Perceived social support received from face to face support group for Irish Family Carers.

Jennifer Millman

BA(Hons) in Psychology

National College Of Ireland

Submitted to the National College of Ireland, April, 2015

Abstract

Introduction: A family caregiver is an individual who provides a level of care or support to another individual, most commonly a family member who has an illness or disability. The family caregiver looks after the cared for emotional and physical needs similar to a professional carer but with no compensation. Social support protects against the negative impacts of providing care. Perceived social support is the knowledge that there are individuals or groups an individual can go to for support during times of difficulty.

Aims: The main aim of the study was to explore the perceived social support Irish family carers receive from face-to-face support groups.

Method: 35 family carers who attend face-to-face support groups participated in the study. This was a quantitative study. The measures used were the General Health Questionnaire 12 and the Carer Support Needs Assessment Tool.

Results: The results showed no significant difference when using a one way between groups analysis of variance to test the difference between the cared for illness and the general health of the caregiver. Results showed no relationship between perceived social support and general health of informal caregivers.

Discussion: The limitations of the study are the small sample size. Future research should have larger sample sizes and start to progress into online support groups.

I would like to extend my gratitude to the individuals who participated in this study for giving up their time and for being willing to share their experiences of being carers with me. I would also like to thank the Carers Association for allowing me to attend their support groups. I would like to thank Dr. Rebecca Maguire, my thesis supervisor, for all her support and assistance.

Submission of Thesis and Dissertation

National College of Ireland
Research Students Declaration Form

Name: Jennifer Millman
Student Number: x12476682
Degree for which thesis is submitted: BA (Hons) Psychology

Material submitted for award

a) I declare that the work has been composed by myself.
b) I declare that all verbatim extracts contained in the thesis have been distinguished by quotation marks and the sources of information specifically acknowledged.
c) My thesis will be included in electronic format in the College Institutional Repository TRAP (thesis reports and projects)
d) I declare that no material contained in the thesis has been used in any other submission for an academic award.

Signature of research student: Jennifer Millman

Date: 29th March 2015

Contents Page

Introduction

The informal caregiver

A family carer or informal caregiver was an individual who did not work in the caring field professionally but provided care to another individual. In most cases the cared for person was a relative of the family carer but occasionally a friend or acquaintance (Gräßel & Adabbo, 2011). The informal caregiver may have been providing support to the cared for person on a physical level or an emotional one (Persson, Wennman-Larson, Sundin & Gustavsson, 2008). Throughout this piece of work the term informal caregiver and family carer was used interchangeably.

In the most recent census, there were 187,112 family carers in Ireland (Central Statistics Office, 2011, CD844), which equates to 4.1% of the population (Care Alliance Ireland, 2015, p.03). In a survey completed by Care Alliance in 2008, 98.3% of caregivers provided some level of care for a family member. Adult children made up the largest group of individuals who provide informal care and this group was predominately made up of daughters (Schofield, Herrman, Bloch, Howe & Singh, 1997). The other main groups of individual to provide care were wives according to Schofield (1997).

In most cases a family carer provided an amount of care within the home but the levels of care varied from quite a relatively low level, where the family carer mainly provided companionship and social supports, to much higher levels, where the cared for was fully dependent on their carer for the majority of their needs, including personal care and social. (Care Alliance, 2015, p. 04). As life expectancy has increased, more and more individuals have found themselves in the position of having to become a family carer (Löckenhoff, Duberstein, Friedman & Costa, 2011). The most recent census of 2011 reported there were 389 centenaries living in Ireland, an increase of 100 individuals since 2006 (Central Statistics Office, 2012, p.26) and an increase of 26,195 family carers from 2006 to 2011 (Central Statistics Office, 2011, CD844). A report commissioned by the European Union on life expectancy showed that men and women over the age of 65 years would spend 4.6 years and 6.4 years respectively with a moderate activity impairment and a further 2.4

years and 3.5 years respectively with a severe activity impairment (European Health & Life Expectancy Information System, 2012, p.26).

The average age of a family carer was 59 years, but the average age was slightly higher for those caregivers who were looking after a person with dementia. However, this seemed to be slightly lower in Ireland where the largest proportion of male and female family carers was in the age range 45 – 55 years and the peak age for woman informal carers was 45 – 49 years (Care Alliance, 2015, p6). At this age the carer giver started to notice signs of their own aging. As well as becoming aware of and accepting their own aging, spousal caregivers, were dealing with age related challenges in their cared for person as well. (Löckenhoff, Duberstein, Friedman, Costa, 2011).

In some cases, when the informal carer began in their caring role to provide care, it was likely to be at a low level in terms of time and intensity. However, as time went on and the illness or disability became more prominent and the cared for person more dependent, a higher level of care was required, increasing over time to a full time commitment. This was the case in the more degenerative illnesses, age related illness or even just mobility problems that might arise due to old age and frailty. In other cases, an accident or sudden severe illness or a child born with a disability meant the carer began by providing a high level of care from the onset and they were also likely be dealing with their own feeling about the illness and sense of loss at the same time. Brady, Goldman and Wandersman (1994) study said that caregivers mourned the loss of the cared for person's personality and future promise. When an individual is put into a caregiver role suddenly they are often unprepared for it.

Most commonly the caregiver was female and males were only more likely to become the caregiver when their spouse was the cared for (Gräßel & Adabbo, 2011). There were 114,113 female family carers in Ireland compared with 72,999 male family carers (Central Statistics Office, 2011, CD844). Both male and female spousal caregivers provided similar amounts of care when over the age of 75 years (McCann, Hebert, Beckett, Morris, Scherr & Evans, 2000). The informal caregiver engaged in tasks similar to that of a professional caregiver. In the case of family carers, it was common to find that the cared for person lived with the family carer. This allowed the family carer to be available 24 hours per day, 7 days per week, to look after the cared for (Gräßel & Adabbo, 2011). This could be detrimental to the caregiver as they were rarely able to take a break from the caring role and this could lead to the caregiver becoming isolated from society (Smith, Egbert, Dellman-Jenkins, Nanna & Palmieri, 2012) particularly if they were providing a high level of care. On average an Irish carer spent up to 33.6 hours providing care for another individual (Care Alliance, 2015, p.04). The total value of caring in Ireland has been estimated at €4.5 billion to €5 billion (Ryan, 2014, *para* 5). Providing this level of care to another individual impacted on the informal caregivers life and most likely required the informal caregiver to make adjustments in his/her life (Persson, Wennman-Larson, Sundin, Gustavsson, 2008).

Impact of caring

Caregiving affected the informal carer’s life in both a positive and negative way. On the positive side, the bond between the caregiver and the cared for was strengthen over the duration of time care was being provided (Boerner, Schulz & Horowitz, 2004), providing care gave the family carer a sense of purpose (Cohen, Colantonio & Vernich, 2002) and caring brought about a number of positive emotions (Redmond & Richardson, 2003). Research completed by Carers Scotland (2011) found that three-quarters of family carers were happy most of the time that they were caring for someone and only 6% did not feel this. A further 58% of respondents felt that they were giving something back to the cared for person most of the time while caring, and 28% felt this sometimes.

