

Effects of caring for individuals with Alzheimer's disease on formal and  
informal caregivers' mental health



**TRINITY COLLEGE DUBLIN**  
COLÁISTE NA TRÍONÓIDE, BAILE ÁTHA CLIATH

THE  
UNIVERSITY  
OF DUBLIN

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Dissertation presented in part fulfilment for the

M.Sc. in Applied Psychology

School of Psychology, Trinity College Dublin

August 2015

## Declaration

I hereby certify that this dissertation is entirely my own work and has not been submitted as an exercise for a degree at any other University. I agree that the library may lend or copy the dissertation on request.

Signed:

A handwritten signature in black ink, appearing to read 'Gareth Duffy', written over a light blue rectangular background.

Date: 1/8/2015

Gareth James Duffy

## **Acknowledgements**

Firstly, I would like to thank Dr. Tim Trimble for his supervision and to the Trinity psychology department for their support. I would also like to thank the Alzheimer Society of Ireland for their genuine enthusiasm and support in this project, and for granting me access to caregiver staff and family caregivers. I would like to give a special thank you to all of the caregivers who took part in the study for their cooperation and time, without which this dissertation would not have been possible. Finally, I would like to thank my girlfriend Elena who has been my biggest support throughout.

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## **Abbreviations**

The abbreviations below are listed in order of appearance. Their meaning is explained the first time they appear in the dissertation and are abbreviated thereafter:

AD = Alzheimer's disease

QoL = Quality of life

EE = Expressed emotion

WEMWBS = Warwick Edinburgh Mental Well-Being Scale

ASI = Alzheimer Society of Ireland

CBI = Caregiver Burden Interview

AC-QoL = Adult Carer Quality of Life questionnaire

PSS = Perceived Stress Scale

MHI = Mental Health Inventory



## **Abstract**

**Objective:** Empirical evidence suggests that caring for individuals with Alzheimer's disease can have a direct negative impact on caregiver well-being. The present study investigated the impact of caring for individuals with Alzheimer's disease on both formal (day-care) and informal (family) caregivers' mental health.

**Method:** Sixty-two caregivers ( $N = 62$ ) comprising twenty-eight formal caregivers ( $N = 28$ ) and thirty-four informal caregivers ( $N = 34$ ) were recruited via the Alzheimer Society of Ireland and compared on levels of caregiver burden, quality of life, stress, and mental health. Caregiver type, gender, caregiver burden, quality of life, and stress were examined via an enter method for hierarchical regression to predict mental health among caregivers.

**Results:** A number of t-tests revealed significant differences between formal and informal caregivers on levels of caregiver burden, quality of life, stress and mental health. A significant hypothesized prediction model of Alzheimer's disease caregiver mental health emerged containing; type of caregiver, gender, caregiver burden, quality of life, and stress, which explained 69% of the variance ( $R^2 = .69$ ,  $F(5, 56) = 24.81$ ,  $p = <.001$ ). A large number of significant exploratory differences and correlations were also found.

**Discussion:** Findings supported the hypothesis that caring for individuals with Alzheimer's disease has a direct negative impact on caregiver mental health. Implications of these findings and the regression model strength were discussed. Limitations of the study were also acknowledged.

**Keywords:** • Alzheimer's disease • Caregivers • Quality of life • Mental health

## **Word count**

Abstract: 227

Introduction: 3185

Method: 881

Results: 1139

Discussion: 3380

References: 1,187

Total: 9,999

## 1. Introduction

### *1.1 Alzheimer's disease*

Alzheimer's disease (AD) is a neurodegenerative disease involving loss or decline in memory, and deficits of cognitive and physical abilities progressively over time. It is the most prevalent dementing disorder, accounting for approximately 60-80% of all dementia diagnoses (Shim, Landerman & Davis, 2011). AD is more than the loss of memory, and constitutes a progressive deterioration in *all* areas of mental ability and function, accompanied by prominent changes in behaviour and personality. As AD progresses, patients change from being healthy, autonomous individuals to becoming completely dependent on others, both physically and mentally (Georges, Jansen, & Meyrieux *et al*, 2008).

AD is pathologically defined by the presence of amyloid (A $\beta$ ) aggregations (plaques) and Tau pathology (neurofibrillary tangles). Common characteristics include problems with memory, thinking, orientation, comprehension, learning capacity, judgment, language, and personality changes (Howcroft, 2004). Cognitive impairments include amnesia, aphasia, apraxia and an array of agnosias. Non-cognitive factors include depression, psychotic symptoms, and behavioural disturbances. AD is further associated with behavioural and mood symptoms including aggression, agitation, anxiety, irritability and wandering (Miller, Rosenheck & Schneider *et al*, 2011).

Research avenues exploring possible causes of AD include the roles of neurotransmitters, brain trauma, infections, genetic factors, and immune responses (Alzheimer Society of Ireland, 2011). One intriguing possible cause of AD has been proposed by Buckner, Snyder and Shannon *et al* (2005), who explored early life risk factors of AD

based on studying default mode network activity in young adults. These researchers questioned how metabolic disruption relates to structural atrophy and underlying neuropathology, and demonstrated a remarkable correlation between default mode network activity patterns in cortical regions, and the topography of amyloid deposits, atrophy and hypo-metabolism in AD patients (Buckner *et al*, 2005). Essentially, plaques seem to develop in the very regions of the brain that are active when healthy people are musing, daydreaming, and letting their minds wander (default mode activity). This suggests that AD could in fact be the result of high metabolic activity over the course of a lifetime, in a sense, the everyday wear and tear caused by day-dreaming and mind-wandering (Schacter *et al*, 2012).

AD is an escalating world health issue, and was the 6th ranked cause of death in the US in 2014. The disease will reach endemic proportions unless new interventions are developed. The worldwide prevalence of AD was estimated at 44 million people in 2015 (Alzheimer's Association, 2015), and is believed to reach 81 million by 2040, and 115 million by 2050. (Gallagher, Mhaolain, & Crosby *et al*, 2011; Levy, Lactot, & Farber *et al*, 2012).

## ***1.2 AD Caregiver burden***

Most patients worldwide with AD are cared for at home by unpaid informal caregivers, i.e. family members, friends or neighbours. Caregivers and individuals with AD believe they are best served provided they can remain at home to function in familiar settings and follow a daily routine. Nevertheless at home, caregivers often experience unfavourable social, financial, psychological and physical caregiving outcomes (Shim *et al*, 2011). The progression of AD manifests in various ways and places exceptional demands on caregivers, and as the patients' functioning deteriorates the pressure on caregivers increases (Tarrier *et*

*al*, 2002). Many caregivers are elderly themselves and their ability to cope may be limited by issues such as their own personal health concerns (Georges *et al*, 2008). The well-being of a person with AD also depends directly on the well-being of the caregiver (Alzheimer Society of Ireland, 2011).

Informal AD caregiving is often referred to as “the unexpected career”, because what begins as part-time assistance can become an all-encompassing role (Mannion, 2008). The role can be detrimental to the caregiver’s physical and mental health, largely because it is chronically stressful and associated with negative health outcomes. For example, Vitaliano, Zhang and Scanlan (2003), conducted a meta-analysis of 23 studies and found that AD caregivers encounter 5 to 15 years of repeated exposure to psychosocial and physical demands from their role. Indeed, AD caregivers are at high risk of developing psychological illnesses, which is directly attributed to the burden of caring (Papastavrau, *et al*, 2011). Most caregivers view their role as a duty, initially adopting it due to their affection for and commitment to the AD patient. Nevertheless, some find the role difficult to accept help from anyone else or allow them into the situation (Rosness *et al*, 2008). The impact on caregiver’s lives is enormous, yet is generally overlooked by health services and policy makers who give little recognition to the vast amount of expenditure they save by care being provided free by family and friends (Georges *et al*, 2008).

One study conducted through Alzheimer Europe’s member organizations in France, Germany, Poland, Spain and the UK, found that time spent caring increases with disease severity, and 50% of caregivers spend more than 10 hours a day caring (Georges *et al*, 2008). As AD progresses, patients depend increasingly on caregivers for aid with instrumental activities of daily living such as managing appointments, and basic activities of daily living such as bathing and feeding. Ninety percent of patients’ exhibit neuropsychiatric symptomology including depression, aggression, apathy, and inappropriate sexual

behaviours, and the presence and severity of these symptoms are significantly and positively associated with higher levels of caregiver burden (Garcia-Alberca, & Lara *et al*, 2014). For example, Lee *et al* (2012), studied 866 AD patients and caregivers and found that severity of neuropsychiatric symptoms was the strongest predictor of burden.

Burden is about the practical demands of the situation and is linked directly to the emotional response of the caregiver regarding the circumstances he or she is facing. Burden can invoke feelings of anger, frustration, resentment, and embarrassment, feelings that caregivers may not wish to acknowledge. Caregivers seldom avail of breaks, and family and friends often stop visiting due to their own implicit prejudices. Burden can lead to increased blood pressure, compromised immune systems, habitual sleep disturbances, caregivers neglecting their own healthcare, and higher stress levels. In fact, caregiver stress and burden are directly correlated with lack of social support and the behavioural problems of the AD patient, and not the functional or cognitive problems or the degree of their disease. Burden is further exacerbated by the premorbid relationship prior to the onset of the disease. Cross-cultural studies also report higher levels of burden among AD caregivers compared with other chronic diseases (Howcroft, 2004).

Behaviours most criticized by caregivers are not those considered to be the most arduous to tolerate such as sleep disturbances or incontinence, but rather behaviours like speech incoherence, messiness, and displays of aggression. Caregivers often criticize these types of behaviours because they perceive them to be more controllable by the patient. Indeed, studies support the view that criticism and hostility reflects the caregiver's beliefs that patients possess the potential to control aspects of their condition and subsequent behaviour (Tarrier *et al*, 2002). Behavioural problems that can invoke burden include, aggression, screaming, depression, wandering, resistance to help, hallucinations, delusions, suspiciousness, and night disturbances. Caregivers often feel that their loved one is

deliberately behaving this way to antagonize them, and the behaviour is further compounded because the individual with AD has trouble articulating their feelings. Caregivers can also trigger these behaviours by asking too much of the person's capabilities (Howcroft, 2004).

### ***1.3 AD caregiver stress and quality of life***

Caring for individuals with AD is associated with high stress, which often results in elevated symptoms of depression and poorer well-being (Mausbach, Flynn, Von-Kanel *et al*, 2014). The stress of AD caregiving is an ongoing process, and while care factors have historically been implicated as the source of caregiver stress, it is now recognised that caregiver's own characteristics also play a large role in the caregiving experience (Campbell, 2009). Lee *et al* (2012) have found that dementia diagnostic subtype, the presence of cognitive fluctuations, and some neuropsychiatric symptoms (psychosis and mood disturbance) predicted caregiver stress. Stress is also correlated with the duration of caring role, amount of weekly hours provided, and severity of cognitive impairment. Behavioural problems such as agitation, wandering, and patient depression are rated as most stressful because they manifest unpredictably and demand continuous monitoring (Mannion, 2008).

Chii-Jun (2005) conducted a cross-sectional study of 388 family caregivers and found that compared to males, females more frequently conveyed a poverty of well-being, diminished psychosocial health and overall self-rated health. Women usually report more health problems than men and experience more stress despite having more social activities and social contacts. Indeed, caregivers who have a decent social network enjoy better self-rated health than those who don't. Men who are exposed to lab-stress typically show higher and more consistent increases in stress hormones neurotransmitter metabolites and blood

pressure than women. This is further augmented when adopting a stressful role like caregiving which is conflicting with men's conventional gender roles (Mannion, 2008).

Spousal caregivers report burden due to low levels of communication, poor rapport, and feeling isolated in their relationship, which often cumulates in a poor quality of life (QoL). Comorbidity in patients, lack of independence, and patients not receiving respite periods also diminish caregiver QoL (Rosness *et al*, 2011). Caregivers also face the piecemeal deterioration of the personality of their loved one, and the inevitably tragic "loss of self" (Mannion, 2008). Indeed, Bartfay and Bartfay (2013) report that the effective loss of companionship and support of their life partner, social isolation, financial challenges and social decision making directly affect caregiver QoL.

