The Relationship Between Loneliness and Quality of Life in Informal Dementia Caregivers

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Abstract

Background Informal caregivers are an essential part of dementia support in New Zealand. . The number of people affected by dementia is increasing. Previous studies have indicated that informal caregivers are at risk of poor mental and physical health outcomes, due to the stressors in the caregiving role. These stressors have been identified as risk factors for loneliness. Research in other populations highlights strong links between loneliness and poor health outcomes. This research explored the relationship between primary caregiving stressors, loneliness, isolation and quality of life (QOL) within the framework of the Stress Process Model.

Methods This research investigated hypothesised factors leading to loneliness and quality of life in a New Zealand sample of informal dementia caregivers (n= 134). It used a cross-sectional survey design and structured questionnaire to explore background and context factors (care duration, hours per week caregiving, relationship length and help hours per week), primary stressors (Activities of Daily Living dependency, frequency of challenging behaviour, caregiver reaction and relational deprivation), loneliness, isolation, and quality of life. Descriptive analysis, correlational analysis, confirmatory factor analysis and path analysis were used to examine the relationships between variables and conduct mediation analyses.

Results The findings indicated that QOL was moderate, with the average rating between ‘neither good nor poor’ and ‘good’. The psychological domain was significantly lower than all other domains. Within the sample there was a high prevalence of loneliness (88%) and lower prevalence of isolation (21%). Overall QOL and QOL domains were significantly associated with total loneliness. Among the primary stressors, only the frequency of challenging behaviour correlated to loneliness. Both the frequency of challenging behaviour and caregiver reaction had significant correlations to QOL. Total loneliness partially

mediated the relationship between primary stressors and QOL. Social loneliness was also found to partially mediate this relationship while emotional loneliness did not.

Conclusions The findings show that there was a high prevalence of loneliness in the sample. They also show that primary caregiving stressors are associated with loneliness and that loneliness is associated with quality of life. This research highlights the importance of addressing loneliness in this population, suggests targeted loneliness interventions and recommends caregivers be screened for loneliness to increase access to appropriate support.

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Table of Contents

Abstract 2

Acknowledgements 4

List of Figures 11

List of Tables 12

Chapter One: What is the Relationship Between Loneliness and Quality of Life in Informal Dementia Caregivers? 13

Informal Dementia Caregivers 14

Cultural Aspects of the Caregiving Role 16

Chapter Two: The Stress Process Model as a Guide for Understanding the Development of Stress and Impact on Health in Informal Caregivers 19

Culture and the Stress Process Model 20

Health Outcomes of Demographic, Background, and Context Factors in Informal Caregivers 23

Primary Stressors in Informal Caregiving 25

Summary 27

Chapter Three: Loneliness 28

Definition and Theories of Loneliness 28

Psychodynamic Approach 28

Existential Approach 29

Cognitive Approach 29

Interactionist Approach 30

Delineating Loneliness and Isolation....31
Cultural aspects of Loneliness and Isolation....32
Loneliness and Isolation as Secondary Role Strains for Informal Caregivers....33
Loneliness in Informal Caregivers....35
Isolation in Informal Dementia Caregivers....37
Impacts of Loneliness and Isolation on Health Outcomes....39
Loneliness, Isolation and Physical Health....40
Loneliness, Isolation, and Psychological Health....42
Loneliness, Isolation and Health Behaviours....43
Chapter Four: Quality of life....44
Culture and Quality of Life....45
Primary Stressors and Quality of Life....46
Loneliness, Isolation and Quality of Life....49
Summary....50
Chapter Five: Rationale for the Current Study....52
Chapter Six: Research Questions and Hypotheses....53
Exploratory Questions....53
Hypotheses....53
H1. Background and Context Factors will be Correlated with Quality of Life (Figure 1)....54
H2. Background and Context Factors will be Correlated with Primary Stressors (Figure 1)....54

H3. Background and Context Factors will be Correlated with Loneliness and Isolation (Figure 1) 54

H4. Primary Stressors will be Correlated with Quality of Life (Figure 1) 55

H5. Primary Stressors will be Related to Emotional Loneliness, Social Loneliness, and Isolation to Differing Degrees (Figure 2). 56

H6. Loneliness and Isolation will be Correlated with Quality of Life (Figure 3) 56

Chapter Seven: Method 58

Overview 58

Choice of Study Design 58

Pilot Study 59

Recruitment 59

Online Survey Considerations 61

Inclusion and Exclusion Criteria 62

Sample 62

Incomplete Responses 67

Measures 68

The Questionnaire 69

Background and Context 69

Primary Stressors 69

Loneliness 72

Isolation 74

Quality of Life 76

Cultural Considerations for Measurement Tools 78
Data Analysis 80
Preliminary Analysis 81
Hypotheses 86
Chapter Eight: Results 88
Descriptive Results 88
Background and Context Factors 90
Primary Stressors 90
Individual Stressors 90
Loneliness 91
Isolation 91
Quality of Life 91
Exploratory Questions Addressed by Descriptive Statistics 92
Confirmatory Factor Analysis 93
WHOQOL-BREF 95
DeJong Gierveld Loneliness Measure 97
Social Deprivation Index 98
Relational Deprivation 99
Revised Memory and Behaviour Checklist 99
Correlational Analysis 103
Hypotheses Addressed by Correlational Analysis 105

Path Analysis 105

Mediation Analysis 106

Hypotheses Addressed by Path Analysis 106

Exploratory Question Addressed by Mediation Analysis 109

Chapter Nine: Discussion 113

Assumptions Required for Causal Inferences 114

Quality of Life Profile of Informal Caregivers in this Research 116

Domain Score Differences 117

The Prevalence of Loneliness and Isolation in this Sample of Caregivers 117

Primary Stressors and Quality of Life 119

The Association Between Primary Stressors, Isolation, Loneliness, and Loneliness Type 121