Although caring for a loved one had many positive effects, there were many negative effects for the family carer also. Past research showed a strong correlation between providing care and poor health levels, in both emotional and physical health. Stress and diseases such as high blood pressure, low immune system, depression and heart disease were not uncommon and these health problems could all lead to a higher mortality rate. The informal caregivers also suffered feelings of loneliness, anxiety and depression that were directly associated with the demands of caring they experienced. (Care Alliance, 2015, p 15). Caregiver stressors were defined as “the problematic conditions and difficult circumstances experienced by caregivers” by Aneshensel, Pearlin, Mullan, Zarit and Whitlatch (1995). Factors that also contributed to the poor health of family carers were low income and lack of respite breaks according to Carers UK (2009). There is some evidence to suggest that the level of patient suffering impacts the health of the caregiver to the same extent as the level of care they provide (Schulz & Sherwood, 2008).

As already mentioned, Irish family carers could spend an average of up to 33.6 hours caring which is very close to the hours of a full time employment. Those family carers in Ireland in receipt of the Carers Allowance or Carers Benefit payment from the Department of Social and Family Affaires must have shown to the satisfaction of the Department that they were delivering a minimum of 40 hours of care per week. The high number of hours of care that carers provided could lead to them becoming isolated from society. A study completed by Carers Scotland (2011) showed that over half of the the carers that took part in their study felt socially isolated. One third of carers over the age of 60 years had no break from the care they provide and a further one third only received a break from caring once every few months according to Princess Royal Trust for Carers (2011).

Due to the behavioral issues that can sometimes arise in those people who have dementia, caregivers for people with dementia had a higher level of stress, as they require greater supervision (Schulz & Sherwood, 2008). In 2012 there was 41,000 individuals living with dementia and this figure was expected to triple over the following 30 years (House of the Oireachtas, 2012). Hooker, Monahan, Bowman, Frazier and Shifren (1998) went as far as to suggest that caregiving was the archetypal means of finding the negative health consequences of chronic stress. However this could also have been impacted by the caregiver’s personality (Löckenhoff, Duberstein, Friedman & Costa, 2011) and attachment orientations (Perrier, Boucher, Sadava & Molnar, 2010). A study in the US found that middle-aged carers were more likely to binge drink

(25.5%), smoke (15.9%) and/or be obese (30.1%) when compared to non-carers and older carers (Care Alliance, 2015, p.18). Those most at risk of psychological distress were spousal carers and mothers who cared for a disabled child. Ill health was most likely to arise during the time period immediately following the cessation of caring (Singleton, Maung, Cowie, *et al* 2002). When the caregiver commences their caring role the levels of stress can be low (Hirst, 2005) and as the caring role progresses the levels of stress increses. Should the cared for individual die, the family carer's health improves to normal levels of fundtioning within a year and the carers have reported feelings of relief after the death (Schulz et al, 2003). However should the cared for be moved into a nursing home the family carer is likely to express the same level of psychiatric morbidity as before placement occurred (Schulz et al, 2004). While most research would suggest that providing care is the reason for the negative health of family caregiver Schulz and Sherwood (2008) proposed that the negative health shown by caregivers when compared with non-caregivers may not be the fact that they are providing care but may reflect differences that existed prior to assuming the caregiving role such as low socioeconomic status. Individual who are have a low socioeconomic status are more likely to be caregivers and low socioeconomic status is a risk factor for poor health.

These negative emotions and feelings could lead to the caregiver providing a substandard level of care (Molloy, Johnston & Witham, 2005). A key protective factor against these difficulties was social support.

Social support

The idea of social support and positive health was introduced by Durkheim (1951), when he researched the relationship between social relationships and suicide. The construct social support was made up of three main parts; the presence of social relationships, the structure of an individual's social network and the functions of social support (House, Kahn, McLeod, & Williams, 1985). The construct of social support could be further broken down into perceived social support and received social support. Received social support was support that had been given to an individual and there were a number of different variables that make it up. Perceived social support looked at support the individual felt was available from their social groups, peers, friends and family etc. Received social support has been correlated with negative outcomes such as negative mood and poor health (Unhino, 2009). Perceived social support however was correlated with a positive outcome. An individual’s perception of available support was more important to their health than actually receiving support. Uchino, Cacioppo & Kiecolt-Glaser (1996) proposed the idea that social support may produce positive health outcome through a stress buffering affect. During times of high stress perceived social support protected the individual from stress, however the opposite occurred with received support during times of high stress. In high stress situations, received support could be worse than receiving no support at all (Bolger, Zuckerman, & Kessler, 2000). Received support was affected by the context of the support, the type of support, when it occurred and if the support was wanted. When these things were put together the support could have either a positive or negative impact on behavior and outcomes. Rafaeli and Gleason (2009) suggest that for received social support to achieve its goal of aiding another individual during a time of distress, it was important to take into account the characteristics of received social support; the type of support, the timing of the support, the manner in which it was being provided, and the roles of both the provider and the receiver.

Social support was thought to buffer the adverse physical and psychological impact of disease by prompting endocrinological, cognitive, and behavioral adaptation (e.g., heightened immune competence, primary and secondary reappraisal of threat and increased compliance with treatment (Stevens, 1998). The knowledge that there were individuals in our lives that we could rely on for support and advice helped reduce stress in times of difficulty (Holt, Bremner, Sutherland, Vliek, Passer & Smith, 2012) and overall improved health (White & Dorman, 2001). Social support provided hope, increased self-confidence, and was an important buffer against loneliness and stress (Sarason & Sarason, 2009). Social support benefited the individual in multiple ways.

Baron, Cutrona, Hicklin, Russell and Lubaroff's (1990) study suggested that high levels of social support increased levels of immune cells. Similar results were found in Anderson, Farrer, Golden-Kreutz, Glaser, Emery, Crespin, Shapiro and Carson III (2004) when they placed cancer patients into support groups and provided strategies to reduce stress, enhance mood, change health behaviors, and keep with the cancer treatment and care. As the participants psychological wellbeing increased and behavior improved so did the participants immune responses. Although social support was suggested to increase immune functioning, Holt et al (2012) proposed it was the decrease in emotional distress from the support that was the better predictor of good health outcomes. Kissane (2009) suggested that social disparity has links with survival rates of cancer patients.

Social support also provided its members with a sense of identity and meaning. This in turn resulted in greater psychological well-being. Social networks provided protective factors to other vulnerability factors, for example loneliness, and having social support could increase an individual's sense of control over stressors. Individuals within a support network could assist others in dealing with stressors in a positive ways. Social support benefited both the recipient and the provider of the support.

Cohan (1988) researched the typologies of social support measures. Yuen-Tsang (1997) identified five aspects of social support: functional, structural, subjective, interactional and the synthetic definition. Other researchers suggested there are only three aspects to social support: structural, functional and appraisal support (Oxman & Hull, 1997). The structural component of social support was made up of the social network and the availability of others to help the individual. The functional component was a mixture of the amount of instrumental, emotional and financial backing the individual had. The appraisal component was subjective to each individual as only they could evaluate their satisfaction of the support they received.