Shim *et al* (2011) report that high levels of *mutuality* (the perception that the quality of the care relationship is positive) can ameliorate negative outcomes. Mutuality is concerned with the level of caring, affection, intimacy, mutual concern and relationship gratification experienced by those involved. Mutuality ameliorates caregiver stress and motivates family members to continue providing home care. Amidst the presence of cognitive decline, mutuality is the ability of the caregiver to gain satisfaction from the relationship by means of perceiving the family member with AD as reciprocating by merit of the caregiver's existence. High levels of pre-dementia mutuality are significantly correlated with less stress, and factors reported to affect mutuality are the care recipient's level of cognitive and physical capabilities. Cognitive impairment has a notable negative impact on mutuality, arguably due to the loss of shared interactions and memories, alterations in personality, and problems such as delusional ideation, paranoia, hallucinations, aggressiveness, and wandering (Shim *et al*, 2011).



*Expressed emotion* (EE) is an important aspect of mutuality. EE is a qualitative measure of the amount of emotion displayed in the family environment based on how relatives spontaneously talk about the AD patient. Caregivers with high levels of EE are often depressed in mood, which will signal mutuality distress. Via examination of causal attribution beliefs expressed spontaneously about patients, it has been revealed that caregivers who show marked criticism and hostility make more attributions to internal, personal and controllable factors of the patient than do caregivers with low EE. High EE in caregivers is significantly correlated with the subjective burden of care measured by distress and strain. The belief that a patients' behaviour is under volitional control is correlated with caregivers being overly-critical, hostile and rejecting. Conversely, the belief that their behaviour is the outcome of external factors is associated with over-involvement (over-protective, intrusive, self-sacrificing) and a belief that whatever the caregiver does will directly influence that patient's behaviour. Causal attribution beliefs pertaining to internal attributions to caregivers themselves (e.g. self-blaming), are also correlated with distress in caregivers. (Tarrier *et al*, 2002).

#### ***1.4 AD caregiver mental health***

The importance of understanding and assessing the well-being of AD caregivers is highlighted by the fact that caring for a relative with dementia is correlated with a higher risk of developing depression. AD caregivers typically experience significantly higher levels of mortality, psychological morbidity, depression and stress than non-caregivers (Shim *et al*, 2011; Posner, Sutter & Perrin *et al*, 2015). Approximately one quarter of family caregivers meet diagnostic criteria for clinically significant anxiety and depression. As a result, the

prevention of psychological distress and the promotion of emotional and social well-being for caregivers is now a worldwide priority (Orgeta *et al*, 2013).

Mental well-being, currently conceptualized as more than the mere absence of mental illness, appears protective for an array of outcomes such as self-rated physical health, stress, and immunity responses. Most mental well-being scales measure aspects of both mental health and mental illness. Orgeta *et al* (2013) employed the Warwick Edinburgh Mental Well-Being Scale (WEMWBS) to identify predictors of mental health in 198 family caregivers of people with dementia. WEMWBS scores showed a negative correlation with anxiety and depression scores, and a positive correlation with physical health status. Regression analyses indicated that almost 70% of the variance was explained by caregiver age, physical health, caregiver stress, and social support. Mental well-being was also higher in male caregivers compared to females (Orgeta *et al*, 2013).

Hayslip, Han, and Anderson (2008), examined predictors of depressed mood among active AD caregivers (those already caring for a relative with AD) and not-as-yet caregivers (caring for an elderly relative who does-not-yet suffer from AD). They found that personality (extraversion) and anxiety about their own coping were the major predictors of depression for active caregivers, whereas perceived lack of social support was the major predictor for not-as-yet caregivers. Rosness *et al* (2011) found that being married is significantly correlated with caregiver depression. Moreover, trait neuroticism has been found to predict response to caregiving demands, caregiver burden and depression (Gallagher *et al*, 2011).

Caregiver burden is often associated with clinically significant anxiety (10% - 35%) and depression (10% - 34%) (Iavarone, Ziello & Pastore *et al*, 2014), and caregiver anxiety and depression have been linked to greater cognitive impairment in the individual with AD (Aguglia, Onor & Trevisiol, *et al*, 2004). Rosness *et al* (2011) found that 32% of caregivers

were characterized as having depression, and these depressive symptoms correlated with patient's behaviour, cognitive, and functional disabilities. A poor prior relationship was predictive of greater caregiver burden and depression and caring for patients younger than 65, and devoting more hours to caring were independent predictors of caregiver depression. The subsequent removal of the AD patient does not appear to improve caregiver well-being, and the psychological outcomes from long-term caring often remain even upon death of the patient (Mannion, 2008).

The strain of witnessing and adapting to the family member's cognitive, behavioural and personality changes are challenging and over-tax personal resources (Au, Lai, & Lau *et al*, 2009). Research suggests that there are 2 major domains affecting burden and depression in informal caregivers: Care demands posed by the recipients' illness, and functional limitations and the adequacy (or lack thereof) of resources available to the caregiver. Regarding resources, the role of formal and informal support, as well as that of self-efficacy have been well documented. Au et al (2009) have found that self-efficacy acts as a mediator between social support and depressive symptoms among informal caregivers.

### ***1.5 Coping as an AD caregiver***

Success or failure to cope as an AD caregiver is directly linked with levels of self-efficacy. Gallagher *et al* (2011) tested the role of self-efficacy as a mediator between certain patient characteristics and symptoms of burden and depression amongst AD caregivers. Results showed that 33% of caregivers reported significant depressive symptoms, and self-efficacy for symptom management, community support and ability to pay revealed significant negative correlations with symptoms of caregiver burden and depression. Self-efficacy for symptom management also independently predicted depressive symptoms and caregiver

burden. These findings indicate that self-efficacy for AD-related tasks has an important role to play alongside other predictors of burden and depression (Gallagher *et al*, 2011).

Individual variations in coping strategies explain differences in mental health outcomes. A study of 315 AD caregivers revealed that adaptive, emotion-focused coping (acceptance, emotional support, humour, positive reframing) is the strategy of choice, and independently predicts caregiver depression. Emotion-focused coping is significantly correlated with having a wider social network, and network size shared significant correlations with caregiver depression (Mannion, 2008).

The employment of positive coping strategies of reappraisal and problem-solving correlates significantly and negatively with caregiver burden. This implies that caregivers who are more certain in their ability to acquire solutions to behavioural problems are more likely to effectively handle troublesome symptoms of AD and alleviate the negative effects associated with caring. Papastavrau *et al* (2011) have confirmed this by showing that it is primarily low-burden caregivers who adopt active coping styles. Positive coping approaches are negatively correlated with caregiver well-being, whereas emotion-based strategies like avoidance and denial correlate positively with depressive symptoms. “Wishful-thinking” strategies are strong predictors of lower caregiver well-being because it is considered a passive coping style and is associated with fewer years of survival for AD patients because caregivers who employ this strategy are less available, deliver less person-centred care, and inevitably play a part in the decline of the patient’s health (Papastavrau *et al*, 2011).

Unfortunately, nearly all existing coping strategies are directed toward slowing down the progression towards institutionalization of the patient and the needs of patient, while completely ignoring the needs of the caregiver. Papastavrau *et al* (2011) contend that since AD caregivers are more prone to develop burden and depression, AD should not be

considered exclusively as a health problem, but as a *social* problem due to the significant ripple effect it creates (Mannion, 2008).

### ***1.6 Rationale for the present study***

Unlike other countries, Ireland has no Community Care Act. This means that there exists no legislative provision underpinning social service delivery and no statutory rights for individuals with dementia or their families to access government funded community services. In the absence of statutory services, Ireland has had a long history of specialist services developing under the auspices of religious or other voluntary organizations. One such voluntary body is The Alzheimer Society of Ireland (ASI).

The ASI is Ireland's leading dementia-care organization, providing dementia-specific services such as in-home support, day-care, and a counselling helpline. Day-care centres have emerged in response to social needs. Day-care service is vital because it affords family members respite from caregiving, which can otherwise extend around the clock and adversely affect physical and psychological health.

There exists a paucity of research pertaining to the circumstances of AD day-care in Ireland. Caregiver's opinions are crucially important, yet research on their perceptions of the merits and demands of the services they provide is virtually non-existent. Examining the mental well-being of formal caregivers is important because the challenges they encounter are often formidable. Furthermore, their insights as front-line workers are extremely valuable for planning future care programmes and nurturing morale and well-being among care staff (Cahill *et al*, 2003). Thus, examining the mental health of informal *and* formal AD caregivers is the primary focus of this study.

### ***1.7 Proposed hypotheses***

- Hypothesis 1: It is hypothesized that informal caregivers will report significantly high levels of caregiver burden.
- Hypothesis 2: It is hypothesized that informal caregivers will have a significantly low level of QoL.
- Hypothesis 3: It is hypothesized that informal caregivers will report significantly high levels of stress.
- Hypothesis 4: It is hypothesized that informal caregivers will have significantly low levels of mental health.
- Hypothesis 5: It is hypothesized that caregiver burden, QoL and stress will significantly predict mental health levels among AD caregivers.

## **1. Method**

### ***2.1 Participants***

Participants were recruited with approval from the ASI. Participants were eligible if they worked as an AD caregiver or were a family caregiver of an individual with AD who attended an ASI day-care centre. Participants were required to be aged 18 years or over and not suffering from a severe psychiatric disorder. The exclusion criteria were; being under 18 years, having a severe intellectual or learning disability, or posing a risk of not understanding the research and consent process.

Sixty-two ( $N = 62$ ) caregivers took part in the study. Twenty-eight ( $N = 28$ ) were formal (day-care) caregivers (45%), and thirty-four ( $N = 34$ ) were informal (family) caregivers (55%). Twenty-six ( $N = 26$ ) were male (42%), and thirty-six ( $N = 36$ ) were female (58%), with an age range of 19 to 88 ( $M = 54.90$ ,  $SD = 1.58$ ).

### ***2.2 Design***

This study was a quantitative, between groups quasi-experiment. Qualitative narrative descriptions of stressful caregiving episodes were also documented. All quantitative and qualitative data was gathered by means of in-depth questionnaires with AD caregivers.

### ***2.3 Measures***

All measures used for this study are valid, reliable and standardised, and have been used in a number of previous published studies.

*The Caregiver Burden Interview (CBI)*, (Zarit, S. H., Reever, K. E., & Bach-Peterson, J., 1983).

This scale consists of 22 items that total to measure levels of caregiver burden. This measure had good internal consistency reliability, with a Cronbach's alpha coefficient of .92, which is not significantly improved by the removal of any of the 22 items. This measure is strongly correlated with the Burden Assessment Scale (BAS), General Health Questionnaire (GHQ-28) and Dementia Management Strategies Scale (DMSS) (Pearson's correlation coefficient: 0.53 to 0.73) (Seng, Luo & Ng et al. 2010).

*The Adult Carer Quality of Life Questionnaire (AC-QoL)*, (Elwick, H., Joseph, S., Becker, S., & Becker, F., 2010).

This scale consists of 40 items and can be divided into 8 subscale of: Support for caring, caring choice, caring stress, money matters, personal growth, sense of value, ability to cope, and carer satisfaction. The authors of the AC-QoL found the internal consistency reliability for the eight subscales ranged from 0.78 to 0.89 and demonstrated convergent validity with self-reports of change. The AC-QoL is a valuable instrument for researchers and practitioners interested in the outcomes of caring and the evaluation of interventions to increase the QoL for caregivers.

*The Perceived Stress Scale (PSS)*, (Cohen, S., 1983).

