Coping strategies, support systems and well-being among unpaid caregivers.

Orla Brady

1624704

Supervisor: Dr. Patricia Frazier

Head of Department: Dr S. Eccles

March 2014

Department of Psychology

Dublin Business School

Contents

Index of tables and figures

Acknowledgements

Abstract

Objective; this research project is to explore coping strategies, support systems and well-being among unpaid caregivers. It aims to add to current research on carer well-being and the efficacy of carers support program. It is hypothesised that there will be a relationship between coping strategies and well-being among caregivers who receive support and there will be a difference in the psychological well-being of males and females who receive support and those who don't. Both qualitative and quantitative analysis will be used to observe relationships.

Method; Sixty four (50 females and 14 males) unpaid caregivers filled out two questionnaires, the caregivers well-being and support questionnaire and the brief cope questionnaire. A qualitative analysis was also used to collect data.

Results, A person's correlation coefficient found that there was significant relationship between well-being and support. An independent samples t test found there was no significant difference between males and female who receive support on the psychological well-being.

Conclusion; Support systems and coping strategies are significantly important for the well-being of caregivers. Further research needs to be conducted using interview style data collect to grasp a full understand of individual caregivers needs.

Introduction

The purpose of this research project is to explore coping strategies, support systems and well-being among unpaid caregivers. It aims to add to current research on carer well-being and the efficacy of carers' support programmes. A mounting body of evidence shows how demanding it is to be a caregiver. This thesis looks at how caregivers deal with the responsibilities imposed upon them through the support they receive and the coping strategies they use to achieve a sense of well-being. The carers involved in the research study attend a community interest company which exists to inspire unpaid carers, delivering personal development programmes and initiatives directed at meeting the needs of carers across all care sectors. The Carer Well-being and Support Questionnaire will be used to measure well-being and support, while the Brief Cope questionnaire will measure coping strategies. This thesis will look for relationships between these variables.

Caregivers are a group of people who selflessly dedicate their time and energy to care for a loved one; the responsibility can be a natural outcome or appear suddenly, automatically becoming filled with obligations and stress. This study will look at the broad spectrum of situations from which the caregiving role can be initiated, such as caregivers with children who have learning or physical disabilities, or with elderly family members who perhaps confront serious illness. Researchers in the field of support systems and coping strategies have described many aspects of the term well-being, and how carers can sustain well-being amidst the pressures of caregiving. In addition to this, the important aspects of respite and coping strategies will be discussed to predict well-being.

The Caregiving Role

Caring is a role that may come suddenly and unexpectedly, for example after injury or sudden illness. Alternatively the carer's role may creep up over time if the person has a progressive condition. The caring role is motivated by love and compassion; each carer faces a unique situation, and in most cases without expert knowledge in comparison to professional healthcare practitioners. The term carer refers to family members, neighbours or friends who provide long-term or substantial and regular care for someone who needs help with daily living activities (Hussein & Manthorpe, 2012). In 2000 there were an estimated 6.8 million adults providing unpaid care in Britain, including 1.7 million who devoted 20 hours or more per week to their carers' roles (Arksey & Hirst, 2005). Carer responsibilities can be a natural outcome, if choosing to look after a close elderly relative; however, the role can take on a different significance when a child suffers from physical and mental disabilities or a family member has just received news of a serious illness.

Any one of us has a 6.6% chance of becoming a caregiver in any one year (Carers Northern Ireland, 2012). Since the 1980s governments have progressively acknowledged that health and social care services would struggle to cope without the contribution of unpaid carers (Arksey & Hirst, 2005). The global cost of replacing unpaid caregivers with formal healthcare support services has been estimated at $30.5 billion (Stockwell-Smith, Kellett, & Moyle, 2010). Studying care-giving, carers' needs, and the recognised strain they experience, is increasingly important as a field of research on an international level (Plank, Mazzoni, & Cavada, 2012). This study focuses on carers with a responsibility to care for individuals who have either serious or minor needs (or in some cases both), the support systems they receive, and how this impacts on their well-being.

Carers of sick and elderly relatives

Caregiving for elderly relatives is increasingly common. Barbosa, Figueiredo, Sousa, & Demain, (2011) report a rising number of elderly people with functional disabilities due to the increase in life expectancy. Studies have shown that mental distress in family members who provide caregiving is higher than in those who do not (Okabayashi et al., 2008). It's important to note research by Collins and Bayless (2013) suggesting that longer life expectancy increases the likelihood that children will take on an informal caring role, which in turn affects their psychological well-being. Pontin, Schwannauer, Tai, & Kinderman, (2013) state that being an unpaid caregiver to an ill elderly or disabled loved one is a risk to the carer's psychological well-being. Plank, Mazzoni, and Cavada (2012) suggest that the growing number of elderly people all over the world place pressure on an already pressured healthcare system; therefore, hospital discharges have become premature in many cases, placing the responsibility of recovery with family or friends. Several studies have shown that recovery can be quicker at home, and that discharging elderly patients to home seems to have positive effects on their recovery and rehabilitation − while on the other hand it puts an extreme burden on their caregivers. Practical and emotional support are vital in helping carers deal with this (Plank et al., 2012).

Caregiving and well-being

Caregiving, according to Plank et al. (2012, p. 208) "can be a demanding and even all-consuming task that takes a lot of time, psychological energy and physical stamina; therefore, it cannot be assumed that families can cope with the demands care-giving brings". Walker, (2012) writes that caregiving challenges have many overwhelming results on families, which in addition can add extra pressure to the normal functioning of a family unit. Hussein and Manthorpe (2012) also

acknowledge that being a carer may be demanding and exhausting. Nabors et al., (2013) describe how the emotions from observing a child suffering heighten a caregiver's stress, affecting the caregiver's own self-care; over an extended time this can become detrimental to health and well-being. A caregiver may feel anger and resentment towards their caring duties; accepting the situation and coming to terms with it can be difficult, and carers who experience anger can be at risk of emotional problems (Márquez-González, López, Romero-Moreno, & Losada, 2012).

Well-being and support

Definitions of well-being vary, and researchers from a variety of disciplines in psychology and social science have difficulty defining it. One definite conclusion is that it is an important goal for most people (Zou, Schimmack, & Gere, 2013). (Pontin et al., 2013, p.108) define well-being as a state "in which the individual is able to develop in their potential, work productively and creatively, build strong and positive relationships with others, and contribute to their community". Venkatapuram (2013, p.7) defines well-being as "meaningful and sustainable interactions between an individual and their social and physical environment", while Zou, Schimmack and Gere (2013) define it by assessing the individual's actual life and their ideal life. There is national well-being, individual well-being, and subjective well-being. Some researchers refer to well-being as solely psychological, for example, happiness, and satisfaction with life. Others refer to the individual's daily living, for example, abilities, opportunities (Venkatapuram, 2013). Within the caregiver role, how do we define well-being if a parent has a child with a severe disability? It is essential to recognise how caregivers preserve their own well-being and mental health during the caregiving role in order to adapt support systems, financial aid and personal development programmes to suit them(Okabayashi et al., 2008).