Why support groups' work?

Support groups were developed with the rise of the self-help movement (Pickett, Heller & Cook, 1998). Face to face support groups tended to expect some level of participation from members. Within the group environment the members both received and provided support (Harel, Shechtman & Cutrona, 2011). Self-disclosure promoted trust within the group. As the members of the group shared their experiences, thoughts and feelings the group developed trust and intimacy. This trust and intimacy encouraged members to further disclose about their caring experience. This allowed for greater emotional involvement and relationship satisfaction. An important factor for ensuring the effectiveness of a support group was supportive relationships between members according to Harel, Shechtman and Cutrona (2011).A support system could include anyone from family, friends, and medical personnel such as your doctor and community nurse and others who were going through similar situations as the individual themselves (Agnew, 2001). Research has shown the majority of who participate in support groups is Caucasian (Pickett, Cook & Heller, 1998). It was found that men preferred the anonymity of the online support group compared to face-to-face support groups according to Finfgeld (2000). Support groups provided hope, understanding and a feeling of belonging to those who participate (Marsh & Johnson, 1997; Nash & Kramner, 1993; Norton, Wanderman & Goldman, 1993). Having a social network to fall back on protects against other risk factors like loneliness (Holt et al, 2012). Caregiving can be seen as a balancing act between the stressors of caregiving and the coping resources, both internal and external the caregiver has (Perkins, Lynn & Haley, 2007).

The Present Study

In summery, previous research has suggested that perceived social support had links to positive health outcomes for family caregivers as the perceived social support acts as a protective factor against carer burden. As mentioned earlier the number of family carers is on the rise and research into areas of caring is important for both a national policy and for service providers for carers. Over the past number of years there has been a decrease within the national budget to provide services both financial and social for family carers (Connolly, 2012, *para*. 1). There has also been a reduction in social welfare payments available to carers over the past number of years (Ryan, 2014, *para* 8). These are extra stresses for the family carer. Further research into the area of social support will allow for service providers to focus their spending on services that benefit both the family carer and the cared for. One of the current trends within the Health Service Executive is community care, where the individual is able to remain within the community instead of an extended stay in hospital or a nursing home. Family caregivers are key to the success of this policy (Cahill, O‘Shea & Pierce, 2012). This trend further increases the likelihood of an individual becoming a family carer and should the Irish government wish these policies to succeed, providing adequate funding and services to those providing the care at home is important.

Aims and Hypothesis

The current study aims to investigate the perceived levels of social support provided by face-to-face support groups in a sample of Irish informal caregivers. As previously mentioned there are a larger proportion of female informal carers in the Irish caregiving population.

Based on this evidence it is hypothesized that there will be a greater female to male ratio in the study. It is expected that the predominate age range will be 45 to 49 as research as shown this to be the peak age for female caregivers. Also male caregivers prefer online support groups to face-to-face support groups (Finfgeld, 2000).

The second hypothesis to be tested in this study is whether the type of condition/ illness the cared for individual has affects the general health of the caregiver. It is expected that informal caregivers who provide care for individuals with Alzheimer’s/dementia will have decreased general health (Schulz & Sherwood, 2008).

The third hypothesis in this study is if the informal caregiver attends a face to face support group will perceive a level of social support and the fourth hypothesis is the perceived social support will improve their general health. Previous research suggests that social support has a positive impact on health and well-being.

Method

Participants

Participants were recruited for the study through support groups for family carers run by the Carer's Association during a limited time period (December 2014 – March 2015). This was a random sample. Any individual who attended the support group the researcher was at was given the option of participating in the study, unless they were under the age of 18. The researcher attended 6 support groups in various locations. The sample was recruited predominately from support groups held in suburban areas and one support group was held in a rural location. Thirty-five individuals took part in the study and a further ten were asked but declined to take part. The participants who completed his or her response at the support group did so in one sitting. Five of the participants took the questionnaire with them and posted completed response back to researcher. The individuals who participated were all family carers.

The majority of participants were fulltime carers and looked after cared for individual for approximately 20 – 24 hours (68.6%) and looked after their spouse (40%), their child (25.7%), their parent (25.7%), their sibling (5.7%) and their in laws (2.9%). The majority of participants were female (91.4%) and the sample's most frequent age range was 60 – 69 (45.7%). Of the participants only 54.3 % was in receipt of the carers allowance or carers benefit and only 45.7% of participants receive respite. The majority of participants have been involved in providing care for the cared for individual for over 15 + years (31.4%) and the other highest time frame for providing caring was between 1 – 4 years (31.4%). The main illnesses the cared for individual has are Alzheimer's/Dementia (25.7%), Neurological conditions/Acquired Brain Injury (20%), Cancer (17.1%), mental health (14.3%), intellectual disabilities (11.4%), frail old age (5.7%) and pulmonary diseases (5.7%). The majority of participants (80%) identified themselves as the sole carer or main carer for the cared for individual. A number of the participants identified as caring for 2 individuals (11.4%).

Design

The design used was a quantitative design. This was a between group design. For the first hypothesis; a greater female to male ratio in the study, was tested using descriptive statistics. For the second hypothesis; the condition of cared for individual affecting the general health of the caregiver, a one way between groups analysis of variance was used. The independent variable was the condition the cared for individual had and the dependent variable was the general health of the caregiver. The third hypothesis; levels of perceived social support will increase general health, a Spearman Rank Order Correlation was carried out as Carer Supports Needs Assessment Tool has ordinal scores. The independent variable was the perceived social support and the dependent variable was the general health scores.

Measures

Demographic questions: The participants were asked to complete a questionnaire, which looked at the demographics of the sample. While the demographic questions did look at information regarding age and gender, there main focus was on the participants role in caring. It included questions about the duration of care, illness of cared for and number of hours spent caring. The demographic questions also covered what type of support groups the participant attends and how frequently.

The General Health Questionnaire – 12 (GHQ-12): The GHQ-12 is a general measure of psychiatric well-being. The GHQ-12 was developed by Goldberg (n.d.) as a unidimensional measure. The measure investigates three variables; anxiety and depression, social dysfunction and loss of confidence. The GHQ-12 is a self-report measure. The questionnaire asks if the participants have experienced a particular behavior or feeling recently. The participant is given the option of 4 responses; less than usual, no more than usual, rather more than usual and much more than usual. The GHQ-12 is measured on a four point Likert scale from 0 to 3. Positive items on the scale are coded from 0 (Much more than usual) and 3 (less than usual) and negative items are coded from 0 (Less than usual) to 3 (Much more than usual). The higher the score the participant receives the poorer off their health is (Kawada & Otsuka, 2012). The total score range of the GHQ-12 is 0 to 36. The GHQ- 12 has been found to be a well-developed and well-tested instrument. In the current study the Cronbach's Alpha coefficient was .73.