This scale consists of 10 items that total to measure levels of perceived stress. Cronbach's alpha values (0.82 for the full scale) for PSS-14 and PSS-10. The PSS exhibited high correlation coefficients with the Depression Anxiety and Stress Scale (DASS-21) subscales scores, meaning stress ( $r = 0.64$ ), depression ( $r = 0.61$ ), and anxiety ( $r = 0.54$ ) (Andreou, Alexopoulos & Lionos et al, 2011).



*The Mental Health Inventory* (MHI-38), (Veit & Ware, 1983).

This scale consists of 38 items and has 6 subscales of: Anxiety, depression, loss of behavioural/emotional control, general positive affect, emotional ties, and life satisfaction. This scale can be divided into 2 global mental health scales of: Psychological distress, and psychological wellbeing. The scale also gives a total global health index score. The MHI-38 has a reported .93 Cronbach alpha rating whereas its abbreviated version has .82. It is well-known and has been field tested in extensive populations. The MHI-38 also shows a high correlation with the Multiple Sclerosis Quality of Life Inventory (MSQLI)

#### **2.4 Procedure**

Participants were invited to take part in the study via collaboration with 4 ASI day-care centres. For ASI caregiver staff, questionnaires were submitted to them to complete at their own discretion. For family caregivers, invitations were sent by the day-care managers on behalf of the researcher inviting them to take part. Questionnaires were subsequently posted to family caregivers who agreed to take part.

A thorough and clearly outlined information sheet was provided disclosing the nature, rationale, purpose of the study, and the rights of the participant. Participants were asked to provide their consent, and then to disclose basic demographic details i.e. age, gender, and caregiver type. Next, participants were asked to think of an example of a particularly stressful episode that they had experienced while caring for their clients or relative, and write a description of the episode.

Following this, participants completed the Caregiver Burden Interview (Zarit *et al*, 1983) (Questions were altered for formal caregivers to pertain to *clients* rather than a

relative), the Adult Carer Quality of Life Questionnaire (Elwick, *et al*, 2010), the Perceived Stress Scale (Cohen, S., 1983), and the Mental Health Inventory (Veil & Ware, 1983).

Upon completion, participants were fully debriefed and provided with all relevant contact details. A number of relevant support services' contact details were offered if participants had any queries or experienced any psychological distress by taking part in the study. Equipment used for the study included Microsoft Word and Excel, Google Docs, and SPSS (22).

## ***2.5 Methods of analysis***

Data was collated by distributing hard copies of the questionnaire or an online version of the questionnaire to participants who preferred this format of participation. Data was stored on a USB key and laptop, both of which were fully encrypted. Statistical tests pertaining to each research hypothesis included independent t-tests, multiple regression, and Pearson's correlations. SPSS (22) was used for all statistical purposes.

## **2. Results**

### ***3.1 Descriptive statistics***

Cronbach's Alpha was used to test internal consistency and reliability of mental health scores. Cronbach's Alpha was sufficient at 0.82. There were 62 participants ( $N = 62$ ), and items on the main dependent variable ( $N = 38$ ). All scale items were positive in item statistics and item-total statistics. Tests for normality were run and assumptions were met to run parametric tests.

Mean scores of caregiver burden for formal AD caregivers was 22.50 ( $SD = 17.11$ ) and 46.16 ( $SD = 15.73$ ) for informal caregivers. Mean scores of QoL for formal AD caregivers was 90.00 ( $SD = 13.39$ ) and 62.29 ( $SD = 16.81$ ) for informal caregivers. Mean scores of stress for formal AD caregivers was 14.96 ( $SD = 6.65$ ) and 20.68 ( $SD = 9.03$ ) for informal caregivers. Mean scores of mental health for formal AD caregivers was 173.79 ( $SD = 26.59$ ) and 147.18 ( $SD = 32.70$ ) for informal caregivers.

Descriptive statistics of study variables are shown in table 1, and a graphical representation of comparisons of mean scores of caregiver burden, QoL, stress and mental health among AD caregivers is shown in figure 1.

### ***3.2 Inferential statistics***

#### ***Hypothesis 1***

Hypothesis 1 was examined by running a t-test to compare formal and informal caregivers on caregiver burden scores. Informal caregivers ( $M = 46.16$ ,  $SD = 15.73$ ) were found to have higher levels of burden than formal caregivers ( $M = 22.50$ ,  $SD = 10.81$ ). The 95% confidence

limits show that the population mean difference of the variables lies somewhere between -30.67 and -16.65. An independent samples t-test found that there was a significant difference between burden level of formal and informal caregivers ( $t(60) = -6.75, p = <.001$ ). Therefore the null was rejected. (See table 1 and figure 1).

### ***Hypothesis 2***

Hypothesis 2 was examined by running a t-test to compare formal and informal caregivers on QoL scores. Informal caregivers ( $M = 62.29, SD = 16.82$ ) were found to have lower levels of QoL than formal caregivers ( $M = 90.00, SD = 13.39$ ). The 95% confidence limits show that the population mean difference of the variables lies somewhere between 19.86 and 35.55. An independent samples t-test found that there was a significant difference between QoL level of formal and informal caregivers ( $t(60) = 7.06, p = <.001$ ). Therefore the null was rejected. (See table 1 and figure 1).

### ***Hypothesis 3***

Hypothesis 3 was examined by running a t-test to compare formal and informal caregivers on stress scores. Informal caregivers ( $M = 20.68, SD = 9.03$ ) were found to have higher levels of stress than formal caregivers ( $M = 14.96, SD = 6.65$ ). The 95% confidence limits show that the population mean difference of the variables lies somewhere between -9.86 and -1.60. An independent samples t-test found that there was a significant difference between stress levels of formal and informal caregivers ( $t(60) = -2.78, p = .007$ ). Therefore the null was rejected. (See table 1 and figure 1).

#### ***Hypothesis 4***

Hypothesis 4 was examined by running a t-test to compare formal and informal caregivers on mental health scores. Informal caregivers (M = 147.18, SD = 32.70) were found to have lower levels of mental health than formal caregivers (M = 173.79, SD = 26.58). The 95% confidence limits show that the population mean difference of the variables lies somewhere between 11.24 and 41.98. An independent samples t-test found that there was a significant difference between mental health scores of formal and informal caregivers ( $t(60) = 3.46, p = .001$ ). Therefore the null was rejected. (See table 1 and figure 1).

Table 1 *T-test results of comparisons of mean scores between formal and informal AD caregivers on variables of interest*

<b>Variables</b>	<b>Mean</b>		<b>SD</b>		<b>T</b>	<b>p</b>
	<i>Formal</i>	<i>Informal</i>	<i>Formal</i>	<i>Informal</i>		
Caregiver age	44.90	63.03	12.46	14.64	-5.02***	.00
Length of caring in months	129.54	59.82	127.67	41.12	3.01***	.00
Hours spent caring per week	35.00	61.18	17.11	25.68	-4.61***	.00
Caregiver burden	22.50	46.16	10.81	15.73	-6.75***	.00
Quality of life	90.00	62.29	13.39	16.81	7.06***	.00
Stress	14.96	20.68	6.65	9.03	-2.78**	.01
Support for caring	10.89	8.38	3.55	4.00	2.59**	.01
Choice for caring	13.14	4.47	3.23	4.49	8.55***	.00
Caring stress	11.11	6.50	3.89	4.83	4.08***	.00
Money matters	6.79	8.76	3.28	3.47	-2.29*	.03
Personal growth	13.29	9.12	2.27	4.10	4.97***	.00
Sense of value	12.36	8.38	2.83	4.30	4.19***	.00
Ability to care	13.04	10.59	2.28	3.06	3.47**	.00
Caregiver satisfaction	13.79	8.15	1.66	3.99	6.98***	.00
Anxiety	18.93	22.09	5.47	8.27	-1.73	.09
Depression	8.11	10.26	3.16	4.17	-2.26*	.03
Loss behavioural/emotional control	17.68	22.82	5.48	6.62	-3.29**	.00
General positive affect	40.75	29.00	10.06	9.35	4.76***	.00
Emotional ties	9.25	6.59	2.48	2.81	3.91***	.00
Life satisfaction	4.11	3.47	1.13	1.19	2.15*	.04
Psychological distress	50.04	63.18	14.75	19.16	-2.97**	.00
Psychological well-being	63.00	46.74	14.41	13.92	4.51***	.00
Mental health	173.79	147.18	26.59	32.70	3.46**	.00

**Note. Statistical significance: \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$**

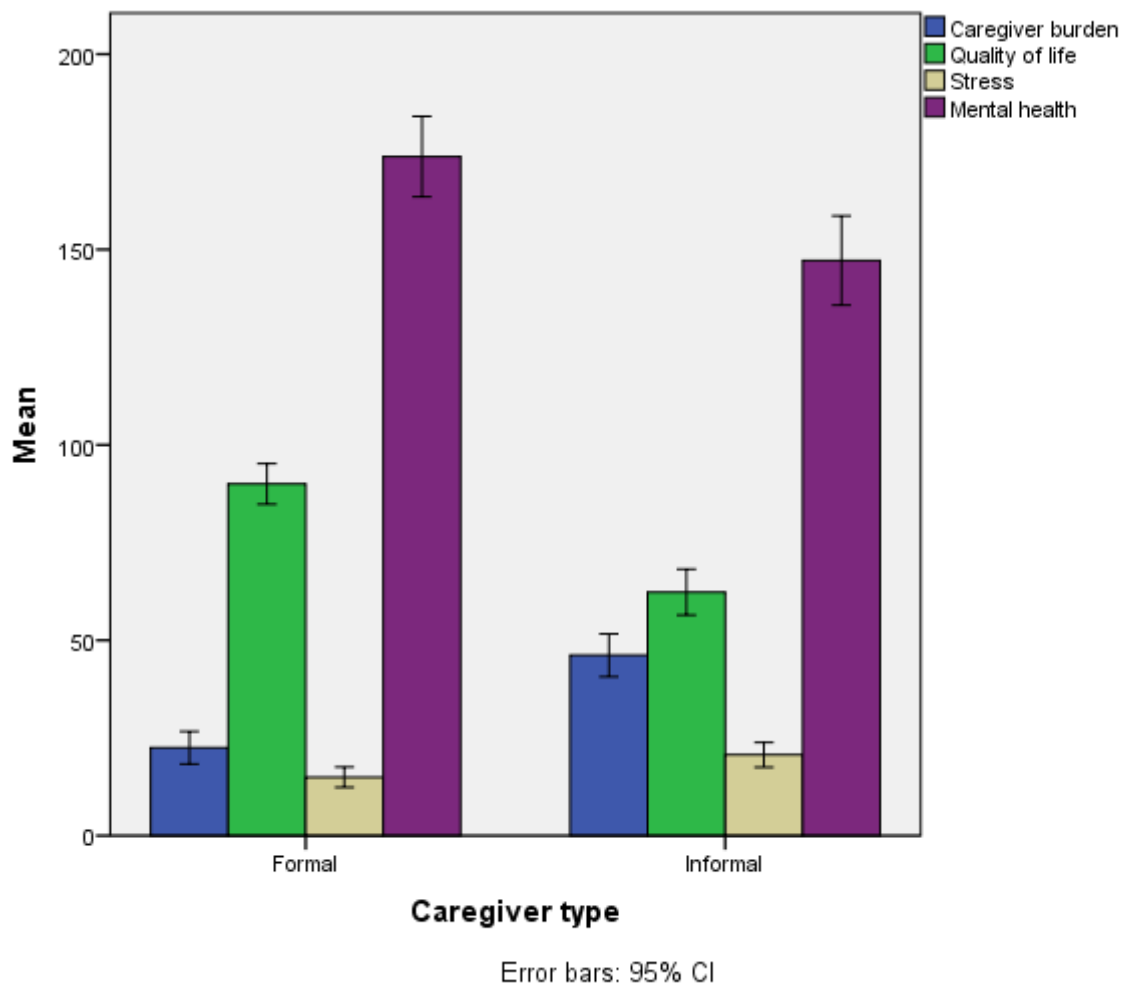


Figure 1 *Comparisons of mean scores of caregiver burden, QoL, stress and mental health between formal and informal AD caregivers*

### **Hypothesis 5**

Hypothesis 5 was examined by running a 4-step hierarchical multiple regression analysis using an enter method. Tests for multicollinearity indicated that a very low level of multicollinearity was present. None of the predictor variables correlated above 0.3 with the criterion variable, and none of the predictors were highly correlated with each other (above 0.7). Tolerance values were all above 0.1 and VIF were all below 10. Eigenvalues were checked and variables did not show multicollinearity by having large variance proportions.

