p= 0.46 2. *t*(100) = 3.76, p=<0.01**
Effects on family	10.7 (6.5)	11.0 (6.2)	6.7 (5.1)	1. *t*(103) = 0.23, p= 0.82 2. *t*(100) = 3.40, p=<0.01**
Need for back up	9.2 (5.5)	8.7 (5.0)	8.5 (5.0)	1. *t*(103) = 0.46, p= 0.64 2. *t*(100) = 0.64, p= 0.52
Dependency	10.5 (5.1)	11.2 (4.3)	7.9 (4.9)	1. *t*(103) = 0.73, p= 0.46 2. *t*(100) = 2.49, p= 0.01**
Loss	13.2 (5.7)	15.2 (5.9)	8.6 (5.2)	1. *t*(103) = 1.64, p= 0.10 2. *t*(100) = 4.08, p=<0.01**
Positive experiences	14.0 (5.5)	13.9 (5.8)	14.1 (6.9)	1. *t*(103) = 0.08, p= 0.93 2. *t*(100) = 0.07, p= 0.94
Good aspects of relationship	12.9 (4.6)	14.2 (4.3)	12.3 (4.5)	1. *t*(103) = 1.42, p= 0.16 2. *t*(100) = 0.63, p= 0.53
ECI total positive	26.9 (8.5)	28.0 (8.8)	26.4 (9.7)	1. *t*(103) = 0.61, p= 0.55 2. *t*(100) = 0.26, p= 0.80
ECI total negative	87.5 (34.1)	84.0 (35.0)	59.1 (32.0)	1. *t*(103) = 0.48, p= 0.63 2. *t*(100) = 4.13, p=<0.01**

Table 14 Experiences of caregiving across conditions

**indicates significance at 0.01 level

1. Carers of people with Anorexia compared with the current carers of people with SEED

2. Carers of people with Psychosis compared with the current carers of people with SEED

From Table 14 it can be seen that there were no significant differences between the carers of people with SEED and the carers of people with AN found by Treasure et al. Consequently, and as Treasure et al reported, there were significant differences (at 0.01 level) in six of the eight negative subscales when compared with carers of people with psychosis. Carers of people with SEED reported significantly higher scores (poorer perceptions) in difficult behaviours, stigma, problems with services, effects on family, dependency and loss.

Consequently the negative total score was also significantly different to carers of people with psychosis. In terms of positive aspects of caregiving there were no significant differences between the scores reported by the carer groups. Due to multiple testing on this part of the analysis, the alpha level was increased from 0.05 to 0.01 to ensure robust results and reduce the possibility of error. Only variables significant at p=0.01 were then used in the multiple regression analyses.

Caregiving competence, personal mastery and expressive support.

The means, standard deviations and one way ANOVA analyses of the three measures across the length of care are shown in Table 15. It can be seen that there were no significant differences across the groups in the amounts of reported caregiving competence, personal mastery or expressive support.

Other measures	**Whole**	**0-2 years**	**2-6 years**	**over 6 years**	**Statistic**
MoCC	8.0 (2.2)	7.6 (2.7)	8.1 (2.0)	8.2 (1.8)	F= 0.74, p= 0.48
MoPM	16.1 (3.3)	16.7 (3.4)	15.9 (2.8)	15.7 (3.6)	F= 0.87, p= 0.42
MoES	24.7 (4.3)	24.4 (4.0)	25.0 (4.5)	24.7 (4.4)	F= 0.17, p= 0.84

Table 15 Data from the other measures across length of care.

Gender of carer also had no impact on caregiving competence, personal mastery or expressive support.

Associations with wellbeing

Correlation coefficients were calculated to determine the relationships between the measured variables and wellbeing as defined by the SF-36. Table 16 is a correlation matrix showing the correlations between scores.

	Physical Summary	**Mental Summary**	**ECI Total Positives**	**ECI Total Negative**	**MoCC Total**	**MoPM Total**	**MoES Total**
SF-36Physical Summary	1.00	-.18	-.06	-.14	-.13	-.15	.08
SF-36 Mental Summary		1.00	-.09	-.53**	.19	-.36**	.17
ECI Total Positives			1.00	.10	.34**	.03	.09
ECI Total Negative				1.00	-.19	.49**	-.07
MoCC Total					1.00	-.24	.17
MoPM Total						1.00	-.24
MoES Total							1.00

Table 16 The correlations for the main total and summary scores.

** Correlation is significant at 0.01 level

Table 16 shows that physical wellbeing scores (SF-36 Physical Summary) did not correlate at a significant level with any of the other main scores. However, mental wellbeing scores (SF-36 Mental Summary) were significantly related to the ECI Total Negative scores (*r* = -.53, p=<0.01). This was a negative correlation indicating that lower scores on the SF-36 Mental Summary (less mental wellbeing) were associated with higher scores on the ECI (more negative perceptions). The Pearson's *r* score of -.53 indicated that 29% of the variation in the SF-36 Mental Summary scores were accounted for by the variation in the ECI Total Negative scores.

Mental wellbeing scores (SF-36 Mental Summary) were also significantly related to the personal mastery (MoPM Total) scores (*r* = -.36, p=<0.01). Lower scores on the SF-36 (less mental wellbeing) were associated with higher scores on the MoPM (lower personal mastery). The Pearson's *r* score of -.36 indicated that 13% of the variation in the SF-36 Mental Summary scores were accounted for by the variation in the MoPM scores.

A correlation matrix was also constructed to show the relationships between carer wellbeing (as defined by the SF-36 summary scales) and the ECI subscales (see Table 17).

Physical wellbeing scores (SF-36 Physical Summary) correlated significantly with Problems with Services scores (*r* = -.27, p=<0.01). Lower scores on the SF-36 Physical Summary (less physical wellbeing) was associated with higher scores (more negative perceptions) on the Problems with Services and Effects on Family subscales.

Mental wellbeing scores (SF-36 Mental Summary) correlated significantly with Difficult Behaviours (*r* = -.46, p=<0.01), Negative Symptoms (*r* = -.43, p=<0.01), Stigma (*r* = -.38, p=<0.01), Problems with Services (*r* = -.30, p=<0.01), Effects on Family (*r* = -.40, p=<0.01), Need for Back-up (*r* = -.36, p=<0.01), Dependency (*r* = -.53, p=<0.01) and Loss (*r* = -.39, p=<0.01).

	SF-36 Physical Summary	**SF-36 Mental Summary**
SF-36 Physical Summary	1.00	-.18
SF-36 Mental Summary	-.18	1.00
Difficult behaviours	-09	-.46**
Negative symptoms	-.05	-.43**
Stigma	-.08	-.38**
Problems with services	-.27**	-.30**
Effects on family	-.20	-.40**
Need for back up	-.04	-.36**
Dependency	-.06	-.53**
Loss	.02	-.39**
Positive experiences	.02	-.09
Good aspects of relationship	-.14	-.07

Table 17 The correlations for carer wellbeing and the subscales of the ECI.

** Correlation is significant at 0.01 level

All of these correlations were negative indicating that less mental wellbeing was associated with more negative perceptions in these areas. The strongest correlation (*r* = -.53 for Dependency), indicated that 29% of the variation in the SF-36 Mental Summary scores were accounted for by the variation in the Dependency scores.

Correlation analyses were conducted between the eight subscales of the SF-36 and the eight subscales of the ECI negative total. Table 18 shows the relationship between specific areas of wellbeing and specific areas of caregivers' experiences. There was a strong correlation between Bodily Pain scores and

Difficult Behaviour scores (*r* = .77, p=<0.01). This positive correlation indicated that low scores on Bodily Pain (less wellbeing) were associated with low scores on Difficult Behaviour (fewer negative perceptions). The Pearson's *r* score of .77 indicated that 59% of the variation in the Bodily Pain scores was accounted for by the variation in the Difficult Behaviour scores. Physical Role (*r* = .69, p=<0.01) and General Health (*r* = .72, p=<0.01) also had strong positive correlations with Difficult Behaviours, yet the other SF-36 subscale that makes up physical wellbeing (Physical Functioning) did not.

Finally, a moderate negative correlation was found between Mental Health scores and Stigma (*r* = -.39, p=<0.01). This indicated that low scores on Mental Health (less wellbeing) were associated with high scores on Stigma (more negative perceptions).

	Physical Functioning	Physical Role	Bodily Pain	General Health	Vitality	Social Functioning	Emotional Role	Mental Health	Difficult behaviours	Negative symptoms	Stigma	Problems with services	Effects on family	Need for back up	Dependency	Loss
Physical Functioning	1.00	.40 **	.54 **	.60 **	.32 **	.22	.14	.15	-.08	-.07	-.12	-.17	-.11	-.13	-.05	-.02
Physical Role		1.00	.45 **	.59 **	.50 **	.44 **	.45 **	.35 **	.69 **	.32 **	-.32 **	-.24	-.27 **	-.41 **	-.43 **	-.14
Bodily Pain			1.00	.42 **	.35 **	.26 **	.06	.16	.77 **	.01	-.08	-.05	-.11	-.24	-.19	-.08
General Health				1.00	.50 **	.39 **	.34 **	.30 **	.72 **	.24	-.30 **	-.24	-.21	-.31 **	-.29 **	-.13
Vitality					1.00	.52 **	.43 **	.72 **	-.37 **	-.37 **	-.25	-.29 **	-.37 **	-.35 **	-.40 **	-.27 **
Social Functioning						1.00	.64 **	.59 **	-.41 **	-.38 **	-.27 **	-.40 **	-.39 **	-.31 **	-.46 **	-.28 **
Emotional Role							1.00	.59 **	-.40 **	-.37 **	-.37 **	-.35 **	-.36 **	-.29 **	-.48 **	-.32 **
Mental Health								1.00	-.41 **	-.36 **	-.39 **	-.22 **	-.38 **	-.32 **	-.44 **	-.36 **
Difficult behaviours									1.00	.80 **	.48 **	.46 **	.65 **	.49 **	.57 **	.64 **
Negative symptoms										1.00	.48 **	.47 **	.49 **	.48 **	.61 **	.54 **
Stigma											1.00	.40 **	.48 **	.34 **	.50 **	.49 **
Problems with services												1.00	.52 **	.33 **	.57 **	.45 **
Effects on family													1.00	.36 **	.51 **	.52 **
Need for back up														1.00	.61 **	.47 **
Dependency															1.00	.57 **
Loss																1.00

Table 18 The correlations for carer wellbeing by subscales and the subscales of the ECI.

** Correlation is significant at 0.01 level

Multiple Regression Analyses – Model 1

Linear multiple regression analysis was conducted with mental wellbeing (SF-36 Mental Summary scores) being the outcome variable. Predictor variables were identified from the previous correlation analyses or from identified robust findings in the research literature (e.g. gender of carer). Those predictor variables identified from the correlation analyses were significant at p=0.01.

Using the "enter" method, the predictor variables used were a) gender of carer, b) length of care, c) ECI Total negative scores, d) MoCC Total (competence) and e) MoPM Total (personal mastery). Inspection of the regression output (see Appendix J) identified that these variables did not highly correlate with the outcome variable, there was reasonable cumulative normal distribution and standardized residuals were acceptable. Field (2009, 233) suggested that multicollinearity is present if variables correlate more than .9. The highest correlation in this model was .52 between mental summary score and ECI total negative score. This suggested that all variables were measuring separate factors. Table 19 shows the beta values (*B*), standard error of beta and the standardized betas (β) for each predictor variable in relation to mental wellbeing (defined by SF-36 Mental Summary scores).

	B	**Standard error *B***	**β**
Constant	53.40	7.69	
ECI Total Negative	-0.14	0.03	- .44**
MoPM Total	-0.27	0.36	- .08
Carer gender	-3.62	2.42	- .14
Length of care	1.52	1.29	.11
MoCC Total	0.44	0.50	.08

Table 19 Regression model 1 statistics

** Significant at 0.01 level

The association between mental wellbeing and the predictor variables was moderate (multiple R = 0.57). Together the ECI Total negative scores, measure of personal mastery, measure of carer competence, carer gender and length of care accounted for 28% (adjusted $R^2 = 0.28$) of the variance in mental wellbeing of carers. The model was significant $F(5, 95) = 8.47$, p=<0.01.

The regression coefficient of the ECI Total negative scores showed that this was the strongest predictor variable (-.44). Furthermore, it was the only variable that was at a significant level. The beta scores indicated that for every increased point in the ECI Total negative scores (more negative perceptions) the mental wellbeing scores decreased by 0.14 (less wellbeing). Personal mastery was also negatively correlated, which indicated that for every increased point in the MoPM total scores (lower personal mastery) mental wellbeing scores decreased by 0.27 (less wellbeing). As carer gender was categorical the regression coefficient predicted that female carers had a decrease of 3.62 in mental wellbeing scores.

Positive regression coefficients were obtained for MoCC total (competence) and length of care. The model predicted that every increased point in the MoCC total scores (more competence), mental wellbeing scores increased by 0.44 (better wellbeing). Finally, length of care was categorical data. The regression coefficient identified that as length of care progressed in the identified categories (0-2 years, 2-6 year, over 6 years) mental wellbeing scores were predicted to increase by 1.52 (better wellbeing).

Multiple Regression Analyses – Model 2

As the ECI Total negative scores were the strongest predictor of mental wellbeing, a multiple regression was conducted whereby the ECI negative subscales were separated. The regression output (see Appendix K) identified that these variables did not highly correlate with the outcome variable, there was reasonable cumulative normal distribution and standardized residuals were acceptable. Table 20 shows the beta values (*B*), standard error of beta and the standardized betas (β) for each subscale predictor variable in relation to mental wellbeing (defined by SF-36 Mental Summary scores).

	B	**Standard error *B***	**β**
Constant	57.25	3.11	
Difficult behaviours	-0.27	0.26	- .18
Negative symptoms	-0.00	0.28	- .00
Stigma	-0.24	0.32	- .08
Problems with services	0.16	0.18	.10
Effects on family	-0.18	0.23	- .09
Need for back-up	0.01	0.25	.00
Dependency	-1.09	0.38	- .40*
Loss	-0.00	0.27	- .00

Table 20 Regression model 2 statistics

* Significant at 0.05 level

The association between mental wellbeing and the subscale predictor variables was moderate (multiple R = 0.58). Together the component subscales of the ECI Total negative scores, accounted for 28% (adjusted $R^2 = 0.28$) of the variance in mental wellbeing of carers. The model was significant *F*(8, 97) = 5.62, p=<0.01.

The regression coefficients of the ECI negative subscale scores showed that “Dependency” was the strongest predictor variable (-.40). Furthermore, it was the only variable that was a significant predictor of wellbeing. This subscale negatively correlated with mental wellbeing. Every increased point in the “Dependency” scores (more negative perceptions) predicted that mental wellbeing scores would decrease by 1.09 (less wellbeing).

Multiple Regression Analyses – Model 3

As the “Dependency” subscale of the ECI was the most associated with mental wellbeing, this variable was included with those variables that were most associated (except ECI Total negative scores) with mental wellbeing from the model 1 analyses (namely personal mastery and gender of carer). A multiple regression was conducted with the three variables above being predictors of mental wellbeing. The regression output (see Appendix L) identified that these variables did not highly correlate with the outcome variable, there was reasonable cumulative normal distribution and standardized residuals were acceptable. Table 21 shows the beta values (*B*), standard error of beta and the standardized betas (β) for each predictor variable in relation to mental wellbeing (defined by SF-36 Mental Summary scores).

	B	**Standard error *B***	**β**
Constant	60.79	5.23	
Dependency	-1.31	0.27	-.49**
Carer gender	-1.53	2.34	-.06
MoPM Total	-0.34	0.35	-.10

Table 21 Regression model 3 statistics

** Significant at <0.01 level

The association between mental wellbeing and the predictor variables was moderate (multiple R = 0.56). Together the “Dependency” subscale, the measure of personal mastery (MoPM) and carer gender accounted for 29% (adjusted R^2 = 0.29) of the variance in mental wellbeing of carers. The model was significant *F*(3, 96) = 14.0, p=<0.01. Every increased point in the “Dependency” scores (more negative perceptions) predicted that mental wellbeing scores would decrease by 1.31 (less wellbeing). Every increased point in the MoPM total scores (poorer personal mastery) mental wellbeing scores decreased by 0.34 (less wellbeing). As carer gender was categorical the regression coefficient predicted that female carers had a decrease of 1.53 in mental wellbeing scores. The main predictor variables and how they relate to mental wellbeing are illustrated in Figure 2. “Dependency” appeared to have the strongest association with carers’ mental wellbeing.

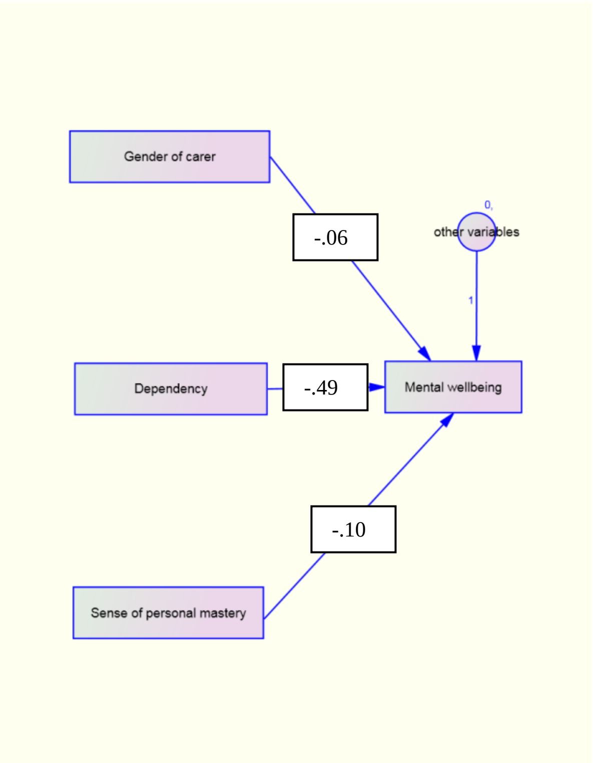


Figure 2 Diagram of the most associated predictor variables on carers' mental wellbeing.

DISCUSSION

Review of results – the specific hypotheses

The main aims of this study were to compare carers' wellbeing of people with ED with community norms; to identify whether gender differences were present in reported wellbeing; to compare the reported carers' wellbeing of people with SEED with reported wellbeing of carers of people with other severe and enduring conditions; to identify what variables (determined by the SPM) were associated with carer wellbeing, and to determine whether "resources" (namely sense of personal mastery, self competence in caregiving and expressive support) were significant predictors of carer wellbeing.

The hypothesis relating to the comparison of wellbeing in carers of people with ED with community norms, found that carers of people with ED reported significantly less wellbeing. This was consistent with previous findings on the wellbeing of carers of people with ED (De La Rie et al., 2005). The current results demonstrated that carers of people with ED reported significantly less wellbeing on seven of the eight domains measured by the SF-36.