Carer Support Needs Assessment Tool (Ewing & Grande, 2013): The Carer Support Needs Assessment (CSNA-T) is a 14 items measure, which looks at the social support for family carers. It is measured on a 4 point Likert scale: no, a little more, quite a bit more and very much more. The test manual has the scoring of 0 (no), 1 (a little more), 2 (quite a bit more) and 3 (very much more) on the 14 items of the scale (Ewing, Brundle, Payne & Grande, 2013) and shows no reverse coding. It also provides information about the scores from the test are all ordinal data. The 14 items are divided into two parts with 7 of the item looking at supports that enable the carer to care and the other 7 items look at personal supports for the carer. In the current study the Cronbach's Alpha coefficient of the CSNA-T was .84. The CNSA-T had an optional additional question of "Anything else" that was not used in this study.

Caregiver Needs Questionnaire

This assessment tool looks at four areas of caregiver needs; assessing medical, educational, psychological and emotional needs (Rosa, Lussignoli, Sabbatini, Chiappa, Di Cesare, Lamanna and Zanetti, 2010). Items are scored on a four point Likert scale and higher scores indicate greater depth of needs. It includes items such as "at this moment, you feel the need to train for effective doctor to patient skills, get emotional support with grief management and get help from social services to know the service available". This tool was given to the pilot support group but was removed from the study because a number of the comments made by participants suggested a number of the items were not applicable to the type support provided by the support group they attended or the type of care they provided.

Procedure

Recruitment of participants

The researcher made contact with the Carers Association, a charity for family carers. This was the largest national charity providing supports and services to informal carers. The researcher requested permission to make contact with and attend some of their local face to face support groups for the following study. The Carers Association granted permission and offered their support.

Pilot study

For the pilot study the researcher attended a support group for family carers. This group met once a month. The researcher joined the group for their meeting and was introduced by the chair of the meeting. The chair gave a general outline of the purpose of the questionnaire and invited the researcher to explain in more detail. Following a full explanation by the researcher, were the researcher outlined the purpose of the study and what it entailed, the researcher also explained that taking part in the study was completely voluntary. In the final 15 minutes of the support group the researcher informed the carers about the study and what it entailed. The researcher explained that taking part in the study was completely voluntary. Further information on the study was provided on an information sheet (Appendix 1) that participants could take with them after the study. The information sheet included contact information for the researcher and thesis advisor should the participants wish to make contact either for further information, to withdraw from the study or should they have any concerns. Upon completion of the questionnaire the pilot group was asked for their feedback. Some adjust were made as result of their comments. It was also felt that more time was needed to complete the battery of tests. Also it was felt that the Caregiver Needs Assessment should be remove as there was negative feedback about it form the pilot group. Minor changes were also made to the demographic questionnaire.

Data Collection

The researcher attended support groups for family carers and the chair of the support groups informed those in attendance of the study in very broad terms. The support group was then run as normal. Allowing new members of the support group to understand what the support group was about and this allowed them to answer the questionnaires on perceived support. In the final 20 minutes of the support group the researcher explained in detail about the nature of the study (see Appendix 1). It was important that participants understood that the data was completely confidential and that the chair of the support group wouldn’t see any of their responses. The questionnaire booklet (see Appendix 3, Appendix 4 and Appendix 5) was handed out to all who wished to take part. Due to the nature of the caring role provisions were made for those unable to stay at the support group and fill in questionnaire. The participants who had to leave received an addressed and stamped envelope so they could return their questionnaire to the researcher by post. The participants were asked to read through the information sheet at the start of the questionnaire booklet. Participants were asked to sign a consent form (see Appendix 2) and the researcher explained that consent form would be stored separately from responses to maintain confidentiality. Participants who could fill in questionnaire at support group had about 20 minutes to complete the questionnaire. The researcher remained in the room while responses were being filled out and answered any questions participants had about the questionnaires. This procedure was carried out at all support groups attended by the researcher.

Debriefing after assessment

After completing the questionnaire participants were asked to detach the information sheet and useful contacts sheet (see Appendix 6) from the booklet and take the two sheets with them. The useful contact sheet provided information of various supports that the informal caregiver may wish to make use of after the assessment in case any distress was caused. Once all the participants had finished the questionnaire they were debriefed and were reminded that participation was voluntary. The researcher further informed them at they could contact the researcher should they have a query about the study at any time or wish to withdraw from the study. The researcher thanked the group for their participation in the study.

Results

Table 1: Frequencies for the current sample of Irish family carers on each demographic variable (N = 35)

Variable	Frequency	Valid Percentage
Gender		
Male	3	8.6
Female	32	91.4
Age		
30 – 39	1	2.9
40 – 49	6	17.1
50 – 59	5	14.3
60 – 69	16	45.7
70 -79	7	20.0
Martial Status		
Single/Never Married	10	28.6
Married	22	62.9
Widowed	3	8.6
Community		
Urban	9	25.7
Rural	6	17.1
Suburban	20	57.1

Employment Status		
Part time employed	4	11.4
Retired	17	48.6
Unavailable to work	9	25.7
Looking for work	1	2.9
Other	4	11.4
No. Cared For		
1 person	31	88.6
2 people	4	11.4
Relationship of cared for to participant		
Spouse	14	40
Child	9	25.7
Parent	9	25.7
Sibling	2	5.7
In Laws	1	2.9
Condition		
Alzheimer’s/Dementia	9	25.7
Neurological Condition/ABI	7	20.0
Intellectual disabilities	4	11.4
Mental Health	5	14.3
Cancer	6	17.1
Frail Old Age	2	5.7
Pulmonary Diseases	2	5.7

Length of time caring		
Less than 1 year	2	5.7
1 – 4 years	11	31.4
5 – 9 years	6	17.1
10 – 14 years	5	14.3
15 + years	11	31.4
2nd cared for relationship to participant		
Not applicable	31	88.6
Child	2	5.7
Parent	1	2.9
In laws	1	2.9
2nd cared for condition		
Not applicable	31	88.6
Intellectual Disabilities	2	5.7
Frail Old Age	2	5.7
Sole Carer		
Yes	28	80.0
No	7	20.0

Time spent caring per day		
1 – 4 hours	1	2.9
4 – 8 hours	4	11.4
8 -12 hours	4	11.4
12 – 16 hours	1	2.9
16 – 20 hours	1	2.9
20 – 24 hours	24	68.6
Receipt of Carers Allowance/Benefit		
Yes	19	54.3
No	16	45.7
Other support groups attended		
Not applicable	24	68.6
Online/forums	6	17.1
Clubs	4	11.4
Counseling Groups	1	2.9
Frequency of face to face support group attendance		
First time	3	8.6
Once a week	2	5.7
Twice a week	1	2.9
Monthly	29	82.9

Frequency of online attendance		
Never	29	82.9
Once a week	1	2.9
Monthly	5	14.3
Receive respite		
Yes	16	45.7
No	19	54.3
Hrs. of respite received per week		
Don’t receive	20	57.1
0 – 2 hours	3	8.6
2 – 4 hours	5	14.3
4 – 6 hours	2	5.7
6 – 8 hours	2	5.7
8 + hours	3	8.6

Statistical analysis

As data for demographic questions was either nominal or ordinal, frequency analysis was used to obtain descriptive analysis. The data provided by the frequency analysis shows us that the majority of the participants are female.