Well-being and support are paramount to enable carers to cope with the uncertainty of their responsibilities. The problems and difficulties faced by unpaid carers are hard to characterise, and on the other hand it is unclear to healthcare professionals whose job it is to support unpaid carers (Salin, Kaunonen, & Åstedt-Kurki, 2009). Hoefman, van Exel, and Brouwer (2013) write that providing care can be rewarding, but it can have a heavy impact on health and well-being depending on the level of caregiving required. Further research states that some policymakers remain ignorant of the importance of interventions in ensuring caregiver support and well-being: cost-effective interventions and support programmes are vital in assisting carers with their caring role. Carers have expressed frustration with the inadequate information from healthcare professions; complicated disabilities and the responsibility of medications add extra strain (Gona, Mung'ala-Odera, Newton, & Hartley, 2011). Carers' psychological well-being is most at risk at the beginning of the caring role and when caregiving comes to an end (Seddon et al., 2010). The present study will examine well-being in carers in relation to what support they receive and how they use coping strategies.

Support systems available for caregivers

The support carers may receive to help in their role begins with their general practitioners, social workers, housing support, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector (Seddon et al., 2010; O'Shea & Goode, 2013; Penfold, 2013). Chappell and Funk (2011) theorised that caregiving was, as a type of social support, an automatic responsibility that fell on the shoulders of immediate family and friends. Chappell and Funk (2011, p. 356) discuss the theory that "there are three aspects to defining social support, social networks (everyone with whom the individual has contact), group affiliations, (those with whom the individual has an

attachment), and interpersonal interaction (active affiliations involving trust and intimacy)." Caregivers who receive positive social interaction within group settings over a long period of time improve their personal psychological health and well-being (Wei et al., 2012).

Caroline Estrella is a learning disability nurse and also the parent of two sons who have autism. Estrella, who understands the healthcare system's perspective and has experience of being a caregiver, says the main needs for carers are resources. Estrella devised the listen, educate, support, structure, observe and normalise (LESSON) model to guide nurses in their work with parents of autistic children. Incorporating the LESSON model to family members, friends and the relevant organisations is essential to sustaining well-being in the long term (Estrella, 2013). Estrella describes looking after a child with autism as like always being on a boat, trying to stay afloat through the darkest storms.

A study done by McGill, Papachristoforou, and Cooper (2006), involving 66 family carers, examined levels of satisfaction with services, professional help and advice received while looking after children with behavioural and developmental disabilities. The results of the study show how dissatisfied the carers were with the support and services they received. Almost half the carers reported receiving no help or advice which would be helpful to them (McGill et al., 2006). Before considering Estrella's theory of LESSON, it is important to recognise (McGill et al., 2006) the behavioural and developmental difficulties experienced by children, to fully understand their requirements. In addition to this, Larson (2010) discusses potential stereotyping among organisations towards caregivers, such as regarding their lives as something to pity and failing to understand the full consequences of the child's condition, and the selfless effort of the caregiver. Such stereotypes can interfere with securing needed services (Larson, 2010).

Parents' expectations for their children –of a future full of prosperity and well-being –descend into reality when they grasp that it just isn't possible for their child due to a disability. The daily needs such as feeding and clothing become a painful reality as the child grows (Gona, Mung'ala-Odera, Newton, & Hartley, 2011). There is a need for better understanding of the burdens faced by the family of a child with complex needs, and an appreciation that these families require a break from caring if they are to continue with the demands of the caring role. A family's needs for respite have begun to be addressed through the provision of a nursing respite service (Thomas & Price, 2012). The research by McGill et al. (2006) suggests that respite is one of the more important support services provided for carers. Respite can be in home or residential care, which is principally provided by healthcare organisations, and usually carers' assessment is a prerequisite to qualify. According to Evans (2013), the service was established to provide a break from carer responsibilities, aiming to support both family and care recipients. Respite permits some time away from the caring role (Evans, 2013). In 1996 respite was specified as a requirement in every health board in Ireland; in addition to this stipulation services should be flexible and include home support, organised holidays and residential care. Funding needs to be "available for all who need the service" (MacDonald, Fitzsimons, & Walsh, 2007, p.63).

Coping strategies among caregivers

Previous research by Zou et al. (2013) led to the present study, which aspires to understand how carers develop positive and negative coping strategies to deal with their responsibilities, accept their actual life, accomplish personal well-being, and achieve their ideal life amidst their obligations as caregivers. Greenglass and Fiksenbaum (2009) report that coping is a reaction to stressful experiences, and a strategy is used once stress had been experienced. Coping is how people deal with

daily problems. (Shiota, 2006) suggests the correct coping strategies increase well-being and reduce stress. Resch, Benz, & Elliott, (2012) explain the importance for parents of children with disabilities to have the required skills and social support to fulfil their duties as a parent. Fears and concerns about how to cope with the illness or disability of the recipient, and about how to organise the various aspects of caring, are particularly frequent (Plank et al., 2012). Solution-focused coaching (SFC) is a therapeutic approach targeting individuals to focus on solutions rather than problems. The study initially aimed at helping staff who deal with severe and moderate intellectual disabilities to develop a useful relationship of trust. SFC was found to highlight self-efficacy, and to encourage helpful coping styles (Roeden, Maaskant, Bannink, & Curfs, 2012).

Religion and spirituality are a factor implicated in coping strategies. Researchers have conferred over the positive and negative aspects of religion and spirituality and the type of relationship the individual has with God. Deferring the problem to God to solve has a negative effect, for example, anxiety. A positive effect is when an individual sees God as a partner in problem solving, which results in a positive outcome, such as greater empowerment. Caregivers who made more use of positive religious or spiritual coping methods showed reduced levels of negative outcomes and higher levels of positive outcomes (Falb & Pargament, 2013).

Psychological strategies or coping skills are fundamental to sustaining a constant feeling of well-being when dealing with persistent demands. A caregiver's coping strategies can be positive and negative, which can be labelled as adaptive (constructive) coping or maladaptive (non-coping) (Eun-Jeong Lee, DeDios, Fong, Simonette, & Lee, 2013). Adaptive coping is defined as behaviour which expresses positive emotions, such as seeking support, active coping, and maintaining optimism.

Non-adaptive behaviours are denial, blaming others, and disengagement (Jacinto, 2010). Further studies into adaptive and maladaptive coping behaviours identify differences between males and females. Eun-Jeong Lee et al. (2013) find the use of criticism and avoidance among females, while avoidance and practical assistance were predictors of strain among male caregivers. This indicates that healthcare practitioners need to understand the needs of different genders to achieve positive adjustment to caregiving responsibilities.

An established viewpoint of coping strategies is problem-focused coping and emotion-focused coping, to which appraisal-focused coping was recently added (Okabayashi et al., 2008). Problem-focused coping involves using personal strengths to adjust to a problem, intending to solve the problem, weighing the pros and cons of different options and implementing stages to solve the problem. Emotion-focused coping is usually defined as managing an emotional stress that is related to the caregiving role; emotion-focused strategies include denial, focusing on and venting emotions, positively reinterpreting events, and pursuing helpful social support (Baker & Berenbaum, 2007). It is however important to note the limitations of existing measures of different coping strategies. Experiences of stressful situations are not necessarily understood in every scenario of caregiving, therefore leading to a situation where the stressor experiences have to fit into specific categories before they could be resolved. Also, emotional-focused coping strategies are often seen as unrealistic and self-blaming (Okabayashi et al., 2008). Conversely, individuals have the ability to disengage from unrealistic goals and reengage into new goals in an attempt to gain a feeling of well-being (Wrosch, Amir, & Miller, 2011).