Out of the sample of 62 participants, ( $N = 62$ ) no outliers were found so this was deemed as normal. Standardized residuals fell between -3 and +3. The histogram and plot for normality was normally distributed. Thus, assumptions were met to run regression analyses.

In the first step of hierarchical multiple regression caregiver type was entered followed by gender, to control for categorical effects in the model. Beta coefficients for the two predictors were caregiver type;  $\beta = .44$ ,  $t = -3.78$ ,  $p = <.001$ ; and gender;  $\beta = .24$ ,  $t = 2.10$ ,  $p = .04$ . The results indicated that the two predictors explained 23% of the variance in mental health ( $R^2 = .23$ ,  $F(2, 59) = 8.54$ ,  $p = .001$ ). After entry of caregiver burden in model 2, the total variance explained by the model was 45%. The introduction of caregiver burden explained an additional 22% of the variance after controlling for caregiver type and gender ( $\Delta R^2 = .22$ ,  $F = 15.58$ ,  $p = <.001$ ). The addition of QoL in model 3 significantly improved the model by 10% and explained 55% of the variance in mental health ( $\Delta R^2 = .10$ ,  $F = 17.47$ ,  $p = <.001$ ). The addition of stress in model 4 significantly improved the model by a further 14% ( $\Delta R^2 = .14$ ,  $F = 24.81$ ,  $p = <.001$ ). The best fitting model for predicting mental health scores was a linear combination of caregiver type, gender, caregiver burden, QoL and stress, which explained 69% of the variance ( $R^2 = .69$ ,  $F(5, 56) = 24.81$ ,  $p = <.001$ ). Stress made the strongest unique contribution to the final model (Beta =  $-.64$ ) (14% of the variance). Therefore the null hypothesis was rejected. Table 2 provides a summary of the results and figure 2 shows a graphical representation of the model fit.

Table 2 *Summary of hierarchical regression analysis showing the predictive power of variables for explaining AD caregiver mental health scores*

	R	R <sup>2</sup>	ΔR <sup>2</sup>	B	SE	B	t
<b>Model 1</b>	.47	.23**					
Caregiver type				-28.42	7.52	-.44	-3.78***
Gender				-15.92	7.59	-.24	-2.10*
<b>Model 2</b>	.67	.45	.22***				
Caregiver type				-.98	8.57	-.15	-.16
Gender				-11.86	6.52	-.18	-1.82
Burden				-1.14	.24	-.63	-4.82***
<b>Model 3</b>	.74	.55	.10***				
Caregiver type				8.58	8.22	.13	1.04
Gender				-12.87	5.93	-.19	-2.17*
Burden				-.49	.28	-.28	-1.79
Quality of life				.89	.25	.57	3.64**
<b>Model 4</b>	.83	.69	.14***				
Caregiver type				-4.29	7.37	-.07	-.58
Gender				-3.41	5.33	-.05	-.64
Burden				-.22	.24	-.12	-.94
Quality of life				-.12	.26	.07	.45
Stress				-2.5	.49	-.64	-4.99***

*Note. Statistical significance: \*p<.05, \*\*p<.01, \*\*\*p<.001*



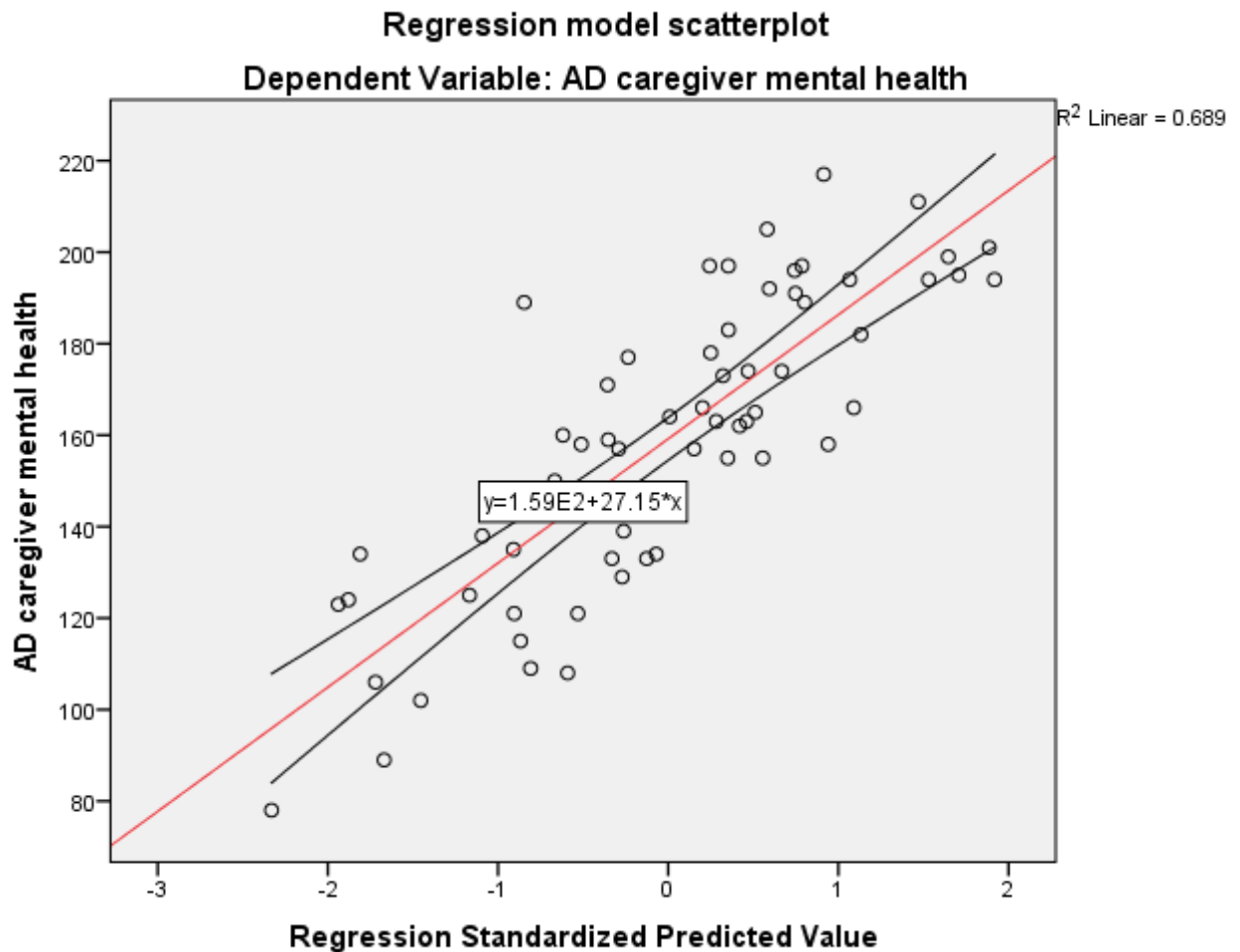


Figure 2 Scatterplot of regression model of AD caregiver mental health showing model fit (red line) and confidence intervals (black lines)

N.B. When the same 4-step regression model was run but split by caregiver type, the same predictor variables in the formal caregiver model explained 58% of the variance in mental health ( $R^2 = .58$ ,  $F(4, 23) = 7.88$ ,  $p = <.001$ ); and 75% of the variance in the informal caregiver model ( $R^2 = .75$ ,  $F(4, 29) = 21.27$ ,  $p = <.001$ ).

### ***3.3 Exploratory analysis***

Exploratory analysis revealed a large number of significant findings. T-tests were run to compare formal and informal caregivers on the study variables of interest. Pearson's correlations were also carried out for these variables addressing both cohorts of caregivers together (see table 1, figure, 3 and table 3). For reasons of parsimony, all significant findings could not be reported, but some of the most notable findings are offered in the exploratory discussion section (see section 4.3).

The present study also documented situations that AD caregivers have experienced as particularly stressful while caring. These accounts were quite varied, but a number of similar episodic themes also emerged (see appendix A).

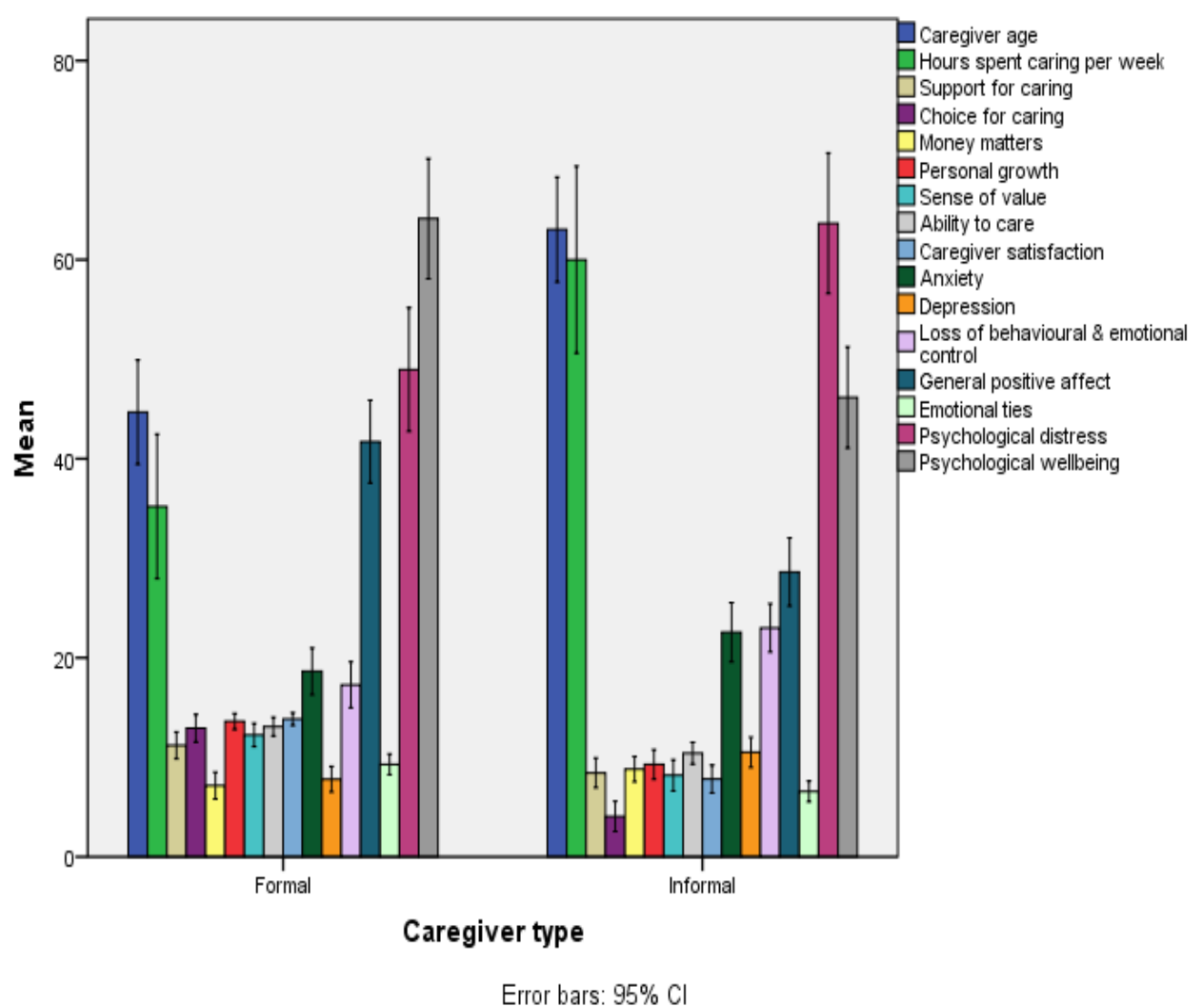


Figure 3 Comparisons of mean scores of exploratory variables between formal and informal AD caregivers