For the General Health Questionnaire 12 a number of the items had to be reversed coded as they were positively worded.

Table 2 **(table for displaying descriptive statistics for continuous variables)**

Descriptive statistics and reliability of all continuous variables

	Total GHQ12
Mean	20.79
Standard Deviation	5.05
Range	8 - 29
Possible Range	0 - 36
Cronbach's Alpha	.73

The General Health Questionnaire had a mean score of 20.79 out of a possible range of 0 – 36. The GHQ-12 had a negative skewness values (-.39) this indicates that there was a clustering of values at the higher end of the scale.

A one-way between groups analysis of variance was conducted to explore the impact of cared for illness on the general health of the caregiver, as measured by the General Health Questionnaire 12. Participants were divided into seven groups (Group 1= Alzheimer's/ Dementia, Group 2 = Neurological Conditions/ Acquired Brain Injury, Group 3 = Intellectual disabilities, Group 4 = Mental Health, Group 5 = Cancer, Group 6 = Frail Old Age and Group 7 = Pulmonary Diseases). There was no significant difference at the p < .05 level in GHQ-12 scores for the seven groups: F (6, 26) = 1.08, p = .4. The difference in mean scores between the groups was quite small. The effect size, calculated using eta squared, was .2. Post-hoc comparisons using the Tukey HSD test indicated that the mean scores for all groups did not differ significantly from any of the groups.

The relationship between perceived social support (as measured by the Carer Support Needs Assessment Tool.) and level of general health (as measured by the General Health Questionnaire 12) was investigated using Spearman Rank Order Correlation. Preliminary analysis was performed to ensure no violation of the assumption of normality, linearity and homoscedasticity. There was no significant relationship between the two variables, r = .15, n = 30, no significance. None of the items within the Carer Support Needs Assessment provided a significant relationship with general health.

Discussion

As expected the majority of the family carers who participated in the study were female however the data collected showed that the most prominent age range within this sample was the age category 60 – 69. This was slightly higher then expected as previous research had shown that in Irish caregivers the largest age group was 45 – 55. This score may have been effected by the fact be that the support groups take place a weekday morning. While most of the family carers in the sample only care for one individual, a small percentage (11.4%) care for two people. The General Health Questionnaire-12 had a mean score of 20.79. This shows that on average the participants have slightly poor health as scores are on the higher side.

Based on previous research it was expected that the caregivers for individuals with Alzheimer's/ dementia would have the highest scores on the GHQ-12, meaning lower levels of general health. However the results from this study suggest that there is no significant difference between the general health of those who care for individuals with dementia/ Alzheimer's and other illness such as intellectual disabilities and cancer. This result may be affected by the small sample size.

The results of the Spearman Rank Order Correlation carried out to test the relationship between perceived social support and general health showed that there was no relationship between the two variables. This was in contradiction with pervious research that proposed that social support can impact the general health in a positive way. However this may be because the participants in the face-to-face support group may not identify with the other members of the groups which can mediate the results (Nakashima, 2013). Some studies group identification and social support in high stress situations can not assist with improved general health.

Limitations

Limitations of this study are the small sample number. This is potentially the biggest limitation of this study

Another limitation of this study is the fact that some of the participants may have forgotten that they were only being asked to consider the support they feel they gain from the support group they attend. The responses a couple of the participants provided would give the idea that they were considering the help they feel they need from all sources.

A limitation of this study is the fact that this study doesn't look at the psychological well being of family carers who do not attend support groups. This data could be used to further analysis the psychological well being of family carers who do attend support groups and investigate the difference in the psychological well being of those who attend support groups against those who don't.

The final limitation of this study is all the data collected is self-report data and this is based solely on participants' perception of their situation (i.e. The social support they feel they have from their support group and their general health.). Social desirability may also impact the responses participants may have given.

Future research

Future research into perceived social support from face-to –face support groups should be carried out with larger sample sizes. Other future research could look at the comparison between levels of social support from face-to-face support groups and the level of social support from online support groups or forums. Considering the prevalence of individuals under 60yrs who use the Internet to research health information (Brodie, Flournoy, Altman, Blendon, Benson & Rosenbaum, 2000) and potential benefits of using support groups it is most likely that online support groups will become increasingly popular. A study by Cyber Dialogue (1998) suggested that 1 in 4 individuals who use the Internet to research illness related information also participate in online support groups. Should it be found that online support groups achieve the same benefits as face-to-face support groups, it would be another support available to individuals who are in a situation where they are unable to attend face-to-face support groups. As previously mentioned there has been a reduction in funding from the government for services for family carers research into online support groups could provide a valuable insight into a form of support group which is cheaper to run as well as allow individuals 24 hour access from any location (White & Dorman, 2001, p694).

In conclusion this study suggests that social support that is perceived from attending a face-to-face support group had no relationship with the general health of informal carers who attend face-to-face support groups. This outcome went against the expected result of previous research. This result may be found due to the small sample size of the study.

References

Agnew, L., S. (2001). Characteristics and Benefits of Online Support Groups. Retrieved from http://ils.unc.edu/MSpapers/2702.pdf

Anderson, B.L., Farrer, W.B., Golden-Kreutz, D.M., Glaser, R., Emery, C.F., Crespin, T.R., Shapiro, C.L. & Carson III, W.E. (2004). Psychological, Behavioural, and Immune Changes after a Psychological Intervention: A Clinical Trial. *Journal of Clinical Oncology 22(17)*, 3570-3580. Doi: 10.1200/JCO.2004.06.030.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C.J. (1995). *Profiles in caregiving: The unexpected career.* San Diego: Academic Press Inc.

Baron, R. S., Cutrona, C. E., Hicklin, D., Russell, D. W., & Lubaroff, D. M. (1990). Social support and immune function among spouses of cancer patients. *Journal of Personality and Social Psychology*, *59*(2), 344-352. doi:10.1037/0022-3514.59.2.344

Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaption to bereavemnet. *Psychology and Aging*, *19*, 668- 678. Doi: 10.1037/0882-7974.19.4.668

Bolger, N., Zuckerman, A., & Kessler, R. C. (2000). Invisible support and adjustment to stress. *Journal of Personality and Social Psychology*, *79*, 953–961. doi:10.1037/0022-3514.79.6.953

Brady, C. F., Goldman, C. R., & Wandersman, A. (1994). Similarities and differences in caregiver adaptation: Focus on mental illness and brain injury. *Psychosocial Rehabilitation Journal*, *18*(1), 35-48. doi:10.1037/h0095535

Brodie, M., Flournoy, R.E., Altman, D. E., Blendon, R. J., Benson, J. M., & Rosenbaum, M. D. (2000). Health Information, the Internet, and the digital divide. *Health Affairs 19*(6), 255 – 265.