Rationale

A good deal of research has been done to date into support systems and coping strategies among caregivers. This present study has paid attention to how

9

support systems and coping strategies influence aspects of well-being among unpaid caregivers. The justification for the present study is to investigate how to improve and sustain well-being among caregivers. The research will be conducted by examining the relationship between the variables. The study is to increase findings in the data and offer suggestions for future research.

Hypothesis

There will be a relationship between coping strategies and well-being among caregivers who receive support.

There will be a difference in the psychological well-being of males and females who receive support and those who don't.

Methodology

Participants

The sample employed is a purposive non-probability sample, with a total of 64 participants (14 males, 50 females). One hundred were targeted, but some chose not to take part in the study. The participants were a representative group from the population of caregivers in a community interest company. The company exists to inspire unpaid carers of children with learning and physical disabilities and of sick or elderly relatives.

Participants were invited to take part in a research and coffee morning while attending a personal development workshop at the company's regular venue. The research was explained to them in advance, and those who wished to take part in the study were given the questionnaire. All participants were informed that if they wished to stop the questionnaire at any point they were more than welcome to do so. Helpline numbers and related contact numbers were also handed out with the questionnaire in case any question caused offence. At the request of the organisation, questions about age and employment status were not collected. There were no inclusion criteria, participants were over 18, and all were able to understand the instructions.

Design

The study was designed as a quantitative correlational survey which is descriptive in nature. The study will measure relationships between variables: coping strategies, support, and social demographics will have an effect on well-being. Well-being is the Criterion variable; support, demographics and cope are the Predictor variables. Demographics relating to males and females will be included.

Materials

The Brief Cope questionnaire (BC) (See appendix 2) and the Carers Well-being and Support questionnaire (CWS) (see appendix 1) were used to evaluate the relationship between variables.

The Brief Cope questionnaire was developed by Charles S. Carver in 1997. It is structured as 28 questions and 14 subscales (see Appendix). The aim of the BC is to evaluate people's coping abilities during times of stress (Carver, 1997). Scoring for the 28 questions is as follows: 1= I haven't been doing this at all; 2=I've been doing this a little bit; 3= I've been doing this a medium amount; and 4= I've been doing this a lot. Subscales are scored by computing two previous questions together. Cronbach's Alpha was used to assess reliability.

Table 1: Scoring of BC subscales and Cronbach's Alpha internal reliability.

Subscale	Items	Cronbach's Alpha
Self-distraction	1 and 19	.37
Active coping	2 and 7	.63
Denial	3 and 8	.64
Substance use	4 and 11	.79
Use of emotional support	5 and 15	.51
Use of instrumental support	10 and 23	.61
Behavioural disengagement	6 and 16	.74
Venting	9 and 21	.44
Positive reframing	12 and 17	.45
Planning	14 and 25	.55
Humour	18 and 28	.05
Acceptance	20 and 24	.47
Religion	22 and 27	.81
Self-Blame	13 and 26	.61

The CWS questionnaire was developed by the Royal College of Psychiatrists' Centre for Quality Improvement in collaboration with Rethink and the Alzheimer's Society. It is a validated tool with psychometric properties, for assessing and monitoring carer well-being and satisfaction with the support they receive. It can be used with carers of people with any mental health problem (common or severe), including dementia. It is a self-report instrument and can be broken down into four sections which can be used together or in isolation, depending on what a service wants to monitor. The Well-being scale can be used on its own or with the Support scale, and you only need to use the invalidated "Your needs" (part 3) and "Background information" (part 4) sections if they are beneficial. In this research paper the well-being scale, support scale and your needs were used in data collection.

The score is computed by a value assigned to each response category in the two CWS scales:

- Well-being 5-point scale: "A lot" concerned = 0, through to "Not at all" = 4

- Support 4-point scale: "Very dissatisfied" with support = 0, through to "Very satisfied" = 3

Thus, the better things are for the carer with regard to their well-being and satisfaction with support, the higher their score will be on each scale. Respondents get two scores, one for Well-being and one for Support: the scores cannot be combined.

Missing data: To maximise the number of cases for whom a scale score can be computed, standard practice is followed and missing data imputed. That is, for respondents who answer at least 50% of items on a particular scale, data is ascribed for every missing item on that scale using a person-specific mean, calculated on the basis of the mean score of non-missing values on that scale for that respondent.

Procedure

Participants were informed about the survey in advance. It was explained to them that all they needed to do was to come along and fill in the questionnaires, and that they could stop at any point in the process. Prior to handing out the questionnaires a briefing was given about the BC and CWS questionnaires, including the number of questions and the fact there was no time limit. An information sheet at the beginning of the survey had helpline numbers and details of other organisations associated with the topics covered, which were there to help if any questions caused upset. This included the supervisor's and the researcher's e-mail addresses.

The participants in the study knew each other from attending meetings together, and during the collection of data they sat closely together. Pens were provided and water was available. The facilitator who normally delivered the meetings handed out the questionnaires; this had been decided earlier, due to the fact that some of the carers knew the researcher personally. After collection of the questionnaires, participants were thanked and tea and coffee were provided before they left the building.

Results

Sixty-four participants took part in the study (50 females and 14 males). The results were gathered from Persons Correlation coefficient analysis; a scatterplot displays the relationship between support and well-being among caregivers in Figure 1. Also an independent samples t-test was used between male and females.

Hypothesis one:

There will be a relationship between coping strategies and well-being among caregivers who receive support. A person's correlation coefficient found that there was a moderate relationship between carers' well-being and support (r(54)=0.34, p=.011). Therefore the null hypothesis is rejected.
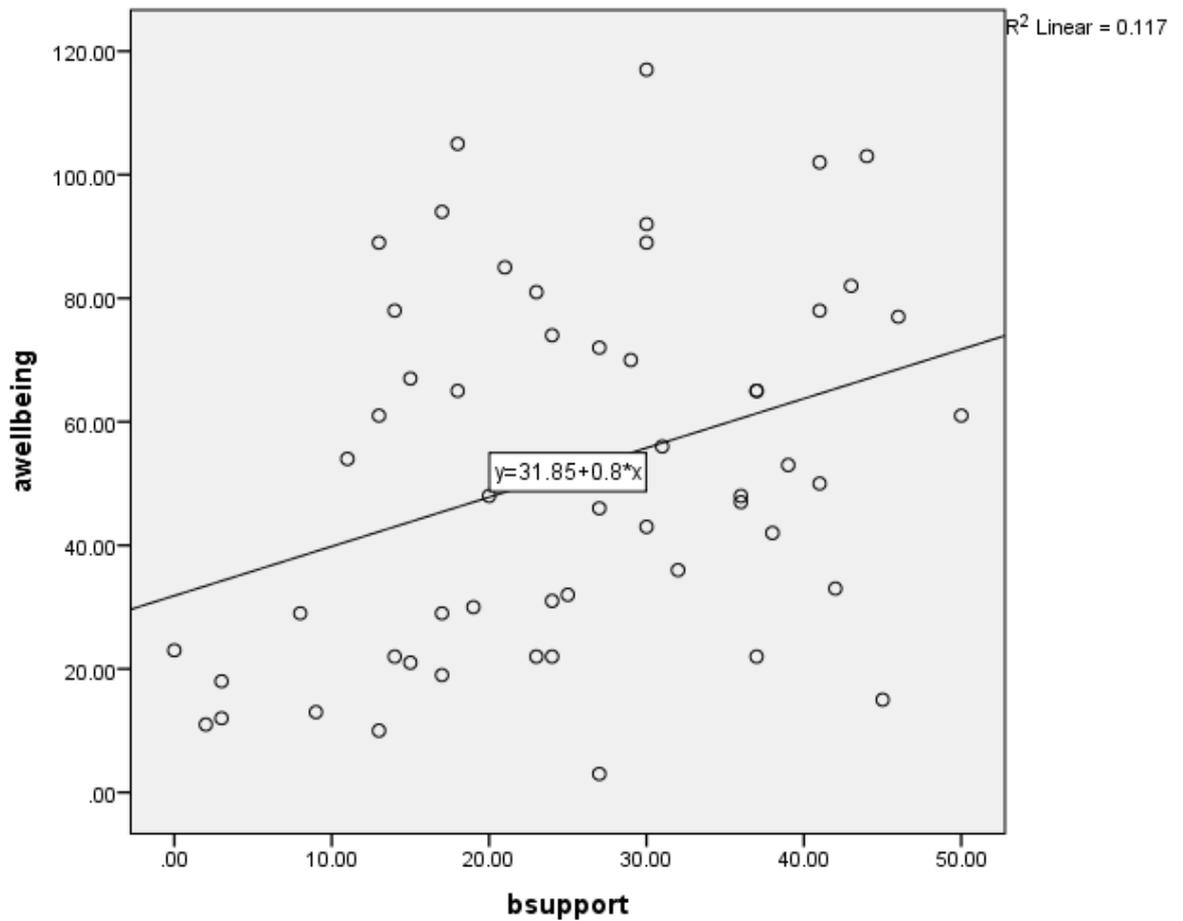
Figure 1: A scatterplot displaying the relationship between well-being and support among caregivers.