Table 3 *Partial correlations of AD caregiving variables with significance values*

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Mental health	-															
2. Age	.48	-														
3. Caregiver type	-.41**	.58***	-													
4. Hours per week	-.14	.48***	.51***	-												
5. Caregiver burden	-.64***	.37**	.66***	.34**	-											
6. Quality of life	.69***	-.31*	-.67**	-.34**	-.79***	-										
7. Stress	-.81**	.06	.34**	.01	-.65***	-.74***	-									
8. Caring support	.27*	.05	-.32*	.08	-.23	.57***	-.42**	-								
9. Caring choice	.62***	-.50***	-.74***	-.53***	-.85***	.77***	-.56**	.19	-							
10. Money matters	.09	.25	.28*	.30*	.09	.15	-.22	.21	.20	-						
11. Personal growth	.32*	-.27*	-.53***	-.38**	-.37**	.63***	-.38**	.39**	.39**	-.07	-					
12. Sense of value	.45***	-.23	-.48***	-.39**	-.55***	.70***	-.36**	.18	.53***	-.00	.43***	-				
13. Ability to care	.35**	-.07	-.41**	.80	-.29*	.53***	-.43***	.39**	.20	-.04	.48***	.43**	-			
14. Carer satisfact/n	.51***	-.45***	-.67***	-.45***	-.65***	.82***	-.49***	.28*	.69***	-.12	.64***	.66***	.51***	-		
15. Anxiety	-.87***	.01	.22	-.02	.59***	-.54***	.77***	-.17	-.44***	-.13	-.15	-.25*	-.35**	-.32*	-	
16. Depression	-.92***	.37	.28*	.13	.56***	-.61***	.72***	-.24	-.51***	-.17	-.27*	-.38**	-.27*	-.41**	.82***	-

*Note. Statistical significance: \*p<.05, \*\*p<.01, \*\*\*p<.001*

### 3. Discussion

#### *4.1 Restated aims of the present study*

The aim of the present study was to examine the effects of caring for individuals with AD on formal and informal caregiver's mental health. The secondary aims were to investigate what differences are apparent between formal and informal AD caregivers on levels of caregiver burden, QoL, stress, and mental health; and to test if caregiver burden, QoL, and stress would predict mental health among AD caregivers.

#### *4.2 (a) Hypothesis 1*

As hypothesized, informal caregivers reported significantly high levels of caregiver burden. This finding supports a growing body of research (e.g. Howcroft, 2004; Levy *et al*, 2012) which has shown that informal AD caregivers experience significantly high levels of burden as a result of caring. Shim *et al* (2011) and Papastavrau *et al* (2011) have also shown that AD caregivers are at high risk of developing psychological illnesses which is directly attributed to the burden of caring. Indeed, informal caregivers in the present study reported significantly high levels of depressive symptoms. However, contrary to Iavarone *et al* (2014), who found that AD caregiver burden is associated with significant anxiety, the present study did not find the same result.

Burden has been mostly correlated with lack of social support and behavioural problems in the AD patient (Howcroft, 2004). Consistent with this finding, informal caregivers reported significantly low levels of support in the present study. In addition, Howcroft (2004) purports that aggression, screaming, resistance to help, hallucinations,

delusions, suspiciousness, and night disturbances can evoke burden, and approximations of all of these types of behaviours were reported by informal caregivers in the present study (See appendix A).

Formal caregivers have a responsibility to maintain their clients' dignity and avoid reacting emotionally when burdensome situations present themselves. They may also feel more comfortable in dealing with these situations because it is their duty to facilitate their clients in the most humane way possible. Unlike family caregivers, formal caregivers do not suffer the progressive build-up of stressors which culminate in high levels of burden caused by often unforeseen caregiving situations that occur in or outside the home. Formal caregivers can also avail of immediate support from fellow staff and a competent nurse-manager. Moreover, Howcroft (2004) has shown that burden is further exacerbated by the premorbid relationship prior to the disease onset. Indeed, formal caregivers have never formed strong pre-illness attachment bonds with their clients or know them personally before the onset of the disease. For family caregivers this is a highly stressful and poignant experience to come to terms with.

#### **4.2 (b) Hypothesis 2**

As hypothesized, informal caregivers reported having a significantly low level of QoL. This finding can be better explained by taking into consideration the individual facets that comprise caregiver QoL. All 8 domains of QoL showed significant differences between both groups of caregivers. For example, *caring choice* which measures the extent to which caregivers feel they have control over their own life and are able to choose ventures outside of caring (e.g. social activities), was significantly low among informal caregivers. Caring choice was also associated significantly with depressive symptoms. Due to the forced choice of having to cope with the myriad of requirements that typically arise from providing care,

informal AD caregivers find little time for breaks or pleasurable activities outside of caring. This “unexpected career” as Mannion (2008) observes, can quickly become an all-encompassing role. By contrast, most formal caregivers have consciously chosen to care for individuals with AD by means of a career path.

The QoL domains of caregiver satisfaction and support for caring were also significantly low among informal caregivers, and their financial woes were significantly high. These findings lend support to Bartfay and Bartfay (2013) who found markedly high levels of financial stress and social isolation among informal AD caregivers. Psychological distress was also significantly high among informal caregivers and supports research by Rosness *et al* (2011) who have shown that psychological distress in AD caregivers diminishes their QoL. Moreover, care demands posed by the recipients’ illness, functional limitations and the adequacy of resources available to the caregivers can result in a lower QoL for informal caregivers (Au *et al*, 2009). Lack of support and witnessing the gradual deterioration of their relative also contribute negatively toward family caregiver QoL. Indeed, the present study revealed that lack of support was strongly associated with QoL which is also consistent with findings from Bartfay and Bartfay (2013), who report that the effective loss of companionship of their life partner and lack of support directly affects caregiver QoL.

#### **4.2 (c) Hypothesis 3**

As hypothesized, informal caregivers reported significantly high levels of stress. Numerous factors can contribute to high levels of stress among informal caregivers, from financial woes to lack of support. Tarrier *et al* (2002) purport that stress can also be amplified by family caregiver’s own criticism about behaviours (e.g. speech incoherence, messiness, aggressive displays) which they perceive as controllable by their relative. Criticism and hostility often reflects the caregiver’s beliefs their loved one possesses the potential to control aspects of

their condition and subsequent behaviour, and this mind-set is associated with caregiver distress and strain. Formal caregivers by contrast, seem to avoid a critical stance, possibly because they may have a better understanding of the attributional locus behind problematic behaviours. As a result, they may have learned to become more accepting of these behaviours and habitually react to a less stressful degree when they encounter frustrating situations. Indeed, Tarrier *et al* (2002) have shown that informal caregiver's causal attributions are associated with their distress, and Howcroft (2004) reports that the stress and burden that caregivers experience is directly tied to the behavioural problems exhibited by the patient, more so than the degree of their disease. Formal caregivers also care for many different clients on a day-to-day basis, and thus may be more prepared for, and have greater experience in handling a wider range of caregiving situations.

*Mutuality* can help further explain the significantly high levels of stress reported by informal caregivers provided we also acknowledge the significantly low sense of value and satisfaction levels they reported. Sense of value pertains to the extent to which the caregiver feels valued and respected and the perception that the quality of the relationship is positive. Having a high sense of value and satisfaction contribute to high levels of mutuality. Indeed, mutuality is concerned with the level of caring, mutual concern and relationship gratification experienced by those involved. Mutuality also ameliorates caregiver stress, and comprises the ability of the caregiver to gain satisfaction from the caregiving relationship. These key features of mutuality dovetail neatly with the significantly low sense of value and satisfaction informal caregivers reported in the present study. Moreover, problems such as the loss of shared interactions and memories, paranoia, hallucinations, aggressiveness, and wandering also have a negative impact on mutuality (Shim *et al*, 2011). Indeed, many informal caregivers in the present study reported experiencing episodes of paranoia, hallucinations, aggression and wandering by their relative (See appendix A).



Consistent with Lee *et al* (2005) who report that stress is associated with the duration of caring role and amount of weekly hours provided, the present study revealed that duration of caring role and amount of weekly hours provided were both significantly high in informal caregivers. The context in which AD caregiving occurs may also help explain stress levels. For example, formal caregivers operate in an environment specifically designed to meet the physiological, psychological, and emotional needs of individuals with AD. This community-based care environment affords caregivers immediate reliable support whenever they encounter stressful situations. By contrast, family caregivers often feel isolated in their own home, and cannot avail of this level and quality of support. Furthermore, caregiver's own characteristics play a large role in caregiving experience of stress (Campbell, 2009). Indeed, formal and informal caregivers differ in a large number of ways such as age, physical health and ability to care, and these mediating factors help further explain the notably high levels of stress reported by family caregivers.

#### **4.2 (d) Hypothesis 4**

As hypothesized, informal caregivers were found to have significantly low levels of mental health. This finding appears to be directly related to, and explained by the levels of burden, stress and QoL they reported and lends support to previous studies (e.g. Tarrier *et al*, 2002; Georges *et al*, 2008: & Shim *et al*, 2011) which have shown that caring for an individual with AD incurs significant psychological distress and attenuated well-being. This finding also supports research by Posner *et al* (2015) who report that AD caregivers typically experience significantly high levels of psychological morbidity, depression and stress, and is consistent with research by Mausbach *et al* (2014) who have shown that caring for individuals with AD

is associated with high stress, often resulting in elevated symptoms of depression and poorer well-being.

Additional mediating factors that appear to diminish the mental well-being of informal caregivers deserve consideration. For example, the frustration of experiencing their relative becoming increasingly dependent on them can have a huge psychological impact. Moreover, causal attribution beliefs pertaining to internal attributions to the caregivers themselves (e.g. self-blaming), are also correlated with distress in informal caregivers (Tarrier *et al*, 2002). These attributions appear to be directly linked with caregivers' perceived ability to care, which was verified by the fact that informal caregivers in the present study reported significantly low levels of ability to care, and high distress. Indeed, as Au *et al* (2009) have shown, self-efficacy and social support directly mitigate the deleterious implications of demands by care recipient characteristics. However, the actual demands of the situation may not be directly predictive of psychological distress among informal caregivers. Instead, caregivers' *perceptions* of the demands of the situation, and their ability to manage these demands may be more directly related to distress. Thus, informal caregivers' perceived ability to care and level of support appear to be key mediating factors for their mental well-being. This was evidenced by the fact that informal caregivers' ability to care and caring support were both significantly low, and were both negatively associated with burden, depressive symptoms and psychological distress.

Many informal caregivers are isolated, lack support, are notably older, and probably don't enjoy the same quality of physical health or have access to the same types of coping resources as formal caregivers. Although the present study did not examine coping strategies, they must nevertheless be considered as a major contributing factor for family caregiver mental health. For example, Mannion (2008) has shown that individual variations in coping strategies explain differences in mental health outcomes. Furthermore, latent variables such

as personality traits (e.g. neuroticism) have been shown to contribute to mental health outcomes among AD caregivers (Gallagher *et al*, 2011). Perhaps most importantly, as Au *et al* (2009) observe, providing care to a family member with AD is associated with depressive symptoms and increased burden due to the fact that the strain of witnessing and adapting to the family members cognitive, behavioural and personality changes over-tax on personal resources. Witnessing the deterioration of the personality of their loved one can be a deeply poignant experience, and the loss of companionship and inability to reminisce upon shared memories that occurs as a result, can very easily erode the mental well-being of caregivers (Mannion, 2008; Bartfay & Bartfay, 2013).