When carer wellbeing was analysed by length of care, no significant differences were found. This corresponds with findings by Montgomery and Williams (2001) who reported that length of care in carers of the elderly was not an independent predictor of carer wellbeing. Indeed, carers of people with SEED reported slightly better wellbeing than the other two carer groups (although not at a significant level). Possible reasons for this are discussed below. Further studies around length of care are required. Following this, the regression analyses used the whole sample, as empirically no differences were found.

The above findings may have been influenced by the unequal number of male and female participants in the whole sample, and also by the fact that the sample of carers of people with SEED included a much higher percentage of male carers than the other two "lengths of care" groups. The findings may also have been influenced by selection bias. Carers were recruited from support groups who may have reported better (or poorer) wellbeing than carers of people with SEED in general. Furthermore, it may have been that differences in carers of people with SEED were hidden by carers of people with ED. This is a possibility because selection to the SEED group was based on self reports. Future studies should attempt to isolate carers of people with SEED and use medical records to certify dates.

In regards to the hypothesis on gender differences, there was no significant effect of carer gender on reported wellbeing. This contrasts the majority of previous findings that have identified that female carers of people with ED (Kyriacou et al., 2008b) and female carers of people with other conditions (Yee & Schulz, 2000) experience less wellbeing than male carers. There may be several explanations for the current results. It is difficult to recruit male carers in research (Macdonald, Murray, Goddard, & Treasure, 2010) and sometimes men will use avoidance and distraction as ways to cope (Whitney et al., 2005). This may have affected the number of male carers at the visited support groups, and consequently the number of available participants. Woodall, Morgan, Sloan and Howard (2010) have reported that men in general tend to be much harder to recruit in mental health research due to stigma and their use of avoidant strategies. It has also been reported that as food and weight are culturally viewed as "female problems", men can find the discourse about these topics and the expression of emotions very difficult (Gillon, 2003). It also might be that male carers who attend support groups are better adjusted than male carers in general. This might contribute to the lack of gender differences in reported wellbeing in this study. However, gender differences were reported in the experiences of caregiving. This will be discussed later.

Regarding the hypothesis that compared wellbeing between carer groups, carers of people with ED and carers of people with SEED specifically, were found to have better physical wellbeing than carers of people with dementia. This may have been influenced by age as the carers of people with dementia were older. There were no significant differences on reported mental wellbeing. Interestingly however, carers of people with ED reported significantly poorer social functioning than carers of people with dementia.

When the reported wellbeing of carers was compared to carers of people with brain injury, carers of people with ED reported significantly less wellbeing on several psychologically orientated subscales. However, there were no significant differences when carers of people with SEED were analysed separately. Similarly, (like the comparison with carers of people with dementia), social functioning was an area that was significantly poorer in carers of people with ED.

When the wellbeing of carers in the current sample were compared to carers of people with ED from a previous study (De La Rie et al., 2005), the findings were generally comparable. The only difference was that the current sample of carers reported significantly worse bodily pain.

The current results have demonstrated that the carers of people with ED reported less mental wellbeing than carers from the other two clinical groups (dementia and brain injury). The hypothesis regarding wellbeing comparisons of other carer groups with carers of people with SEED can be partially supported, as carers of people with SEED were found to be generally comparable on wellbeing to carers of people with a shorter duration of ED. However, as the sample of carers of people with SEED was small, further research is needed to confirm this. Carers of people with SEED may report a difference in their wellbeing which could be explained by different theoretical positions e.g. “wear and tear” (Pearlin et al., 1981) or “adaptation model” (Whitlatch et al., 1997). For example carers of people with SEED may be despondent and developed a sense of helplessness, or alternatively they may have adapted to their caring role and adjusted as their recipient’s needs have changed.

The hypothesis regarding possible “resources” being associated with wellbeing was tested by conducting correlational analyses and multiple regression. Mental wellbeing scores significantly correlated with the ECI negative total scores and the MoPM total scores. When the ECI negative total scores were broken down, “Dependency” scores significantly correlated with mental wellbeing scores. When this was interpreted in terms of the domains of the SPM, the association with carer wellbeing in these results suggest that “subjective primary stressors” and “resources” were influential in this sample of carers. Therefore the null hypothesis can be rejected.

Dependency, carer gender and a sense of personal mastery accounted for 29% of the variance in mental wellbeing scores. The other “resources” named “competence in caregiving” and “expressive support” were not significant predictors of carer wellbeing and did not add to the variance explained. Although previous studies on carers have robustly highlighted that an increased sense of personal mastery may protect against psychological distress (Mausbach et al., 2006), the current results did not show this to be significant. Yates et al. (1999) reported that a sense of personal mastery had both a direct and indirect effect on mental wellbeing in carers of the elderly. Au et al. (2009) also found that mastery or self efficacy could mediate the effects of social support on mental wellbeing. In the current results, correlational analyses identified that there was a significant association between a sense of personal mastery and expressive support. Gaugler et al. (2009) have suggested that other variables could mediate mastery and wellbeing. Research would need to investigate mediators further.

Although most researchers investigating carers of people with ED have not conceptualised their dependent and independent variables in reference to the SPM, the perception of dependency has been previously shown to be a predictor of distress in carers of people with ED (Whitney et al., 2007). However, one study that did use the SPM as a framework, found that burden (in which dependency might be conceptualised to be a part) and family conflict did not predict carers' psychological distress at a significant level (Dimitropoulos et al., 2008).

Current results in relation to the SPM

The SPM is a useful theoretical model for understanding the stress and wellbeing of caregivers. It has been used in caregiver research generally, but not with research on carers of people with ED. This study did not aim to test the full SPM due to the vast number of factors involved. Other factors such as "sense of mattering" (Fazio, 2010)", "importance of the neighbourhood" (Sampson, Morenoff, & Gannon-Rowley, 2002), "life stages" (Turner & Schieman, 2008), and “emotional reliance” (Turner, Taylor, & Van Gundy, 2004) are factors that have been added to the SPM more recently, and the model becomes more and more complex. Moderators and mediators that affect wellbeing are difficult to isolate and future research will need to focus on specific areas of the model and use statistical methodology such as structural equation modelling. Wheaton (2009) suggested that although parsimony is the norm in research, the SPM continues to develop in complexity over time. This however has not led to ambiguity as the additions to the model have improved clarity. However, it has made it more difficult to communicate the overall process and when researchers focus on elements of the SPM they may be omitting important contributions that were not investigated. Wheaton (2009) referred to the SPM as an “open source model” which allows for further elaboration and specification, which consequently has made it an ongoing successful paradigm.

What appears to be important within this study is the level of dependency that the caregivers’ perceived. Pincus and Gurtman (1995) stated that interpersonal dependency is the complexity of thoughts, feelings and behaviours which reflect the need to associate closely with, interact with and rely upon valued others. This seems to be closely linked to Turner et al's. (2004) concept of ”emotional reliance”. This was defined as the

> *“emphasis on others’ appraisals for derivation of personal worth. An elevated sense of dependence can incite keen apprehension about abandonment by others, prompting intense feelings of helplessness, hopelessness and despair” (p36).*

Carers of people with ED may feel like they are failing in their role, and their level of self worth might be affected by the quality of the relationship and how the wellbeing of their loved one is perceived. Furthermore, as Dimitropoulos et al. (2008) found, stigma was an important predictor of caregiver outcomes (e.g. psychological distress). This could also be associated with the level of perceived dependency. In this study “dependency and “stigma” were moderately correlated at a significant level (*r* = .50).

The perceived experiences of caregivers can be interpreted as “resources” if positive, and as a “primary subjective stressors” if negative (synonymous with burden). In this study, although carers of people with SEED were not significantly different to other carers of people with ED on “primary subjective stressors” (e.g. negative subscales of the ECI), they were significantly different on some “resources” (e.g. positive subscales of the ECI). In this study, there were no significant differences in reported wellbeing, yet this may have been due to other “resources” that were not measured.

The current results do re-emphasise the findings of Dimitropoulos et al. (2008) in that the use of the SPM is an appropriate framework for research on carers of people with ED and SEED.

Review of results – other findings

Although the following findings were not part of the main hypotheses for this research, some additional results in regards to demographics and carers’ experiences were noted.

Treasure et al. (2001) reported that the mean duration of illness for their care recipients was 95.4 months (SD 4) for AN and 97 months (SD 9) for psychosis. This equates to approximately 7 to 8 years which closely matches the current classification of SEED (over 6 years). In Table 22 it can be seen that Treasure et al's AN sample was largely comparable with the carer sample used in this research. The majority of carers were parents and a large proportion of carers lived with their care recipients.

	Current Study		**Treasure et al (2001)**	
	SEED sample N=34	**Whole Eating Disorders sample N=104**	**Psychosis sample N=68**	**Eating Disorders sample N=71**
% of carers living with care recipient	47%	63%	54%	76%
Relationship with care recipient				
• **Parent**	79%	86%	36%	60%
• **Spouse**	18%	7%	22%	16%
• **Sibling**		3%		12%
• **Other**	2%	4%	42%	12%

Table 22 Comparison of demographic details between carer samples.

The carers' experiences were measured by the ECI. When carers were split by the length of time they had cared for people with ED, there was a significant difference between the groups. Specifically, it was found that carers of people with SEED (over 6 years) reported significantly fewer positive experiences of caregiving compared to carers who had been in their role for a shorter period of time. Cohen, Colantonio and Vernich (2002) reported that when carers of people with dementia perceived that they had some positive experiences in their role, there was an association with lower scores measuring their mental distress. However, in this study, more positive experiences of caregiving scores did not significantly associate with better mental wellbeing scores. In contrast, carers of people with SEED who reported fewer positive experiences than carers of people with a shorter duration of ED also reported mean scores indicating better wellbeing (although not at a significant level). Cohen et al. (2002) reported that it may be that some positive experiences of caregiving are more protective of wellbeing than others. For example, Grant, Ramcharan, McGrath, Nolan and Keady (1998) have suggested that positive experiences can be interpersonal, intrapsychic or from a desire to promote a positive or avoid a negative outcome. According to Walker, Acock, Bowman and Li (1996) positive experiences of caregiving were unrelated to the duration of care when this was assessed in carers of physically impaired elderly women. However, in the current data, it may be that carers of people with ED have many different factors to manage. For example, carers tend to have uncertainty about the aetiology and adopt feelings of guilt; care recipients are usually much younger; typically greater mental health and behavioural difficulties are present, and the fact that ED are not normative, all may jeopardise how positive experiences are perceived as the duration of care lengthens. Honey and Halses' (2006) qualitative study on the experiences of carers of people with ED identified that some positive experiences do exist and carers may use “positive reappraisal” of their experiences as a kind of coping strategy. Hope is a feeling that can help to facilitate positive reappraisal and can potentially be triggered by former patients telling their stories of recovery. However, it may be that as the ED develops into a more enduring state this becomes more difficult for the carer to feel and carry out. Further research on how duration of care affects carers’ perception of positive experiences is needed.

When carers' experiences were split by gender, there was a significant difference on the reported positive experiences. Male carers reported significantly fewer positive experiences. This does not support the limited research findings conducted previously. Ribeiro and Paul (2008) interviewed older male carers and found that sixty percent reported at least one positive experience about their role. Furthermore, Milne and Hatzidimitriadou (2003) reported that husband carers had positive meanings about their caregiving experiences which contrasted sharply with wife carers. However, these studies did not use carers who were younger nor were fathers. Positive experiences of caregiving have not been previously investigated in male carers of people with ED. Whitney et al. (2005) found that male carers of people with AN used more cognitive and avoidant coping strategies. Such strategies may reduce the opportunity for male carers to have positive experiences, which could be an explanation for the current results. Further research on positive experiences in caring for people with ED is needed. Improving positive experiences could have clinical implications (Ribeiro & Paul, 2008).

When caregivers' negative experiences were split by gender no significant differences were found. These results are concordant with another study on carers of people with ED that found no gender differences (Santonastaso et al., 1997), but in contrast to a more recent study that found female carers of people with ED reported significantly increased negative experiences (Kyriacou et al., 2008b).

When carers' negative experiences were split by length of care, no significant differences were found using the summary scales of the ECI. However, Whitney et al. (2007) found that carers who had been caring for a person with a shorter duration of ED reported significantly more negative caregiving experiences. Whitney et al. (2007) suggested that carers find it difficult to adjust to caring for someone with an ED and to access specialist services. The current results followed this trend in that carers earlier in their caring career when compared to carers of people with SEED reported slightly more negative experiences, but this was not at a significant level. It may be that the significant level (p = 0.01) of the unbalanced gender ratio of carers in the SEED group was influential on this result.

When the experiences of caregiving (negative and positive) were compared with the data reported by Treasure et al. (2001), there were no differences between the current sample of carers of people with SEED and Treasure et al's sample of carers of people with AN. The current results also support the claim that perceived negative experiences of carers of people with ED are increased when compared to the perceived negative experiences of carers of people with psychosis. No significant differences were found in positive experiences across the groups.

Limitations of this study

Future research should recruit more males. As previous studies have found carer wellbeing in the ED field to be significantly influenced by gender of carer (Kyriacou et al., 2008b; Ma, 2010), future research must attempt to make the gender ratio equal. Furthermore, as previous findings have indicated that males tend to be less willing to disclose negative feelings and health difficulties (Kroenke & Spitzer, 1998), future research must find ways to enhance alliances and help males to report their difficulties. As was implemented in the current study, this could be helped by increasing anonymity of what carers report and reminding carers that it is important that their accurate thoughts and feelings are stated.

Although the regression model 3 accounted for 29% of the variance in mental wellbeing scores, 71% remained unaccounted. It may be that some of the variables had indirect effects on mental wellbeing, but this study was unable to confirm this. Future studies on carer wellbeing must consider excluded factors such as coping strategies (Lobera, Garrido, Fernandez, & Bautista, 2010).

Carers were recruited via self help support groups and this may have influenced carer wellbeing scores. For example, it may have been that carers were more distressed than carers in general because of seeking a support group. Alternatively, carers may have benefitted from the group and have better wellbeing than carers of people with ED in general. Although the procedure of contacting carer groups made data collection more achievable, the wellbeing reported may not be generalised to all carers of people with ED. Furthermore, as the wellbeing of carers of people with SEED were not significantly different to the other length of care groups, it would be beneficial to obtain the duration of attendance at the carers group and utilise some measurement of whether it is perceived as helpful. Other recruitment strategies should also be considered. For example, Kyriacou et al (2008b) recruited participants from a database of research willing carers supplied by the eating disorders national charity (B-eat) and the Eating Disorders Unit of the Institute of Psychiatry and the Maudsley Hospital. Advertisements about the research on websites related to eating disorders may also be a potential strategy.

The current sample of carers used the cut off point of over 6 years as the classification of SEED. Other researchers have suggested that this should be over 10 years (Arkell & Robinson, 2008). As the classification of SEED has not been clearly agreed, future research should attempt to separate carers with a longer duration of caring. Furthermore, accurate hours of contact should be obtained and be utilised more thoroughly in the analyses. In studies investigating carers of people with dementia, hours of care has been frequently obtained objectively. In this study, carers self reported their contact time or chose to ignore the question. Only 85% of carers chose to answer this question and many carers put a range of hours (e.g. between 2 and 8 per day). Although the mean was entered into the analysws, it seems that this was hard for participants to specify. In carers of people with ED it maybe that carers find it more difficult to accurately state their level of contact, especially when this varies considerably. Care recipients with ED are generally younger in age and sometimes they continue to hold down functional lives (e.g. college and work) (Robinson, 2009). Nevertheless, Winn et al. (2007) found that increased contact time and level of expressed emotion in carers of people with BN accounted for 18% of the variance in negative caregiving experiences.

Future research may also benefit from longitudinal studies that assess carer wellbeing as the carer progresses through their caring career. This will better determine how carers of people with ED manage as their care recipient moves towards recovery or develops the SEED classification.

The present study also used the carers self report of how long their care recipient had the diagnosis of an ED. In future it may be more accurate to use clinical notes to determine the diagnosis date and to specify the actual diagnosis.

Like Whitney et al. (2007), this study did not have enough power to separate carers of BN and AN. As Graap et al. (2008b) found, the wellbeing of carers of BN may not be as adversely affected due to the overt perception of the disorder. Even though the classifications of the disorders were not segregated in this study, carers of people with ED require additional support to maintain their wellbeing. Future research should investigate how the support required specifically differs for carers of people with different classifications of ED.

Finally, all carers of people with ED cope with their situation differently (Honey & Halse, 2006), and the present study aims did not specifically focus on these. However, Coomber and King (2011) have shown that maladaptive coping strategies are a unique predictor of burden and less wellbeing in carers of people with ED. Therefore future research must more closely take into account the methods that carers use to cope with their caregiving situation and how these impact on wellbeing.

Strengths of this study

A strength of this study is that it is the first to specifically consider that the length of care in carers of people with ED might be influential on wellbeing. Robinson (2009) has suggested that interventions for people with SEED need to differ from people with shorter durations of ED, and so the needs of carers may also be different. Although this study found no differences in the wellbeing of carers of people with SEED, it has identified that carers of people with SEED reported fewer positive experiences of caregiving. This could potentially be influential on wellbeing but larger samples of carers of people with SEED are needed in future research.

Another strength is that the SPM is a useful way to better understand the needs of carers of people with SEED and ED. “Resources” and “subjective primary stressors” are areas that services could focus on to improve carer wellbeing. Although this study has not identified what specific “resources” do improve carer wellbeing, it has identified that carers’ increased perceived dependency is associated with less carer wellbeing.

This study used a standardised global measure to assess wellbeing. Many other studies assessing the wellbeing of carers of people with ED have used the General Health Questionnaire (GHQ) (Goldberg & Williams, 1988). The SF-36 (used in this study) provides good psychometric properties and assesses wellbeing more thoroughly than measures that focus on depressive and anxiety symptomology. Furthermore, it has been recommended as a suitable measure for carer wellbeing (Harvey et al., 2008).

This study has confirmed other research findings that carers of people with ED and SEED do have less mental wellbeing than carers of other diagnostic conditions, and therefore services need to develop the support they offer to carers, especially as people with ED are increasingly being cared for in the community.

A final strength of this study is that it has identified areas of future research to investigate in carers of people with SEED or ED. Although these results have not clearly linked wellbeing to “resources”, it does appear that a sense of personal mastery is associated to carer wellbeing. Furthermore, this study found that significantly reduced social functioning was reported when compared with carers of people with dementia and carers of people with brain injury. As the SPM has identified that such “resources” may benefit carer wellbeing, these are areas that could be further investigated in carers of people with ED.

Clinical implications

The main observation in this study is that carers' perceptions of dependency are associated with less mental wellbeing; therefore interventions should be put in place to attempt to reduce this perception. Carers' negative appraisals of their role could be mediated and explored through psychological therapies such as family therapy or cognitive behavioural therapy possibly by utilising "expert service users" who have successfully completed their caring role with people recovered from ED. Carers' whose wellbeing is negatively affected by the perception that their care recipients' wellbeing, is dependent on them, may find psychoeducation about the nature of ED helpful, particularly those in the early stages of their caregiving role. Education about how to communicate with care recipients may also enhance the carers' positive experiences of caregiving.