<u>Hypothesis two</u>

There will be a difference in the psychological well-being of males and females who receive support and those who don't.

Females (mean 25.82, SD 12.98) were found to have a higher level of support than males (mean 21.91, SD 11.72). The 95% confidence limits show that the

population mean difference of the variables lies somewhere between -4.39 and 12. An independent samples t-test found that there was a no significant difference between support of males and females (t(55)=.943, p=.35). Therefore null could not be rejected.

No other significant results were found, but it is important to note that a person's correlation coefficient found that there was a weak relationship between carers' well-being and denial (r(57) = 0.26, p = .051). This result was approaching significance.

Qualitative Analysis

In Section C of the CWS questionnaire there are three parts to "your needs". <u>Part one asks: Would you like more support to help you in your role as a carer?</u>

The responses are: no not at all; yes a little; and yes a lot. Translated into percentages, 39=61% of respondents answered yes a lot, 22=34% answered yes a little, and 3=5% stated no not at all.

Pie chart showing the number of respondents who need support
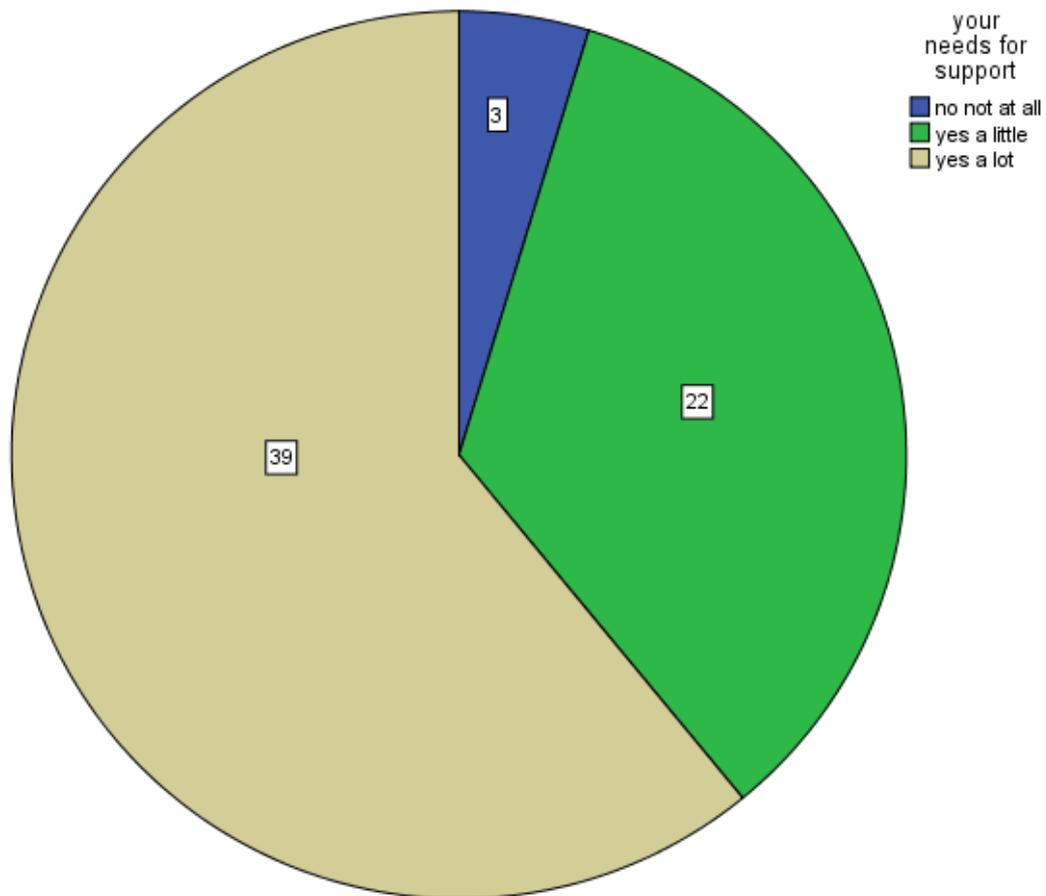
Figure 2 above shows a pie chart which displays how the 64 respondents in the study replied to part one of the questions

<u>Part two of Section C asked: What types of additional support would you most like to receive?</u>

Forty-four carers answered this section, with various responses. It is important to document these responses for this research paper. Respondent 7 stated how important it was to receive "support and more available information and, training from professionals/organisations". Many of the carers felt overwhelmed with the lack of support from professional bodies. Respondent 16, like many other carers, stated that respite would be the best type of support needed: "at present respite takes my son for one hour per fortnight, he would benefit from a lot more respite and so would I". Respondent 28, who looks after her daughter who has severe mental health challenges and for whom the caring responsibility is 24/7, explains: "To tell you the truth life is so hectic with caring I am unable to think at present", adding that she has

concerns for her own medical and physical health. In total 35 respondents stated that respite would be a great support to them.

Respondent 37 explains, "Challenging behaviour is very difficult to deal with. Maybe a support group to discuss with others how this affects our whole family. Bee Free groups help as we can all get together and discuss many topics." The Bee Free group is one of many personal development workshops run by the community interest company. Respondent 16 also explains how a support group called "Time for Me", run by the company, helped her realise "that I am not the only one dealing with the stress of being a carer". Respondent 46 reports that being a member of the Social Butterflies group has "been a lifeline when things are bad (and good) as everyone's situation is different but equally stressful". Respondent 49 says, "I've been attending me-unltd and find it very helpful and encouraging in my role as a carer. The benefits I have received since joining keep me sane". Respondent 27 states that the support most welcome is the Riverside Carers Group for male carers: "something to look forward to helps you to de-stress, meet people like myself and know what I am going through also doing something different every week". Respondent 24 states, "the only group that has helped me through my caring role was Me Time". In total 17 respondents concluded that they benefited from personal development programmes and group get-togethers; however, there were concerns these facilities would end due to funding discontinuing.

