Stress, Loneliness and Depression Levels among Spousal Caregivers for Persons with Dementia Compared to Married Non-caregivers

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Abstract

The aims of the current study were to determine if spousal caregivers for persons with dementia would endure higher levels of stress, loneliness and depression compared to married non-caregivers, and to determine if female spousal caregivers would report higher levels of stress, loneliness and depression when compared to male caregivers in the same role. Stress, loneliness and depression were the dependent variables in the current study. The study hypothesised that spousal caregivers for persons with dementia would report higher levels of stress, loneliness and depression compared to married non-caregivers. It was also hypothesised that female spousal caregivers would report higher levels of stress, loneliness and depression compared to male caregivers in the same role. A survey containing the Perceived Stress Scale, the UCLA Loneliness Scale and Beck's Depression Inventory was used to examine each of the variables and the survey was published into several online dementia caregiver support group pages. Data was collected from 136 participants. Two Independent Samples T-Tests were carried out to compare the mean scores of the dependent variables between spousal caregivers for people with dementia and married non caregivers, and to compare the mean scores of the dependent variables between male and female caregivers for persons with dementia. Results found that there were no significant differences between stress, loneliness and depression for spousal caregivers and married non-caregivers. The results also found that there were no statistically significant differences in stress, loneliness and depression among male and female spousal caregivers for persons with dementia. There were several implications in the current study such as age, cultural and received support differences which were not considered. Research in this field is of upmost importance as there are many gaps in the literature of the psychological wellbeing of spousal caregivers for people with dementia.

CONTENTS

Introduction	6-14
Procedure	15 – 21
Results	22-24
Discussion	25-31
Conclusion	32-33
References	29-36
Appendix	37-52

Introduction

Dementia is an umbrella term for diseases that damage the nerve cells in the brain which in turn changes the brain's physiological function. Dementia is an irreversible neurodegenerative disease and it can greatly affect the person that is living with this disease in terms of memory, cognitive abilities, mood, behaviour and use of language (World Health Organisation, 2017). Many pharmaceutical methods of coping with dementia have become popular over the last 40 years. Such medications can help to ease agitation in the evening during 'sundowning'- a phenomenon which causes increased confusion and agitation for persons with dementia in the evening. Dementia is the 7th leading cause of death in Ireland. Within the next 30 years, it is predicted that the number of individuals living with the disease is likely to triple. Although dementia is most prevalent in elderly adults, early onset dementia can also occur. Early onset dementia is classified as having dementia under the age of 65. The majority of individuals who live with dementia are cared for by a relative or spouse for years prior to possibly going into full-time care in a nursing home. Caring for an individual with dementia can be very difficult, time consuming and exhausting for the carer, depending on the stage of dementia that the person is going through. The individual living with this disease can eventually become progressively more difficult to care for, as they become increasingly confused, upset and agitated or aggravated. Caring for an individual who has dementia can lead to social isolation due to decreased participation in activities with friends or family, as it can be extremely time-consuming caring for a person with dementia. The caregiver can suffer psychological effects as a result of caring for an individual with dementia. Effects may include loneliness due to social isolation and stress due to the daily stressors which they experience as a result of caring for the individual living with dementia. Depression can

also result from caring for someone who has dementia. A spousal carer may dwell on the thought that their lives may drastically change over the coming years and could become distressed knowing that this is a progressive and irreversible disease. A spousal caregiver may have decreased feelings self-worth and independence as it is possible that all of their time and energy is put towards caring for their spouse.

Many studies research stress, loneliness and depression levels for carers of individuals living with dementia, but only a select few studies examine the effects which spousal caregivers caring for their spouse with dementia might endure. One would struggle to find research comparing married couples in which one spouse is caring for their partner with dementia, to married couples in which neither spouse is a caregiver for their spouse, as their spouse does not have the disease.

The rationale for this research is to add to the knowledge of the adverse psychological effects that caregiving for a spouse with dementia can cause. A fundamental purpose for the research is due to the gap in the literature. As mentioned above, through extensive search it is difficult to find research studies that compare spousal caregivers for individuals with dementia and married individuals who do not care for a spouse with dementia. It is expected that a correlation will be found between stress, loneliness and depression and spousal caregivers caring for a spouse with dementia. This is expected as caregivers experience many stressors throughout their caregiving day. Loneliness could be predicted for the caregiver as caregivers have restricted recreational and social time as caregiving is exhausting and time consuming, therefore caregivers may lose touch and contact with their friends and may become increasingly lonely as time goes on. Depression experienced by the caregiver could also arise as a result from caregiving as both the

caregiver and the care receiver are in a very sorrowful situation. It would be fair to predict that the caregiver could become increasingly distressed and unsettled knowing that the situation they find themselves in along with the situation that the care-receiver finds themselves in, is a tremendously upsetting time of their lives and is unfortunately unchangeable. The caregiver may not be able to receive professional help for their depressive symptoms as they simply may not have the time, resources or support they need, as the care receiver is dependent on their caregiver.

The main aims of this study is to determine if spousal caregivers will report higher levels of stress, loneliness and depression in comparison to those who do not care for their spouse and to determine if female spousal caregivers for an individual with dementia will report higher levels of stress, loneliness and depression compared to male caregivers caring for a spouse with dementia. The research questions for this study are 'Will stress, loneliness and depression levels differ for those who care for their spouse suffering from dementia compared to married non-caregivers?' and 'Will female spousal caregivers for persons with dementia report higher levels of stress, loneliness and depression compared to male spousal caregivers in the same role?'. The hypotheses for this study are as follows; 'Spousal caregivers will have statistically significant higher levels of stress, loneliness and depression compared to married non-caregivers', 'Female caregivers for persons with dementia will report statistically significant higher levels of stress, loneliness and depression in comparison to male caregivers. The null hypothesis is 'spousal caregivers will not have statistically significant higher levels of stress, loneliness and depression compared to married non-caregivers as their spouse does not suffer from dementia'.

Wallsten and Snyder (1991) conducted a study which examined perceptions of stress in daily experiences in caregivers compared to non-caregivers. Twenty-one

caregivers and twenty non-caregivers were recruited for this study. Participants were recruited through local home health agencies, Duke's Respite Care Project, Duke's Rapid Autopsy Programme for Alzheimer's Victims and Alzheimer's Support Groups.

Seventeen of the caregivers were female and the remainder were male. Fifteen of the non-caregivers were female and the remainder were male. Participants were required to complete two scales; The Routines, Uplifts, Challenges and Hassle List and The Hopkins Symptom Checklist. The results showed that caregivers rated a higher negative impact of daily experiences than the non-caregivers. It was also found that there was no buffering effect on caregiver's stress when a positive experience would occur for them throughout the day, but it was found that negative experiences could in fact worsen the individual's stress levels. A limitation to this study is that the population size is too small and therefore the results cannot be generalised to the wider population.

In contrast to this study, Nogales- Gonzaleza, Romero- Morenoa, Losadda, Arquez- Gonz & Zaritc (2014) conducted a study to examine self-efficacy on the relationship between problem behaviour and stress on the caregiver of a person living with dementia. Two hundred and thirty-one family caregivers for persons suffering with dementia were recruited for this study and their frequency of distress was assessed. The results showed that participants with high levels of self-efficacy whom experienced high levels of problem behaviour from the person with dementia displayed low levels of stress. These results show that positive experience such as self-efficacy did in fact buffer the stress levels of the carer, unlike the study carried out by Wallsten and Snyder.