Sepulveda et al. (2008a) conducted a six session skills-based workshop with carers of people with ED based on the "Maudsley Method". Specialist skills such as motivational interviewing techniques, alongside problem solving, goal setting and functional analysis techniques were taught to carers. They found that the carers' levels of distress and negative caregiving experiences were significantly reduced following this intervention. B-eat (the national ED charity) are now aiming to roll out these workshops (project called "Empowering Families") to carer support groups across the UK in the hope that similar results can be obtained. On the basis of the current results, it may also benefit carers if the perception of dependency is looked at explicitly. Carers should also be encouraged to continue their own social activities as this was found to be depleted in carers of people with ED.

The current results indicated that carers of people with SEED and male carers reported significantly fewer positive experiences of caregiving. Workshops for carers could help carers to reflect on and share positive experiences and offer suggestions to how carer and recipient relationships can be enhanced. Improving the relationship can potentially facilitate recovery. Expressed emotion in carers of people with ED can be high (Zabala et al., 2009), which can be detrimental to carers' and recipients' wellbeing. Sepulveda et al. (2010) have demonstrated that carer workshops that focus on education about expressed emotion and ED, and assist carers in behaviour change, can significantly reduce levels of expressed emotion. If the relationship improves it is more likely that positive experiences of caregiving will arise.

It is apparent that more carer support groups and carer training workshops are needed. ED services must coordinate or collaborate with these groups so that carers have the opportunity to, learn more about ED; improve their skills in communication; reduce levels of expressed emotion; increase their social functioning; share positive caregiving experiences; become less isolated and develop ways to challenge their thoughts about dependency. Support group facilitators should be mindful that male carers and carers of people with SEED may particularly benefit from the sharing of positive caregiving experiences.

During times of austerity services may find it difficult to offer intense support for carers of people with ED, however an adequate level of carer support is necessary to promote care in the community. Services and staff should help educate carers about ED, promote carer self care and offer support for them to develop useful communication skills with their care recipient. Services should also help carers set up their own peer support groups.

Finally, the marketing of and the evaluation of carer support groups need to be considered. Anecdotally, when the author visited carer support groups around the country, a repeated message was that carers found it difficult to be aware of the existence of support groups. ED services and GPs must help to signpost carers to the available support. It may also be pertinent to add the current implications around carer support to the MARSIPAN document that offers clinical guidance to practitioners working with patients with SEED.

Conclusions

This study has highlighted that carers of people with ED have less wellbeing than community norms and have less mental wellbeing than carers of people with some other long term conditions. Particularly carers of people with ED appeared to have poorer social functioning. The wellbeing of carers of people with SEED (over 6 years) appeared to be comparable with the whole sample of carers of people with ED, but as this study is preliminary, further research on the wellbeing of carers of people with SEED is needed. The SPM appeared to be a useful framework to assess the wellbeing of carers of people with SEED and the perception of dependency was a significant predictor of carers' mental wellbeing. There may be differences in how male carers and/or carers of people with SEED perceive positive experiences of caregiving. "Resources" may have some positive impact on wellbeing, but future research needs to better understand possible moderators and mediators of carer wellbeing.

REFERENCES

Aneshensel, C., Pearlin, L., & Mullan, J. (1995). *Profiles of Caregiving: The Unexpected Career*. New York: Academic Press.

Argimon, J. M., Limon, E., Vila, J., & Cabezas, C. (2004). Health-related quality of life in carers of patients with dementia. *Family Practice., 21*(4), 454-457.

Arkell, J., & Robinson, P. (2008). A pilot case series using qualitative and quantitative methods: Biological, psychological and social outcome in severe and enduring eating disorder (anorexia nervosa). *International Journal of Eating Disorders, 41*(7), 650-656.

Asada, T., Kinoshita, T., & Kakuma, T. (2000). Analysis of behavioral disturbances among community-dwelling elderly with Alzheimer disease. *Alzheimer Disease & Associated Disorders, 14*(3), 160.

Au, A., Lai, M.-K., Lau, K.-M., Pan, P.-C., Lam, L., Thompson, L., et al. (2009). Social support and well-being in dementia family caregivers: The mediating role of self-efficacy. *Aging & Mental Health, 13*(5), 761 - 768.

Ayres, L. (2000). Narratives of family caregiving: The process of making meaning. *Research in Nursing and Health, 23*(6), 424-434.

Bandura, A. (1997). *Self-efficacy: The Exercise of Control*. New York: W H Freeman and Company.

Baronet, A. (2003). The Impact of Family Relations on Caregivers Positive and Negative Appraisal of Their Caretaking Activities. *Family Relations, 52*, 137-142.

Barrett, L. F., Robin, L., Pietromonaco, P. R., & Eyssell, K. M. (1998). Are Women the "More Emotional" Sex? Evidence From Emotional Experiences in Social Context. *Cognition and Emotion, 12*, 555-578.

Barrowclough, C. (2005). Families of people with schizophrenia. In N. Sartorius, A. Okasha & M. Maj (Eds.), *Families and Mental Disorders: From Burden to Empowerment* (pp. 1 - 24). Chichester: John Wiley and Sons.

Barsky, A., Peekna, H., & Borus, J. (2001). Somatic symptom reporting in women and men. *Journal of General Internal Medicine, 16*(4), 266-275.

Beck, A., Steer, R., & Brown, G. (1996). BDI-II, Beck depression inventory: Manual. *San Antonio, TX: The Psychological Corporation*.

Benazon, N., & Coyne, J. (2000). Living With a Depressed Spouse. *Journal of Family Psychology, 14*(1), 71 - 79.

Bibou-Nakou, I., Dikaiou, M., & Bairactaris, C. (1997). Psychosocial dimensions of family burden among two groups of carers looking after psychiatric patients. *Social Psychiatry and Psychiatric Epidemiology, 32*(2), 104-108.

Bolden, L., & Wicks, M. (2009). Predictors of Mental Health, Subjective Burden, and Rewards in Family Caregivers of Patients with Chronic Liver Disease. *Archives of Psychiatric Nursing, 24*(2), 89-103.

Bolton, C., Calam, R., Barrowclough, C., Peters, S., Roberts, J., Wearden, A., et al. (2003). Expressed emotion, attributions and depression in mothers of children with problem behaviour. *Journal of Child Psychology and Psychiatry, 44*(2), 242-254.

Bookwala, J., & Schulz, R. (2000). A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: The caregiver health effects study. *Psychology and Aging, 15*(4), 607-616.

Brodaty, H., Green, A., & Koschera, A. (2003). Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. *Journal of the American Geriatrics Society, 51*(5), 657-664.

Chambers, M., Ryan, A. A., & Connor, S. L. (2001). Exploring the emotional support needs and coping strategies of family carers. *Journal of Psychiatric and Mental Health Nursing, 8*, 99-106.

Childs, S., & Griffiths, C. (2003). Severe and enduring mental illness: . In T. Everett, M. Donaghy & S. Feaver (Eds.), *Interventions for Mental Health: An Evidence-Based Approach for Physiotherapists and Occupational Therapists*. London: Butterworth - Heinemann.

Chronister, J., & Chan, F. (2006). A stress process model of caregiving for individuals with traumatic brain injury. *Rehabilitation Psychology, 51*(3), 190.

Clipp, E. C., & George, L. K. (1993). Dementia and Cancer: A Comparison of Spouse Caregivers. *Gerontologist, 33*(4), 534-541.

Clyburn, L., Stones, M., Hadjistavropoulos, T., & Tuokko, H. (2000). Predicting caregiver burden and depression in Alzheimer's disease. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 55*(1), 2.

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17*(2), 184-188.

Cohen, S. (2004). Social relationships and health. *American Psychologist, 59*, 676-684.

Colvez, A., Joël, M., Ponton-Sanchez, A., & Royer, A. (2002). Health status and work burden of Alzheimer patients' informal caregivers Comparisons of five different care programs in the European Union. *Health Policy, 60*(3), 219-233.

Coomber, K., & King, R. (2011). Coping strategies and social support as predictors and mediators of eating disorder carer burden and psychological distress. *Social Psychiatry and Psychiatric Epidemiology*, 1-8.

Corrigan, P., & Miller, F. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health, 13*(6), 537-548.

Crisp, A., Gelder, M., Rix, S., Meltzer, H., & Rowlands, O. (2000). Stigmatisation of people with mental illnesses. *The British Journal of Psychiatry, 177*(1), 4.

Cuijpers, P. (1999). The effects of family interventions on relatives' burden: A meta-analysis. *Journal of Mental Health, 8*(3), 275-285.

De La Rie, S. M., Van furth, E. F., De Koning, A., Noordenbos, G., & Donker, M. C. H. (2005). The Quality of Life of Family Caregivers of Eating Disorder Patients. *Eating Disorders: The Journal of Treatment & Prevention, 13*(4), 345 - 351.

Derogatis, L. (1983). *SCL-90-R: Administration, Scoring and Procedures Manual for the Revised Version* (2nd ed.). Towson, MD: Clinical Psychometric Research.

Dimitropoulos, G., Carter, J., Schachter, R., & Woodside, D. B. (2008). Predictors of family functioning in carers of individuals with anorexia nervosa. *International Journal of Eating Disorders, 41*(8), 739-747.

Dimitropoulos, G., Klopfer, K., Lazar, L., & Schacter, R. (2009). Caring for a sibling with anorexia nervosa: A qualitative study. *European Eating Disorders Review, 17*(5), 350-365.

DoH. (2000). *National Service Framework: Mental Health*. Retrieved 29 October 2009 from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009598.

DoH. (2011). *No Health Without Mental Health: A Cross Government Mental Health Outcomes Strategy for People of All Ages*. Retrieved 28 May 2011 from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766

Dopke, C., & Milner, J. (2000). Impact of child noncompliance on stress appraisals, attributions, and disciplinary choices in mothers at high and low risk for child physical abuse. *Child Abuse and Neglect, 24*(4), 493-504.

Doran, T., Drever, F., & Whitehead, M. (2003). Health of young and elderly informal carers: analysis of UK census data. *BMJ: British Medical Journal, 327*(7428), 1388.

Edwards, A., Zarit, S., Stephens, M., & Townsend, A. (2002). Employed family caregivers of cognitively impaired elderly: An examination of role strain and depressive symptoms. *Aging and Mental Health, 6*(1), 55-61.

Ergh, T. C., Rapport, L. J., Coleman, R. D., & Hanks, R. A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *The Journal of Head Trauma Rehabilitation, 17*(2), 155.

Fazio, E. M. (2010). Role Occupancy, Physical Health and the Diminishment of the Sense of Mattering in Late Life. In W. R. Avison, S. Schieman, C. S. Aneshensel & B. Wheaton (Eds.), *Advances in the Conceptualisation of the Stress Process: Essays in Honor of Leonard I. Pearlin*. London: Springer.

Fichter, M. M., Quadflieg, N., & Hedlund, S. (2006). Twelve-year course and outcome predictors of anorexia nervosa. *International Journal of Eating Disorders, 39*(2), 87-100.

Field, A. P. (2009). *Discovering Statistics Using SPSS*. London: SAGE publications Ltd.

Foldemo, A., Gullberg, M., Ek, A. C., & Bogren, L. (2005). Quality of life and burden in parents of outpatients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 40*(2), 133-138.

Gallagher-Thompson, R., Haley, W., & Czaja, S. (2000). Understanding the interventions process: A theoretical/conceptual framework for intervention approaches to caregiving. *Handbook on Dementia Caregiving: Evidence-based Interventions for Family Caregivers*, 33-60.

Gaugler, J., Kane, R., Kane, R., & Newcomer, R. (2005). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and Aging, 20*, 100-116.

Gaugler, J., Linder, J., Given, C., Kataria, R., Tucker, G., & Regine, W. (2008). The proliferation of primary cancer caregiving stress to secondary stress. *Cancer Nursing, 31*(2), 116.

Gaugler, J., Linder, J., Given, C., Kataria, R., Tucker, G., & Regine, W. (2009). Family Cancer Caregiving and Negative Outcomes: The Direct and Mediational Effects of Psychosocial Resources. *Journal of Family Nursing, 15*(4), 417.

Gaugler, J., & Teaster, P. (2007). The family caregiving career: implications for community-based long-term care practice and policy. *Family and Aging Policy,* 141.

Gaugler, J., Zarit, S., & Pearlin, L. (2003). Family involvement following institutionalization: Modeling nursing home visits over time. *The International Journal of Aging and Human Development, 57*(2), 91-117.

Gecas, V. (1989). The social psychology of self-efficacy. *Annual Review of Sociology, 15*(1), 291-316.

Gerson, K. (2002). Moral dilemmas, moral strategies, and the transformation of gender: Lessons from two generations of work and family change. *Gender & Society, 16*(1), 8.

Gibbons, J., Horn, S., Powell, J., & Gibbons, J. (1984). Schizophrenic patients and their families. A survey in a psychiatric service based on a DGH unit. *The British Journal of Psychiatry, 144*(1), 70-77.

Gilliam, C., & Steffen, A. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *Aging & Mental Health, 10*(2), 79-86.

Gillon, E. (2003). Can men talk about problems with weight? The therapeutic implications of a discourse analytic study. *Counselling and Psychotherapy Research, 3*(1), 25-32.

Given, C. W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing and Health, 15*(4), 271-283.

Goldberg, D. P., & Williams, P. (1988). *A User's Guide to the General Health Questionnaire.* Windsor: NFER-Nelson.

Goode, K. T., Haley, W. E., Roth, D. L., & Ford, G. R. (1998). Predicting Longitudinal Changes in Caregiver Physical and Mental Health: A Stress Process Model. *Health Psychology, 17*(2), 190-198.

Goodman, C. R., Zarit, S. H., & Steiner, V. L. (1997). Personal orientation as a predictor of caregiver strain. *Aging and Mental Health, 1,* 149-157.

Graap, H., Bleich, S., Herbst, F., Scherzinger, C., Trostmann, Y., Wancata, J., et al. (2008a). The needs of carers: a comparison between eating disorders and schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 43*(10), 800-807.

Graap, H., Bleich, S., Herbst, F., Trostmann, Y., Wancata, J., & de Zwaan, M. (2008b). The needs of carers of patients with anorexia and bulimia nervosa. *European Eating Disorders Review, 16*(1), 21-29.

Grange, D. l., Lock, J., Loeb, K., & Nicholls, D. (2010). Academy for eating disorders position paper: The role of the family in eating disorders. *International Journal of Eating Disorders, 43*(1), 1-5.

Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research, 42*(1), 58-71.

Gutiérrez-Maldonado, J., Caqueo-Urízar, A., & Kavanagh, D. (2005). Burden of care and general health in families of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 40*(11), 899-904.

Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of Depression and Life Satisfaction Among Spousal Caregivers in Hospice: Application of a Stress Process Model. *Journal of Palliative Medicine, 6*(2), 215-224.

Hall, J. (1990). Towards a psychology of caring. *The British Journal of Clinical Psychology/The British Psychological Society, 29,* 129.

Harris, E., & Barraclough, B. (1998). Excess mortality of mental disorder. *The British Journal of Psychiatry, 173*(1), 11.

Harvey, K., Catty, J., Langman, A., Winfield, H., Clement, S., Burns, E., et al. (2008). A review of instruments developed to measure outcomes for carers of people with mental health problems. *Acta Psychiatrica Scandinavica, 117*(3), 164-176.

Hayslip, B., Han, G., & Anderson, C. L. (2008). Predictors of Alzheimer's Disease Caregiver Depression and Burden: What Noncaregiving Adults Can Learn From Active Caregivers. *Educational Gerontology, 34*(11), 945-969.

Hepburn, K., Lewis, M., Narayan, S., Center, B., Tornatore, J., Bremer, K., et al. (2005). Partners in caregiving: A psychoeducation program affecting dementia family caregivers' distress and caregiving outlook. *Clinical Gerontologist, 29*(1), 53.

Herzog, W., Deter, H., Fiehn, W., & Petzold, E. (1997). Medical findings and predictors of long-term physical outcome in anorexia nervosa: a prospective, 12-year follow-up study. *Psychological Medicine, 27*(02), 269-279.

Highet, N., McNair, B., Davenport, T., & Hickie, I. (2004). " How much more can we lose?": carer and family perspectives on living with a person with depression. *Medical Journal of Australia, 181*(7), 6.

Highet, N., Thompson, M., & King, R. (2005). The Experience of Living with a Person with an Eating Disorder: The Impact on the Carers. *Eating Disorders, 13,* 327-344.

Hirst, M. (2005). Carer distress: A prospective, population-based study. *Social Science & Medicine, 61*(3), 697-708.

Honey, A., Boughtwood, D., Clarke, S., Halse, C., Kohn, M., & Madden, S. (2008). Support for Parents of Children with Anorexia: What Parents Want. *Eating Disorders: The Journal of Treatment & Prevention, 16*(1), 40 - 51.

Honey, A., & Halse, C. (2006). The Specifics of Coping: Parents of Daughters With Anorexia Nervosa. *Qualitative Health Research, 16*(5), 611-629.

Hooker, K., Bowman, S. R., Coehlo, D. P., Lim, S. R., Kaye, J., Guariglia, R., et al. (2002). Behavioral Change in Persons With Dementia: Relationships With Mental and Physical Health of Caregivers. *Journal of Gerontology Series B: Psychological Sciences Social Sciences, 57*(5), P453-460.

Hunt, C. K. (2003). Concepts in Caregiver Research. *Journal of Nursing Scholarship, 35*(1), 27-32.

Jang, Y., Borenstein-Graves, A., Haley, W. E., Small, B. J., & Mortimer, J. A. (2003). Determinants of a Sense of Mastery in African American and White Older Adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 58*(4), S221-S224.

Jones, K. (2009). Addressing the needs of carers during early psychosis. *Early Intervention in Psychiatry, 3*(s1 Early Intervention in Schizophrenia), 22-26.

Juratovac, E. (2009). *Effort in Caregiving and its Relationship to Caregiver Depressive Symptoms.* Case Western Reserve University.

Kiecolt-Glaser, J., Glaser, R., Shuttleworth, E., Dyer, C., Ogrocki, P., & Speicher, C. (1987). Chronic stress and immunity in family caregivers of Alzheimer's disease victims. *Psychosomatic Medicine, 49*(5), 523.

Kinney, J., Stephens, P., Ann, M., Franks, M., & Norris, V. (1995). Stresses and satisfactions of family caregivers to older stroke patients. *Journal of Applied Gerontology, 14*(1), 3.

Klump, K., Bulik, C., Kaye, W., Treasure, J., & Tyson, E. (2009). Academy for Eating Disorders Position Paper: Eating Disorders Are Serious Mental Illnesses. *International Journal of Eating Disorders, 42*(2), 97-103.