Part three of Section C asked: Is there anything else that's important to your well-being that you'd like help with or would change?

Thirty-two carers completed part three of the questionnaire. The results showed that continued financial support was important to the carers due to their fear that workshops and support groups would cease. Respondent 7 explains that for well-being, "more funding being made available to me-unltd so they can provide more

training, activities and support which is consistent and ongoing". For many of the carers, feeling isolated and housebound results in stress and being overwhelmed. Respondent 33 describes the sense of isolation as "unbearable", requesting support groups and workshops to aid personal well-being. Respondent 24 reports that on days when unable to leave the home, someone from the community interest company always keeps in contact by phone. Respondent 27 again also benefits from "someone at the end of the phone", saying "it helps me to cope through the week, there is always someone at the end of the phone to help which lifts your spirits".

The majority of responses were directed towards personal development workshops. Respondent 29 indicates that "attending programmes has really turned around my life". Several stated they would like to be able to attend workshops and "more therapies delivered on an ongoing basis to help in the caring role". Respondent 8 "suffers several disabilities therefore at times can neglect own l health issues attending social groups provides time for self". Respondents 19, 48, 62, and 37 all feel it is important to learn health and well-being by attending personal development courses.

Discussion

The purpose of this research project is to explore coping strategies, support systems and well-being among unpaid caregivers. It aims to add to current research on carer well-being and the efficacy of carers' support programmes. The results found in hypothesis one reinforced that there is a relationship between coping strategies and well-being among caregivers who receive support. A person's correlation coefficient found that there was a relationship between carers' well-being and support. This result supports the research of Seddon et al. (2010), Gona et al. (2011) and Hoefman et al. (2013), suggesting that support programmes are vital in assisting carers with their caring role, complicated disabilities and lack of professional assistance. Psychological well-being is most at risk to the carer at the beginning of the caring role (Falb & Pargament, 2013), therefore reflecting the importance of carer well-being among individual carers in this study.

Hypothesis two anticipated a difference in the psychological well-being of males and females who receive support and those who don't. The results did not reinforce this hypothesis. An independent samples t-test found no significant difference between support of males and females, therefore the null could not be rejected. There is a deficit in research articles relating to male carers. Eun-Jeong Lee et al. (2013) discuss the difference in behaviour associated between males and females and how they cope with the caregiving role in different ways; this could be considered a weakness in relation to the present study; also denial is one of the non-adaptive behaviours associated with male carers (Jacinto, 2010). Before considering Eun-Jeong Lee and colleagues' (2013) suggestion it is important to reference MacDonald et al, (2007) proposal that female carers used more problem-solving strategies than male carers. In this research paper there was an outcome approaching significance which was a relationship between well-being and denial. It is however

also important to observe the limitations of research which has uneven numbers of male and female participants.

The qualitative analysis showed a high number of respondents who would like more support to help with the caring role. The results of a study completed by Arksey and Hirst (2005) explain how difficult it is for health and social care services to cope with the growing number of caregivers. Further research in the area of healthcare support services estimated a global price tag of $30.5 billion (Stockwell-Smith et al., 2010). The results of these studies provide an understanding into the requirement for unpaid caregivers to receive the support they need and an already stretched health care support system. Respondent 28 explained that the caring role is 24/7 and that there is a need for ongoing support. Other respondents reported feeling overwhelmed with the lack of support by professionals. Walker also reports the overwhelming responsibilities carers cope with and how it affects other family members. Continued comments throughout the questionnaire reflected the frustration of the carers to be heard by professional bodies. Gona et al. (2011) also discuss inadequate information from healthcare professionals. Further studies have implied that understanding carers' needs and personal experiences demands continuing research on an international level (Plank, Mazzoni, &Cavada, 2012).

The results of the qualitative analysis also provide an understanding into the demand for respite services. Plank et al. (2012) suggest that the physical stamina required to maintain the caring role is engulfing. Returning to respondent 28's request for respite, the 24/7 responsibility of caregiving means that respite becomes a requirement rather than a request. Venkatapuram (2013, p. 7) defines well-being as "meaningful and sustainable", therefore 24/7 caregiving can jeopardise an individual's well-being. McGill et al. (2006) indicate that the most important support service is respite, and in the present study carers reported a need for more respite;

many respondents reported a feeling of exhaustion because of constant caregiving. Further research in the area of respite also shows that initially the service was established to provide a break from caring (Evans, 2013). Before considering applying residential respite it is important to note that not all carers want the facility, due to the impact it has on other family members. McGill et al. (2006) discuss the possibility of home respite, which some of the respondents stated they would prefer.

Further studies by MacDonald et al, (2007) have examined the relationship between challenging behaviour and respite care, suggesting families' use of respite is related to challenging behaviour. Jacinto (2010) discusses non-adaptive behaviour such as disengagement preventing a sense of well-being; this study revealed no significant relationship between well-being and behavioural disengagement. Respondent 37 found the experience of challenging behaviour very difficult, and also expressed a preference for support from social interaction from group settings offering advice on health and well-being. Building upon this answer and adding to previous research conducted by Wei et al. (2012), psychological health and well-being improve social interaction. The results of this study showed there is a relationship between support and well-being, also providing from the qualitative analysis an understanding of the majority of respondents' wishes for personal development workshops and health and well-being advice. Okabayashi et al. (2008) recognise the importance of developing personal development programmes to suit individual needs.

Respondent 7 states that one of the most valuable support services is to ensure future funding for the community interest company that runs personal development courses and workshops offering guidance on health and well-being. Other carers voiced concerns that funding would discontinue. The only time away from caring is attending such events; some carers reported having previously

experienced isolation due to being house bound. A carer describes isolation as "unbearable" and sees the workshops as a lifeline. MacDonald et al. (2007) discuss the importance of funding being available for such services, including organised holidays; respondent 63 reported not having had a holiday in 23 years due to the caring role.

Limitations

Recognising the sensitive subject of caregiving is the first limitation. Researchers attempting to gather information need to develop a deep understanding of the level of sacrifice these carers make in their caring role: they take their caring role very seriously. Choosing the correct questionnaire for the research study is therefore vital. The CWS questionnaire had focused mainly on mental health problems and dementia in the background information section of the form. There is a sense that carers have been disrespected, as there was nowhere on the form to say who they were caring for, which led to frustration. This narrowed the spectrum, and stating their true role became inaccessible to the majority of the carers. However, as the questionnaire had three parts to it (Section A: well-being; B: support; C: your needs as a carer), this allowed for the appropriate data to be collected for this research project.

The research-gathering has implications for real-life applications; some carers were unable to fill out the questionnaire as they were exhausted from the caring role. Future research in this area would benefit much more from doing individual interview type data collection, firstly to assure carers their role is being taken seriously and respectfully, but also to gain a deeper insight into the real-life role the carers are living with in their caring responsibilities. Careful thought went into the delivery method of the questionnaires, due to some of them knowing the researcher;

the decision was made for the facilitator at each venue to hand out the questionnaires. In hindsight this was possibly the wrong decision.