Research carried out by Pinquart and Sorensen (2003) examines the literature of caregivers and non-caregivers examining stress and depression furtherly supports the findings of the above papers. In a particular study, 100 participants with a mean age of

62.5 years and 58% of them being caregivers for persons with dementia were required to complete four scales; The Perceived Stress Scale, The Hamilton Depression Rating Scale, Beck's Depression Inventory and The Centre of Epidemiologic Studies Depression Scale. The results found that both depression and stress were independently higher for caregivers than for non-caregivers.

Similarly, research carried out by Gaugler et al (2009) interviewed caregivers for the first time prior to placing the dementia sufferer into full time care, a second time 6 months post placement and a final interview 12 months post placement. Interviews were given to a total of 2726 participants by nurses and social workers. The results found that depression and stress levels rated high prior to fulltime care placement, decreased slightly 6 months post placement and significantly decreased 12 months post placement.

Contrary to such findings, Flaskerud, Carter and Lee (2009) conducted a study investigating distressing emotions in female caregivers. Participants were those who were professional caregivers who were recruited from clinics serving people with AIDS, dementia and cancer. Caregiving participants were interviewed to measure and assess depressive symptoms and anxiety. Results found that caregivers showed no significant difference in depressive mood but had increased distressing symptoms.

Placing an individual with dementia into fulltime care has shown to significantly decrease such adverse effects for the carer. With similar results to those of the above study, Mausbach et al., (2014) carried out a five-year longitudinal study examining the well-being of the carer after placing the sufferer into full-time care. One hundred and twenty-six participants who were at least 55 years old, were recruited from dementia research centres and local dementia support groups. Forty-four of these participants placed their dementia suffering partner in fulltime care. Participants were required to complete

three scales; The Centre of Epidemiologic Studies Depression Scale, Activity Restriction Scale and the Pearlen Mastery Scale. Results showed that after placing the sufferer in long term care, the carer experienced decreased depressive symptoms and increased personal mastery due to decreased activity restrictions, which may reduce previously reported loneliness, compared to the control group who did not place the sufferer in long term care.

Kiecolt-Glaser, Dura, Speicher, Trask & Glaser (1991) conducted a longitudinal study on spousal caregivers of persons with dementia. It included 138 participants; 20 men and 49 women who were spousal caregivers for 5 years and 20 men and 49 women in a control group. The participants were given structured clinical interviews for DSM-III-R (Diagnostic Statistical Manual for Mental Disorders) and a non-patient version of this interview was used for the control group. Follow up versions of this interview were completed by the participants some years later. The results found that depressive symptomology increased for spousal care givers over time. There are many strengths to this study, one which includes this study's results show that spousal caregiver's mental health can deteriorate over time as the victim of dementia progresses.

Beeson, Horton- Deutsch, Farran, & Neundorfer (2000) carried out a study on 242 husbands, wives and daughters of dementia sufferers who they cared for to test loneliness and depression levels. They were tested on variables including quality of past relationships, relational deprivation, quality of current relationship and distance felt due to care giving. The results found that loneliness significantly related to depression, relationship deprivation and poorer quality relationships. Women scored higher than men in depression and loneliness. It was found that increased levels of loneliness caused for increased levels of depression. Loneliness was the only variable that effected depression levels of the participants in this study. Although this study examines not only spousal

caregivers of a dementia sufferer but family caregivers also, it fails to accommodate for other potential life factors that may occur in the life of family caregivers such as work, financial problems and family life.

Beeson (2003) conducted a study examining loneliness and depression levels among 49 individuals who cared for a spouse who was living with dementia. The control group consisted of 52 non-caregivers. The results showed that in the comparison of the two groups, both loneliness and depression levels were higher for caregivers than non-caregivers. This study also showed that wives caring for their husbands with dementia displayed higher levels of loneliness and depression than husbands caring for their wife with dementia.

Ekwall, Sivberg and Hallberg (2005) conducted a study which examined loneliness as a predictor of quality of life among older caregivers. This study included a postal questionnaire which consisted of The Short Form Health Survey. This survey was posted to houses at random and resulted in the use of 4278 participants. The participants were all over the age of 75 and 18% of the participants were caregivers for individuals suffering from dementia. Results of this study found that caregivers had a small, less efficient social network which resulted in them reporting feelings of loneliness. They had higher levels of loneliness compared to non-caregivers for this reason. Similar to the study above, it was also found that women had higher levels loneliness levels compared to the loneliness levels that the males in the study reported to endure.

For the current study it would be worthy to acknowledge the literature investigating if married individuals are less prone or more vulnerable to stress, loneliness

or depression. In a study examining stress among married and non-married individuals (Chin, Murphy, Janicki-Deverts & Cohen, 2017), it was found that married individuals had lower cortisol levels, a physiological indicator of lower levels of stress. A separate study conducted to examine loneliness levels among married individuals and non-married individuals (Pinquart, 2003) concluded that loneliness levels were low in those who were widowed, never married or divorced, but were higher in married individuals. In a study carried out by Thomeer, Umberson & Pudrovska (2013) depression between married and non-married individuals was investigated. It was found that married couples did not have significantly higher depression levels in comparison to non-married individuals, but it is noteworthy that this study found that a wife's depressive symptoms could greatly influence future depressive symptoms for her husband. It is also interesting to note that this was not the case for a husband's depressive symptoms influencing his wife's future depressive symptoms.

According to the World Health Organisation, women are more likely to suffer from mental health disorders in comparison to men (WHO, 2019). Such mental disorders in which women predominate include depression, anxiety, stress and bipolar disorder. The World Health Organisation also reported that not only are women more likely to suffer from mental health disorders such as depression, but such a mental disorder is more persistent in women than it is in men. Such findings can support that of other research carried out such as that of a National Health Surveilence Survey which also found that women have higher mental health disorder rates than their male counterparts.

To conclude, literature on the topic of dementia has been researched and studied, more so focusing on the possible effects of stress, loneliness and depression levels of those caring for a spouse with dementia and differences in stress, loneliness and depression in

males and females in such roles. There are many studies which show the effects of stress, loneliness and depression levels, but there is little research on comparing such variables among married couples who care for their spouse with dementia and married couples who do not care for their spouse as their spouse does not have dementia. The majority of the studies researching dementia which compare stress, loneliness and depression levels tend to compare such variables between caregivers and non-caregivers. Therefore, the gap in the literature is evident; Comparisons are made between caregivers and non-caregivers, but not married spousal caregivers and married non-spousal caregivers, which is why I have chosen to do my research on stress, loneliness and depression levels among spousal caregivers for individuals with dementia and married non-spousal caregivers.

Procedure

The sample used in the current study consisted of 136 participants aged between 30 and 79. This sample was composed of 18 male participants and 118 female participants.

Each participant was either married to and caring for their spouse who had dementia (N=90) or was married but did not care for their spouse as their spouse did not have dementia (N=46). As random sampling gives each member of a given population an equal opportunity for participation and allows the researcher to make inferences about the population, this method of research sampling was chosen. Convenience sampling was also chosen as another research sampling method as participants were convenient and cost efficient to the researcher. The current study aims to investigate three dependent variables; Stress, Loneliness and Depression levels for those who care for their spouse with dementia and compare them to those who do not (independent variable). Such data was obtained using quantitative methods.

To measure each dependent variable, three globally recognised scales were used; The Perceived Stress Scale (Cohen, Kamarck & Mermelstein, 1983), The UCLA Loneliness Scale (Russell, Peplau & Ferguson, 1978) and Beck's Depression Inventory (Beck, 1961). The Perceived Stress Scale is a globally recognised and validated scale used to test the perceived stress levels of individuals. The Perceived Stress Scale comes in the form of a 4, 10 or 14- question survey in which participants are required to answer all elements. Participants are presented with many statements and must choose how much each statement relates to them and do so by choosing from the numbers 0-4, 0 being 'Never' and 4 being 'Very Often'. Scores are then reverse scored when necessary and are then added together to find a total stress score for each participant.