Cahill, S. , O‘Shea, E & Pierce, M. (2012). Creating Excellence in Dementia Care: A Research Review for Ireland‘s National Dementia Strategy A Research Review for Ireland‘s National Dementia Strategy. Trinity College, Dublin/National University of Ireland, Galway. Accessed at: https://www.tcd.ie/Communications/content/pdf/Creating_Excellence_in_Dementia_Care2012.pdf

Care Alliance Ireland (2015) *Family Caring in Ireland.* Retrieved from http://www.carealliance.ie/userfiles/file/Family%20Caring%20in%Ireland%20Pdf.pdf

Carers Scotland (2011). Sick, Tired and Caring: The impact of unpaid caring on health and long term conditions

Carers UK (2009) Policy Briefing: Facts about Carers. Retreived from: www.hscf.org.uk/sites/default/files/article_attachments/Facts_about_carers_2012.pdf

Central Statistics Office. (2011). CD844: Carers by Age Group, Sex, Census Year and Statistic. Retrieved from http://www.cso.ie/px/pxeirestat/Statire/SelectVarVal/saveselections.asp

Central Statistics Office. (2012). *Profile 2: Older and Younger*. Retrieved from http://www.cso.ie/en/media/csole/census/documents/census2011profile2/Profile2_Older_and_Younger_Entire_Document.pdf

Chen, X., & Silverstein, M. (2000). Intergenerational Social Support and the Psychological Well-being of Older Parents in China. Research on Aging, 22, 43-65.

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Roundig out the caregiver experience. *International Journal of Geriatic Psychiatry, 17,* 184-188. Doi: 10.1002/gps.561

Connolly, P. (2012, December 5). 20% Budget cut to Respite Grant care Grant alienates carers. Retrieved from http://www.inclusionireland.ie/content/media/1006/20-budget-cut-respite-care-grant-alienates-carers

Cyper Dialogue, Inc. (1998). Internet Health Seekers Reach Critical Mass. [Online]. Available from http://www.cyberdialogue.com/press/releases/intel_health_day.html. In Finfgeld, D. L. (2000). THERAPEUTIC GROUPS ONLINE: THE GOOD, THE BAD, AND THE UNKNOWN. *Issues In Mental Health Nursing*, *21*(3), 241-255.

Durkheim, E. (1951). *Suicide.* New York, NY: Free Press. In Gleason, M. J., & Iida, M. (2015). Social Support. In M. Mikulincer, P. R. Shaver, J. A. Simpson, J. F. Dovidio, M. Mikulincer, P. R. Shaver, ... J. F. Dovidio (Eds.) , *APA handbook of personality and social psychology, Volume 3: Interpersonal relations* (pp. 351-370). Washington, DC, US: American Psychological Association. doi:10.1037/14344-013

European Health & Life Expectancy Information System. (2013) *Health Expectancy in Ireland.* Retrieved from http://www.maryland.mri.cnrs.fr/hly/pdf/CountryReports_Issue6/Ireland_Issue6.pdf

Ewing, G., & Grande, G. (2013). Carer Support Needs Assessment Tool. *Psyctests,* doi:10.1037/t30960-000

Ewing, G., Brundle, C., Payne, S., & Grande, G. (2013). The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study. *Journal Of Pain And Symptom Management*, *46*(3), 395-405. doi:10.1016/j.jpainsymman.2012.09.008

Finfgeld, D. L. (2000). THERAPEUTIC GROUPS ONLINE: THE GOOD, THE BAD, AND THE UNKNOWN. *Issues In Mental Health Nursing, 21*(3), 241-255.

Goldberg, D. P. (n.d). General Health Questionnaire-12. *Psyctests*, doi:10.1037/t00297-000

Gräßel, E. & Adabbo, R. (2011). Perceived Burden of informal caregivers of a chronically ill older family member: Burden in the context of the transactional stress model of Lazarus and Folkman. *Geropsych: The Journal of Gerontopsychology and Geriatric Psychiatry, 24(3),* 143-154. Doi: 10.1024/1662-9647/a000042.

Harel, Y., Shechtman, Z., & Cutrona, C. (2011). Individual and group process variables that affect social support in counseling groups. *Group Dynamics: Theory, Research, And Practice*, *15*(4), 297-310. doi:10.1037/a0025058

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

Holt, N., Bremner, A., Sutherland, E., Vliek, M., Passer, M. & Smith, R. (2012). Psychology: The Science of Mind and Behaviour (2nd Ed.). Berkshire, UK: McGraw Hill Education.

Hooker, K., Monahan, D. J., Bowman, S. R., Frazier, L. D., & Shifren, K. (1998). Personality counts for a lot: Predictors of mental and physical health of spouse caregivers in two disease groups. *Journals of Gerontology Series B-Psychological Sciences and Social Sciences*, *53,*73-85.

House, J. S., Kahn, R. L., McLeod, J. D., & Williams, D. (1985). Measures and concepts of social support. In Gleason, M. J., & Iida, M. (2015). Social Support. In M. Mikulincer, P. R. Shaver, J. A. Simpson, J. F. Dovidio, M. Mikulincer, P. R. Shaver, ... J. F. Dovidio (Eds.) , *APA handbook of personality and social psychology, Volume 3: Interpersonal relations* (pp. 351-370). Washington, DC, US: American Psychological Association. doi:10.1037/14344-013

House of the Oireachtas (2012). Seanad Public Consultation Committee Report on The Rights of Older People: March 2012. Retreived from http://www.tilda.tcd.ie/assets/pdf/Seanad%20Report.pdf

Kawada, T., & Otsuka, T. (2012). Psychological well-being using the 12-item General Health Questionnaire (GHQ12) and age in Japanese working men. *Journal Of Psychiatric And Mental Health Nursing*, *19*(8), 758-760. doi:10.1111/j.1365-2850.2012.01936.x

Kissane, D. W. (2009). Beyond the psychotherapy and survival debate: the challenge of social disparity, depression and treatment adherence in psychosocial cancer care. *Psycho-Oncology 18(1)*, 1-5.

Löckenhoff, C. E., Duberstein, P. R., Friedman, B., & Costa, P. J. (2011). Five-factor personality traits and subjective health among caregivers: The role of caregiver strain and self-efficacy. *Psychology and Aging*, *26*(3), 592-604. doi:10.1037/a0022209

Marsh, D. & Johnson, D.L. (1997). The family experience of mental illness: Implications for intervention. *Professional Psychology: Research and Practice*, 28(3), 229 – 237.

McCann, J.J., Hebert, L.E., Beckett, L.A., Morris, M. C., Scherr, P. A. & Evans, D. A. (2000). Comparison of informal caregiving by black and white older adults in a community population. *Journal of the American Geriatrics Society 48*, 1612 – 1617.

Molloy, G. J., Johnston, D. W., & Witham, M. D. (2005). Family caregiving and congestive heart failure. Review and analysis. *European Journal of Heart Failure, 7,* 592-603. Doi: 10.1016/j.ejheart.2004.07.008

Nakashima, K. M. (2013). How does higher in-group social value lead to positive mental health? An integrated model of in-group identification and support. *Asian Journal Of Social Psychology*, *16*(4), 271-278.