#### **4.2 (e) Hypothesis 5**

As hypothesized, caregiver burden, QoL and stress significantly predicted AD caregiver mental health. Caregiver type and gender were controlled for before adding each hypothesized predictor variable to the regression model. Results revealed that the hypothesized model was highly predictive of AD caregiver mental health. Caregiver type and gender explained 23% of the variance in mental health. When caregiver burden was entered into model 2 it strengthened the model by 22% and this model explained almost half the variance (45%) in mental health. Indeed, Ivarone *et al* (2014) report that burden alone is highly correlated with domains of AD caregiver mental well-being such as anxiety and depressive symptoms, and Papastravau *et al* (2011) have shown that AD caregivers are at high risk of developing psychological illnesses, which is directly attributed to the burden of caring.

When QoL was entered into model 3, it strengthened the model by a further 10% and resulted in the model explaining over half the variance (55%) in mental health. Moreover, dimensions of QoL including caring supports, perceived choice in caring, caregiver

satisfaction and caregiver sense of value, were all significantly associated with the psychological well-being of caregivers in the present study. This finding is consistent with research by Shim *et al* (2011) who have shown that high levels of mutuality and the ability of the caregiver to gain satisfaction by means of the individual with AD reciprocating by merit the caregiver's existence increases QoL and psychological well-being for the caregiver.

When stress was entered into model 4 it significantly strengthened the model by 14% and resulted in the model explaining 69% of the variance of mental health. Stress also made the largest contribution to this model which was not entirely surprising considering for example that Mausbach *et al* (2014) have shown that AD caregiving is associated with high stress often resulting in elevated symptoms of depression and poorer well-being.

The model fit showed that an exceptionally large proportion of AD caregiver mental health was explained by a parsimonious model tested with a relatively modest sample size. These findings support a substantial body of research exploring burden, QoL, stress and mental well-being among AD caregivers (e.g. Papastravau *et al*, 2011; Posner *et al*, 2015). The regression model also demonstrated similar predictive power to that of Orgeta *et al* (2013) who examined the predictors of caregiver age, physical health, stress, and social support, and found their model predicted almost 70% of the variance in mental well-being among AD caregivers.

#### ***4.3 Exploratory, non-hypothesised findings***

Informal caregivers reported significantly high levels of depressive symptoms. This finding supports research by Orgeta *et al* (2013) who have shown that caring for a relative with dementia is correlated with a higher level of developing depression, and Posner *et al* (2015) who report that informal AD caregivers typically experience high levels of depression. Moreover, because the present study employed a comparison group of formal AD caregivers

instead of a typical comparison group of non-AD caregivers, this finding is probably not attributable to the illness itself, but more to the conditions and circumstances in which informal caregivers care for their relative, such as caring in the family home with limited support. Indeed, informal caregivers reported having significantly low support for caring. Implicit prejudices of family and friends or the reluctance of caregivers to accept help or allow others into the situation may help partially explain this finding (Howcroft, 2004).

Ability to care was significantly and negatively associated with caregiver burden and depressive symptoms, which supports research by Gallagher *et al* (2011) who have shown that self-efficacy is significantly and negatively correlated with symptoms of caregiver burden and depression. Papastravau *et al* (2011) have also shown that caregivers who are more certain in their ability to care are more likely to effectively handle the troublesome symptoms of AD and alleviate the negative effects associated with caring.

Informal caregivers reported significantly low levels of caregiver satisfaction. This finding is most likely attributable to the lack of choice they have regarding the circumstances they are faced with and the poignancy of their relatives' decline. Formal caregivers may be more enthusiastic and motivated toward helping individuals with AD and as a result, experience an elevated level of satisfaction from their daily interactions with AD clients. Formal caregivers adopt a different approach to caring compared to informal caregivers, and may find it easier to be facilitating toward their clients and build rapport. They also deal with many clients on a daily basis in a social environment which is vastly different to caring for a relative with AD at home with inadequate support.

Formal caregivers also reported having a significantly greater sense of value compared to informal caregivers. Family caregivers may not feel appreciated by their relative within the home environment, and thus may not gain any real sense of value because it is a

role that is demanding, ostensibly unrewarding and one they did not choose to adopt. Conversely, formal caregivers may experience a high sense of value by being part of a team whose very purpose is to engage with and accommodate their clients e.g. by facilitating conversation and organising activities such as memory games, music and art. Formal caregivers also reported significantly high levels of personal growth, which may be because they find their role intrinsically rewarding, are notably younger, and work in an applied setting which affords the opportunity for their own personal and professional development.

Most informal caregivers reported spending over 70 hours per week caring which supplements previous findings from Howcroft (2004), and Georges *et al* (2008). Stress levels were also highly correlated with the duration of caring and amount of weekly hours provided, which is consistent with Lee *et al* (2012), and women reported experiencing more stress than men which supports findings by Mannion (2008).

#### ***4.4 Strengths and limitations***

The findings from the present study support a growing body of research on caregiver burden, stress, QoL, and mental health characteristics among AD caregivers. A considerable number of significant findings and large effect sizes were revealed with a relatively modest sample size. Furthermore, the hypothesized regression model for AD caregiver mental health was parsimonious and demonstrated exceptionally high predictive strength by explaining almost 70% of the variance in mental health scores. One can purport that the findings from the present study are unique because previous designs have typically compared informal AD caregivers to age-matched non-caregivers, or to non-AD caregivers. By contrast, the present design employed a cohort of formal AD caregivers as a comparison group. Formal caregivers experience a significant variety of caregiving relationships and encounter a broad range of

cognitive and behavioural challenges due to the fact they care for many individual clients on a day-to-day basis, and hence serve as an ideal comparison group for AD family caregivers.

One can purport that the present study made a novel contribution to AD caregiving research by examining critical variables that pertain directly to the psychological well-being of both formal and informal caregivers. It is however important to note some limitations. Firstly, some results were only partially interpretable and hence further research may be required. Secondly, the sample size was somewhat modest and thus may not have been as representative of AD caregivers as would be desired.

#### ***4.5 Caveats and future implications***

One caveat to be mindful of is that the self-report measure of mental health used for the present study summarized symptoms retrospectively over a period of time, e.g. the degree to which caregivers felt “lonely” during the previous month. This type of retrospective recall can be affected by bias such as current mood state or recall biases (Fonareva, Amen, & Ellingson *et al*, 2012).

Future longitudinal studies which begin when the client has received their AD diagnosis up until the point where long-term care is necessary might elucidate aspects of the experiential trajectory of caregiving, and highlight pertinent moments of the illness itself that impact upon the well-being of the caregiver. Studies conducted within Alzheimer’s day-care centres that log caregivers’ daily observations, fluctuations and feelings about their experience might also afford the chance to provide better caring provisions for both the AD client and caregivers. Further research investigating the phenomena of mutuality and expressed emotion experienced by AD caregivers would also be welcome. Additional studies

focusing on the individual coping strategies and personality traits of AD caregivers may also help further isolate important mediating factors of AD caregiver mental health.

#### ***4.6 Concluding statement***

The poignancy of having to come to terms with the cognitive, behavioural and personality changes of the family member who has AD can incur a huge range of emotions for caregivers. Witnessing the gradual decline of a loved one is an extremely difficult situation to stoically accept. However, having a good quality relationship with the individual who has AD appears to serve as a significant protective and supporting factor in helping caregivers cope with the unpredictable frustrations they endure. It is hoped that the present study has made a notable contribution to understanding the impact AD has on the mental health of caregivers in both formal and informal settings.



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## Appendices

### Appendix A

#### *Examples of stressful caregiving episodes:*

Formal caregivers reported stressful incidents including aggression, anger, stumbling or falling, confusion in the client, refusing to eat or drink, spitting food, difficulty communicating, weak mobility, being overly verbal or verbally abusive, and toileting difficulties. One caregiver reported that a client tried to stab him with a pen, and another reported a female client becoming extremely violent towards her. Another reported witnessing a client having a stroke in front of her which caused her great distress. Some staff also felt they are unsupported by other staff members.

Informal caregivers reported stressful incidents including difficulties in dressing, showering, going missing, anger and annoyance, incontinence, hallucinations, paranoia, toileting problems, refusal, time constraints, and repeating the same questions over and over again. One caregiver reported that it is very stressful when his wife doesn't know who people are including himself. Another client reported how their loved one had severe toileting problems and smeared faeces all over walls in two rooms.

Below are examples of narrative accounts of stressful caregiving episodes:

*(Formal) Female caregiver, 47:* “There is one male client who is very vocal and very loud, and quite abusive verbally, pair that with his facial expressions and it can be a bit menacing, there are days when the name calling and shouting can wear me down, but I know it's the dementia and he can't help it, other days I can just get on with my job and put it out of my mind”

**(Formal) Male caregiver, 48:** “One client got very aggressive with another client and then tried to stab me with a pen. I found it very challenging to calm her down”

**(Formal) Female caregiver, 55:** “I think the most challenging and stressful situations are when clients think we are going to do them harm when trying to help them. It is very distressing for them and difficult for us trying to gain their confidence. We don’t always know their past and these memories are the ones that stay and often resurface at a very difficult time. We just have to take it one step at a time, sometimes very small steps”

**(Informal) Female caregiver, 47:** “While in Santiago, 3 years ago we took a day trip on a mini bus, he got totally paranoid that the bus driver was trying to deceive us and take our money, by the end of the day he was convinced that everyone else on the tour were in on it also, we tried to reassure him many times, but he even looked at us as if he could not trust us either, by the time we got back to the city, we practically had to carry him back to the hotel as he was barely able to walk, we were not sure if it was the heat or just unfamiliar surroundings that triggered this episode”

**(Informal) Female caregiver, 56:** “Much earlier in the disease process, I arrived at my mother’s to escort her to church. Instead of finding her dressed and ready to go, I arrived to discover her and two rooms covered in faeces. It was as if a shit bomb had exploded and she was oblivious to what had happened. If she did have any realization of a problem, she had no idea what to do. It was a sad morning”.

*(Informal) Male caregiver, 53:* “Some time ago whilst leaving my father to a medical appointment he lost control of his bowel movements which resulted in a very uncomfortable period of time until we could pull off the motorway to attend to the unfortunate episode. Although he had forgotten about the incident within minutes of it occurring it brought home the demeaning and sad effects of Alzheimer’s. If someone had suggested to me even 5 years ago that my kind, capable and intelligent Father would lose his mental and cognitive facilities so quickly I wouldn’t have believed them”.



## Appendix B



TRINITY  
COLLEGE  
DUBLIN

Dear caregiver,

I am a social care worker who works for the Alzheimer Society of Ireland, and a student in Trinity College. This is an invitation asking you to take part in research I am doing on caring for people with Alzheimer's disease. Specifically, the impact caring has on carer quality of life and wellbeing. The research is for my masters' dissertation in applied psychology, and will contribute to the understanding of carer experience in Ireland.

The Alzheimer Society are supporting me with my research, and Trinity College ethics committee have approved my study. The study is completely confidential. It does not require you to disclose any personal details, and you have the right to withdraw at any moment. It takes the form of a very basic questionnaire that asks you to rate answers to questions on a scale of 1-5, you simply tick the rating of the question asked. Completion takes approximately **20 minutes**.

I will provide a thorough and clear participant information sheet outlining all aspects of the study, an informed consent sheet, and a full debriefing sheet. I have provided my own and my university supervisor's full contact details below if you have any queries.

The online version of the questionnaire is very easy to complete and may be more convenient. If you would hopefully like to answer the questionnaire, can you please contact me and I will email or post you the questionnaire, whatever you would prefer. I would be greatly indebted to you if you could help me with my research.

Thank you for your time, I really hope to hear from you.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Gareth Duffy', written over a blue horizontal line.