In a review of the psychometric evidence of the Perceived Stress Scale (Lee, 2013) it was reported that The Perceived Stress Scale possesses internal consistency reliability, factorial validity, and hypothesis validity. Other studies such as one conducted by Roberti and colleagues (2006) support these findings. The UCLA Loneliness scale is a widely used valid measure of loneliness levels in individuals. It has been reported that 80% of research studying Loneliness uses the UCLA loneliness scale. Different versions of the UCLA Loneliness vary in terms of how many items each version consists of. Participation in the UCLA Loneliness Scale requires the participant to answer each element of the survey.

Participants are presented with many statements in which they must answer; Often, Sometimes, Rarely or Never, depending on how much the statement relates to their life. The scores are recoded, reversed scored where applicable and summed together to find a total loneliness score for the participant. Many studies have carried out psychometric tests on the UCLA Loneliness Scale to investigate the scale's validity and reliability. Such studies which investigate such means have found that the UCLA Loneliness Scale is highly reliable in terms of internal consistency and test-retest reliability (Russell, 1978). Convergent Validity, Construct Validity and Confirmatory factor analysis were also measured, and results of this analysis furtherly supported the hypothesis that the UCLA Loneliness Scale is a valid and reliable scale (Hartshorne, 1993). For the current study question 1-15 of the UCLA Loneliness Scale were used. A globally recognised measure of depression is Beck's Depression Inventory. This measure consists of 21-items in which participants much choose one statement presented in each item, that best relates to their life. The scores are recoded and summed together to find a total score of each participant's depression level.

Dissimilar to findings that suggest Beck's Depression Inventory discriminates against subtypes of depression (Beck, Steer & Carbin, 1988), there is copious amounts of research that suggests otherwise. Such a study conducted by Richter and colleagues (1998) reported that Becks Depression Inventory has high internal consistency, high content validity, validity in differentiating between depressed and non-depressed subjects and has sensitivity to change.

The current study is a quantitative study and uses a cross-sectional research design. A cross-sectional research design is appropriate for this study as the participants vary in levels of the variables of interest; stress, loneliness and depression also known as the dependent variables, but they also share similar characteristics such as socio-economic background and marital status. The current study also uses a between group design. Such a design includes the two groups of participants (married to and caring for their spouse with dementia and married but not caring for their spouse) being exposed to the same condition and every condition (i.e.) each group of participants will be required to answer the same questions as each other and no group will answer questions that the other group was not given the opportunity to answer.

The survey used for this study was used to examine the stress, loneliness and depression levels of those who were married to and cared for their spouse with dementia and of those who were married and not caring for their spouse as their spouse did not have dementia. The Perceived Stress Scale (see appendix i), The UCLA Loneliness Scale (see appendix ii) and Beck's Depression Inventory (see appendix iii) were the measures used for investigation. The survey was created using Google Forms (see appendix iv). The title of the study and an information sheet were the first elements provided in the survey. The information sheet provided the participant with information regarding the current study

and information about the researcher. An option for the participant to proceed was presented under the information sheet. This was followed by a debriefing sheet which provided the participant with information on how to participate in the current study. This sheet also provided helplines for those who might need them, along with the researcher's email address in which they could use as a form of contact with the researcher if any problems were to arise. The debriefing sheet was followed by a consent from in which the participants were informed that all data would remain completely anonymous and they could withdraw at any time without penalty during the course of the study. They were also informed of any possible risks that could arise during the course of the study. The participants were informed that if they had any further questions regarding the study that they could contact the researcher via email and that email was provided. The above was followed by the Perceived Stress Scale, the UCLA Loneliness Scale and Beck's Depression Inventory which required the participants to complete each section of each survey. The survey ended with a note thanking the participant for their participation and again reminded the participant that if they had any queries or concerns regarding the study that they could contact the researcher via email.

The survey was published in several different public groups on the social networking site 'Facebook' which did not need approval from the creator of the groups. These online groups were created as support groups for people who cared for family members with dementia. The survey was published in many different dementia-caregiver support groups in hopes that those who cared for their spouse with dementia would participate. Many members of these groups were not carers for their spouse with dementia but may have been a part of the group in search of support in which they could pass on to their family members who cares for their spouse with dementia. The survey link was

published along with a short description of what this research involved and informed individuals on the requirements needed in order to be eligible to participate.

As each participant participated in the study, their response was automatically recorded on Google Forms where the researcher could examine the responses. By the end of the data collection window, the researcher collected 147 responses. Eleven of these responses were removed from the data set as they did not comply with the inclusion criteria. After the remaining 136 eligible responses were reviewed for final examination, the responses were downloaded from Google Forms to Excel. Unnecessary information downloaded with the responses such as date and time of response was removed from the excel spread sheet and replaced with necessary information just as the inputting of Participant ID. The researcher had an excel file with Participant ID, Age, Gender, Marital Status, Spouse Dementia and Caring for spouse with dementia information. Each question of the survey was located in columns across the spread sheet, with answers from the participants to each of the rows underneath each question.

Each participant's answer was then recoded. Gender was recoded; 'Males' recoded to 0 and 'Females' recoded to 1. The answers for marital Status, spouse suffering with dementia and caring for spouse with dementia were all recoded. Each 'Yes' answer for these questions was recoded to 1 and each 'No' answer for these questions was recoded to 0. The scores for the Perceived Stress Scale were recoded as follows 'Never' = 0, 'Almost Never' = 1, 'Sometimes' = 2 'Fairly Often' = 3, 'Very Often' = 4. The scores were then reverse coded where applicable; Questions 4,5,7 and 8 were reverse scores as follows; 0=4, 1=3, 2=2, 3=1 and 4=0. The scores for the UCLA Loneliness Scale were recoded as follows; 'Never'= 1, 'Rarely'=2, 'Sometimes' = 3, Often = 4. The scores were then reverse coded where applicable; Questions 1,5,6,9,10 and 15 and were reverse scored as follows;

1=4,2=3,3=2 and 4=1. The answers from Beck's Depression Inventory were recoded 0-3, 0 being the least extreme of the statements to choose from and 3 being the most extreme of the statements to choose from in each item of the survey. On completion of the above, the excel file was saved and then exported onto SPSS Database System. Under the 'Type' column each row was changed to numeric as recoding had taken place previously in Excel. The rows under the 'Width' column were changed to the correct width for each question, mostly 3,2 and 1. Decimals were changed to 0 as none of the answers obtained by participants contained a decimal. Labels were created for each row to furtherly explain their meaning. Values were inserted for each row to explain what each numeric answer represented. A missing value of -99 was inserted to ensure no values were missing.

Finally, each row was assigned a measure; the surveys all being nominal and demographic questions being scale and nominal. To find a total score for each participant for each dependent variable, the scores for each part of each survey were added using the 'Compute Variable' option in SPSS. The total sum of the dependant variables was labelled as 'Total Stress', 'Total Loneliness' or 'Total Depression' where applicable. A reliability test for each of the scales used for testing stress, loneliness and depression was carried out using SPSS's feature that tests scale's reliability. The stress scale scored a satisfactory Cronbach's alpha score (.87), similar to what the relaibility score should be for the Perceived Stress Scale (.82) (Andreou et al., 2011). A satisfactory Cronbach alpha score for the depresson scale was also scored (.92), again similar to what the Cronbach's alpha score of reliability for the depression scale should be (.89) (Lee, Lee, Hwang, Hong & Kim, 2017). Finally, the Cronbach's alpha scored for the UCLA Loneliness Scale was .15, dissimilar to what it should be (.89) (Russell, 1996).