Nash, K. B. & Kramner, K. D. (1993). Self-help for sickle cell disease in African American communities. Special issue: Advances in understanding self-help groups. *Journal of Applied Behavioural Science 29*(2), 202 – 215.

Norton, S., Wanderman, A., & Goldman, C. R. (1993). Perceived costs and benefits of membership in a self-help group: Comparisons of members and nonmembers of the Alliance for the Mentally Ill. *Community Mental Health Journal 29*(2), 143 – 160.

Oxman, T. E. & Hull, J.G. (1997). Social Support, Depression and Activities of Daily Living in Older Heart Surgery Patients. *Journal of Gerontology: Psychological Sciences*, 52B, 1-14.

Perkins, E. A., Lynn, N., & Haley, W.E. (2007). Caregiver issues associated with wandering. In Nelson, A. & Algase, D. (Eds.). Evidence based protocols for managing wandering behaviours. New York: Springer.

Perrier, C. K., Boucher, R., Etchegary, H., Sadava, S. W., & Molnar, D. S. (2010). The overlapping contributions of attachment orientation and social support in predicting life-events distress. *Canadian Journal Of Behavioural Science / Revue Canadienne Des Sciences Du Comportement*, *42*(2), 71-79. doi:10.1037/a0018337

Persson, C., Wennman-Larson, A., Sundin, K. & Gustavsson, P. (2008). Assessing informal caregivers’ experiences: a qualitive and psychometric evaluation of the Caregiver Reaction Assessment Scale. *Eurpoean Journal of Cancer Care, 17,* 189-199. Doi: 10.1111/j.1365-2354.2007.00833.x

Pickett, S. A., Cook, J. A., & Heller, T. (1998). Support Group Satisfaction: A Comparison of Minority and White Families. *New Directions For Mental Health Services (77),* 63 – 73.

Pickett, S.A., Heller, T., & Cook, J. A. (1998). Professional – Led versus Family – Led Support Groups: Exploring the Differences. *Journal of Behavioural Health Services + Research 25*(4) 437-445.

Princess Royal Trust for Carers (2011) Always on Call, Always Concerned: A survey of the experiences of older carers. Retreived from: www.carers.org/sites/default/files/always_on_call_always_concerned.pdf

Rafaeli, E., & Gleason, M. E. J. (2009). Skilled support within intimate relationships. *Journal of Family Theory and Review, 1,* 20–37. doi:10.1111/j.1756- 2589.2009.00003.x

Redmond, B. & Richardson, V. (2003). Just getting on with it: Explorig the service needs of Mothers who care for yong children with severe/ profound and life-threathening intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *16,* 205-218. Doi: 10.1046/j.14683148.2003.00165

Rosa, E., Lussignoli, G., Sabbatini, F., Chiappa, A., Di Cesare, S., Lamanna, L., & Zanetti, O. (2010). Caregiver Needs Assessment Questionnaire. *Psyctests*, doi:10.1037/t23756-000

Ryan, O. (2014, June 15). The number of people receiving a carer's allowance has increased by 40%. [Online]. Retrieved from www.thejournal.ie/carers-allowance-ireland-1511817-jun2014.

Sarason, I. G., & Sarason, B. R. (2009). Social support: Mapping the construct. *Journal of Social and Personal Relationships*, *2*, 113– 120. doi: 10.1177/0265407509105526

Schofield, H. L., Herrman, H. E., Bloch, S., Howe, A. & Singh, B. (1997). A Profile of Australian family caregiver: Diversity of roles and circumstances. *Austrailian and New Zealand Journal of Public Health*, *21,* 59-66. Doi: 10.1111/j.1467-842X.1997.tb01655.x

Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, s., Thompson, L., & Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *The New England Journal Of Medicine*, *349*(20), 1936-1942. doi:10.1056/NEJMsa035373

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. *Journal of the American Medical Association, 292*(8), 961 – 967. Doi: 10.1001/jama.292.8.961.

Schulz, R., & Sherwood, P. R. (2008). Physical and Mental Health Effects of Family Caregiving. *Journal of Social Work Education* 44, 105 – 113.

Singleton, N., Maung, N. A., Cowie, J., *et al* (2002) *Mental Health of Carers*. London: Office for National Statistics.

Smith, G. C., Egbert, N., Dellman-Jenkins, M., Nanna, K., & Palmieri, P. A. (2012). Reducing depression in stroke survivors and their informal caregivers: A randomized clinical trial of a web-based intervention. *Rehabilitation Psychology*, *57*(3), 196-206. doi:10.1037/a0029587

Stevens, M. J. (1998). Correlates of participation in a breast cancer support group. *Journal of Psychosomatic Research, 45*(3). 263-275.

Uchino, B. N. (2009). Understanding the links between social support and physical health: A life-span perspective with emphasis on the reparability of perceived and received support. *Perspectives on Psychological Science, 4*, 236–255. doi:10.1111/ j.1745-6924.2009.01122.x

Uchino, B. N., Cacioppo, J. T., & Kiecolt-Glaser, J. K. (1996). The relationship between social support and physiological processes: A review with empha- sis on underlying mechanisms and implications for health. *Psychological Bulletin, 119*, 488–531. doi:10.1037/0033-2909.119.3.488

White, M & Dorman, S., M. (2001). Receiving social support online: implications for health education. *Heath education research: Theory and Practise*, *16(6),* 693-707. Retrieved from http://her.oxfordjournals.org/content/16/6/693.full.pdf+html

Yuen-Tsang, A. W. K. (1997). Towards A Chinese Conception of Social Support. Hants: Ashgate Publishing Ltd

Appendix

Appendix A: Information Sheet

Purpose of the study: As part of my undergraduate degree in psychology at the National College of Ireland I am carrying out a research study. This study looks at the benefits of support groups for carers, both online and face-to-face, to establish if there are any differences in the levels of support experienced. This survey will also ask you to reflect on your experiences of caring so we can have a better understanding about the supports you may need.

Participation: Participation is completely voluntary. You have the right to withdraw from the study at any point even if you have previously consented to the study. The decision to withdraw from the study will be respected by the researcher. Due to the fact that some questions in the study relate to aspects of your role as a carer there is a chance that some distress may arise. Information of various charities is provided should you wish to discuss any distress you feel. The contract information of both my thesis advisor, Dr Rebecca Maguire and myself are provided below.

Confidentiality: The data you provide will be kept confidential. I, Jennifer Millman will be the only individual with access to the data you provide. No identifying data or information will be part of the final thesis. The data will be kept confidential for the duration of the study. On completion of the thesis, they will be retained for a further six months and then destroyed.

What will happen to the results? The results will not contain any personal information related to any participant. All information will have a number of tests run on it and the results present in the final study will be in statistical form and percentages. The results will be presented in the thesis. My supervisor, a second marker and the external examiner will see them. Future students on the course may read the thesis.

Who has reviewed this study? This study has been reviewed and approved by the National College of Ireland's Ethics Committee.

Any further queries: Should you have any questions please contact me, Jennifer Millman on [redacted] or [redacted] or my final project supervisor, Dr Rebecca Maguire, at [redacted] or [redacted].