Another weakness with the study was the imbalance between male and female participants. Unfortunately this could not be prevented, but it is appropriate to mention as a possible limitation to the study. There were strengths to the study, as it will add to previous research and offer the chance of future research using different variables such as bigger samples (e.g., through online data collection). There is also a need for research on male carers and coping strategies. A deficit in research in male carers is obvious, so this is another possible avenue for further research.

Conclusion

Much research has gone into understanding the responsibility and function of caregivers. The caring role can appear suddenly or gradually, and with a growing elderly population there is an even greater need to predict how to achieve a sense of well-being through successful coping strategies –for both the carer and the person needing care. Researchers have found a significant relationship between well-being and community support systems. This paper found a significant relationship between well-being and support. However there was no relationship between male and female caregivers on Psychological well-being between those who receive support and those who don't. Respondents in this study stated that personal development programmes helped them cope with the pressures of caregiving, and that they aim to continue attending these courses.

References

Arksey, H., & Hirst, M. (2005). Unpaid carers' access to and use of primary care services. *Primary Health Care Research & Development (Sage Publications, Ltd.)*, *6*(2), 101–116. doi:10.1191/1463423605pc230oa

Baker, J. P., & Berenbaum, H. (2007). Emotional approach and problem-focused coping: A comparison of potentially adaptive strategies. *Cognition & Emotion*, *21*(1), 95–118. doi:10.1080/02699930600562276

Barbosa, A., Figueiredo, D., Sousa, L., & Demain, S. (2011). Coping with the caregiving role: Differences between primary and secondary caregivers of dependent elderly people. *Aging & Mental Health*, *15*(4), 490–499. doi:10.1080/13607863.2010.543660

Chappell, N. L., & Funk, L. M. (2011). Social support, caregiving, and aging. *Canadian Journal on Aging*, *30*(3), 355–370. doi:10.1017/S0714980811000316

Collins, J., & Bayless, S. (2013). How caring for a parent affects the psychosocial development of the young. *Nursing Children & Young People*, *25*(10), 16–21.

Estrella, C. (2013). Parental perspectives on the care of children with autism. *Learning Disability Practice*, *16*(9), 24–28.

Eun-Jeong Lee, DeDios, S., Fong, M. W. M., Simonette, C., & Lee, G. K. (2013). Gender differences in coping among spousal caregivers of persons with Multiple Sclerosis. *Journal of Rehabilitation*, *79*(4), 46–54.

Evans, D. (2013). The provision of health and social care services for older people by respite providers. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, *45*(2), 255–263. doi:10.5172/conu.2013.45.2.255

Falb, M. D., & Pargament, K. I. (2013). Buddhist coping predicts psychological outcomes among end-of-life caregivers. *Psychology of Religion and Spirituality*, *5*(4), 252–262. doi:10.1037/a0032653

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2011). Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience? *Child: Care, Health & Development*, *37*(2), 175–183. doi:10.1111/j.1365-2214.2010.01124.x

Greenglass, E. R., & Fiksenbaum, L. (2009). Proactive coping, positive affect, and well-being: Testing for mediation using path analysis. *European Psychologist*, *14*(1), 29–39. doi:10.1027/1016-9040.14.1.29

Hoefman, R. J., van Exel, J., & Brouwer, W. B. F. (2013). Measuring the impact of caregiving on informal carers: A construct validation study of the CarerQol

instrument. *Health & Quality of Life Outcomes*, *11*(1), 1–23.
doi:10.1186/1477-7525-11-173

Hussein, S., & Manthorpe, J. (2012). The diversity of staff supporting family carers
in England: Findings from an analysis of a national data set. *Diversity &
Equality in Health & Care*, *9*(2), 101–111.

Jacinto, G. A. (2010). Caregivers' coping and self-forgiveness after the death of a
care-receiver. *Journal of Social Service Research*, *36*(3), 206–215.
doi:10.1080/01488371003697939

Larson, E. (2010). Identifying indicators of well-being for caregivers of children with
disabilities. *Occupational Therapy International*, *17*(1), 29–39.
doi:10.1002/oti.284

Mac Donald, E., Fitzsimons, E., & Walsh, P. N. (2007). Use of respite care and
coping strategies among Irish families of children with intellectual
disabilities. *British Journal of Learning Disabilities*, *35*(1), 62–68.
doi:10.1111/j.1468-3156.2006.00399.x

Márquez-González, M., López, J., Romero-Moreno, R., & Losada, A. (2012). Anger,
spiritual meaning and support from the religious community in dementia
caregiving. *Journal of Religion & Health*, *51*(1), 179–186.
doi:10.1007/s10943-010-9362-7

McGill, P., Papachristoforou, E., & Cooper, V. (2006). Support for family carers of
children and young people with developmental disabilities and challenging
behaviour. *Child: Care, Health & Development*, *32*(2), 159–165.
doi:10.1111/j.1365-2214.2006.00600.x

Nabors, L. A., Kichler, J. C., Brassell, A., Thakkar, S., Bartz, J., Pangallo, J., …
Lundy, H. (2013). Factors related to caregiver state anxiety and coping with a
child's chronic illness. *Families, Systems, & Health*, *31*(2), 171–180.
doi:10.1037/a0031240

O'Shea, R., & Goode, D. (2013). Effects of stroke on informal carers. *Nursing
Standard*, *28*(15), 43–47.

Okabayashi, H., Sugisawa, H., Takanashi, K., Nakatani, Y., Sugihara, Y., &
Hougham, G. W. (2008). A longitudinal study of coping and burnout among
Japanese family caregivers of frail elders. *Aging & Mental Health*, *12*(4),
434–443. doi:10.1080/13607860802224318

Penfold, J. (2013). Innovative electronic advice for carers of poorly children.
Primary Health Care, *23*(5), 6–7.

Plank, A., Mazzoni, V., & Cavada, L. (2012). Becoming a caregiver: New family
carers' experience during the transition from hospital to home. *Journal of
Clinical Nursing*, *21*(13/14), 2072–2082. doi:10.1111/j.1365-
2702.2011.04025.x

Pontin, E., Schwannauer, M., Tai, S., & Kinderman, P. (2013). A UK validation of a general measure of subjective well-being: the modified BBC subjective well-being scale (BBC-SWB). *Health & Quality of Life Outcomes*, *11*(1), 1–9. doi:10.1186/1477-7525-11-150

Resch, J. A., Benz, M. R., & Elliott, T. R. (2012). Evaluating a dynamic process model of wellbeing for parents of children with disabilities: A multi-method analysis. *Rehabilitation Psychology*, *57*(1), 61–72. doi:10.1037/a0027155

Roeden, J. M., Maaskant, M. A., Bannink, F. P., & Curfs, L. M. G. (2012). Solution-focused coaching of staff of people with severe and moderate intellectual Disabilities: A Case Series. *Journal of Policy & Practice in Intellectual Disabilities*, *9*(3), 185–194. doi:10.1111/j.1741-1130.2012.00352.x

Salin, S., Kaunonen, M., & Åstedt-Kurki, P. (2009). Informal carers of older family members: How they manage and what support they receive from respite care. *Journal of Clinical Nursing*, *18*(4), 492–501. doi:10.1111/j.1365-2702.2008.02550.x

Seddon, D., Robinson, C., Tommis, Y., Woods, B., Perry, J., & Russell, I. (2010). A Study of the carers strategy (2000): Supporting carers in Wales. *British Journal of Social Work*, *40*(5), 1470–1487. doi:10.1093/bjsw/bcp081

Shiota, M. N. (2006). Silver linings and candles in the dark: Differences among positive coping strategies in predicting subjective well-being. *Emotion*, *6*(2), 335–339. doi:10.1037/1528-3542.6.2.335

Stockwell-Smith, G., Kellett, U., & Moyle, W. (2010). Why carers of frail older people are not using available respite services: An Australian study. *Journal of Clinical Nursing*, *19*(13/14), 2057–2064. doi:10.1111/j.1365-2702.2009.03139.x

Thomas, S., & Price, M. (2012). Respite care in seven families with children with complex care needs. *Nursing Children & Young People*, *24*(8), 24–27.