Statistical analysis was carried out using SPSS; An Independent-Samples T-Test to test the mean difference of Stress, Loneliness and Depression Levels among those who were married to and caring for their spouse with dementia and those who were married but did not care for their spouse as their spouse did not have dementia. An Independent Samples T-Test to test the mean differences of stress, loneliness and depression levels among male and female spousal caregivers was also conducted. A Preliminary Analysis was conducted to ensure no violation of the assumption of normality, linearity and homoscedasticity.

Results

Descriptive Statistics

Descriptive statistics of all continuous variables

	Mean (95% Confidence	Std. Error	Median	SD	Range
	Intervals)	Mean			
Age	58	1.02	54.5	11.92	49
Stress	23.9 (22.59-25.21)	.99	25	7.7	37
Loneliness	27.25 (36.55-37.96)	.35	38	4.14	20
Depression	18.77 (16.8-20.74)	.14	18	11.61	50

Descriptive statistical analysis was carried out to describe the basic features of the data in the current study. The average age of this sample was aged 58 years. There was an age range of 49 years from the youngest participant to the eldest participant. The Descriptive Statistics report that Loneliness levels were found the be the highest scoring dependent variable (M= 27.25, SD=2.14) followed by Stress (M=23.9, SD = 7.7). Depression levels (M= 18.77, SD 11.61) did not score as high as Stress or Loneliness. This dependent variable's score was significantly lower than the other two dependent variables.

Table for displaying information of categorical variables.

Frequencies for the current sample of male and female individuals married to and caring for their spouse suffering with dementia and individuals married but not caring for their spouse as their spouse does not suffer from dementia (N=136)

Variable	Frequency	Valid Percentage
Gender		
Male	18	13.2
Female	118	86.8
Marriage		
Yes	136	100
Participant's Spouse Suffers with Dementia		
Yes	90	33.8
No	46	66.2
Participants Cares for		
Spouse with Dementia		
Yes	90	65.9
No	46	34.1

A frequency analysis was carried out to report the frequency answers from each categorical variable in the current study. From the table above, it is reported that 18 participants were male, and 118 participants were female. All participants were married, ninety of whom were married to a person with Dementia. Ninety of these ninety people cared for their spouse with Dementia and forty-six did not.

Inferential Statistics

An independent samples t-test was conducted to compare levels of Stress, Loneliness and Depression between individuals who cared for their spouse with dementia and those who did not care for their spouse with dementia, as their spouse did not have dementia. There was no significant difference in scores of Stress, Loneliness or Depression for those who cared for their spouse with dementia; Stress (t (133) = 1.78,

p = .07), Loneliness (t (133_ = 1.16, p = .24) and Depression (t (133) = 1.66, p = .99) with people who care for their spouse with dementia (M = 90, SD = .38.27) scoring higher than those who do not (M = 46, SD = 40.49). The magnitude of the differences for Stress (mean difference = 3.48, 95% CI: 7.30 - .35), Loneliness (mean difference = .08, 95% CI: 1.99 – 2.16) and Depression (mean difference = 4.55, 95% CI: 10.33 – 1.23) was small (Cohen's d = .31).

A second independent samples t-test was conducted to compare levels of Stress, Loneliness and Depression between males and females' caregivers. There was no significant difference in scores of Stress, Loneliness or Depression for males and females who cared for their spouse with dementia; Stress (t(84) = 1.81, p = .73), Loneliness (t(84) = 1.05, p = .29) and Depression (t(84) = 1.29, p = .20) with female caregivers (M = 25.15, SD = 6.85) scoring higher than male care givers (M = 20, SD = 10.75) for stress. Females caregivers scored higher on the loneliness scale (M = 37.54, SD = 3.67) in comparison to male caregivers (M = 36, SD = 4.2). Females scored higher on the depression scale (M=20.37, SD=11.42) when compared to the male caregivers used in this data set (M=14.42, SD=14.61). The magnitude of the differences for Stress (mean difference = 5.15, 95% CI: 10.8 - .49), Loneliness (mean difference = 1.54, 95% CI: 4.46 - 1.37) and Depression (mean difference = 5.95, 95% CI: 15.11 - 3.21) was small.

Discussion

The current study investigated if those who cared for their spouse suffering with dementia would report higher levels of stress, loneliness and depression in comparison to married individuals who do not care for their spouse as their spouse does not have dementia. The study also investigated if female spousal caregivers would report higher levels of stress, loneliness and depression when compared to male spousal caregivers. The findings of this study have reported that levels of stress, loneliness and depression among spousal caregivers for people with dementia are not significantly higher than stress, loneliness and depression levels among married individuals who are not caregivers.

A descriptive statistical analysis was run in an effort for the researcher to describe the basic features in the data provided by the participants. The descriptive statistics table provided above explains the Mean, the Standard Error Mean, the Median, the Standard Deviation and the Range of all continuous variables in the current study's data set; Age, totals stress scores, total loneliness scores and total depression scores. A frequency analysis was conducted to examine the frequency of categorical variables for the current study. An Independent Samples T-Test was carried out to examine differences in the levels of stress, loneliness and depression among two groups. An Independent Sample T-Test was the statistical analysis used to investigate the hypothesis and this analysis was chosen as it is most suitable to compare the means of dependent variables between two groups. One of these two groups consisted of participants who were married to and caring for their spouse with dementia.

The second group consisted of participants who were married but not a care giver for their spouse as their spouse did not have dementia. Those who cared for their spouse with dementia scored a higher mean score (M=24.87) on the stress scale than those who

were married, but not a caregiver (M=22.43). Spousal caregivers scored a higher mean score (M=37.6) on the loneliness scale in comparison to those who were married but not a caregiver (M=36.7). The results from the depression scale differ to the results of the stress and loneliness scales in terms of the variation in the mean scores of each group. There is a larger difference in the mean scores of the two groups in the depression scale in comparison to the scores on both the stress scale and the loneliness scale. Spousal caregivers for people with dementia reported a higher score on the depression scale (M=20.08) when compared to their married non-caregiver counterparts (M=16.6).

Although the results show that stress, loneliness and depression scores are all higher for spousal caregivers than non-spousal caregivers the difference is insignificant. The P value scored .77 (p= 0.77) for stress, .24 (p=0.24) for loneliness and the P value for depression scored .99 (p= 0.99). From the results of the P values for each dependent variable, we can see that the differences in the mean of these variables are not statistically significant as their P values exceed the 0.05 P value limit for a statistically significant difference. The effect size also reports that the size of the differences between the mean scores of each variable in each group are small (Cohen's d = .31). This is considered a statically small effect size.

A second Independent Samples T-Test was conducted to examine the mean differences of stress, loneliness and depression among female caregivers for their spouse with dementia and male spousal caregivers for their spouse with dementia. Females scored higher on the stress scale (M = 25.15) in comparison to male caregivers (M = 20). They also scored higher on the loneliness scale (M = 37.54), male caregivers scoring (M = 36). The depression scale saw larger differences than the previous two scales with females scoring higher (M = 20.37) than males (M = 14.42).