Appendix B: Consent Form

I ____________________________ have agreed to participate in the following study.

The study is looking at the benefits of face-to-face support groups and online support groups and differences in levels of support between them.
I am participating in this study voluntarily. I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.
The data will be securely stored for 6 months after the study is finished and will then be destroyed in a secure manner in accordance with the PSI guidelines.
Should you have any questions please contact the researcher, Jennifer Millman on [redacted] or at [redacted]. My thesis advisor, Dr Rebecca Maguire, can be contacted at [redacted] or [redacted].

Signed ___________________________________
Print name ________________________________
Date _________________________

Appendix C: Demographic Questions

What is your gender?
Male ☐ Female ☐ ☐

What age are you?
18 – 29 ☐ 30 - 39 ☐ ☐ 40 - 49 ☐☐ 50 - 59 ☐
☐
60 - 69 ☐ 70 - 79 ☐ ☐ 80+ ☐ ☐

What is your marital status?
Single/never married ☐ ☐ Married or domestic partnership ☐
Widowed ☐ Divorced ☐ ☐ Other ☐
☐

Where do you live?
Urban community ☐☐ Rural community ☐☐ Suburban community ☐ ☐

What is your employment status?
Fulltime employed ☐ ☐ part-time employed ☐☐
retired ☐ ☐
Unavailable to work ☐☐ looking for work ☐☐ other
☐

Number of people you provide care for?
1 ☐ 2 ☐ 3 ☐ 4 ☐☐

Who do you care for?
Spouse ☐☐ Child ☐ Parent ☐ Other
☐☐
If other please specify ___________________________________

What condition does the person you care for have?
Alzheimer’s/dementia disease ☐ ☐
Neurological condition/Acquired Brain Injury ☐☐
Intellectual disabilities (autism, downs syndrome etc.) ☐ ☐ Mental health ☐ Cancer ☐ ☐ Paralysis ☐ ☐
other ☐ ☐
If other please specify
____

How long have you been caring for individual?
Less than 1 year ☐ ☐ 1 – 4 years ☐ ☐ 5 – 9 years ☐ ☐
10 – 14 years ☐☐ 15 + years ☐ ☐

If you care for a second individual, who are they?

Not applicable ☐ Spouse ☐ Child ☐
Parent ☐ Other ☐
If other please specify ______________________

If you care for a second individual, what condition do they have?
Not applicable ☐ Alzheimer's/Dementia disease ☐
Neurological Condition/Acquired Brain Injury ☐
Intellectual Disabilities ☐ Mental Health ☐
Cancer ☐ Paralysis ☐ Other ☐
If other please specify ___________________________________

Are you the sole carer?
Yes ☐ ☐ No ☐ ☐

What is the approximate time you spend caring per day? (Number of hours)

____

Are you in receipt of carers' allowance / carers benefit?
Yes ☐ ☐ No ☐ ☐

Do you attend support group?
Yes ☐ ☐ No ☐ ☐

If yes please answer the following (tick all appropriate)
Online/forums ☐ ☐
Meetings (Face to face groups) ☐ ☐
Other ☐ ☐
If other please specify ____________________________________

How frequently do you attend face-to-face support groups?
First time to attend ☐ ☐ Everyday ☐ ☐ Once a week ☐ ☐ Twice a week ☐ ☐ Monthly ☐ ☐

How frequently do you attend online support groups?
At least once a day ☐ ☐ More than once a day ☐ ☐ Once a week ☐ Twice a week ☐ ☐ Monthly ☐ ☐
Never ☐☐
First time to attend ☐

Do you receive respite?
Yes ☐ No ☐

If yes how many hours do you receive? (Hours per week)
0 - 2 hours ☐ 2 - 4 hours ☐ 4 - 6 hours ☐
6 – 8 hours ☐ 8+ hours ☐

General Health Questionnaire 12

We want to know how you have been feeling since you have been caring. Please read the statement and the four responses. Please choose the response that best applies to you.

Have you recently…

1. Been able to concentrate

less than usual   no more than usual   rather more than usual   much more than usual

2. Felt capable of making decisions

less than usual   no more than usual   rather more than usual   much more than usual

3. Been able to face up to problems

less than usual   no more than usual,   rather more than usual   much more than usual

4. Lost sleep over worry

less than usual   no more than usual   rather more than usual   much more than usual

5. Felt constantly under strain

less than usual   no more than usual   rather more than usual   much more than usual

6. Could not overcome difficulties

less than usual   no more than usual   rather more than usual   much more than usual

7. Felt unhappy and depressed

less than usual   no more than usual   rather more than usual   much more than usual

8. Been losing of confidence in self

less than usual   no more than usual   rather more than usual   much more than usual

9. Been thinking of self as worthless

less than usual   no more than usual   rather more than usual   much more than usual

10. Feel you play useful part in things

less than usual   no more than usual   rather more than usual   much more than usual

11. Been enjoying day-to-day activities

less than usual no more than usual rather more than usual much more than usual

12. Feeling reasonably happy

less than usual no more than usual rather more than usual much more than usual

Carer Support Needs Assessment Tool (CSNAT)

Please answer these questions as honesty as possible. When answering consider how the support group/online support you receive impacts these items. Please circle correct answer.

Does the support group assist you with/offer advice on..?

Understanding your relative's illness?	No	A little	Quite a bit	Very much
Managing your relative's symptoms, including giving medicines?	No	A little	Quite a bit	Very much
Providing personal care for your relative (e.g., dressing, washing, and toileting)?	No	A little	Quite a bit	Very much
Knowing who to contact if you are concerned about your relative (for a range of needs, including at night)?	No	A little	Quite a bit	Very much
Equipment to help care for your relative?	No	A little	Quite a bit	Very much
Talking with your relative about his or her illness?	No	A little	Quite a bit	Very much
Knowing what to expect in the future when caring for your relative?	No	A little	Quite a bit	Very much

Do you need more support with…?

Having time for yourself in the day?	No	A little	Quite a bit	Very much
Your financial, legal, or work issues?	No	A little	Quite a bit	Very much
Dealing with your feelings and worries?	No	A little	Quite a bit	Very much
Looking after your own health (physical problems)?	No	A little	Quite a bit	Very much
Your beliefs or spiritual concerns?	No	A little	Quite a bit	Very much
Practical help in the home?	No	A little	Quite a bit	Very much
Getting a break from caring overnight?	No	A little	Quite a bit	Very much

Appendix Useful contacts

Charity	Telephone number	Website
Carers Association	1800240724	www.carersireland.com
Alzheimer's Society of Ireland	1800341341	www.alzheimer.ie
Aware	1890303302	www.aware.ie
Console	1800201890	www.console.ie
Bethany	0879905299	www.bethany.ie
Irish Hospice foundation	01 6793188	www.hospice-foundation.ie
Irish Rural Link	0906482744	www.irishrurallink.ie
Money advice and Budget Service	1890283438	www.mabs.ie
Senior Help Line	1850440444	www.seniorhelpline.ie
Society of St Vincent de Paul	01 8386990	www.svp.ie