Kramer, B. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, *37*(2), 218.

Krishnasamy, M., & Plant, H. (2004). Carers, caring, and cancer-related fatigue. *Fatigue in Cancer,* 157.

Kroenke, K., & Spitzer, R. (1998). Gender differences in the reporting of physical and somatoform symptoms. *Psychosomatic Medicine, 60*(2), 150-155.

Kyriacou, O., Treasure, J., & Schmidt, U. (2008a). Expressed emotion in eating disorders assessed via self-report: An examination of factors associated with expressed emotion in carers of people with anorexia nervosa in comparison to control families. *International Journal of Eating Disorders, 41*(1), 37-46.

Kyriacou, O., Treasure, J., & Schmidt, U. (2008b). Understanding how parents cope with living with someone with anorexia nervosa: Modelling the factors that are associated with carer distress. *International Journal of Eating Disorders, 41*(3), 233-242.

Li, L., Seltzer, M., & Greenberg, J. (1999). Change in depressive symptoms among daughter caregivers: An 18-month longitudinal study. *Psychology and Aging, 14,* 206-219.

Lobera, I. J., Garrido, O., Fernandez, M. J. S., & Bautista, E. Á. (2010). Social comparison as a coping strategy among caregivers of eating disorder patients. *Journal of Psychiatric and Mental Health Nursing, 17*(9), 775-782.

Long, C. G., Fitzgerald, K.-A., & Hollin, C. R. (2011). Treatment of chronic anorexia nervosa: a 4-year follow-up of adult patients treated in an acute inpatient setting. *Clinical Psychology & Psychotherapy*, 18: n/a. doi: 10.1002/cpp.738

Ma, J. L. C. (2010). An exploratory study of the impact of an adolescent's eating disorder on Chinese parents' well being, marital life and perceived family functioning in Shenzhen, China: implications for social work practice. *Child & Family Social Work, 16*(1), 33-42.

Macdonald, P., Murray, J., Goddard, E., & Treasure, J. (2010). Carer's experience and perceived effects of a skills based training programme for families of people with eating disorders: A qualitative study. *European Eating Disorders Review*, .

Machnicki, G., Allegri, R., Ranalli, C., Serrano, C., Dillon, C., Wyrwich, K., et al. (2009). Validity and Reliability of the SF-36 Administered to Caregivers of Patients with Alzheimer's Disease: Evidence from a South American Sample. *Dementia and Geriatric Cognitive Disorders, 28*(3), 206.

Marshall, G., & Lang, E. (1990). Optimism, self-mastery, and symptoms of depression in women professionals. *Journal of Personality and Social Psychology, 59*(1), 132-139.

Martín, J., Padierna, A., Aguirre, U., Quintana, J., Hayas, C., & Muñoz, P. (2011). Quality of life among caregivers of patients with eating disorders. *Quality of Life Research,* 1-11.

Mausbach, B. T., Patterson, T. L., von Kanel, R., Mills, P. J., Ancoli-Israel, S., Dimsdale, J. E., et al. (2006). Personal Mastery Attenuates the Effect of Caregiving Stress on Psychiatric Morbidity. *The Journal of Nervous and Mental Disease, 194*(2), 132-134

McPherson, K., Pentland, B., & McNaughton, H. (2000). Brain injury-the perceived health of carers. *Disability & Rehabilitation, 22*(15), 683-689.

Miller, B., Townsend, A., Carpenter, E., Montgomery, R., Stull, D., & Young, R. (2001). Social support and caregiver distress: A replication analysis. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 56*(4), 249.

Milne, A., & Hatzidimitriadou, E. (2003). “Isn’t he wonderful?” Exploring the contribution and conceptualization of older husbands as carers. *Ageing International, 28*(4), 389-407.

Mitchley, N., Gray, J., & Pentland, B. (1996). Burden and coping among the relatives and carers of brain-injured survivors. *Clinical Rehabilitation, 10*(1), 3.

Moen, P., Robison, J., & Fields, V. (1994). Women's work and caregiving roles: A life course approach. *The Journal of Gerontology, 49*(4), S176.

Møller, T., Gudde, C. B., Folden, G. E., & Linaker, O. M. (2009). The experience of caring in relatives to patients with serious mental illness:

gender differences, health and functioning. *Scandinavian Journal of Caring Sciences*, *23*(1), 153-160.

Montgomery, R. J. V., & Williams, K. N. (2001). Implications of differential impacts of care-giving for future research on Alzheimer care. *Aging and Mental Health*, *5*, 23-34.

Morano, C. (2003). Appraisal and Coping: Moderators Mediators of Stress in Alzheimer's Disease Caregivers? *Social Work Research, 27*(2), 116-129.

NICE. (2004). Eating Disorders: Core Interventions in the Treatment and Management of Anorexia Nervosa, Bulimia Nervosa and Related Eating Disorders. [Electronic Version]. Retrieved 25 October 2009 from http://www.nice.org.uk/nicemedia/pdf/CG9FullGuideline.pdf.

Nielsen, S., & Bara´-Carril, N. (2005). Family, Burden of Care and Social Consequences. In Janet Treasure, Ulrike Schmidt & E. v. Furth (Eds.), *Handbook of Eating Disorders* (pp. 191-206). London: John Wiley & Sons, Ltd.

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R., & van den Bos, G. (1999). Measuring both negative and positive reactions to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment (CRA). *Social Science and Medicine, 48*(9), 1259-1270.

O'Brien, R. A., Wineman, N. M., & Nealon, N. R. (1995). Correlates of the Caregiving Process in Multiple Sclerosis. *Research and Theory for Nursing Practice, 9*, 323-338.

O'Reilly, F., Finnan, F., Allwright, S., Smith, G., & Ben-Shlomo, Y. (1996). The effects of caring for a spouse with Parkinson's disease on social, psychological and physical well-being. *The British Journal of General Practice, 46*(410), 507.

Ory, M. G., Hoffman, R. R., III, Yee, J. L., Tennstedt, S., & Schulz, R. (1999). Prevalence and Impact of Caregiving: A Detailed Comparison Between Dementia and Nondementia Caregivers. *Gerontologist, 39*(2), 177-186.

Oswald, A., & Wu, S. (2010). Objective Confirmation of Subjective Measures of Human Well-Being: Evidence from the USA. *Science, 327*(5965), 576.

Oyebode, J. (2003). Assessment of carers' psychological needs. *Advances in Psychiatric Treatment*, *9*(1), 45.

Pavalko, E., & Woodbury, S. (2000). Social roles as process: Caregiving careers and women's health. *Journal of Health and Social Behavior, 41*(1), 91-105.

Pearlin, L., & Aneshensel, C. (1994). Caregiving: The unexpected career. *Social Justice Research, 7*(4), 373-390.

Pearlin, L., Menaghan, E., Lieberman, M., & Mullan, J. (1981). The stress process. *Journal of Health and Social Behavior, 22*(4), 337-356.

Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583.

Pearlin, L., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19*(1), 2-21.

Perlick, D. A., Hohenstein, J. M., Clarkin, J. F., Kaczynski, R., & Rosenheck, R. A. (2005). Use of mental health and primary care services by caregivers of patients with bipolar disorder: a preliminary study. *Bipolar Disorders, 7*(2), 126-135.

Pilling, S., Bebbington, P., Kuipers, E., Garety, P., Geddes, J., Orbach, G., et al. (2002). Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy. *Psychological Medicine, 32*(05), 763-782.

Pincus, A. L., & Gurtman, M. B. (1995). The three faces of interpersonal dependency: Structural analyses of self-report dependency measures. *Journal of Personality and Social Psychology, 69*(4), 744.

Pinquart, M., & Sorensen, S. (2001). Gender Differences in Self-Concept and Psychological Well-Being in Old Age: A Meta-Analysis. *Journals of Gerontology Series B: Psychological Sciences Social Sciences, 56*(4), P195-213.

Pinquart, M., & Sorensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 58*(2), 112.

Pinquart, M., & Sorensen, S. (2006). Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis. *Journal of Gerontology Series B: Psychological Sciences Social Sciences, 61*(1), P33-45.

Pinquart, M., & Sorensen, S. (2007). Correlates of Physical Health of Informal Caregivers: A Meta-Analysis. *Journal of Gerontology Series B: Psychological Sciences Social Sciences, 62*(2), P126-137.

Radloff, L. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*(3), 385.

Rapp, S., & Chao, D. (2000). Appraisals of strain and of gain: effects on psychological wellbeing of caregivers of dementia patients. *Aging and Mental Health, 4*(2), 142-147.

Ravi, S., Forsberg, S., Fitzpatrick, K., & Lock, J. (2009). Is there a relationship between parental self-reported psychopathology and symptom severity in adolescents with anorexia nervosa? *Eating Disorders, 17*(1), 63-71.

Reekum, R., Bolago, I., Finlayson, M., Garner, S., & Links, P. (1996). Psychiatric disorders after traumatic brain injury. *Brain Injury, 10*(5), 319-328.

Ribeiro, O., & Paul, C. C. A. (2008). Older male carers and the positive aspects of care. *Ageing and Society, 28*(02), 165-183.

Riley, G. A. (2007). Stress and depression in family carers following traumatic brain injury: the influence of beliefs about difficult behaviours. *Clinical Rehabilitation, 21*(1), 82-88.

Robinson, K., & Austin, J. (1998). Wife caregivers' and supportive others' perceptions of the caregivers' health and social support. *Research in Nursing and Health, 21*(1), 51-57.

Robinson, P. (2009). *Severe and Enduring Eating Disorder (SEED). Management of Complex Presentations of Anorexia and Bulimia Nervosa*. Chichester: Wiley Blackwell.

Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A Broader View of Family Caregiving: Effects of Caregiving and Caregiver Conditions on Depressive Symptoms, Health, Work, and Social Isolation. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 64B*(6), 788-798.

Rodriguez, R., & Crowther, M. (2006). A Stress Process Model of Grandparent Caregiving: The Impact of Role Strain and Intrapsychic Strain on Subjective Well-Being. *Custodial Grandparenting: Individual, Cultural, and Ethnic Diversity*, 287-302.

Rose-Rego, S. K., Strauss, M. E., & Smyth, K. A. (1998). Differences in the Perceived Well-Being of Wives and Husbands Caring for Persons with Alzheimer's Disease. *The Gerontologist, 38*(2), 224-230.

Ruggeri, M., Leese, M., Thornicroft, G., Bisoffi, G., & Tansella, M. (2000). Definition and prevalence of severe and persistent mental illness. *The British Journal of Psychiatry, 177*(2), 149.

Sadik, K., & Wilcock, G. (2003). The increasing burden of Alzheimer disease. *Alzheimer Disease & Associated Disorders, 17*, S75.

Sampson, R. J., Morenoff, J. D., & Gannon-Rowley, T. (2002). Assessing" neighborhood effects": Social processes and new directions in research. *Annual Review of Sociology, 28*, 443-478.

Santonastaso, P., Saccon, D., & Favaro, A. (1997). Burden and psychiatric symptoms on key relatives of patients with eating disorders: a preliminary study. *Eating and Weight Disorders: EWD, 2*(1), 44.

Sartorius, N., Okasha, A., & Maj, M. (2005). *Families and Mental Disorders: From Burden to Empowerment*. Chichester: John Wiley & Sons

Scharlach, A., Li, W., & Dalvi, T. (2006). Family Conflict as a Mediator of Caregiver Strain. *Family Relations, 55*(5), 625-635.

Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Jama, 282*(23), 2215.

Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term Care Placement of Dementia Patients and Caregiver Health and Well-being. *Jama, 292*(8), 961-967.

Schulz, R., Mendelsohn, A., Haley, W., Mahoney, D., Allen, R., Zhang, S., et al. (2003). Resources for Enhancing Alzheimer’s Caregiver Health Investigators. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine, 349*(20), 1936-1942.

Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine, 19*(2), 110-116.

Schulz, R., & Quittner, A. L. (1998). Caregiving for Children and Adults With Chronic Conditions: Introduction to the Special Issue. *Health Psychology, 17*(2), 107 - 111.

Schulz, R., & Williamson, G. (1997). The measurement of caregiver outcomes in Alzheimer disease research. *Alzheimer Disease and Associated Disorders, 11*, 117-124.

Sepulveda, A. R., Lopez, C., Todd, G., Whitaker, W., & Treasure, J. (2008a). An examination of the impact of “the Maudsley eating disorder collaborative care skills workshops” on the well being of carers. *Social Psychiatry and Psychiatric Epidemiology, 43*(7), 584-591.

Sepulveda, A. R., Todd, G., Whitaker, W., Grover, M., Stahl, D., & Treasure, J. (2010). Expressed emotion in relatives of patients with Eating Disorders following skills training program. *International Journal of Eating Disorders, 43*(7), 603-610.

Sepulveda, A. R., Whitney, J., Hankins, M., & Treasure, J. (2008b). Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. *Health and Quality of Life Outcomes, 6*(1), 28.

Shah, A. J., Wadoo, O., & Latoo, J. (2010). Psychological Distress in Carers of People with Mental Disorders. *British Journal of Medical Practitioners, 3*(3).

Skaff, M., Pearlin, L., & Mullan, J. (1996). Transition in the caregiving career: Effects on sense of mastery. *Psychology and Aging, 11*(2), 247-257.

Slade, M., Powell, R., & Strathdee, G. (1997). Current approaches to identifying the severely mentally ill. *Social Psychiatry and Psychiatric Epidemiology, 32*(4), 177-184.

Son, J., Erno, A., Shea, D. G., Femia, E. E., Zarit, S. H., & Parris Stephens, M. A. (2007). The Caregiver Stress Process and Health Outcomes. *Journal of Aging Health, 19*(6), 871-887.

Spitzer, R., Gibbon, M., Williams, J., & Endicott, J. (1996). Global assessment of functioning (GAF) scale. *Outcomes Assessment in Clinical Practice,* 76–78.

Steffen, A. M., McKibbin, C., Zeiss, A. M., Gallagher-Thompson, D., & Bandura, A. (2002). The Revised Scale for Caregiving Self-Efficacy: Reliability and Validity Studies. *Journal of Gerontology, Behavioral Psychological Sciences, 57*(1), P74-86.

Steinglass, P. (1998). Multiple family discussion groups for patients with chronic medical illness. *Families Systems and Health, 16*(1), 55-70.

Steinhausen, H.-C. (2002). The Outcome of Anorexia Nervosa in the 20th Century. *American Journal of Psychiatry, 159*(8), 1284-1293.

Strober, M., Freeman, R., Lampert, C., Diamond, J., & Kaye, W. (2000). Controlled Family Study of Anorexia Nervosa and Bulimia Nervosa: Evidence of Shared Liability and Transmission of Partial Syndromes. *American Journal of Psychiatry, 157*(3), 393-401.

Surgenor, L., Rau, J., Snell, D., & Fear, J. (2000). Educational needs of eating disorder patients and families. *European Eating Disorders Review, 8*(1), 59-66.

Szmukler, G. I., Burgess, P., Herrman, H., Bloch, S., Benson, A., & Colusa, S. (1996). Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemiology, 31*(3), 137-148.

Tennstedt, S., Cafferata, G. L., & Sullivan, L. (1992). Depression among Caregivers of Impaired Elders. *Journal of Aging Health, 4*(1), 58-76.

Thornicroft, G. (2000). National Service Framework for mental health. *Psychiatric Bulletin, 24*(6), 203.

Tierney, S., & Fox, J. R. E. (2009). Chronic anorexia nervosa: A Delphi study to explore practitioners' views. *International Journal of Eating Disorders, 42*(1), 62-67.

Treasure, J., Gavan, K., Todd, G., & Schmidt, U. (2003). Changing the environment in eating disorders: working with carersfamilies to improve motivation and facilitate change. *European Eating Disorders Review, 11*(1), 25-37.

Treasure, J., Murphy, T., Szmukler, G., Todd, G., Gavan, K., & Joyce, J. (2001). The experience of caregiving for severe mental illness: a comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology, 36*(7), 343-347.

Treasure, J., Sepulveda, A. R., MacDonald, P., Whitaker, W., Lopez, C., Zabala, M., et al. (2008). The assessment of the family of people with eating disorders. *European Eating Disorders Review, 16*(4), 247-255.

Treasure, J., Smith, G., & Crane, A. (2007). *Skill-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method*. London: Routledge: Taylor & Francis Group.

Turner, H. A., & Schieman, S. (2008). Stress processes across the life course: introduction and overview. *Stress Processes Across the Life Course, 13*, 1-15.

Turner, R. J., Taylor, J., & Van Gundy, K. (2004). Personal resources and depression in the transition to adulthood: ethnic comparisons. *Journal of Health and Social Behavior, 45*(1), 34.

Uher, R., Brammer, M. J., Murphy, T., Campbell, I. C., Ng, V. W., Williams, S. C. R., et al. (2003). Recovery and chronicity in anorexia nervosa:: brain activity associated with differential outcomes. *Biological Psychiatry, 54*(9), 934-942.

Vitaliano, P., Echeverria, D., Yi, J., Phillips, P., Young, H., & Siegler, I. (2005). Psychophysiological mediators of caregiver stress and differential cognitive decline. *Psychology and Aging, 20*(3), 402.

Vitaliano, P., Zhang, J., & Scanlan, J. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*, 946-972.

Walker, A. J., Acock, A. C., Bowman, S. R., & Li, F. (1996). Amount of Care Given and Caregiving Satisfaction: A Latent Growth Curve Analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 51B*(3), P130-P142.

Wancata, J., Krautgartner, M., Berner, J., Alexandrowicz, R., Unger, A., Kaiser, G., et al. (2005). The Carers' Needs Assessment for Dementia (CNA-D): development, validity and reliability. *International Psychogeriatrics, 17*(03), 393-406.

Ware, J., Kosinski, M., & Keller, S. (1994). *SF-36® Physical and Mental Health Summary Scales: A User's Manual,* Boston, MA: The Health Institute

Ware, J., Snow, K., Kosinski, M., & Gandek, B. (1993). *SF-36 Health Survey: Manual and Interpretation Guide*: The Health Institute, New England Medical Center.

Ware Jr, J. (1999). SF-36 Health Survey. In *The Use of Psychological Testing for Treatment Planning and Outcomes Assessment (2nd ed.).* (pp. 1227-1246): Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers.

Wentz, E., Gillberg, I. C., Anckarsater, H., Gillberg, C., & Rastam, M. (2009). Adolescent-onset anorexia nervosa: 18-year outcome. *The British Journal of Psychiatry, 194*(2), 168-174.

Wheaton, B. (2009). The Stress Process as a Successful Paradigm. In W. R. Avison, S. Schieman, C. S. Aneshensel & B. Wheaton (Eds.), *Advances in the Conceptualization of the Stress Process: Essays in Honor of Leonard I Pearlin* (pp. 231). London: Springer.