The current study expected to find statistically significant higher levels of stress, loneliness and depression among spousal caregivers for people with dementia compared to married non-spousal care givers. This was not found in the current study, as although stress, loneliness and depression levels were higher for married individuals caring for their spouse with dementia, the differences were not statistically significant. Due to the findings of the current study, we can reject the hypothesis that spousal caregivers for people with dementia will report statistically significant higher levels of stress, loneliness and depression in comparison to those who are married but not caring for their spouse with dementia as their spouse does not have dementia. As we are rejecting the hypothesis, we can accept the null hypothesis which states that spousal caregivers will not have statistically significant higher levels of stress, loneliness and depression compared to married non-caregivers as their spouse does not suffer from dementia.

The current study also hypothesised that female caregivers in the sample would have statistically significant higher levels of stress, loneliness and depression compared to male caregivers. The findings of the current study have indicated that this hypothesis cannot be accepted as although female caregivers do in fact display higher levels of stress, loneliness and depression, the differences in the levels of which they do so are not statistically significant, and therefore the hypothesis must be rejected.

The findings of the current study are more tentative than conclusive. Although the aim of the current study was achieved, the hypothesis must be rejected. The current study's results are nonconclusive as they do not prove anything; They do not prove that stress, loneliness and depression levels are significantly higher in spousal caregivers for persons with dementia compared to married non-caregivers, nor do they prove they are the same as or less than married non-caregivers. They do not prove that females endure

significantly higher levels of stress, loneliness and depression while caregiving for their spouse with dementia compared to male spousal caregivers in the same role. The results found for the current study can be generalised to a wider population as the current study uses a sufficient sample size valid for generalisation, as this study's sample consists of 136 participants from different countries all over the world; Mainly Ireland, Britain, Canada and the USA.

The sample used in this study consisted of 90 individuals who were spousal caregivers caring for their spouse with dementia who were randomly recruited from dementia caregivers support groups and not hand-picked from one single dementia caregiver support group. The sample used in the current study also recruited married individuals who were not caring for their spouse as their spouse did not have dementia (N=46), who were also recruited at random and were not hand-picked from one institution, which furtherly allows for generalisation.

The findings of this study greatly challenge the findings of the current literature on stress, loneliness and depression levels among spousal caregivers for persons with dementia and the current literature based on caregiver gender differences for stress, loneliness and depression. As stated above, this study has found no significant differences in stress, loneliness or depression for individuals who care for their spouse living with dementia compared to married non-caregivers. Results also show that there are no statistically significant differences in stress, loneliness or depression levels between male and female caregivers for persons with dementia, furtherly challenging current literature on the topic.

There are many implications from the current study. The findings of the current study are valuable when adding knowledge to the ever-growing literature on caregivers for

persons with dementia. The findings of the current study call for more research to be conducted in an effort to furtherly investigate stress, loneliness and depression among spousal caregivers for persons with dementia.

Limitations

The current study poses many limitations in receiving accurate results for such hypotheses. The current study consists of an uneven number of men and women which could greatly skew the results as the prevalence of mental disorders such as depression is typically higher in women than it is in men (Albert, 2015). Age differences in the sample used could be considered another limitation. It is likely that the older individuals in the sample could experience higher levels of stress, loneliness or depression (Wang, Hu, Xiao & Zhou, 2017) simply due to the likelihood of enduring more harrowing life experiences such as stress from illnesses or family worries and could experience higher levels of depression in comparison to their younger counter parts, from life stressors such as marital, financial or wellbeing problems. It is noteworthy that the World Health Organisation reported that over 20% of adults suffer with a mental health disorder (WHO, 2017).

Cultural differences within the sample is an implication. As the survey was published on dementia caregivers support groups pages on 'Facebook', it is evident that the survey was available to individuals of all cultures and ethnicity backgrounds and the current study did not control for such cultural variations. Different cultures have very different ways of life, vary in how they live their lives and one individual's norm may not be the norm for the next individual. In some cultures, such as those in the Americas and Europe, it is usual for adult children and spouses to care for their parent or spouse who has dementia as much as they can until the care receiver might need full-time care. This may

not be the case in the middle east. For example, according to the Global Age Watch Index, in 2014 India ranked 71st out of 96 countries who used elderly care such as nursing homes (Global Age Watch Index, 2014). As India has the second highest population of elderly people in the world (DNA India, 2015) it is interesting that the use of full-time care for the elderly in India is ranked very low. This could be due to a law that has been passed in recent years in India; Maintenance and Welfare of Parents and Senior Citizens Act, 2007 which requires adult children to take care of their aging parents. It is very common in India for the elderly to live in multigenerational homes. For example, elderly people may live with their children, grandchildren and possibly great grandchildren, therefore spouses or adult children caring for their spouse or parent with dementia will have extra help and support from other family members living in the home. Such full-time support may not be given to those in the same role in Europe or the Americas and the current study did not control for such instances, therefore the results may not be accurate for all cultures.

Another limitation for this study is those who participated had access to the internet and a computer, laptop, phone or other technological devices. Many elderly caregivers may not have access to such equipment or may not know how to use such equipment and such individuals did not have the opportunity to participate in the research. The current study consisted of an uneven number of spousal caregivers for people with dementia (N=90) and married non spousal caregivers (N=46). This could skew the results as it is likely that stress, loneliness and depression levels will be higher for the group with a higher number of individuals, and the results reported this. An uneven number of female caregivers and male caregivers is another limitation for the current study. A lack of consideration was given to the time scales of spousal caregiving. Data for how long a spouse has been caring for their spouse with dementia was not recorded, which could

conclude with inaccurate results. An individual who has been caring for their spouse with dementia for 3 months may have lower stress, loneliness and depression levels in comparison to those who have endured such experiences for 5 years and this limitation was not considered in the current research. Similarly, no data was collected on what stage of dementia that the care receiver is at. An individual who is caring for the spouse with dementia who is at a severe stage of dementia may have different levels of stress, loneliness and depression in comparison to an individual who has been caring for their spouse at a mild stage of dementia. The current study did not collect data on the level of support that the spousal caregiver might receive. This could greatly skew the results as a spousal caregiver caring for their spouse with dementia who receives support from adult children, activity day centres or support groups may have lower levels of stress, loneliness and depression in comparison to spousal caregivers who do not receive such supports. A final limitation that this study possesses is that previous experiences of stress, loneliness and depression for the caregiver are not considered and there is copious amounts of research that suggest the recurrence of mental illnesses in individual's who previously suffered from a mental illness; Kartalova-O'Doherty & Tedstone Doherty (2010); Fikreyesus, Soboka & Feyissa (2016) & Burcusa & Iacono (2007).

Conclusion

To conclude, the current study found that there were no significant differences in the levels of stress, loneliness and depression of spousal caregivers for individuals caring for their spouse with dementia compared to married individuals who were not carers for their spouse as their spouse did not have dementia. The study also found that there were no statistically significant differences in levels of loneliness, stress and depression among male and female spousal caregivers for persons with dementia. The two hypotheses for the current study were rejected and the null hypothesis was accepted. There were several constraints in the current study including; An uneven number of men and women, age differences, cultural differences, the need for access to the internet and a technological device, an uneven number of spousal caregivers and non-caregivers, an uneven number of female caregivers and male caregivers. Time spent caring and stage of dementia were two more constraints of the current study along with no consideration for potential received support or previous mental health disorders such as stress loneliness or depression. Although the current study poses many limitations, it also possesses many strengths such as having a sufficient sample size for generalisation. The data collection was cost-efficient and was not drastically time consuming. The current study allowed caregivers to participate in research in a field in which most likely interests them. It also gave caregiving participants a place to anonymously voice their opinion how they are feeling in terms of stress, loneliness and depression as many may not be asked how they are coping. Caregiver participation in this study may have given them a sense of self-worth as they were presented with a study that wanted and needed them as participants. Both caregiver and non-caregiver participants were presented with hotlines in which they could ring for support on any troubles they might be facing, and by including hotlines in the debriefing sheet could help someone in need. The methodology presented allows for exact replication

for future research which may examine stress, loneliness and depression among spousal caregivers and married non caregivers. Future research on this topic may wish control for age and cultural differences, received support, stage of the care receiver's dementia and the time spent caring for the person with dementia. Such controls could allow for more accurate results in a field of ever-growing research.