Venkatapuram, S. (2013). Subjective wellbeing: A primer for poverty analysts. *Journal of Poverty & Social Justice*, *21*(1), 5–17. doi:10.1332/175982713X664029

Walker, L. J. (2012). An Emotional and Financial MRI: What Are the Challenges? *Journal of Financial Planning*, *25*(7), 54–60.

Wei, Y.-S., Chu, H., Chen, C.-H., Hsueh, Y.-J., Chang, Y.-S., Chang, L.-I., & Chou, K.-R. (2012). Support groups for caregivers of intellectually disabled family members: Effects on physical-psychological health and social support. *Journal of Clinical Nursing*, *21*(11/12), 1666–1677. doi:10.1111/j.1365-2702.2011.04006.x

Wrosch, C., Amir, E., & Miller, G. E. (2011). Goal adjustment capacities, coping, and subjective well-being: The sample case of caregiving for a family

member with mental illness. *Journal of Personality and Social Psychology*, *100*(5), 934–946. doi:10.1037/a0022873

Zou, C., Schimmack, U., & Gere, J. (2013). The validity of well-being measures: A multiple-indicator–multiple-rater model. *Psychological Assessment*, *25*(4), 1247–1254. doi:10.1037/a0033902

Carer Well-Being & Support

A questionnaire for carers of people with

a mental health problem or dementia

Before you start filling this questionnaire in, there are a few things you should know.

❖ This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carers' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs.

❖ It can be filled in by anyone who has a role in caring for someone with a mental health problem or dementia. You don't have to be a person's main carer or live at the same address as them.

❖ Please try to answer every question; there are no wrong or right answers.

❖ We recognise that some carers may be caring for more than one person. For each question, **choose one answer** that best reflects your caring responsibilities as a whole.

❖ The first section of the questionnaire asks about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell us why this has been an unusual time, there is space to do so in the section about your needs, on page 7.

A. Well-Being

The questions in Part A are about aspects of **your general well-being**. All of the questions are about how you have been over the <u>past four weeks</u>.

We recognise that some carers may be caring for more than one person. For each question, **tick**

one box on each line that best reflects your caring responsibilities as a whole.

Please write <u>today's date</u>: _____

Your role as a carer

The first set of questions asks about your **role as a carer**. (Please tick one box on each line.)

During the <u>past 4 weeks</u>, **how concerned** were you about…	A lot	Quite a bit	Moder-ately	A little	Not at all
1. not having enough time to yourself?	□	□	□	□	□
2. having to put the needs of the person you care for ahead of your own needs?	□	□	□	□	□
3. not being able to take a break from caring?	□	□	□	□	□
4. not being able to plan for the future?	□	□	□	□	□
5. not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?	□	□	□	□	□

Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. (Please tick one box on each line.)

During the <u>past 4 weeks</u>, **how concerned** were you about…	A lot	Quite a bit	Moder-ately	A little	Not at all
6. strains in your relationship with the person you care for?	□	□	□	□	□
7. the person you care for being too dependent on you <u>at the moment</u>?	□	□	□	□	□
8. the person you care for becoming too dependent on you <u>in the future</u>?	□	□	□	□	□
9. the person you care for saying things that upset you?	□	□	□	□	□
10. feeling irritable with the person you care for?	□	□	□	□	□
11. reaching 'breaking point', where you feel you can't carry on with things as they are?	□	□	□	□	□

Your relationships with family and friends

(Please tick one box on each line.)

During the <u>past 4 weeks</u>, **how concerned** were you about…	A lot	Quite a bit	Moder-ately	A little	Not at all
12. strains in your relationships with family and friends, because of your caring responsibilities?	□	□	□	□	□
13. "drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	□	□	□	□	□
14. feeling isolated and lonely because of the situation you are in?	□	□	□	□	□
15. not getting the support you need from family and friends?	□	□	□	□	□

Your financial situation (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	Moder- ately	A little	Not at all
16. your own financial situation?	□	□	□	□	□
17. the financial situation of the person you care for?	□	□	□	□	□
18. having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?	□	□	□	□	□

Your physical health (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	Moder- ately	A little	Not at all
19. your own physical health?	□	□	□	□	□
20. your caring role making your physical health worse?	□	□	□	□	□

Your emotional well-being (Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	Moder- ately	A little	Not at all
21. being unable to cope with the "constant anxiety" of caring?	□	□	□	□	□
22. feeling depressed?	□	□	□	□	□
23. being unable to see anything positive in your life?	□	□	□	□	□
24. lack of sleep brought about through worry or stress?	□	□	□	□	□
25. lack of sleep caused by the person you care for keeping you awake at night?	□	□	□	□	□
26. feeling so exhausted that you can't function properly?	□	□	□	□	□

Stigma and discrimination

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about…	A lot	Quite a bit	Moder-ately	A little	Not at all
27. people treating you differently because of the illness/condition of the person you care for?	☐	☐	☐	☐	☐

Your own safety

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about the person you care for…	A lot	Quite a bit	Moder-ately	A little	Not at all
28. accidentally doing something that puts you at risk (e.g. leaving the gas on)?	☐	☐	☐	☐	☐
29. being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?	☐	☐	☐	☐	☐

The safety of the person you care for

(Please tick one box on each line.)

During the past 4 weeks, **how concerned** were you about the person you care for…	A lot	Quite a bit	Moder-ately	A little	Not at all
30. harming themselves?	☐	☐	☐	☐	☐
31. getting themselves into dangerous situations?	☐	☐	☐	☐	☐
32. relapsing or deteriorating, such that it puts their safety at risk?	☐	☐	☐	☐	☐

B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you may receive** to help you in your role as a carer. Support may be provided by people working in the voluntary, private or statutory sectors, such as GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector.

Please tick the box on each line that best reflects your level of satisfaction with **the support you receive as a whole**.

Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

In general, **how satisfied** are you…	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
1. that you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?	☐	☐	☐	☐
2. that you have enough information about how their condition/illness is likely to develop in the longer-term?	☐	☐	☐	☐
3. that you can get whatever information you need when you need it (e.g. through your doctor or on your own)	☐	☐	☐	☐
4. with how easy it is to understand the information you have?	☐	☐	☐	☐
5. with the amount of advice available to you (e.g. from healthcare workers or other carers)?	☐	☐	☐	☐
6. that you are clear about who to go to for the information and advice you need?	☐	☐	☐	☐
7. that you are clear about who to contact if there is an emergency and you need help right away?	☐	☐	☐	☐
8. that you are clear about who to call if you have a routine inquiry?	☐	☐	☐	☐

Your involvement in treatment and care planning

(Please tick one box on each line.)