Whitlatch, C., Feinberg, L., & Sebesta, D. (1997). Depression and health in family caregivers: Adaptation over time. *Journal of Aging and Health, 9*(2), 222-243.

Whitney, J., Haigh, R., Weinman, J., & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *British Journal of Clinical Psychology, 46,* 413-428.

Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2005). Experience of caring for someone with anorexia nervosa: qualitative study. *The British Journal of Psychiatry, 187*(5), 444.

Winn, S., Perkins, S., Walwyn, R., Schmidt, U., Eisler, I., Treasure, J., et al. (2007). Predictors of mental health problems and negative caregiving experiences in carers of adolescents with bulimia nervosa. *International Journal of Eating Disorders, 40*(2), 171-178.

Woodall, A., Morgan, C., Sloan, C., & Howard, L. (2010). Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers? *BMC Psychiatry, 10*(1), 103.

Xie, J., Brayne, C., & Matthews, F. (2008). Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *British Medical Journal*.

Yates, M. E., Tennstedt, S., & Chang, B.-H. (1999). Contributors to and Mediators of Psychological Well-Being for Informal Caregivers. *Journal of Gerontology B Psychological Sciences, 54B*(1), P12-22.

Yates, P. J. (2003). Psychological adjustment, social enablement and community integration following acquired brain injury. *Neuropsychological Rehabilitation, 13*(1), 291-306.

Yee, J. L., & Schulz, R. (2000). Gender Differences in Psychiatric Morbidity Among Family Caregivers: A Review and Analysis. *Gerontologist, 40*(2), 147-164.

Yin, T., Zhou, Q., & Bashford, C. (2002). Burden on family members: caring for frail elderly: a meta-analysis of interventions. *Nursing Research, 51*(3), 199.

Zabala, M. J., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review, 17*(5), 338-349.

Zarit, S. H., & Edwards, A. B. (2008). Family caregiving: research and clinical intervention. In R. Woods & L. Clare (Eds.), *Handbook of the Clinical Psychology of Aging*. Chichester: John Wiley and sons.

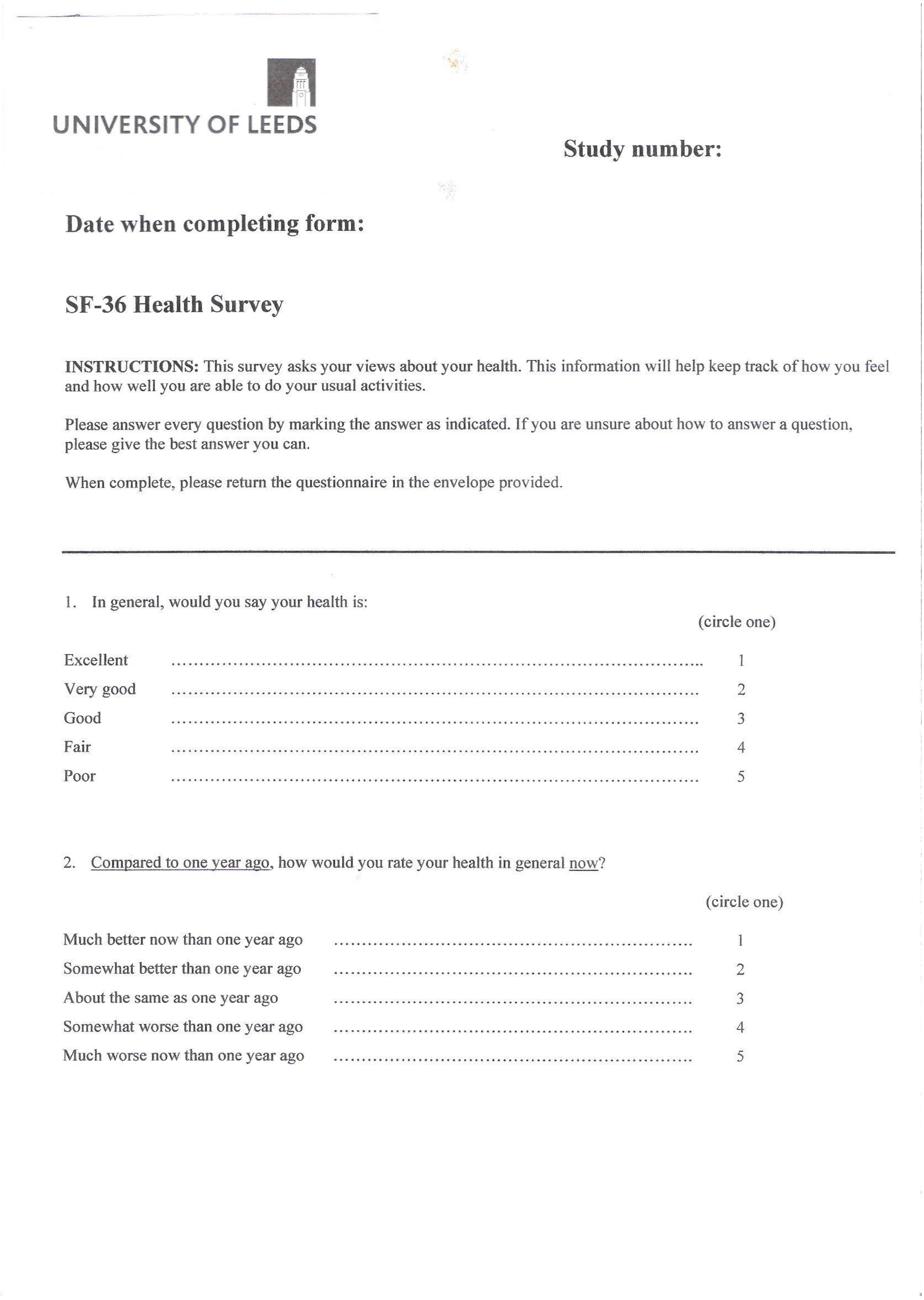
Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *The Hidden Victims of Alzheimer's Disease : Families Under Stress*. London: New York University Press.

APPENDICES

Appendix A – ED carer support groups involved in research

	Participants	*contact type*
Beat Ambassador Event, London	15	Presented
Bristol ED carer support group	1	Email/post
Cambridge ED carer support group	9	Presented
Chelmsford ED carer support group	3	Email/post
Cirencester ED carer support group	3	Email/post
Coventry ED carer support group	2	Presented
Dorset ED carer support group	1	Email/post
FEAST ED carers support group	2	Email/post
First steps (Derby) ED carer support group	9	Presented
Freed Beeches (Worksop) ED carer support group	4	Presented
Hull ED carer support group	7	Presented
Leicester ED carer support group	10	Presented
Lincoln ED carer support group	3	Presented
Oxford ED carer support group	2	Email/post
St Albans ED carer support group	1	Email/post
Stafford ED carer support group	3	Presented
SYEDA (Sheffield) ED carer support group	4	Presented
Talking Eating Disorders (Liverpool) carer support group	2	Presented
The Retreat (York) ED carer support group	10	Presented
Ware ED carer support group	2	Email/post
Yorkshire Centre for ED (Leeds) carer support group	12	Presented

Appendix B – The SF-36 version 1



UNIVERSITY OF LEEDS

Study number:

Date when completing form:

SF-36 Health Survey

INSTRUCTIONS: This survey asks your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Please answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

When complete, please return the questionnaire in the envelope provided.

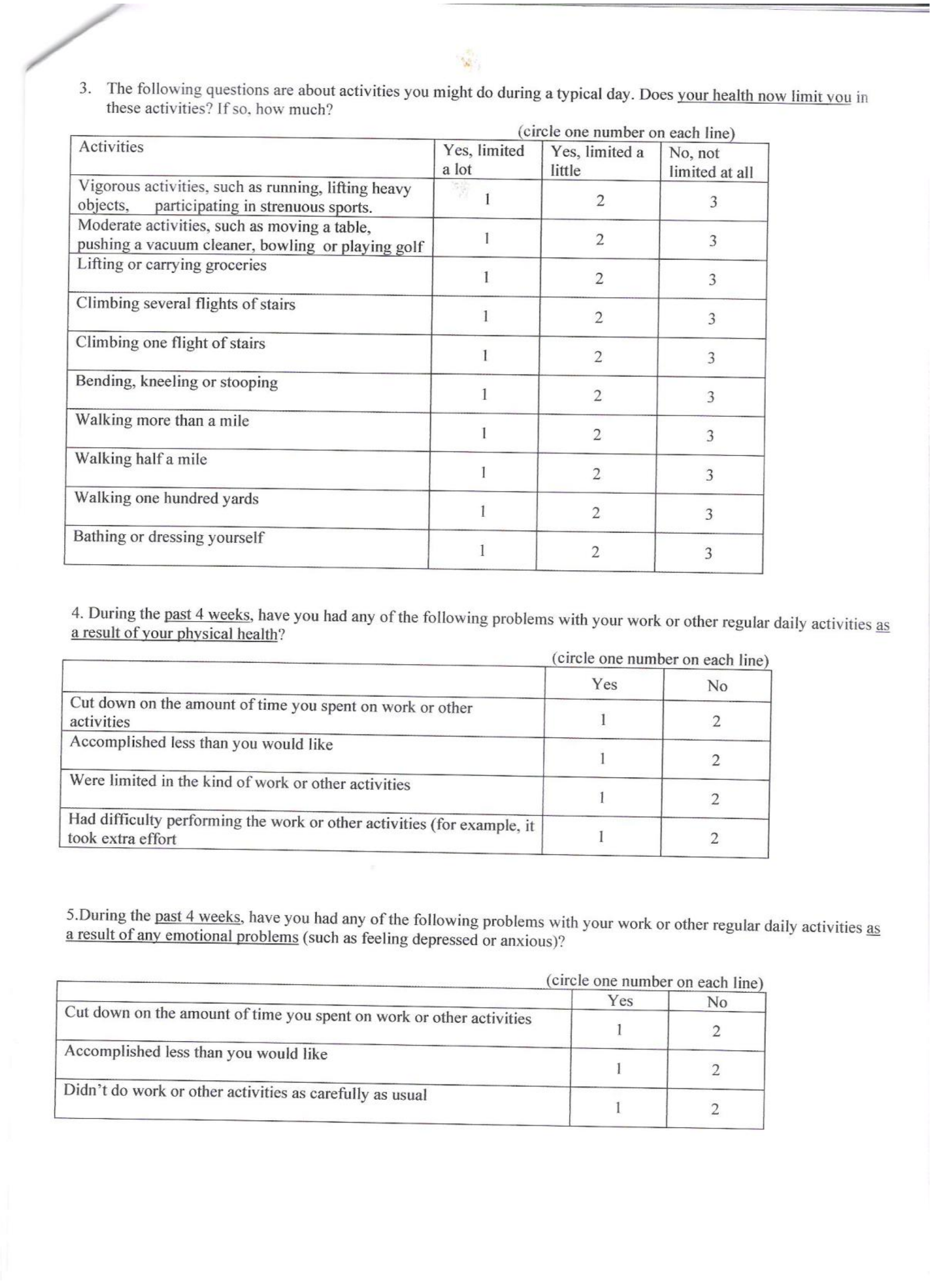
---

1. In general, would you say your health is:

	(circle one)
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Compared to one year ago, how would you rate your health in general now?

	(circle one)
Much better now than one year ago	1
Somewhat better than one year ago	2
About the same as one year ago	3
Somewhat worse than one year ago	4
Much worse now than one year ago	5



3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

Activities	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
Lifting or carrying groceries	1	2	3
Climbing several flights of stairs	1	2	3
Climbing one flight of stairs	1	2	3
Bending, kneeling or stooping	1	2	3
Walking more than a mile	1	2	3
Walking half a mile	1	2	3
Walking one hundred yards	1	2	3
Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

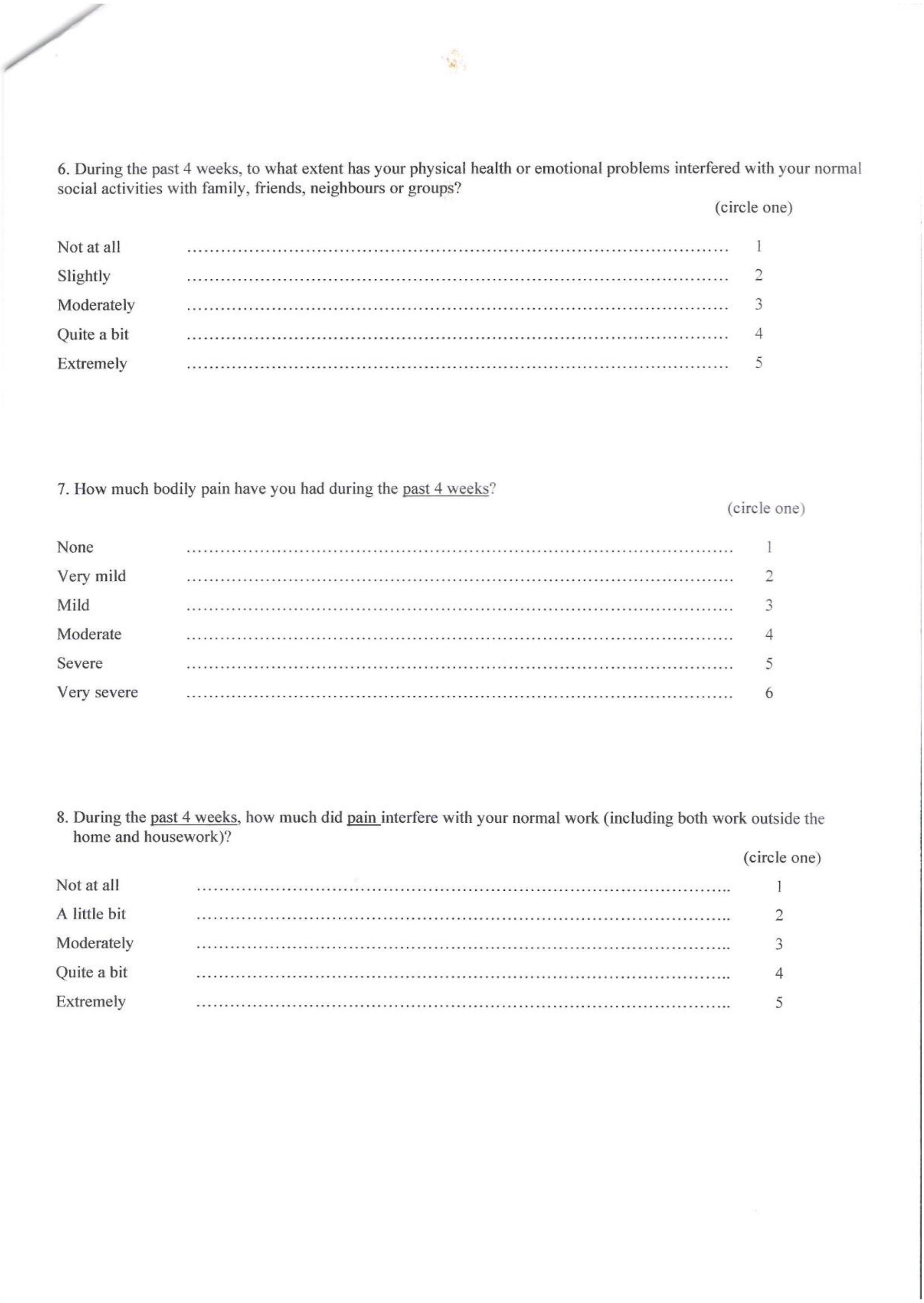
(circle one number on each line)

	Yes	No
Cut down on the amount of time you spent on work or other activities	1	2
Accomplished less than you would like	1	2
Were limited in the kind of work or other activities	1	2
Had difficulty performing the work or other activities (for example, it took extra effort	1	2

5.During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	Yes	No
Cut down on the amount of time you spent on work or other activities	1	2
Accomplished less than you would like	1	2
Didn't do work or other activities as carefully as usual	1	2



6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

(circle one)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	1	2	3	4	5	6
Have you been a very nervous person?	1	2	3	4	5	6
Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
Have you felt calm and peaceful?	1	2	3	4	5	6
Did you have a lot of energy?	1	2	3	4	5	6
Have you felt downhearted and low?	1	2	3	4	5	6
Did you feel worn out?	1	2	3	4	5	6
Have you been a happy person?	1	2	3	4	5	6
Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

(circle one)

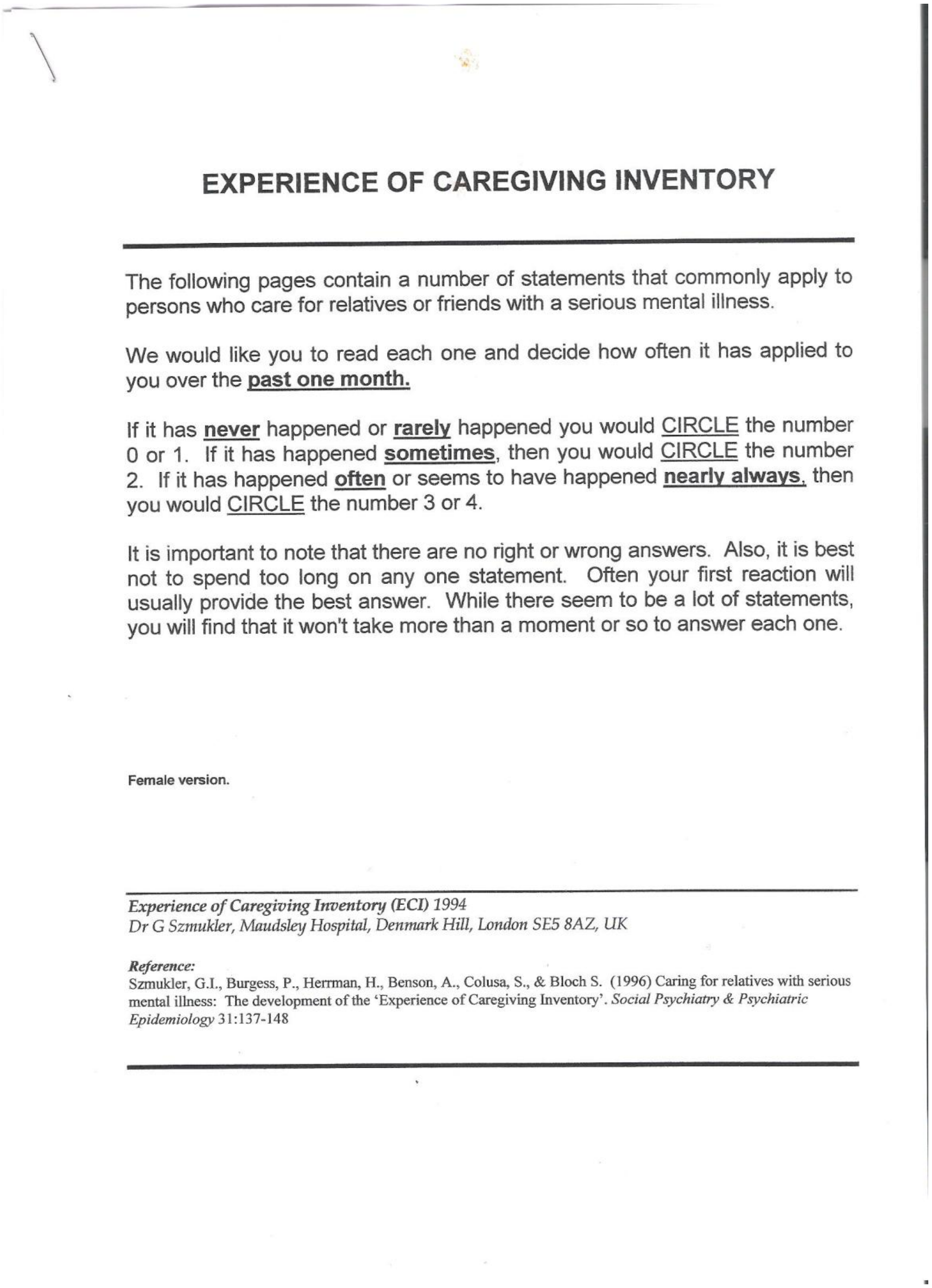
All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

11. How TRUE or FALSE is each of the following statements to you?

(circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get ill more easily than other people	1	2	3	4	5
I am as healthy as anybody I know	1	2	3	4	5
I expect my health to get worse	1	2	3	4	5
My health is excellent	1	2	3	4	5

Appendix C – The Experience of Caregiving Inventory (ECI)



EXPERIENCE OF CAREGIVING INVENTORY

The following pages contain a number of statements that commonly apply to persons who care for relatives or friends with a serious mental illness.