References

- Albert, P. (2015). Why is depression more prevalent in women? *Journal of Psychiatry & Neuroscience*, 40(4), 219-221.
- Andreou, E., Alexopoulos, E., Lionis, C., Varvogli, L., Gnardellis, C., Chrousos, G., & Darviri, C. (2011). Perceived Stress Scale: Reliability and Validity Study in Greece. *International Journal of Environmental Research and Public Health*, 8(8), 3287-3298.
- Beck, A. (1961). An Inventory for Measuring Depression. *Archives of General Psychiatry*, 4(6), 561.
- Beck, A., Steer, R., & Carbin, M. (1988). Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review*, 8(1), 77-100.
- Beeson, R. (2003). Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Archives of Psychiatric Nursing*, 17(3), 135-143.
- Burcusa, S., & Iacono, W. (2007). Risk for recurrence in depression. *Clinical Psychology Review*, 27(8), 959-985.
- Chin, B., Murphy, M., Janicki-Deverts, D., & Cohen, S. (2017). Marital status as a predictor of diurnal salivary cortisol levels and slopes in a community sample of healthy adults. *Psychoneuroendocrinology*, 78, 68-75.
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 385–396
- DNA India. (2015). Elderly care: Why India is one of the worst countries to grow old in. Retrieved from https://www.dnaindia.com/analysis/standpoint-elderly-care-why-india-is-one-of-the-worst-countries-to-grow-old-in-2138686
- Ekwall, A., Sivberg, B. and Hallberg, I. (2005). Loneliness as a predictor of quality of life among older caregivers. *Journal of Advanced Nursing*, 49(1), 23-32.
- Flaskerud, J., Carter, P. and Lee, P. (2009). Distressing Emotions in Female Caregivers of People With AIDS, Age-Related Dementias, and Advanced-Stage Cancers. *Perspectives in Psychiatric Care*, *36*(4), 121-130.
- Fikreyesus, M., Soboka, M., & Feyissa, G. (2016). Psychotic relapse and associated factors among patients attending health services in Southwest Ethiopia: a cross-sectional study. *BMC Psychiatry*, *16*(1).
- Gaugler, J., Mittelman, M., Hepburn, K. and Newcomer, R. (2009). Predictors of change in caregiver burden and depressive symptoms following nursing home admission. *Psychology and Aging*, 24(2), 385-396.
- Global Age Watch Index. (2014). Global Age Watch Index 2014: Insight report, summary and methodology. Retrieved from https://www.helpage.org/global-agewatch/reports/global-agewatch-index-2014-insight-report-summary-and-methodology/

- Hartshorne, T. (1993). Psychometric Properties and Confirmatory Factor Analysis of the UCLA Loneliness Scale. *Journal of Personality Assessment*, 61(1), 182-195.
- Kartalova-O'Doherty, Y., & Tedstone Doherty, D. (2010). Recovering from recurrent mental health problems: Giving up and fighting to get better. *International Journal of Mental Health Nursing*, 19(1), 3-15.
- Kiecolt-Glaser, J., Dura, J., Speicher, C., Trask, O. and Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity and health. *Psychosomatic Medicine*, *53*(4), 345-362.
- Lee, E. (2013). Erratum to Review of the Psychometric Evidence of the Perceived Stress Scale [Asian Nursing Research 6 (2012) 121–127]. *Asian Nursing Research*, 7(3), 160
- Lee, E., Lee, S., Hwang, S., Hong, S., & Kim, J. (2017). Reliability and Validity of the Beck Depression Inventory-II among Korean Adolescents. *Psychiatry Investigation*, *14*(1), 30. doi: 10.4306/pi.2017.14.1.30
- Mausbach, B., Chattillion, E., Ho, J., Flynn, L., Tiznado, D., von Känel, R., Patterson, T. and Grant, I. (2014). Why does placement of persons with Alzheimer's disease into long-term care improve caregivers' well-being? Examination of psychological mediators. *Psychology and Aging*, 29(4), 776-786.
- National Public Radio. (2010). India: No Country for Old People? Retrieved from https://www.npr.org/templates/story/story.php?storyId=128196971&t=1553249977 423
- Pinquart, M. (2003). Loneliness in married, widowed, divorced, and never-married older adults. *Journal of Social and Personal Relationships*, 20(1), 31-53.
- Pinquart, M. and Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250-267.
- Richter, P., Werner, J., Heerlein, A., Kraus, A., & Sauer, H. (1998). On the Validity of the Beck Depression Inventory. *Psychopathology*, *31*(3), 160-168.
- Roberti, J., Harrington, L., & Storch, E. (2006). Further Psychometric Support for the 10-Item Version of the Perceived Stress Scale. *Journal of College Counselling*, 9(2), 135-147.
- Russell, D., Peplau, L., & Ferguson, M. (1978). Developing a Measure of Loneliness. *Journal of Personality Assessment*, 42(3), 290-29
- Russell, D. (1996). UCLA Loneliness Scale (Version 3): Reliability, Validity, and Factor Structure. *Journal of Personality Assessment*, 66(1), 20-40.
- Thomeer, M., Umberson, D., & Pudrovska, T. (2013). Marital Processes around Depression. *Society and Mental Health*, *3*(3), 151-169.
- Wallsten, S. and Snyder, S. (1990). A comparison of elderly family caregivers' and noncaregivers' perceptions of stress in daily experiences. *Journal of Community Psychology*, 18(3), 228-238.

- Wang, G., Hu, M., Xiao, S., & Zhou, L. (2017). Loneliness and depression among rural empty-nest elderly adults in Liuyang, China: a cross-sectional study. *BMJ Open*, 7(10), e016091.
- World Health Organisation. (2017). A report about Mental Health for Older Adults. Retrieved from https://www.who.int/news-room/fact-sheets/detail/mental-health-of-older-adults.

Appendix

(i) Perceived Stress Scale
0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often
1. In the last month, how often have you been upset because of
something that happened unexpectedly?
\circ 0
0 1
0 2
o 3 o 4
2. In the last month, how often have you felt that you were unable to
control the important things in your life?
\circ 0
0 1
23
o 3 o 4
3. In the last month, how often have you felt nervous and "stressed"?
\circ 0
0 1
0 2
34
4. In the last month, how often have you felt confident about your
ability to handle your personal problems?
0 0
0 1
0 2
34
0 4
5. In the last month, how often have you felt that things were going
your way?
\circ 0
0 1
o 2 o 3
0 4

0	1	
0	2	
0	3	
0	4	
-		
7. In the	last month, how often have you been able to control irritations	
in your	life?	
0	0	
0	1	
0	2	
0	3	
0	4	
8. In the	last month, how often have you felt that you were on top of	
things?		
0	0	
0	1	
0	2	
0	3	
0	4	
9. In the	last month, how often have you been angered because of	
things tl	nat were outside of your control?	
0	0	
0	1	
0	2	
0	3	
0	4	
10. In th	ne last month, how often have you felt difficulties were piling up	
so mgn	that you could not overcome them?	
0	0	
0	1	
0	2	
0	3	
0	4	

6. In the last month, how often have you found that you could not cope

with all the things that you had to do?