Gareth Duffy - Social carer with The Alzheimer Society & psychology student at Trinity College Dublin

**Contact details for request of questionnaire:**

**Phone:** 085\*\*\*\*\*

**Email:** duffyg5@tcd.ie

**Address:** \*\*, \*\*\*\*\*, \*\*\*\*\*, Co. Dublin

TCD supervisor: Dr. Tim Trimble:

Phone: 01\*\*\*\*\*

Email: [tim.trimble@tcd.ie](mailto:tim.trimble@tcd.ie)

## Appendix C

### Participant information sheet

*Researcher: Gareth Duffy, MSc Applied Psychology at Trinity College Dublin.*

You are invited to participate in a research study that will form the basis for a postgraduate thesis. If you choose to complete this questionnaire, please post it back to the researcher after you have finished using the stamped addressed envelope provided. Please read the following information before deciding whether or not to participate.

*What are the objectives of the study?*

I am conducting research on the experience of caring for individuals with Alzheimer's disease, specifically, quality of life and mental health among caregivers. Full ethical approval has been given by The Alzheimer Society of Ireland. A complete debriefing will be offered after participation, where any questions will be answered.

*Why have I been asked to participate?*

The research requires participants to take part that meet the following criteria:

- Aged 18 years or over
- Of sound mental health, i.e. you are not suffering from a severe psychiatric disorder

You are not/do not have:

- A severe intellectual or learning disability
- Might not understand the research and consent process
- Individuals or groups receiving regular help (e.g. counselling or psychoanalysis), or help through the voluntary sector.
- Other vulnerable groups

*What does participation involve?*

The study requires participants to answer all questions and complete all sections of the following document which pertains to their experience of Alzheimer's disease care giving. The study takes approximately 20 minutes to complete. Complete anonymity is guaranteed. Full details of the study will be provided after data has been collected.

*Right to withdraw*

All participants are free to withdraw from the study and/or to decline to answer any of the questions at any point in time, without prejudice. If at the end of the study participants decide that they do not want information to be included in the study their rights shall be fully reserved. Participants may contact the researcher or research supervisor at any stage regarding the study. A full debrief will be offered and full contact details for the researcher, research supervisor, and full contact details of three mental health organizations are also provided for all participants.

*Are there any benefits from my participation?*

While there will be no direct benefit from participation, studies like this can make an important contribution to our understanding of the impact of Alzheimer's disease caregiving on caregivers mental health. As such, the findings from this study may be presented at a college symposium, at a national conference, or submitted for publication in peer-reviewed journals. Interim and final reports will be prepared. However no individual participant will be identified in any publication. Individuals will not be offered any monetary or other rewards for their participation.

*Are there any risks involved in participation?*

There are no known risks associated with participation. Any inconvenience involved in taking part will be limited. Complete anonymity is guaranteed, and participants have the right to withdraw at any time and will be offered a full debriefing upon completion.

#### *Confidentiality*

All individual information collected as part of the study will be used solely for experimental purposes. They will be stored safely and will not be publicly displayed or published without prior consent. In accordance with PSI Code of Professional Ethics, confidentiality will only be ensured. All information will be held under the Data Protection Act 1988 (amendment 2003) and also the Freedom of Information Act 2003. Data will be retained for a period of 10 years in accordance with the Psychological Society of Ireland's Policy. Data will be kept securely. Physical data will be stored in a locked filing cabinet and destroyed 10 years after publication of the study. Only the primary researcher and research supervisor will have access to this material. However, the research supervisor will not have access to identifying information of the participants unless in the event of a breach of ethics being reported.

#### *Contact Details*

If you have any further questions about the research you can contact:

Research student:

Gareth Duffy

School of Psychology, Áras an Phiarsaigh, Trinity College, Dublin 2

085\*\*\*\*\*

duffy5@tcd.ie

Research supervisor:

Dr. Tim Trimble

School of Psychology, Áras an Phiarsaigh, Trinity College, Dublin 2

01\*\*\*\*\*

tim.trimble@tcd.ie

\*Additional mental health resources and support contact details will be offered at the end of the study

## Appendix D

### Participant informed consent form

Researcher: Gareth Duffy, MSc Applied Psychology at Trinity College Dublin.

This study requires you the participant to complete the questionnaire pertaining to the impact of Alzheimer's disease on caregiver quality of life and mental health.

I have read and understood the attached information sheet for this study. The nature and purpose of this study has been explained to my satisfaction. I understand that I can ask for further information at any time from the researcher, Mr. Gareth Duffy and/or his research supervisor, Prof. Tim Trimble. My taking part in this study is entirely voluntary and I understand that I have the right to withdraw at any time without prejudice.

I am aware that information gained in the study will be used to advance research in this area but that I will not be identifiable and that all information will be treated with the strictest of confidence. The data will be stored safely in a locked filing cabinet and only the researcher and supervisor will have access to the data

Under the Freedom of Information Act, I understand that I am entitled to a copy of the study's findings.

I confirm that I freely agree to take part in this research study.

\_\_\_\_\_  
Signature of researcher

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Researcher (Print name)

\_\_\_\_\_  
Participant (Print name)

*Research student:*

Gareth Duffy  
School of Psychology,  
Áras an Phiarsaigh,  
Trinity College, Dublin 2  
085\*\*\*\*\*  
[duffyg5@tcd.ie](mailto:duffyg5@tcd.ie)

*Research supervisor:*

Dr. Tim Trimble  
School of Psychology,  
Áras an Phiarsaigh,  
Trinity College, Dublin 2  
01 \*\*\*\*\*  
[tim.trimble@tcd.ie](mailto:tim.trimble@tcd.ie)

## **Appendix E**

### **Participant debrief sheet**

Thank you for your participation.

This study will hopefully provide valuable information in understanding burden, quality of life, stress and overall mental health among caregivers of Alzheimer's disease clients. It is hoped that this research will contribute to a growing body of literature on Alzheimer's disease caregiving related issues.

If you have been affected by any of the content of the study or have any concerns or general queries please contact:

Research student:

Gareth Duffy

School of Psychology, Áras an Phiarsaigh, Trinity College, Dublin 2

085\*\*\*\*\*

[duffyg5@tcd.ie](mailto:duffyg5@tcd.ie)

Research supervisor:

Dr. Tim Trimble

School of Psychology, Áras an Phiarsaigh, Trinity College, Dublin 2

01 \*\*\*\*\*

[tim.trimble@tcd.ie](mailto:tim.trimble@tcd.ie)

### **Mental health supports and resources:**

Alzheimer's Society of Ireland national helpline: 1800 341 341 (<http://www.alzheimer.ie/Home.aspx>)

Samaritans: 1850 609 090 (<http://www.samaritans.org.uk/talk/branches/ireland.shtm>)

AWARE: 1890 303 302 (<http://www.aware.ie/helpline.htm>)

## Appendix F



17 October 2014

To whom it may concern

I am writing to confirm that The Alzheimer Society of Ireland will provide support to Gareth Duffy in recruiting a sample for his MSc Psychology Dissertation.

This support will include:

- Access to formal (paid) carers in four ASI Dublin-based sites.
- Information about his project will be passed to family carers, where they can then opt-in to be involved in the project.

Yours sincerely

---

Dr. Emer Begley

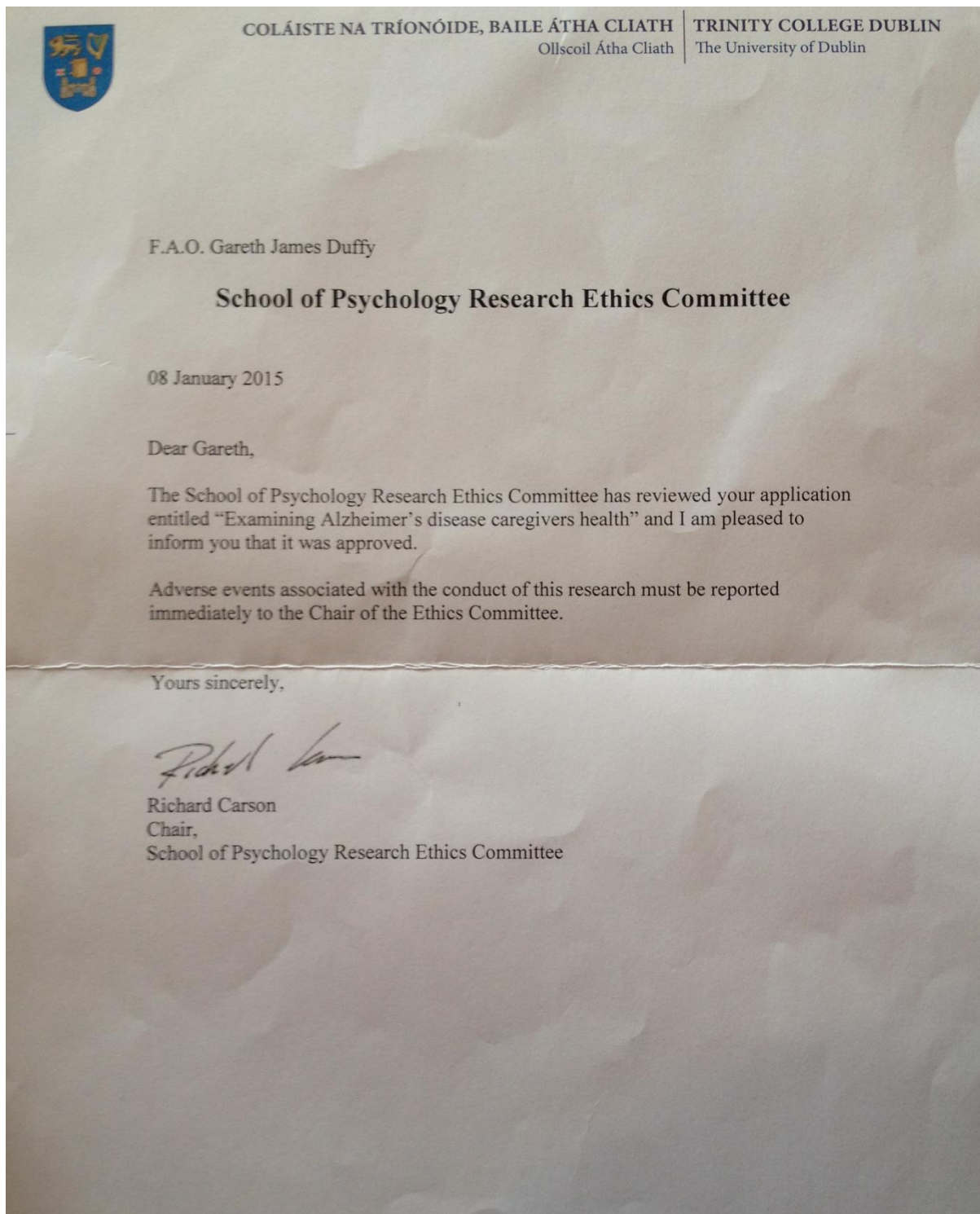
Policy and Research Manager

The Alzheimer Society of Ireland

The Alzheimer Society of Ireland  
National Office  
Temple Road, Blackrock,  
Co. Dublin, Ireland.

PHONE	+353 (0)1 207 3800
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EMAIL	info@alzheimer.ie
WEBSITE	www.alzheimer.ie

## Appendix G



## Appendix H

### Caregiver Burden Scale

Caregiver's name: \_\_\_\_\_ Date: \_\_\_\_\_

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0	1	2	3	4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4



## Appendix I

### The Adult Carer Quality of Life Questionnaire (AC-QoL)

#### How to Fill in the Questionnaire

This questionnaire asks you about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer. The questionnaire shouldn't take more than 10 minutes.

Please answer all questions as honestly as you can.