We would like you to read each one and decide how often it has applied to you over the **past one month.**

If it has **never** happened or **rarely** happened you would CIRCLE the number 0 or 1. If it has happened **sometimes**, then you would CIRCLE the number 2. If it has happened **often** or seems to have happened **nearly always**, then you would CIRCLE the number 3 or 4.

It is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While there seem to be a lot of statements, you will find that it won't take more than a moment or so to answer each one.

Female version.

Experience of Caregiving Inventory (ECI) 1994
Dr G Szmukler, Maudsley Hospital, Denmark Hill, London SE5 8AZ, UK

Reference:
Szmukler, G.I., Burgess, P., Herrman, H., Benson, A., Colusa, S., & Bloch S. (1996) Caring for relatives with serious mental illness: The development of the 'Experience of Caregiving Inventory'. *Social Psychiatry & Psychiatric Epidemiology* 31:137-148

During the past month how often have you thought about:

0 = never
1= rarely
2= sometimes
3= often
4= nearly always

PLEASE CIRCLE

1. your covering up her illness 0 1 2 3 4
2. feeling unable to tell anyone of the illness 0 1 2 3 4
3. her difficulty looking after money 0 1 2 3 4
4. having to support her 0 1 2 3 4
5. what sort of life she might have had 0 1 2 3 4
6. her risk of committing suicide 0 1 2 3 4

7. I have learnt more about myself 0 1 2 3 4
8. I have contributed to others understanding of the illness 0 1 2 3 4
9. being unable to do the things you want to do 0 1 2 3 4
10. how health professionals do not take you seriously 0 1 2 3 4
11. her dependence on you 0 1 2 3 4
12. helping her to fill in the day 0 1 2 3 4

13. I have contributed to her wellbeing 0 1 2 3 4
14. that she makes a valuable contribution the household 0 1 2 3 4
15. the effect on your finances if she becomes more seriously ill 0 1 2 3 4
16. dealing with psychiatrists 0 1 2 3 4
17. her always being at the back of your mind 0 1 2 3 4
18. whether you have done something to make her ill 0 1 2 3 4

19. that she has shown strengths in coping with her illness 0 1 2 3 4
20. I have become more confident in dealing with others 0 1 2 3 4
21. how family members do not understand your situation 0 1 2 3 4
22. that she is good company 0 1 2 3 4
23. I have become more understanding of others with problems 0 1 2 3 4
24. how she thinks a lot about death 0 1 2 3 4

25. her lost opportunities 0 1 2 3 4
26. how to deal with mental health professionals 0 1 2 3 4
27. feeling unable to have visitors at home 0 1 2 3 4
28. how she gets on with other family members 0 1 2 3 4
29. backing her up when she runs out of money 0 1 2 3 4
30. how family members do not understand the illness 0 1 2 3 4

31. how she deliberately attempts to harm herself 0 1 2 3 4
32. I have become closer to some of my family 0 1 2 3 4
33. I have become closer to friends 0 1 2 3 4
34. I share some of her interests 0 1 2 3 4
35. I feel useful in my relationship with her 0 1 2 3 4
36. how health professionals do not understand your situation 0 1 2 3 4

During the past month how often have you thought about:

0 = never
1= rarely
2= sometimes
3= often
4= nearly always

PLEASE CIRCLE

37. whether she will ever get well 0 1 2 3 4
38. feeling the stigma of having a mentally ill relative 0 1 2 3 4
39. how to explain her illness to others 0 1 2 3 4
40. others leaving home because of the effect of the illness 0 1 2 3 4
41. setting her up in accommodation 0 1 2 3 4
42. how to make complaints about her care 0 1 2 3 4

43. I have met helpful people 0 1 2 3 4
44 I have discovered strengths in myself 0 1 2 3 4
45. feeling unable to leave her home alone 0 1 2 3 4
46. the effect of the illness on children in the family 0 1 2 3 4
47. the illness causing a family breakup 0 1 2 3 4
48. her keeping bad company 0 1 2 3 4

49. how her illness effects special family events 0 1 2 3 4
50. finding out how hospitals or mental health services work 0 1 2 3 4
51. doctors knowledge of the services available to families 0 1 2 3 4
52. the difficulty getting information about her illness 0 1 2 3 4

During the past month how often have you thought about her being:

53. moody 0 1 2 3 4
54. unpredictable 0 1 2 3 4
54. withdrawn 0 1 2 3 4
56. uncommunicative 0 1 2 3 4
57. not interested 0 1 2 3 4
58. slow at doing things 0 1 2 3 4
59. unreliable about doing things 0 1 2 3 4
60. indecisive 0 1 2 3 4

61. irritable 0 1 2 3 4
62. inconsiderate 0 1 2 3 4
63. behaving in a reckless way 0 1 2 3 4
64. suspicious 0 1 2 3 4
65. embarrassing in appearance 0 1 2 3 4
66. behaving in a strange way 0 1 2 3 4

Appendix D – Measure of personal mastery

Measure of personal mastery (Adapted from Pearlin & Schooler, 1978)

How strongly do you agree or disagree that:

	Strongly agree (4)	Agree (3)	Disagree (2)	Strongly disagree (1)
I have little control over the things that happen to me.	☐	☐	☐	☐
There is really no way I can solve some of the problems I have	☐	☐	☐	☐
There is little I can do to change many of the important things in my life	☐	☐	☐	☐
I often feel helpless in dealing with the problems of life.	☐	☐	☐	☐
Sometimes I feel that I'm being pushed around in life.	☐	☐	☐	☐
What happens to me in the future mostly depends on me.	☐	☐	☐	☐
I can do just about anything I really set my mind to do.	☐	☐	☐	☐

Thank you for your participation

Appendix E – Measure of caregiver competence

Measure of caregiving competence (Adapted from Pearlin, Mullan, Semple & Skaff, 1990)

How much do you....:

	Very much (3)	Somewhat (2)	Just a little (1)	Not at all (0)
Believe that you've learned how to deal with a very difficult situation	☐	☐	☐	☐
Feel that all in all, you're a good caregiver.	☐	☐	☐	☐

Think about all the daily ups and downs that you face as a caregiver; the job you are doing; and the way you deal with the difficulties. Putting all these things together……..

	Very (3)	Fairly (2)	Just a little (1)	Not at all (0)
…..how competent do you feel?	☐	☐	☐	☐
…..how self confident do you feel?	☐	☐	☐	☐

Thank you for your participation.

Appendix F – Measure of expressive support

Measure of expressive support (Adapted from Pearlin, Mullan, Semple & Skaff, 1990)

Thinking about friends or family, other than the person you care for, please indicate the extent to which you agree or disagree with the following statements.

	Strongly agree (4)	Agree (3)	Disagree (2)	Strongly disagree (1)
There is really no one who understands what you are going through *	☐	☐	☐	☐
The people close to you let you know that they care about you	☐	☐	☐	☐
You have a friend or relative in whose opinions you have confidence.	☐	☐	☐	☐
You have someone who you feel you can trust.	☐	☐	☐	☐
You have people around you who help you to keep your spirits up.	☐	☐	☐	☐
There are people in your life who make you feel good about yourself.	☐	☐	☐	☐
You have at least one friend or relative you can really confide in.	☐	☐	☐	☐
You have at least one friend or relative you want to be with when you are feeling down or discouraged.	☐	☐	☐	☐

Thank you for your participation.

Appendix G – Caregiver information questionnaire (CIQ)

Carer Info Questionnaire (CIQ)

Please complete the below questions. Your answers will remain completely confidential.

1. What is your gender? Male ☐ Female☐

2. What is your age category?

Under 18 ☐
18-30 ☐
31-40 ☐
41-50 ☐
51-60 ☐
61-70 ☐
71 and over ☐

3. What is the gender of the person you care to? Male ☐ Female☐

4. What is the age category of the person you provide care to?

Under 18 ☐
18-30 ☐
31-40 ☐
41-50 ☐
51-60 ☐
61-70 ☐
71 and over ☐

5. What is your relationship to the person you provide care?

Parent ☐
Sibling ☐
Spouse ☐
Son/daughter ☐
Friend ☐
Other ☐ please state ______________________________

6. Do you *currently* live with the person that you care for?

Yes ☐ (go to Q7)
No ☐ (go to Q8)

7. Is your care recipient in hospital or some other form of residential care?

Yes ☐
No ☐

8. How much contact time (in hours) each day do you spend with your care recipient?

____

9. What diagnostic category has the person you provide care to been given?

Anorexia Nervosa ☐
Bulimia Nervosa ☐
Other ☐ please state ______________________________

10. When was this diagnosis given? Please state month and year

____

11. How long before the diagnosis did the person you provide care to start to display symptoms?

Less than 6 months ☐
6 to 24 months ☐
Two to six years ☐
Over six years ☐

12. How long have you been providing care (in relation to their condition) to this person?

Less than 6 months ☐
6 to 24 months ☐
Two to six years ☐
Over six years ☐

13. When faced with a difficult situation with your care recipient, how do you best cope with it? (please briefly state one thing you do, feel or think to cope)

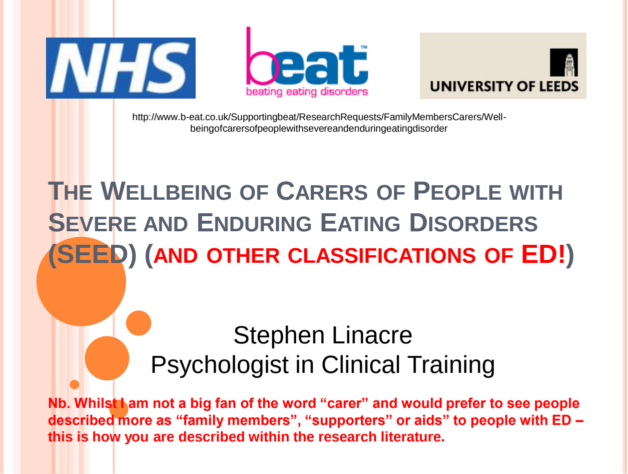
____

14. Do you have any psychological health diagnoses yourself?

Yes I have a psychological health diagnosis ☐
No I do not have a psychological health diagnosis ☐

Thank you for your participation

Appendix H – Carer group presentation



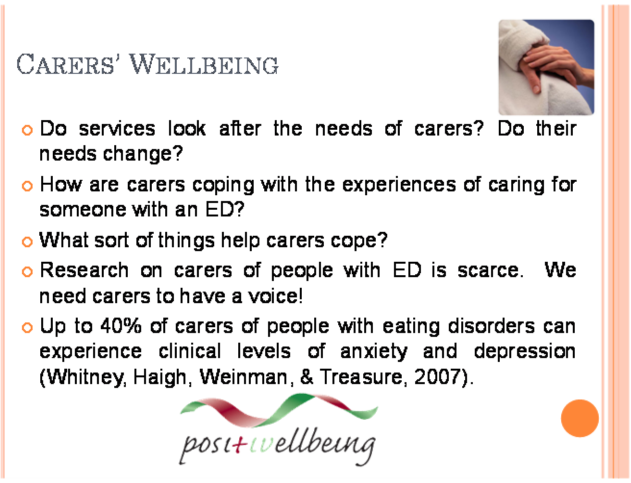
NHS
beat
beating eating disorders
UNIVERSITY OF LEEDS

http://www.b-eat.co.uk/Supportingbeat/ResearchRequests/FamilyMembersCarers/Well-beingofcarersofpeoplewithsevereandenduringeatingdisorder

THE WELLBEING OF CARERS OF PEOPLE WITH SEVERE AND ENDURING EATING DISORDERS (SEED) (AND OTHER CLASSIFICATIONS OF ED!)

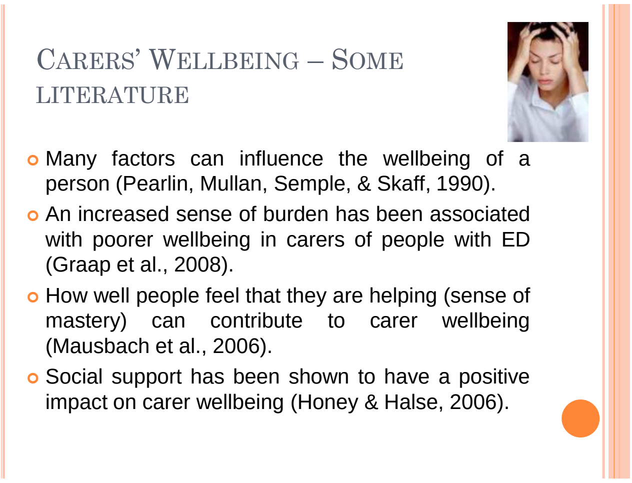
Stephen Linacre
Psychologist in Clinical Training

Nb. Whilst I am not a big fan of the word "carer" and would prefer to see people described more as "family members", "supporters" or aids" to people with ED – this is how you are described within the research literature.



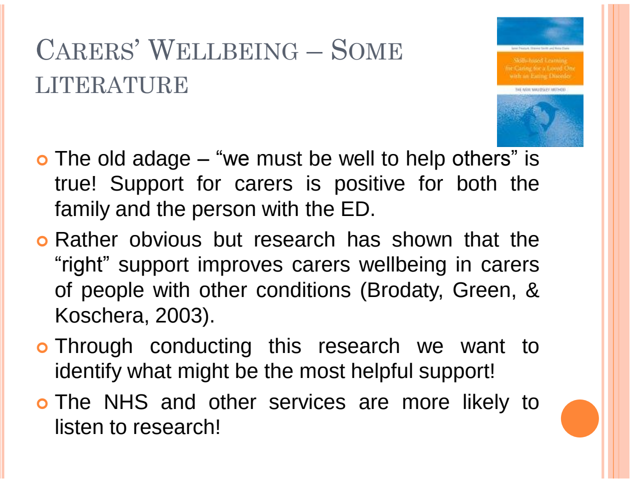
CARERS' WELLBEING

- Do services look after the needs of carers? Do their needs change?
- How are carers coping with the experiences of caring for someone with an ED?
- What sort of things help carers cope?
- Research on carers of people with ED is scarce. We need carers to have a voice!
- Up to 40% of carers of people with eating disorders can experience clinical levels of anxiety and depression (Whitney, Haigh, Weinman, & Treasure, 2007).



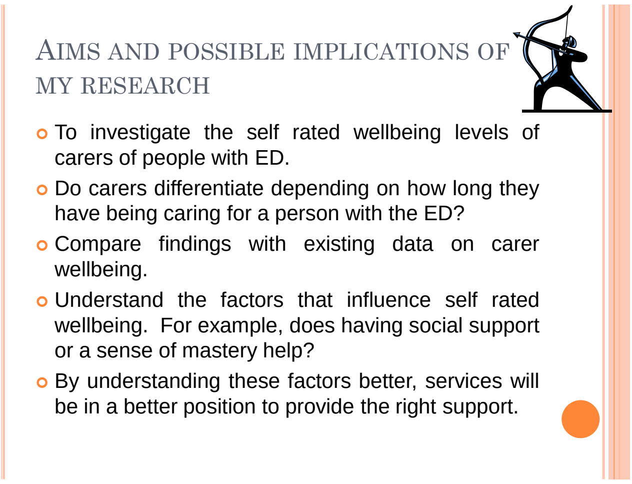
CARERS' WELLBEING – SOME LITERATURE

- Many factors can influence the wellbeing of a person (Pearlin, Mullan, Semple, & Skaff, 1990).
- An increased sense of burden has been associated with poorer wellbeing in carers of people with ED (Graap et al., 2008).
- How well people feel that they are helping (sense of mastery) can contribute to carer wellbeing (Mausbach et al., 2006).
- Social support has been shown to have a positive impact on carer wellbeing (Honey & Halse, 2006).



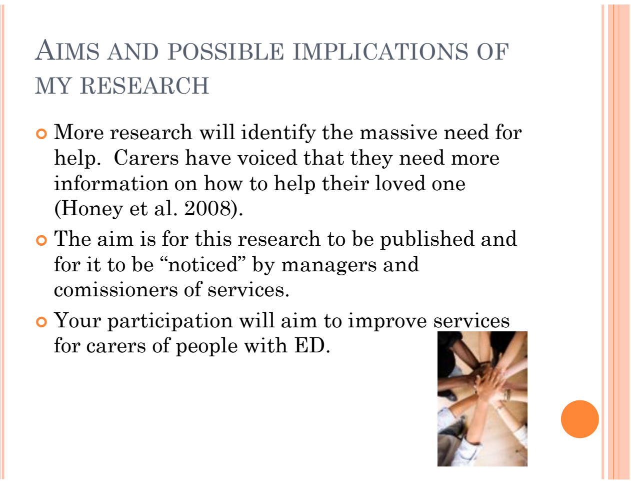
CARERS' WELLBEING – SOME LITERATURE

- The old adage – "we must be well to help others" is true! Support for carers is positive for both the family and the person with the ED.
- Rather obvious but research has shown that the "right" support improves carers wellbeing in carers of people with other conditions (Brodaty, Green, & Koschera, 2003).
- Through conducting this research we want to identify what might be the most helpful support!
- The NHS and other services are more likely to listen to research!