(ii) UCLA Loneliness Scale

This scale is used to measure an individual's loneliness levels. Please choose an option under each which is most applicable to you.	statement	
1. I am unhappy doing so many things alone		
o Often		
o Sometimes		
o Rarely		
o Never		
2. I have nobody to talk to		

- - o Often
 - o Sometimes
 - o Rarely
 - o Never
- 3. I cannot tolerate being so alone
 - o Often
 - o Sometimes
 - o Rarely
 - o Never
- 4. I lack companionship
 - o Often
 - Sometimes 0
 - o Rarely
 - o Never
- 5. I feel as if nobody really understands me
 - o Often
 - Sometimes
 - o Rarely
 - o Never
- 6. I find myself waiting for people to call or write
 - o Often
 - o Sometimes
 - o Rarely
 - o Never
- 7. There is no one I can turn to
 - o Often
 - o Sometimes
 - o Rarely
 - o Never

	STRESS, LONELINESS AND DEPRESSION LEVELS AMOUNG SPOUSAL CAREGIVERS AND MARRIED NON-CAREGIVERS
8. I am	no longer close to anyone
0	Often
0	Sometimes
0	Rarely
0	Never
9. My is	often Sometimes Rarely Never

10. I feel left out

- o Often
- o Sometimes
- o Rarely
- o Never

11. I feel completely alone

- o Often
- Sometimes
- o Rarely
- o Never

12. I am unable to reach out and communicate with those around me

- o Often
- o Sometimes
- o Rarely
- o Never

13. My social relationships are superficial

- o Often
- o Sometimes
- o Rarely
- o Never

14. I feel starved for company

- o Often
- o Sometimes
- o Rarely
- o Never

15. No one really knows me well		
o Often		
SometimesRarely		
o Never		
(iii) Beck's Depression Inventory		
1.		
0 I do not feel sad.		
1 I feel sad		
2 I am sad all the time and I can't snap out of it.		
3 I am so sad and unhappy that I can't stand it.		
2.		
0 I am not particularly discouraged about the future.		
1 I feel discouraged about the future.		
2 I feel I have nothing to look forward to.		
3 I feel the future is hopeless and that things cannot improve		
3.		
0 I do not feel like a failure.		
1 I feel I have failed more than the average person.		
2 As I look back on my life, all I can see is a lot of failures.		
3 I feel I am a complete failure as a person.		
4.		
0 I get as much satisfaction out of things as I used to.		
1 I don't enjoy things the way I used to.		
2 I don't get real satisfaction out of anything anymore.		
3 I am dissatisfied or bored with everything.		
5.		
0 I don't feel particularly guilty		
1 I feel guilty a good part of the time.		
2 I feel quite guilty most of the time.		
3 I feel guilty all of the time.		

6.
0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.
7.
0 I don't feel disappointed in myself.
1 I am disappointed in myself.
2 I am disgusted with myself.
3 I hate myself.
8.
0 I don't feel I am any worse than anybody else.
1 I am critical of myself for my weaknesses or mistakes.
2 I blame myself all the time for my faults.
3 I blame myself for everything bad that happens.
9.
0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.
10.
0 I don't cry any more than usual.
1 I cry more now than I used to.
2 I cry all the time now.
3 I used to be able to cry, but now I can't cry even though I want to.
11.
0 I am no more irritated by things than I ever was.
1 I am slightly more irritated now than usual.
2 I am quite annoyed or irritated a good deal of the time.
3 I feel irritated all the time.

12.
0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people.
13.
0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions more than I used to.
3 I can't make decisions at all anymore.
14.
0 I don't feel that I look any worse than I used to.
1 I am worried that I am looking old or unattractive.
2 I feel there are permanent changes in my appearance that make me look
unattractive
3 I believe that I look ugly.
15.
0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.
16.
0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
$2\ \mathrm{I}$ wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
$3\ I$ wake up several hours earlier than I used to and cannot get back to sleep.
17.
0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.

3 I am too tired to do anything.



- 0 My appetite is no worse than usual.
- 1 My appetite is not as good as it used to be.
- 2 My appetite is much worse now.
- 3 I have no appetite at all anymore.

19.

- 0 I haven't lost much weight, if any, lately.
- 1 I have lost more than five pounds.
- 2 I have lost more than ten pounds.
- 3 I have lost more than fifteen pounds.

20.

- 0 I am no more worried about my health than usual.
- 1 I am worried about physical problems like aches, pains, upset stomach, or constipation.
- 2 I am very worried about physical problems and it's hard to think of much else.
- 3 I am so worried about my physical problems that I cannot think of anything else.

21.

- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I have almost no interest in sex.
- 3 I have lost interest in sex completely.

(iv) Published Survey

Stress, Loneliness and Depression among spousal caregivers for persons with dementia versus non-caregivers.

For my thesis I am investigating the Stress, Loneliness and Depression levels of those who are the primary caregiver for their spouse suffering from dementia and among those who are married but do not care for a spouse suffering from dementia.

Information Sheet

My name is Sascha Ryan and I am a Psychology student. I am in my final year and I am conducting this piece of research as part of my final year project. I have decided to conduct my thesis on Stress, Loneliness and Depression levels among spousal caregivers and non-caregivers. My research project will be supervised by Dr. Andrew Allen. The purpose of this study is to examine if stress, loneliness and depression levels differ among people caring for their spouses with dementia and those who do not. In order to meet the criteria for participation, participants must be married and aged between 30 and 80 years old.

Please do not provide any personal information.

I have read the above and I wish to proceed

o Yes

Debriefing Sheet

Dear Participant,

I would like to thank you for your participation in the current study. To carry out participation in this study please follow the following instructions and be aware that you can withdraw from this study at any time without penalty. Your anonymity is of upmost importance and the data collected will remain anonymous throughout the duration of the conduction of the current study. Please fill out three questionnaires by choosing one answer or statement which best describes how you feel. The three questionnaires which must be completed are The Perceived Stress Scale and The UCLA Loneliness Scale and Beck's Depression Inventory.

The Perceived Stress Scale is a 10 item Likert scale which ranges from 0-4. 0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often. Beside each of the ten statements please choose the number in which represents how the statement relates to you. For example, in part 5 it is asked 'In the last month, how often have you felt that things were going your way?' If you feel things have never gone your way in the past month, choose 0. The version of the UCLA Loneliness Scale is a 15-item scale which gives you answer options of Often, Sometimes, Rarely and Never. Please choose an answer which best describes how the statement given relates to you. Becks Inventory Scale is a 21-item scale which requires you to choose from four different statements in each sector. Please choose the statement which relates to you best.

Helplines are available for support for those caring for individuals suffering for dementia. In particular, there is a helpline for family carers. Freephone 1800 24 07 24.

If you have any questions regarding the study or regarding data which you have submitted please do not hesitate to contact me via email at x16499942@student.ncirl.ie or contact my supervisor via email at Andrew.Allen@ncirl.ie

Consent Form

It is important that you understand the potential risks involved with participating in this study. It is possible that you may become upset or distressed while answering the three questionnaires based on personal topics used in this study. If you become distressed and/or upset during or after participation in the current study, there are helplines in which you can contact for help and guidance located in the debriefing form. This study is completely voluntary, and you can withdraw from the study at any time with no penalty if you wish to do so. The data obtained from this study will remain completely anonymous and you will not be identified at any stage during this study. Your privacy and confidentiality are of upmost importance to the researcher. Your data will be stored safely. Each participant's data collected will be used to investigate the hypothesis of this study and may be published a second time if it is accepted by the Psychology Society of Ireland's congress when put forward. If you have any further questions about this study, please do not hesitate to contact me via email at x16499942@student.ncirl.ie.