	Never	Some of the time	A lot of the time	Always
<b>Support for Caring</b>				
01. I have a good level of emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
02. My needs as a carer are considered by professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
03. I am happy with the professional support that is provided to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
04. I feel able to get the help and information I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
05. I have all the practical support I need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Caring Choice</b>				
06. I feel that my life is on hold because of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
07. My social life has suffered because of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
08. I feel I have less choice about my future due to caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
09. I feel I have no control over my own life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Caring stops me doing what I want to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Caring Stress</b>				
11. I feel depressed due to caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I feel worn out as a result of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I am mentally exhausted by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I am physically exhausted by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I feel stressed as a result of caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Never	Some of the time	A lot of the time	Always
<b>Money Matters</b>				
16. I worry about going into debt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I feel satisfied with my financial situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I am able to save for a rainy day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I worry about money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. There is enough money in our house to pay for the things we need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Personal Growth</b>				
21. I have become a more tolerant person through my caring role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Because of caring, I have learnt a lot about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Because of caring, I feel that I have grown as a person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I have experienced many positive things through caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I feel that I have become a better person by caring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Sense of Value</b>				
26. I feel valued by the person I am looking after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. The person I look after respects me for what I do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. The person I look after makes me feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I get a lot from the person I am looking after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I have a good relationship with the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Ability to Care</b>				
31. I am satisfied with my performance as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I can take care of the needs of the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I feel I am able to make the life of the person I am looking after better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I can manage most situations with the person I care for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I am able to deal with a difficult situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Carer Satisfaction</b>				
36. Caring is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I resent having to be a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I feel frustrated with the person I am caring for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I enjoy being a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I am satisfied with my life as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix J

### Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

Name \_\_\_\_\_ Date \_\_\_\_\_

Age \_\_\_\_\_ Gender (Circle): M F Other \_\_\_\_\_

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 | 4 |
| 4. In the last month, how often have you felt confident about your ability to handle your personal problems? .....         | 0 | 1 | 2 | 3 | 4 |
| 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 | 1 | 2 | 3 | 4 |
| 7. In the last month, how often have you been able to control irritations in your life? .....                              | 0 | 1 | 2 | 3 | 4 |
| 8. In the last month, how often have you felt that you were on top of things? ..   | 0 | 1 | 2 | 3 | 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 |
| 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? ..... | 0 | 1 | 2 | 3 | 4 |

## Appendix K

### The Mental Health Inventory (MHI-38)

**INSTRUCTIONS:** Please read each question and tick the box by the ONE statement that best describes how things have been FOR YOU during the past month. There are no right or wrong answers.

1. How happy, satisfied, or pleased have you been with your personal life during the past month? *(Tick one)*
  - 1 ☐ Extremely happy, could not have been more satisfied or pleased
  - 2 ☐ Very happy most of the time
  - 3 ☐ Generally, satisfied, pleased
  - 4 ☐ Sometimes fairly satisfied, sometimes fairly unhappy
  - 5 ☐ Generally dissatisfied, unhappy
  - 6 ☐ Very dissatisfied, unhappy most of the time
2. How much of the time have you felt lonely during the past month? *(Tick one)*

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time
3. How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month? *(Tick one)*

1 <input type="checkbox"/> Always	4 <input type="checkbox"/> Sometimes
2 <input type="checkbox"/> Very often	5 <input type="checkbox"/> Almost never
3 <input type="checkbox"/> Fairly often	6 <input type="checkbox"/> Never
4. During the past month, how much of the time have you felt that the future looks hopeful and promising? *(Tick one)*

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time
5. How much of the time, during the past month, has your daily life been full of things that were interesting to you? *(Tick one)*

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time
6. How much of the time, during the past month, did you feel relaxed and free from tension? *(Tick one)*

1 <input type="checkbox"/> All of the time	4 <input type="checkbox"/> Some of the time
2 <input type="checkbox"/> Most of the time	5 <input type="checkbox"/> A little of the time
3 <input type="checkbox"/> A good bit of the time	6 <input type="checkbox"/> None of the time

7. During the past month, how much of the time have you generally enjoyed the things you do? *(Tick one)*
- |   |   |
|---|---|
| <input type="checkbox"/> 1 All of the time        | <input type="checkbox"/> 4 Some of the time     |
| <input type="checkbox"/> 2 Most of the time       | <input type="checkbox"/> 5 A little of the time |
| <input type="checkbox"/> 3 A good bit of the time | <input type="checkbox"/> 6 None of the time     |
8. During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory? *(Tick one)*
- |   |
|---|
| <input type="checkbox"/> 1 No, not at all                                       |
| <input type="checkbox"/> 2 Maybe a little                                       |
| <input type="checkbox"/> 3 Yes, but not enough to be concerned or worried about |
| <input type="checkbox"/> 4 Yes, and I have been a little concerned              |
| <input type="checkbox"/> 5 Yes, and I am quite concerned                        |
| <input type="checkbox"/> 6 Yes, I am very much concerned about it               |
9. Did you feel depressed during the past month? *(Tick one)*
- |  |
|--|
| <input type="checkbox"/> 1 Yes, to the point that I did not care about anything for days at a time |
| <input type="checkbox"/> 2 Yes, very depressed almost every day                                    |
| <input type="checkbox"/> 3 Yes, quite depressed several times                                      |
| <input type="checkbox"/> 4 Yes, a little depressed now and then                                    |
| <input type="checkbox"/> 5 No, never felt depressed at all   |
10. During the past month, how much of the time have you felt loved and wanted? *(Tick one)*
- |   |   |
|---|---|
| <input type="checkbox"/> 1 All of the time        | <input type="checkbox"/> 4 Some of the time     |
| <input type="checkbox"/> 2 Most of the time       | <input type="checkbox"/> 5 A little of the time |
| <input type="checkbox"/> 3 A good bit of the time | <input type="checkbox"/> 6 None of the time     |
11. How much of the time, during the past month, have you been a very nervous person? *(Tick one)*
- |   |   |
|---|---|
| <input type="checkbox"/> 1 All of the time        | <input type="checkbox"/> 4 Some of the time     |
| <input type="checkbox"/> 2 Most of the time       | <input type="checkbox"/> 5 A little of the time |
| <input type="checkbox"/> 3 A good bit of the time | <input type="checkbox"/> 6 None of the time     |
12. When you have got up in the morning, this past month, about how often did you expect to have an interesting day? *(Tick one)*
- |   |   |
|---|---|
| <input type="checkbox"/> 1 Always       | <input type="checkbox"/> 4 Sometimes    |
| <input type="checkbox"/> 2 Very often   | <input type="checkbox"/> 5 Almost never |
| <input type="checkbox"/> 3 Fairly often | <input type="checkbox"/> 6 Never        |
13. During the past month, how much of the time have you felt tense or "high-strung"? *(Tick one)*
- |   |   |
|---|---|
| <input type="checkbox"/> 1 All of the time        | <input type="checkbox"/> 4 Some of the time     |
| <input type="checkbox"/> 2 Most of the time       | <input type="checkbox"/> 5 A little of the time |
| <input type="checkbox"/> 3 A good bit of the time | <input type="checkbox"/> 6 None of the time     |
14. During the past month, have you been in firm control of your behaviour, thoughts, emotions or feelings? *(Tick one)*
- |   |  |
|---|--|
| <input type="checkbox"/> 1 Yes, very definitely   | <input type="checkbox"/> 4 No, not too well                |
| <input type="checkbox"/> 2 Yes, for the most part | <input type="checkbox"/> 5 No, and I am somewhat disturbed |
| <input type="checkbox"/> 3 Yes, I guess so        | <input type="checkbox"/> 6 No, and I am very disturbed     |

15. During the past month, how often did your hands shake when you tried to do something? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Always       | 4 <input type="checkbox"/> Sometimes    |
| 2 <input type="checkbox"/> Very often   | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never        |
16. During the past month, how often did you feel that you had nothing to look forward to? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Always       | 4 <input type="checkbox"/> Sometimes    |
| 2 <input type="checkbox"/> Very often   | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never        |
17. How much of the time, during the past month, have you felt calm and peaceful? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
18. How much of the time, during the past month, have you felt emotionally stable? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
19. How much of the time, during the past month, have you felt downhearted and blue? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
20. How often have you felt like crying, during the past month? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Always       | 4 <input type="checkbox"/> Sometimes    |
| 2 <input type="checkbox"/> Very often   | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never        |
21. During the past month, how often have you felt that others would be better off if you were dead? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Always       | 4 <input type="checkbox"/> Sometimes    |
| 2 <input type="checkbox"/> Very often   | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never        |
22. How much of the time, during the past month, were you able to relax without difficulty? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
23. How much of the time, during the past month, did you feel that your love relationships, loving and being loved, were full and complete? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |



24. How often, during the past month, did you feel that nothing turned out for you the way you wanted it to? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Always       | 4 <input type="checkbox"/> Sometimes    |
| 2 <input type="checkbox"/> Very often   | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never        |
25. How much have you been bothered by nervousness, or your "nerves", during the past month? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Extremely so, to the point where I could not take care of things | 4 <input type="checkbox"/> Bothered some, enough to notice  |
| 2 <input type="checkbox"/> Very much bothered   | 5 <input type="checkbox"/> Bothered just a little by nerves |
| 3 <input type="checkbox"/> Bothered quite a bit by nerves                                   | 6 <input type="checkbox"/> Not bothered at all by this      |
26. During the past month, how much of the time has living been a wonderful adventure for you? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
27. How often, during the past month, have you felt so down in the dumps that nothing could cheer you up? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Always       | 4 <input type="checkbox"/> Sometimes    |
| 2 <input type="checkbox"/> Very often   | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never        |
28. During the past month, did you think about taking your own life? *(Tick one)*
- |   |
|---|
| 1 <input type="checkbox"/> Yes, very often        |
| 2 <input type="checkbox"/> Yes, fairly often      |
| 3 <input type="checkbox"/> Yes, a couple of times |
| 4 <input type="checkbox"/> Yes, at one time       |
| 5 <input type="checkbox"/> No, never              |
29. During the past month, how much of the time have you felt restless, fidgety, or impatient? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
30. During the past month, how much of the time have you been moody or brooded about things? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
31. How much of the time, during the past month, have you felt cheerful, lighthearted? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |

32. During the past month, how often did you get rattled, upset or flustered? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Always       | 4 <input type="checkbox"/> Sometimes    |
| 2 <input type="checkbox"/> Very often   | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never        |
33. During the past month, have you been anxious or worried? *(Tick one)*
- |   |
|---|
| 1 <input type="checkbox"/> Yes, extremely to the point of being sick or almost sick |
| 2 <input type="checkbox"/> Yes, very much so  |
| 3 <input type="checkbox"/> Yes, quite a bit   |
| 4 <input type="checkbox"/> Yes, some, enough to bother me                           |
| 5 <input type="checkbox"/> Yes, a little bit  |
| 6 <input type="checkbox"/> No, not at all   |
34. During the past month, how much of the time were you a happy person? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
35. How often during the past month did you find yourself trying to calm down? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> Always       | 4 <input type="checkbox"/> Sometimes    |
| 2 <input type="checkbox"/> Very often   | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never        |
36. During the past month, how much of the time have you been in low or very low spirits? *(Tick one)*
- |   |   |
|---|---|
| 1 <input type="checkbox"/> All of the time        | 4 <input type="checkbox"/> Some of the time     |
| 2 <input type="checkbox"/> Most of the time       | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time     |
37. How often, during the past month, have you been waking up feeling fresh and rested? *(Tick one)*
- |  |   |
|--|---|
| 1 <input type="checkbox"/> Always, every day | 4 <input type="checkbox"/> Some days, but usually not   |
| 2 <input type="checkbox"/> Almost every day  | 5 <input type="checkbox"/> Hardly ever                  |
| 3 <input type="checkbox"/> Most days         | 6 <input type="checkbox"/> Never wake up feeling rested |
38. During the past month, have you been under or felt you were under any strain, stress or pressure? *(Tick one)*
- |  |
|--|
| 1 <input type="checkbox"/> Yes, almost more than I could stand or bear |
| 2 <input type="checkbox"/> Yes, quite a bit of pressure                |
| 3 <input type="checkbox"/> Yes, some more than usual                   |
| 4 <input type="checkbox"/> Yes, some, but about normal                 |
| 5 <input type="checkbox"/> Yes, a little bit                           |
| 6 <input type="checkbox"/> No, not at all                              |