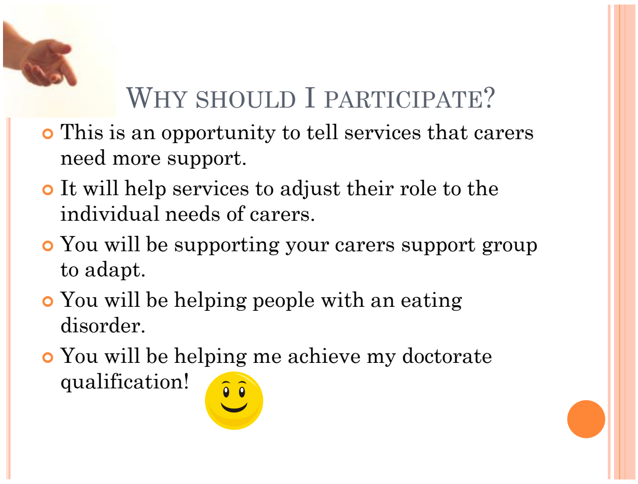
AIMS AND POSSIBLE IMPLICATIONS OF MY RESEARCH

- To investigate the self rated wellbeing levels of carers of people with ED.
- Do carers differentiate depending on how long they have being caring for a person with the ED?
- Compare findings with existing data on carer wellbeing.
- Understand the factors that influence self rated wellbeing. For example, does having social support or a sense of mastery help?
- By understanding these factors better, services will be in a better position to provide the right support.



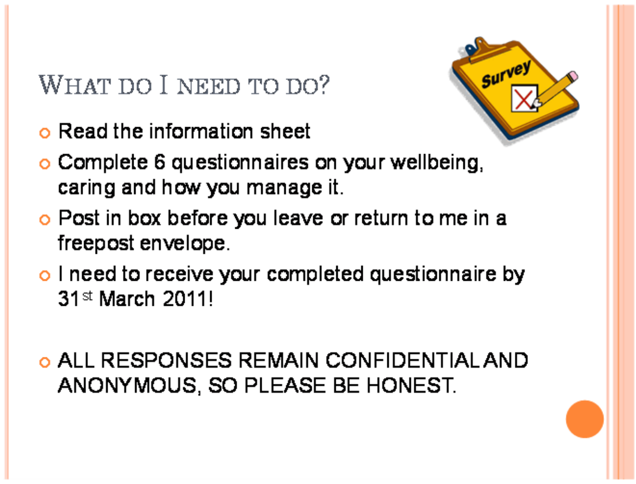
AIMS AND POSSIBLE IMPLICATIONS OF MY RESEARCH

- More research will identify the massive need for help. Carers have voiced that they need more information on how to help their loved one (Honey et al. 2008).
- The aim is for this research to be published and for it to be "noticed" by managers and comissioners of services.
- Your participation will aim to improve services for carers of people with ED.



WHY SHOULD I PARTICIPATE?

- This is an opportunity to tell services that carers need more support.
- It will help services to adjust their role to the individual needs of carers.
- You will be supporting your carers support group to adapt.
- You will be helping people with an eating disorder.
- You will be helping me achieve my doctorate qualification!

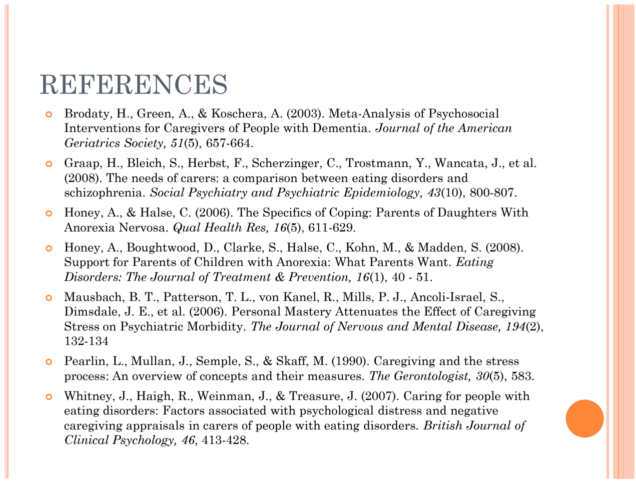


WHAT DO I NEED TO DO?

- Read the information sheet
- Complete 6 questionnaires on your wellbeing, caring and how you manage it.
- Post in box before you leave or return to me in a freepost envelope.
- I need to receive your completed questionnaire by 31st March 2011!

- ALL RESPONSES REMAIN CONFIDENTIAL AND ANONYMOUS, SO PLEASE BE HONEST.

ANY QUESTIONS?



REFERENCES

- Brodaty, H., Green, A., & Koschera, A. (2003). Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. *Journal of the American Geriatrics Society, 51*(5), 657-664.
- Graap, H., Bleich, S., Herbst, F., Scherzinger, C., Trostmann, Y., Wancata, J., et al. (2008). The needs of carers: a comparison between eating disorders and schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 43*(10), 800-807.
- Honey, A., & Halse, C. (2006). The Specifics of Coping: Parents of Daughters With Anorexia Nervosa. *Qual Health Res, 16*(5), 611-629.
- Honey, A., Boughtwood, D., Clarke, S., Halse, C., Kohn, M., & Madden, S. (2008). Support for Parents of Children with Anorexia: What Parents Want. *Eating Disorders: The Journal of Treatment & Prevention, 16*(1), 40 - 51.
- Mausbach, B. T., Patterson, T. L., von Kanel, R., Mills, P. J., Ancoli-Israel, S., Dimsdale, J. E., et al. (2006). Personal Mastery Attenuates the Effect of Caregiving Stress on Psychiatric Morbidity. *The Journal of Nervous and Mental Disease, 194*(2), 132-134
- Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583.
- Whitney, J., Haigh, R., Weinman, J., & Treasure, J. (2007). Caring for people with eating disorders: Factors associated with psychological distress and negative caregiving appraisals in carers of people with eating disorders. *British Journal of Clinical Psychology, 46*, 413-428.

Appendix I – Participant information sheet

Participation Information Sheet for Carers' Wellbeing Study

Title of study:	The wellbeing of carers.
Principal investigator:	Stephen Linacre, Psychologist in Clinical Training
Supervisors:	Professor Andrew Hill Dr Suzanne Heywood-Everett
Contact details	Clinical Psychology Administration Office, University of Leeds Charles Thackrah Building 101 Clarendon Road Leeds, LS2 9LJ
Email	umsjl@leeds.ac.uk

About me

I am a Psychologist in Clinical Training at the University of Leeds. This research is part of my training.

Why have I been invited?

You have been contacted because you have been involved in a carers support group. I am interested in your views on care giving and what aspects of the role you find positive, negative, demanding or rewarding.

What is the purpose of this study?

This research will be investigating your (carers) wellbeing and seeing whether this has any association with how long you have been caring, the amount of burden you experience, or the level of confidence you have about the caring role. This will help health services to recognise the needs of carers and help them in their role.

What will be involved if I decide to take part?

If you agree to take part you will be asked to sign the consent form at the end of this information. This is to acknowledge that you have read these guidelines and you understand why the study is being conducted. There will also be six short questionnaires that will take you about 20-25 minutes in total to complete.

At no point on any questionnaire will you be asked to provide your name or any identifiable information. When I receive back the completed research pack the only information I will know will be from which caring group you are from. The consent form you are asked to sign will be separated from the completed questionnaires. Your responses will therefore remain anonymous.

I am interested in your views so therefore it is important that you complete the research pack on your own. Please do not confer with your care recipient.

Once you have completed all the questionnaires please place them in the envelope provided and seal it. If you are completing this at the carers support group please return them to me. If you are completing them at home and I am not present, please return the completed research pack in the stamped addressed envelope provided.

Will information I give remain confidential?

Information you give will be treated with upmost care and will be strictly confidential. The data will be stored at the University of Leeds, Charles Thackrah building for a maximum of 7 years in a secure environment (locked filing cabinets) with access strictly permitted to the research team.

What benefit is there from me taking part?

Your views will help carers' views in general to be acknowledged by services. The information you provide will contribute to my research thesis. The findings will hopefully be published in an academic journal. You will each receive a summary of the findings. The support group will also receive a small donation to thank you collectively for your participation.

Are there any risks in me taking part?

It is not anticipated that any physical or psychological harm will occur from participation in this study. However, providing care can be a stressful activity and some of the questions may make you more aware of these difficulties. People who take part at their carers support group will be able to talk about any concerns with myself or with other group members.

If I don't want to take part?

Your participation in this study is entirely voluntary.

What now?

If you have read all the above information and would like to participate, please complete the consent form.

Contact for further information

If you have any queries then please contact me. I will be available and pleased to answer your questions at the carer support group. Alternatively, you can always email me at umsjl@leeds.ac.uk if you prefer. If you would like to speak to someone regarding this project, you can you can contact me or Professor Andrew Hill via the Clinical Psychology course office on 0113 3432732.

If you have any complaints regarding this project you can contact the University of Leeds research governance department on 0113 3432274 or Leeds Partnership NHS Foundation Trust PALS on freephone 0800 0525 790.

Thank you for reading this information

Stephen Linacre – Principle researcher

Participant Consent Form for Carers' Wellbeing Study

Please initial all boxes if you agree to participate:

☐ I have read the participant information sheet (PIS V2) regarding the study.

☐ I have had opportunity to ask any questions either in person or by email.

☐ I understand that the information I provide will be kept confidential.

☐ I agree to take part in the study.

Name

Signature

Date

Signature of principle researcher

Appendix J – Multiple regression output, model 1

Descriptive Statistics

	Mean	Std. Deviation	N
MenSum	39.579	11.6778	96
CarerGender	.74	.441	96
providecareinto3	2.02	.821	96
ECITotNeg	93.25	35.833	96
competenceTOT	7.86	2.155	96
MasteryTot	16.17	3.308	96

Correlations

		MenSum	CarerGender	providecareinto3	ECITotNeg	competenceTOT	MasteryTot
Pearson Correlation	MenSum	1.000	-.210	.215	-.522	.171	-.336
	CarerGender	-.210	1.000	-.217	.128	.140	.073
	providecareinto3	.215	-.217	1.000	-.133	.133	-.133
	ECITotNeg	-.522	.128	-.133	1.000	-.177	.497
	competenceTOT	.171	.140	.133	-.177	1.000	-.224
	MasteryTot	-.336	.073	-.133	.497	-.224	1.000
Sig. (1-tailed)	MenSum	.	.020	.018	.000	.048	.000
	CarerGender	.020	.	.017	.107	.087	.239
	providecareinto3	.018	.017	.	.099	.099	.098
	ECITotNeg	.000	.107	.099	.	.042	.000
	competenceTOT	.048	.087	.099	.042	.	.014
	MasteryTot	.000	.239	.098	.000	.014	.
N	MenSum	96	96	96	96	96	96
	CarerGender	96	96	96	96	96	96
	providecareinto3	96	96	96	96	96	96
	ECITotNeg	96	96	96	96	96	96
	competenceTOT	96	96	96	96	96	96
	MasteryTot	96	96	96	96	96	96

Variables Entered/Removed[b]

Model	Variables Entered	Variables Removed	Method
1	MasteryTot, CarerGender, providecareinto3, competenceTOT, ECITotNeg[a]	.	Enter

a. All requested variables entered.

b. Dependent Variable: MenSum

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.566[a]	.320	.282	9.8940	.320	8.469	5	90	.000

a. Predictors: (Constant), MasteryTot, CarerGender, providecareinto3, competenceTOT, ECITotNeg

b. Dependent Variable: MenSum

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	4145.000	5	829.000	8.469	.000[a]
	Residual	8810.159	90	97.891		
	Total	12955.158	95			

a. Predictors: (Constant), MasteryTot, CarerGender, providecareinto3, competenceTOT, ECITotNeg

b. Dependent Variable: MenSum

Coefficients^a

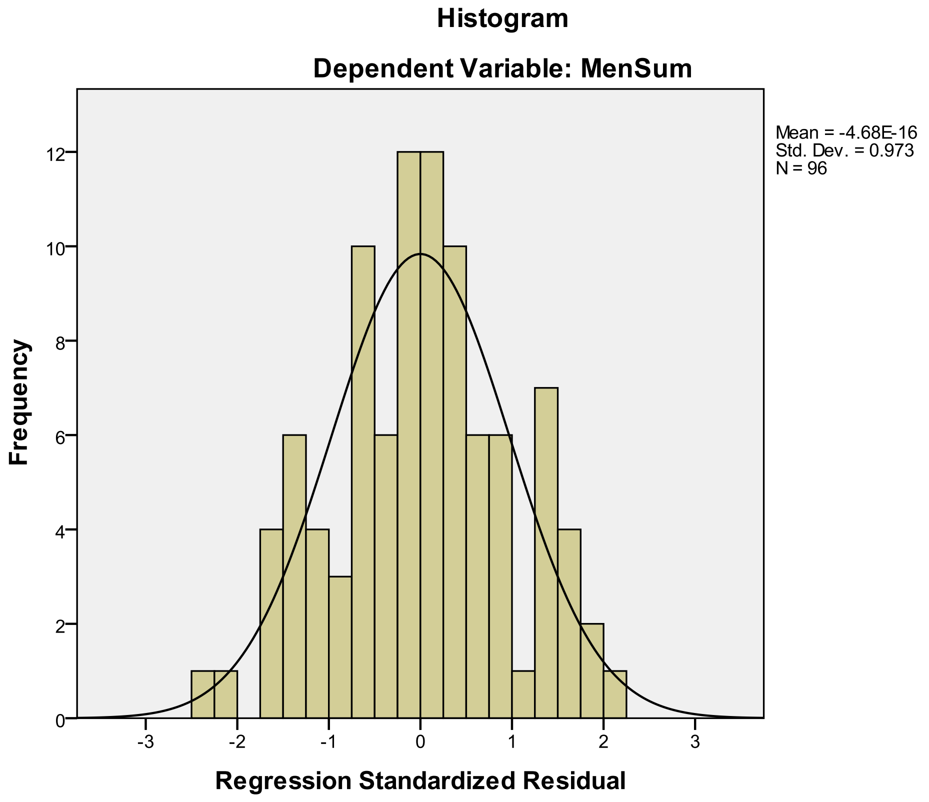
Model		Unstandardized Coefficients		Standardized Coefficients			Correlations			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	53.404	7.689		6.945	.000					
	CarerGender	-3.623	2.417	-.137	-1.499	.137	-.210	-.156	-.130	.906	1.103
	providecareinto3	1.518	1.292	.107	1.175	.243	.215	.123	.102	.917	1.090
	ECITotNeg	-.143	.033	-.438	-4.329	.000	-.522	-.415	-.376	.736	1.358
	competenceTOT	.437	.497	.081	.880	.381	.171	.092	.077	.898	1.113
	MasteryTot	-.268	.359	-.076	-.746	.458	-.336	-.078	-.065	.731	1.368

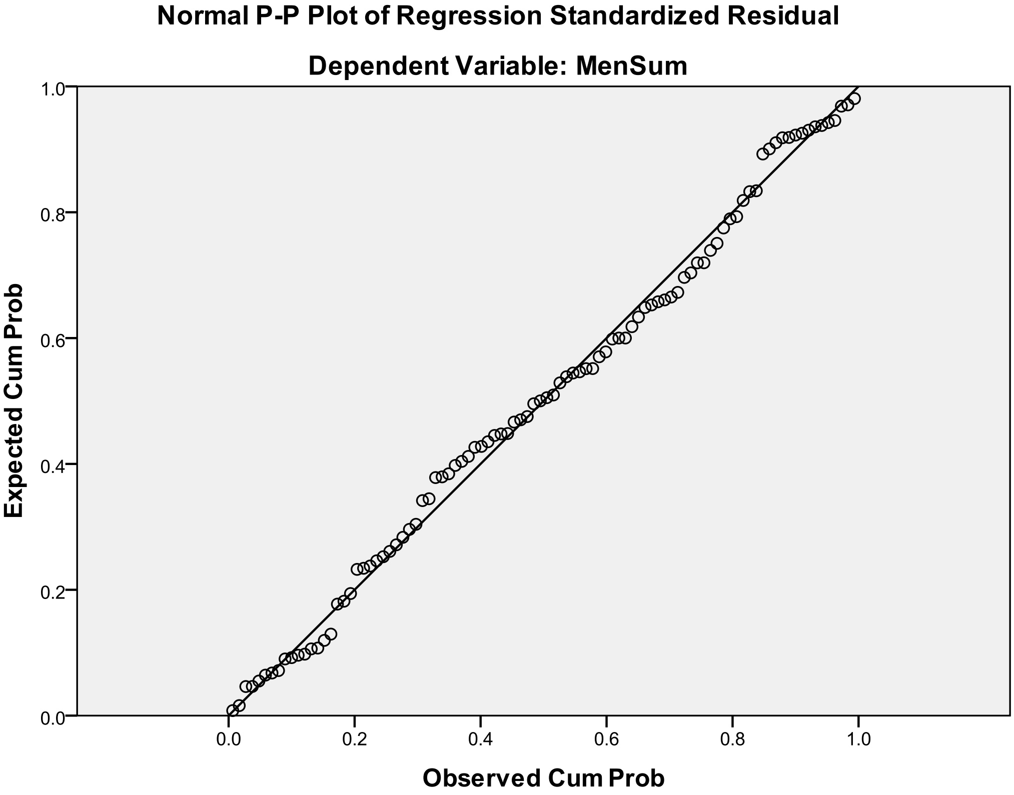
a. Dependent Variable: MenSum

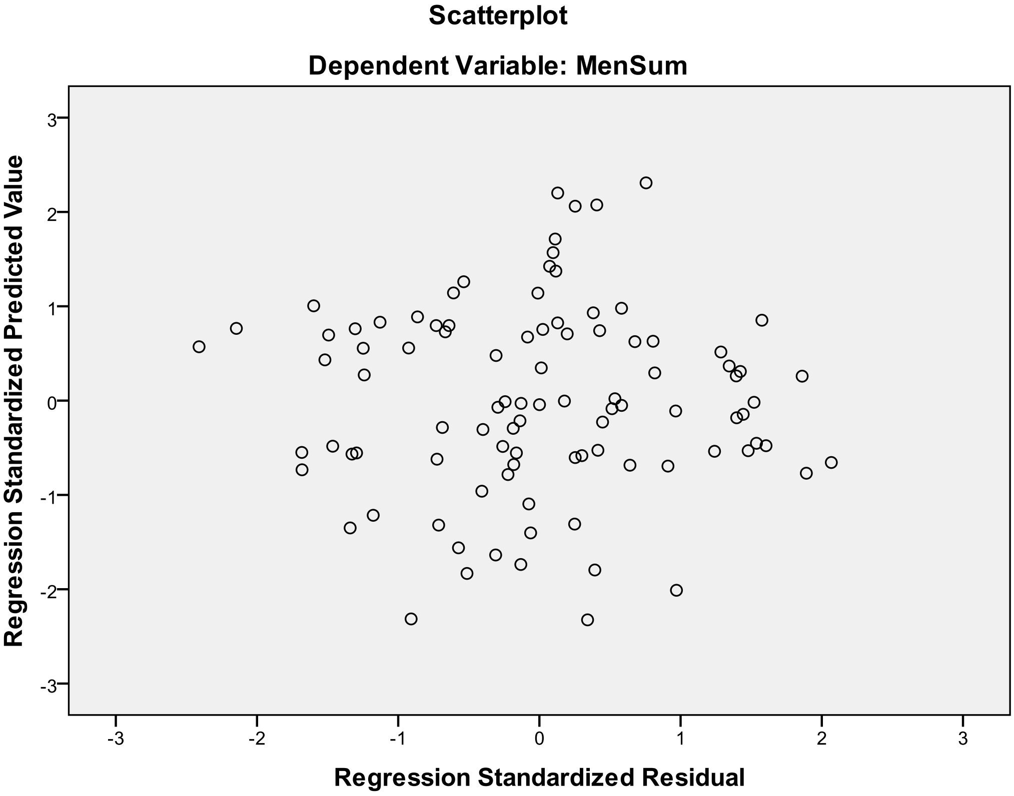
Residuals Statistics^a

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	24.225	54.826	39.579	6.6054	96
Residual	-23.8490	20.4559	.0000	9.6301	96
Std. Predicted Value	-2.325	2.308	.000	1.000	96
Std. Residual	-2.410	2.068	.000	.973	96

a. Dependent Variable: MenSum




Normal P-P Plot of Regression Standardized Residual
Dependent Variable: MenSum
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0