I have been thoroughly informed about this study and I am aware of my role as a participant. I am aware that I can withdraw from this study at any time without penalty.

Please state your age

Please state your gender

- Male
- Female

Are you married?

Yes

If yes, are you a carer for your spouse suffering from dementia?
 Yes, I care for my spouse suffering with Dementia No, I do not care for my spouse as they do not suffer from dementia
Perceived Stress Scale
0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often
1. In the last month, how often have you been upset because of
something that happened unexpectedly?
 0 1 2 3 4
2. In the last month, how often have you felt that you were unable to
control the important things in your life?
 0 1 2 3 4
3. In the last month, how often have you felt nervous and "stressed"?
 0 1 2 3
44. In the last month, how often have you felt confident about your ability to handle your personal problems?
 0 1 2 3 4

Does your spouse suffer from dementia?

YesNo

5. In the last month, how often have you felt that things were going
your way?
 0 1 2 3 4
6. In the last month, how often have you found that you could not cope
with all the things that you had to do?
 0 0 1 2 3 4
7. In the last month, how often have you been able to control irritations in your life?
o 0 o 1
0 2
o 3 o 4
8. In the last month, how often have you felt that you were on top of
things?
\circ 0
0 1
o 2 o 3
0 4
9. In the last month, how often have you been angered because of
things that were outside of your control?
 0 1 2 3 4

STRESS, LONELINESS AND DEPRESSION LEVELS AMOUNG SPOUSAL CAREGIVERS AND MARRIED NON-CAREGIVERS		
10. In the last month, how often have you felt difficulties were piling up		
so high that you could not overcome them?		
\circ 0		
0 1		
\circ 2		
0 3		
0 4		
(ii) UCLA Loneliness Scale		
This scale is used to measure an individual's loneliness levels. Please choose an option under each statement		

This scale is used to measure an individual's loneliness levels. Please choose an option under each statement which is most applicable to you.

- 1. I am unhappy doing so many things alone
 - o Often
 - o Sometimes
 - o Rarely
 - o Never
- 2. I have nobody to talk to
 - o Often
 - o Sometimes
 - Rarely
 - o Never
 - 3. I cannot tolerate being so alone
 - o Often
 - o Sometimes
 - o Rarely
 - o Never
- 4. I lack companionship
 - o Often
 - o Sometimes
 - o Rarely
 - o Never
- 5. I feel as if nobody really understands me
 - o Often
 - o Sometimes
 - o Rarely
 - o Never
- 6. I find myself waiting for people to call or write
 - o Often
 - o Sometimes
 - o Rarely
 - o Never

	STRESS, LONELINESS AND DEPRESSION LEVELS AMOUNG SPOUSAL CAREGIVERS AND MARRIED NON-CAREGIVERS	50
7. There is no one I can turn to		
0 0 0	Often Sometimes Rarely Never	
8. I am no longer close to anyone		
0	Often	
0	Sometimes	
0	Rarely	
0	Never	

9. My interests and ideas are not shared by those around me

12. I am unable to reach out and communicate with those around me

OftenSometimesRarelyNever

10. I feel left out

OftenSometimesRarelyNever

OftenSometimesRarelyNever

OftenSometimesRarelyNever

OftenSometimesRarelyNever

OftenSometimesRarelyNever

14. I feel starved for company

13. My social relationships are superficial

11. I feel completely alone

- 15. No one really knows me well
 - Often
 - o Sometimes
 - o Rarely
 - o Never

Beck's Depression Inventory

This section measures one's depression levels. Please choose an option most suited to you.

1.

- o I do not feel sad.
- o I feel sad
- o I am sad all the time and I can't snap out of it.
- o I am so sad and unhappy that I can't stand it.

2.

- o I am not particularly discouraged about the future.
- o I feel discouraged about the future.
- o I feel I have nothing to look forward to.
- o I feel the future is hopeless and that things cannot improve.

3.

- o I do not feel like a failure.
- o I feel I have failed more than the average person.
- o As I look back on my life, all I can see is a lot of failures.
- o I feel I am a complete failure as a person.

4.

- o I get as much satisfaction out of things as I used to.
- o I don't enjoy things the way I used to.
- o I don't get real satisfaction out of anything anymore.
- o I am dissatisfied or bored with everything.

5.

- o I don't feel particularly guilty
- o I feel guilty a good part of the time.
- o I feel quite guilty most of the time.
- o I feel guilty all of the time.

6.

- o I don't feel I am being punished.
- o I feel I may be punished.
- o I expect to be punished.
- o I feel I am being punished.

7.

- o I don't feel disappointed in myself.
- o I am disappointed in myself.
- o I am disgusted with myself.
- o I hate myself.

8.

- o I don't feel I am any worse than anybody else.
- o I am critical of myself for my weaknesses or mistakes.
- o I blame myself all the time for my faults.
- o I blame myself for everything bad that happens.

9.

- o I don't have any thoughts of killing myself.
- o I have thoughts of killing myself, but I would not carry them out.
- o I would like to kill myself.
- o I would kill myself if I had the chance.

10.

- o I don't cry any more than usual.
- o I cry more now than I used to.
- o I cry all the time now.
- o I used to be able to cry, but now I can't cry even though I want to.

11.

- o I am no more irritated by things than I ever was.
- o I am slightly more irritated now than usual.
- o I am quite annoyed or irritated a good deal of the time.
- o I feel irritated all the time.

12.

- o I have not lost interest in other people.
- o I am less interested in other people than I used to be.
- o I have lost most of my interest in other people.
- o I have lost all of my interest in other people.

13.

- o I make decisions about as well as I ever could.
- o I put off making decisions more than I used to.
- o I have greater difficulty in making decisions more than I used to.
- o I can't make decisions at all anymore.

14.

- o I don't feel that I look any worse than I used to.
- o I am worried that I am looking old or unattractive.
- o I feel there are permanent changes in my appearance that make me look
- o unattractive
- I believe that I look ugly.

15.

- o I can work about as well as before.
- o It takes an extra effort to get started at doing something.
- I have to push myself very hard to do anything.
- o I can't do any work at all.

16.

- o I can sleep as well as usual.
- o I don't sleep as well as I used to.
- o I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
- o I wake up several hours earlier than I used to and cannot get back to sleep.

17.

- o I don't get more tired than usual.
- o I get tired more easily than I used to.
- o I get tired from doing almost anything.
- o I am too tired to do anything.

18.

- o My appetite is no worse than usual.
- o My appetite is not as good as it used to be.
- o My appetite is much worse now.
- I have no appetite at all anymore.

19.

- o I haven't lost much weight, if any, lately.
- o I have lost more than five pounds.
- o I have lost more than ten pounds.
- o I have lost more than fifteen pounds.

20.

- o I am no more worried about my health than usual.
- I am worried about physical problems like aches, pains, upset stomach, or constipation.
- o I am very worried about physical problems and it's hard to think of much else.
- I am so worried about my physical problems that I cannot think of anything else.

21.

- o I have not noticed any recent change in my interest in sex.
- o I am less interested in sex than I used to be.
- o I have almost no interest in sex.
- o I have lost interest in sex completely.

Thank you for your participation

Thank you for your participation. If you have any queries, please contact me via email at x16499942@student.ncirl.ie or my supervisor via email at Andrew.Allen@ncirl.ie. For help and guidance for dementia caregiving please Freephone 1800 240724

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