In general, **how satisfied** are you with…	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
9. your involvement in important decisions (e.g. medication, hospitalisation)?	☐	☐	☐	☐
10. your ability to influence important decisions?	☐	☐	☐	☐

Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** - that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists). (Please tick one box on each line.)

In general, **how satisfied** are you with…	Very satisfied	Somewhat satisfied	Somewhat Dissatisfied	Very dissatisfied
11. how easy it is to get help and support from staff for the *person you care for* (e.g. to prevent relapse)?	☐	☐	☐	☐
12. how easy it is to get help and support from staff for *yourself* (e.g. advice on how to deal with certain behaviours)	☐	☐	☐	☐
13. thequality of help and support from staff for the *person you care for*?	☐	☐	☐	☐
14. your relationships with key staff who support the *person you care for?*	☐	☐	☐	☐
15. how well the staff you have contact with are communicating with each other (i.e. that they share important information)	☐	☐	☐	☐
16. how seriously staff take what you say to them?	☐	☐	☐	☐
17. the level of understanding staff have of what it must be like to be in your situation?	☐	☐	☐	☐

C. Your Needs

The questions in Part C are about **your needs for support** to help you in your role as a carer

1. Would you like more support to help you in your role as a carer?

No, not at all   □

Yes, a little   □

Yes, a lot   □

2. What types of additional support would you most like to receive?

3. Is there anything else that's important to your well-being that you'd like help with or would like to change?

D. Background Information

The following information will help us to understand your caring situation better and interpret your answers more effectively.

About you

1. Your date of birth? _____

2. Your gender?   Female ☐   Male ☐

3. Your ethnic background?

White: British   ☐
        Irish   ☐
        Other White background ☐

please state_____

Mixed: White and Black Caribbean ☐
        White and Black African   ☐
        White and Asian   ☐
        Other Mixed background ☐

please state_____

Asian or Asian British:
        Indian   ☐
        Pakistani   ☐
        Bangladeshi   ☐
        Other Asian background ☐

please state_____

Black or Black British:
        Caribbean   ☐
        African   ☐
        Other Black background ☐
please state_____

Chinese or other ethnic group:
        Chinese   ☐
        Other   ☐
please state_____

4. Your environment (the area you live in)?

   Rural   ☐

   Semi-urban   ☐

   Urban   ☐

5. Your employment status?

   Employed full-time   ☐

   Employed part-time   ☐

   Self-employed   ☐

   Unemployed   ☐

   Retired   ☐

   Student   ☐

   Unable to work due to caring
   responsibilities   ☐

   Unable to work due to ill-health
   /disability   ☐

   Other (please specify)   ☐

6. In <u>what year</u> did you first start caring for someone with a mental health problem/dementia? (If you don't remember the exact year, please give an estimate of the year you started caring.)

_____

7. Please estimate as best you can how many hours you spent <u>last week</u> looking after someone with a mental health problem/dementia?
_____

Was this:

More hours than usual?   ☐

About the same number of hours as usual?   ☐

Fewer hours than usual?   ☐

8. How many people <u>with a mental health problem/dementia</u> do you currently care for?

    1 person   ☐

    2 persons   ☐

    3 + persons   ☐

About the Person or Persons You Care For

This next section asks about the person or persons you care for with a mental health problem or dementia. Please respond about the person you care for using the first column of boxes ('Person 1'). If you care for more than one person with a mental health problem or dementia, please tick relevant boxes in the other two columns (Persons 2 & 3). There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

9. Who do you care for?

	Person 1	Person 2	Person 3
My **son/daughter**	☐	☐	☐
My **partner/spouse**	☐	☐	☐
My **brother/sister**	☐	☐	☐
My **parent**	☐	☐	☐
My **friend**	☐	☐	☐
Other (please specify below tick box)	☐	☐	☐
	_____	_____	_____

10. What is their illness/condition?

	Person 1	Person 2	Person 3
Dementia (e.g. Alzheimer's Disease)	☐	☐	☐
Psychosis/schizophrenia	☐	☐	☐
Bi-polar disorder/manic depression	☐	☐	☐
Depression	☐	☐	☐
Anxiety	☐	☐	☐
Other mental health problem	☐	☐	☐
(please specify below tick box)	_____	_____	_____

11. Do you live with each other at the moment?

	Person 1	Person 2	Person 3
Yes	☐	☐	☐
Some of the time	☐	☐	☐
No	☐	☐	☐

➥**If no, where are they currently living?**

	Person 1	Person 2	Person 3
Own/rented accommodation	☐	☐	☐
Supported accommodation	☐	☐	☐

	Person 1	Person 2	Person 3
With other family member/friend	☐	☐	☐
Care home	☐	☐	☐
Hospital	☐	☐	☐
Other(please specify below tick box)	☐	☐	☐
	_____	_____	_____

12. Which of the following statements best describes your role as a carer at the moment?

	Person 1	Person 2	Person 3
I am the **only** caregiver	☐	☐	☐
I **share** caring responsibilities with others, but **I** am the **main** caregiver	☐	☐	☐
I **share** caring responsibilities with others	☐	☐	☐
I share caring responsibilities, but **someone else** is the **main** caregiver	☐	☐	☐
Other (please specify below tick box)	☐	☐	☐
	_____	_____	_____
	_____	_____	_____

Taking a Break

13. Which of the following types of support, if any, do you use to allow you to take a break from caring? (Tick more than one box if required.)

Friends/family providing temporary care☐

Paid carers coming into the home ☐

Paid carers providing care away from the home (e.g. care home)   ☐

Supported activities out of the home, for the person you care for   ☐

Supported breaks for you and the person you care for, away from the home   ☐

Other respite care (please specify below) ☐
_____
_____

I'm unable to take a break from caring ☐

I do not need support to take a break from caring   ☐

I do not need to take a break from caring ☐

The score is computed by a value assigned to each response category in the two

Well-being 5-point scale: "A lot" concerned = 0, through to "Not at all" = 4 Support

4-point scale: "Very dissatisfied" with support = 0, through to "Very satisfied" = 3

Appendix 2: Brief Cope questionnaire and scoring chart

These items deal with ways you've been coping with the stress in your life. There are many ways to try to deal with problems. These items ask what you've been doing in general to cope with stressful events. Obviously, different people deal with things in different ways, but think about what you usually do when you are under a lot of stress. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not-just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't reaL".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Scoring

The Brief COPE scale yields a number of subscale scores covering how much the person uses various coping methods. To calculate the total for each subscale add together the scores from the items listed below for the appropriate subscale. The higher the total the greater the use of that coping method. (note that the scale does not   yield an overall total but instead rates how <u>much the person uses the different coping strategies).</u>

Subscale	Items
Self -distraction	1 + 19
Active coping	2+7
Denial	3+8
Substance use	4+ 11
Use of emotional support	5 + 15
Use of instrumental support	10+23
Behavioural disengagement	6+ 16
Venting	9+21
Positive reframing	12 + 17
Planning	14+25
Humour	18 +28
Acceptance	20+24
Religion	22+27
Self-blame	13 +26

Reference.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief
COPE. *International Journal of Behavioral Medicine,* 4, 92-100.