Scatterplot
Dependent Variable: MenSum
Regression Standardized Predicted Value
Regression Standardized Residual
-3
-2
-1
0
1
2
3

Appendix K – Multiple regression output, model 2

Variables Entered/Removed^{b}

Model	Variables Entered	Variables Removed	Method
1	Loss, ProbsServices, NeedBckup, Stigma, EffFam, NegSymp, Dependency, DiffBeh^{a}	.	Enter

a. All requested variables entered.

b. Dependent Variable: MenSum

Model Summary^{b}

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Durbin-Watson
1	.579^{a}	.336	.276	10.0804	1.975

a. Predictors: (Constant), Loss, ProbsServices, NeedBckup, Stigma, EffFam, NegSymp, Dependency, DiffBeh

b. Dependent Variable: MenSum

ANOVA^{b}

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	4566.808	8	570.851	5.618	.000^{a}
	Residual	9043.666	89	101.614		
	Total	13610.474	97			

a. Predictors: (Constant), Loss, ProbsServices, NeedBckup, Stigma, EffFam, NegSymp, Dependency, DiffBeh

b. Dependent Variable: MenSum

Coefficients[a]

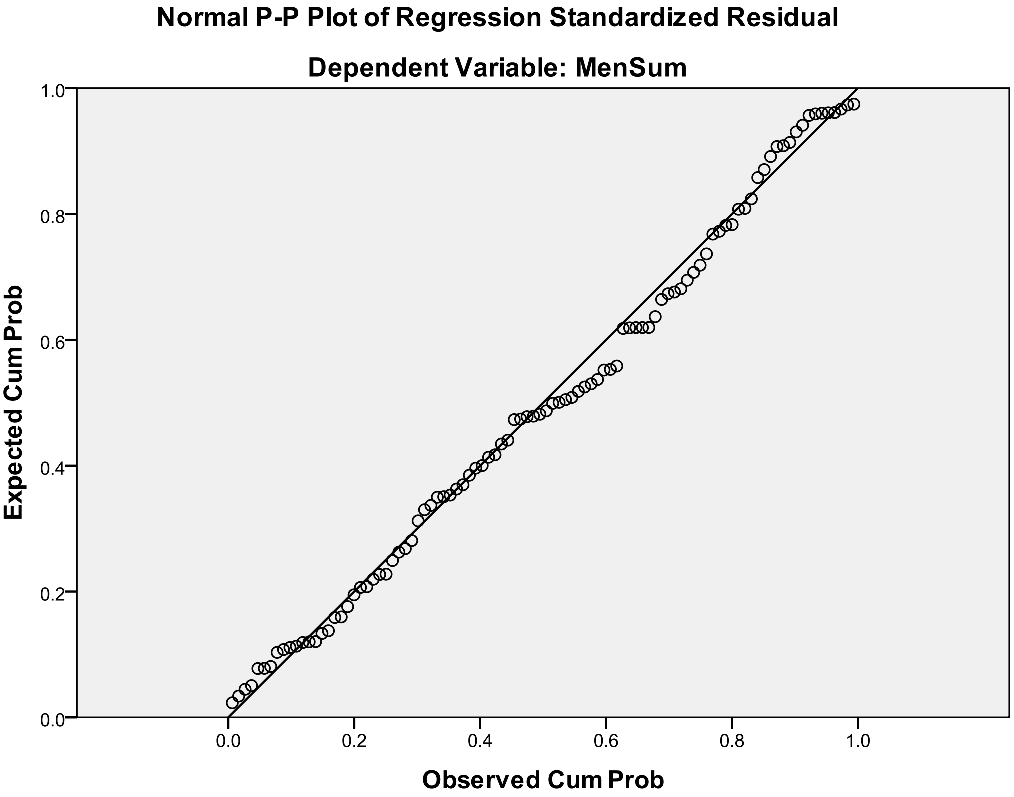
Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	57.253	3.110		18.408	.000
	DiffBeh	-.270	.262	-.175	-1.028	.307
	NegSymp	-.003	.276	-.002	-.011	.991
	Stigma	-.240	.317	-.082	-.757	.451
	ProbsServices	.158	.181	.099	.874	.385
	EffFam	-.175	.232	-.094	-.753	.454
	NeedBckup	.008	.251	.004	.033	.974
	Dependency	-1.092	.379	-.403	-2.879	.005
	Loss	-.003	.268	-.002	-.013	.990

a. Dependent Variable: MenSum

Residuals Statistics[a]

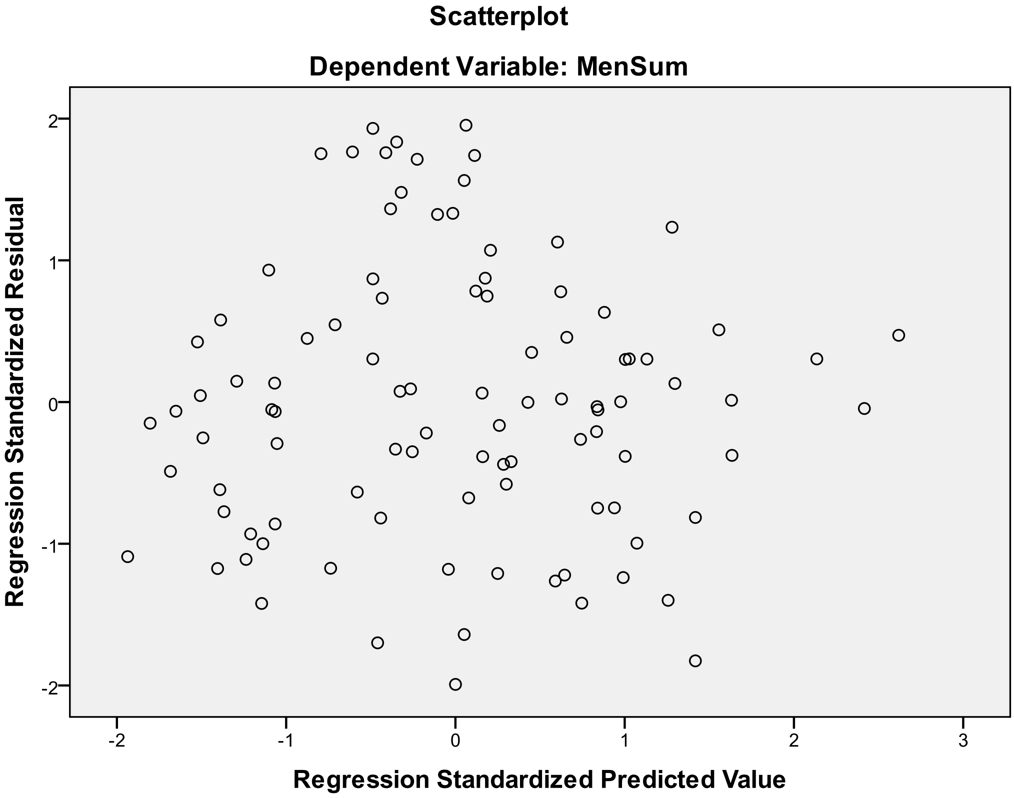
	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	26.297	57.554	39.584	6.8615	98
Residual	-20.0862	19.6875	.0000	9.6558	98
Std. Predicted Value	-1.936	2.619	.000	1.000	98
Std. Residual	-1.993	1.953	.000	.958	98

a. Dependent Variable: MenSum



Normal P-P Plot of Regression Standardized Residual

Dependent Variable: MenSum



Scatterplot

Dependent Variable: MenSum

Appendix L – Multiple regression output, model 3

Descriptive Statistics

	Mean	Std. Deviation	N
MenSum	39.395	11.7578	97
CarerGender	.73	.445	97
Dependency	11.21	4.390	97
MasteryTot	16.15	3.292	97

Correlations

		MenSum	CarerGender	Dependency	MasteryTot
Pearson Correlation	MenSum	1.000	-.179	-.548	-.326
	CarerGender	-.179	1.000	.231	.078
	Dependency	-.548	.231	1.000	.460
	MasteryTot	-.326	.078	.460	1.000
Sig. (1-tailed)	MenSum	.	.040	.000	.001
	CarerGender	.040	.	.011	.223
	Dependency	.000	.011	.	.000
	MasteryTot	.001	.223	.000	.
N	MenSum	97	97	97	97
	CarerGender	97	97	97	97
	Dependency	97	97	97	97
	MasteryTot	97	97	97	97

Variables Entered/Removed[b]

Model	Variables Entered	Variables Removed	Method
1	MasteryTot, CarerGender, Dependency[a]	.	Enter

a. All requested variables entered.

b. Dependent Variable: MenSum

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.557[a]	.311	.288	9.9188	.311	13.966	3	93	.000

a. Predictors: (Constant), MasteryTot, CarerGender, Dependency

b. Dependent Variable: MenSum

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	4121.998	3	1373.999	13.966	.000[a]
	Residual	9149.530	93	98.382		
	Total	13271.527	96			

a. Predictors: (Constant), MasteryTot, CarerGender, Dependency

b. Dependent Variable: MenSum

Coefficients[a]

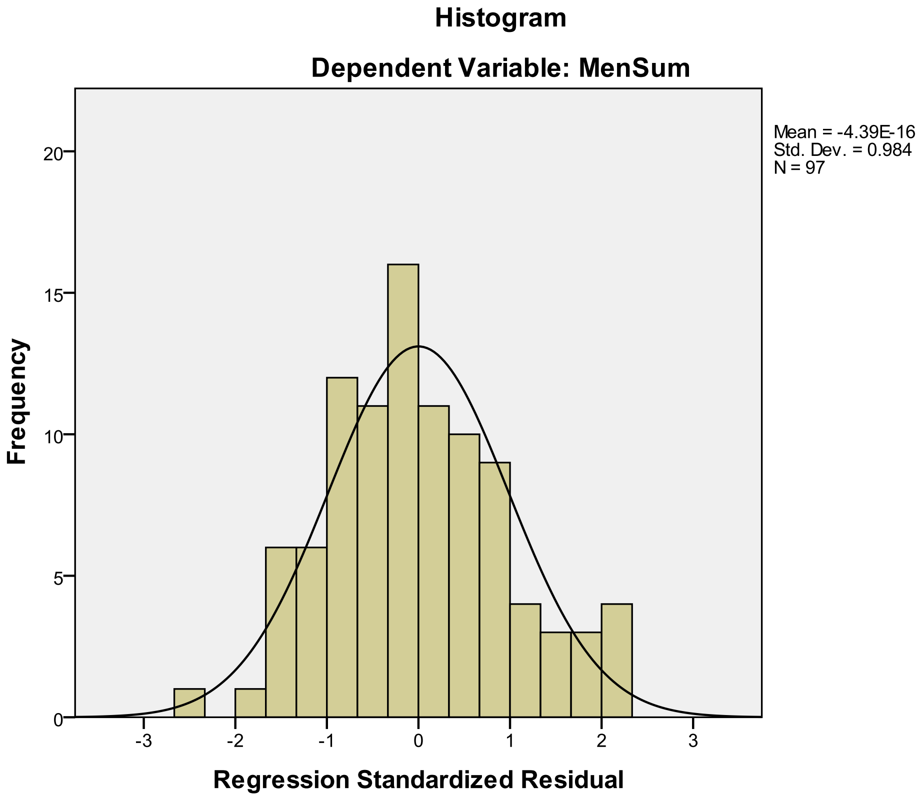
Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	60.785	5.227		11.628	.000					
	CarerGender	-1.534	2.338	-.058	-.656	.514	-.179	-.068	-.056	.946	1.058
	Dependency	-1.314	.266	-.490	-4.935	.000	-.548	-.456	-.425	.750	1.333
	MasteryTot	-.343	.346	-.096	-.991	.324	-.326	-.102	-.085	.788	1.269

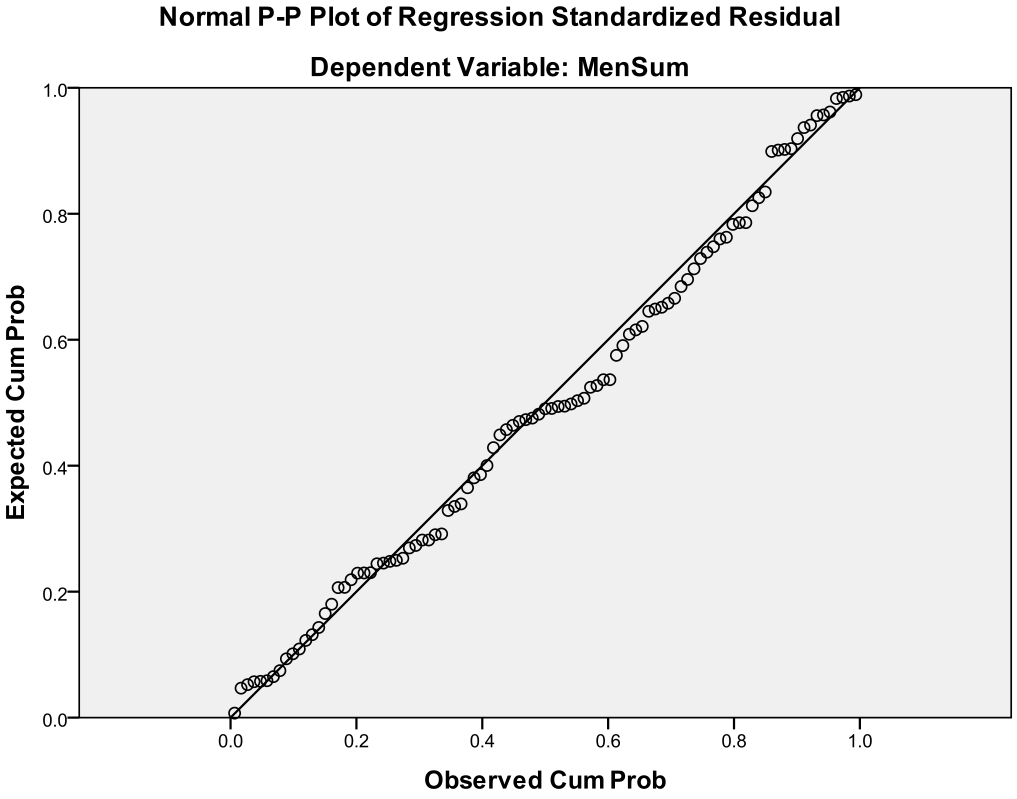
a. Dependent Variable: MenSum

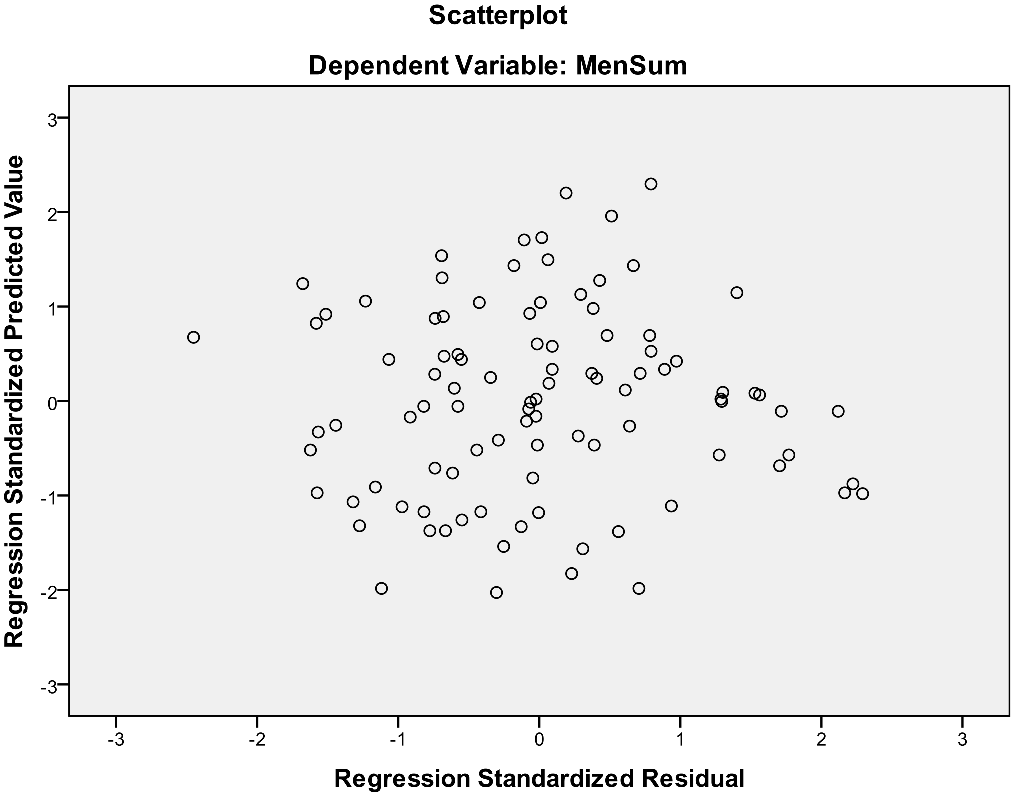
Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	26.111	54.446	39.395	6.5527	97
Residual	-24.3121	22.7366	.0000	9.7626	97
Std. Predicted Value	-2.027	2.297	.000	1.000	97
Std. Residual	-2.451	2.292	.000	.984	97

a. Dependent Variable: MenSum




Normal P-P Plot of Regression Standardized Residual
Dependent Variable: MenSum
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0


Scatterplot
Dependent Variable: MenSum
Regression Standardized Predicted Value
Regression Standardized Residual
-3
-2
-1
0
1
2
3