Relationships Between Individual Primary Stressors, Loneliness, Isolation, and Loneliness Type 122

The Relationship Between Loneliness, Isolation and Quality of Life 124

Loneliness as a Mediator Between Primary Stress and Quality of Life 125

The Limited Role of Background and Context Factors in the Relationship Between the Caregiving Role and Quality of Life 126

Relationships Between Background and Context Factors and Primary Stressors 127

Relationships Between Background and Context Factors and Loneliness and Isolation 127

Relationship Length Did Not Correlate to any Outcome Variables 128

Implications....129
Limitations....132
Impact of COVID-19 Lockdown on Recruitment and Study Variables....132
Omission of Socio-Economic Status in Demographic Information....133
Methodological limitations....134
Cultural Limitations and Reflections....136
Directions for Future Research....138
Conclusion....139
References....141
Appendix A....176
Participant Information and Survey....176
Appendix B....207
Research Case Study....207

List of Figures

Figure 1 *Modified Stress Process Model of the Research Variables* 53

Figure 2 55

The Relationship Between Primary Stressors, Emotional Loneliness, Social Loneliness and Isolation 55

Figure 3 *The Relationship Between Emotional Loneliness, Social Loneliness, Isolation, and Quality of Life* 56

Figure 4 *Total Number of Participants who Completed each Measure* 63

Figure 5 *Four Factor Structure for the WHOQOL-BREF* 96

Figure 6 *Two-factor Structure of the DeJong Gierveld Loneliness Measure* 97

Figure 7 *The Single Factor Structure of the Social Disconnection Index* 98

Figure 8 *Single Factor Structure of the Relational Deprivation Measure* 99

Figure 9 *Three Factor Structure of the Revised Memory and Behaviour Checklist – Frequency* 100

Figure 10 *Three Factor Structure of the Revised Memory and Behaviour Checklist – Reaction* 102

Figure 11 *Path Diagram: The Relationships Between Primary Stressors and Loneliness, Isolation and Quality of Life* 108

Figure 12 *Path Diagram: The Relationships Between Loneliness, Isolation and Quality of Life* 108

Figure 13 *Path Diagram: Loneliness as a Partial Mediator in the Relationship Between Primary Stressors and Quality of Life* 110

Figure 14 *Path Diagram: Test of Loneliness Types as Partial Mediators Between Primary Stressors and Quality of Life* 111

List of Tables

Table 1 *Demographic Characteristics of the Sample* 64

Table 2 *Areas Assessed by the NZ WHOQOL-BREF* 77

Table 3 *Fit Indices Used to Evaluate Model Fit and Description of Each* 85

Table 4 *Hypotheses and Acceptance Criteria* 86

Table 5 *Descriptive Statistics for Survey Scales (World Health Organisation Quality of Life – BREF, de Jong Gierveld Loneliness Scale, Social Disconnection Index, Relational Deprivation, Activities of Daily Living Alzheimer's, Revised Memory, and Behaviour Checklist) and Background and Context Factors.* 88

Table 6 *Results of Wilcoxon Signed Ranks Test Comparing Quality of Life and Health Satisfaction* 92

Table 7 *Fit Statistics for Confirmatory Factor Analysis and Path diagrams* 94

Table 8 *Spearman's Correlations of Background and Context factors to Study Variables* .. 104

Table 9 *Results of Mediation Analysis: Loneliness as Mediator Variable Between Primary Stressors and Quality of Life* 110

Table 10 *Results of Mediation Analysis: Emotional Loneliness and Social Loneliness as Mediator Variables Between Primary Stressors and Quality of Life* 112

Chapter One: What is the Relationship Between Loneliness and Quality of Life in Informal Dementia Caregivers?

The family members, friends and non-professionals who help someone with an illness or disability are referred to as, informal caregivers, carers, family caregivers and care partners (Grimmond, 2014; Maidment & Beddoe, 2016). Burholt et al. (2022), estimated that 70,000 people were living with dementia in New Zealand in 2022. The New Zealand prevalence is expected to reach 170,212 by 2050 (Alzheimers New Zealand, 2012). Around 50% of people with dementia in New Zealand are cared for in the community by an informal caregiver (Alzheimers New Zealand, 2012). In 2016 there were approximately 40,000 people providing 45 million hours of care to people living with dementia in NZ with an estimated cost of NZ$68.6 million (Burholt et al., 2022). The 2021 Improving Dementia Mate Wareware Services in Aotearoa New Zealand Action Plan identifies that most family/whānau in New Zealand have someone affected by the diagnosis. The plan, has been developed to drive the sector towards addressing the challenges of dementia in light of the growing impacts. One of the objectives of the plan is to support people with dementia and the people who care for and support them to live well (Croucher et al., 2021).

There is a large body of literature investigating the impacts of caregiving on the health and wellbeing of informal caregivers; informal dementia caregivers have been found to have significantly poorer quality of life and greater risk for psychiatric morbidity than non-caregivers (Goren et al., 2016; Lwi et al., 2017; Mohamad Asfia et al., 2022; Moreno et al., 2015; Roth et al., 2015; Schulz et al., 2020). It is thought that stress, that develops from the caregiving role, is one of the main drivers of these health outcomes (Pinquart & Sörensen, 2004; Roth et al., 2015). Dementia care is said to be more stressful and difficult than caring for other conditions (Basu &

Mukhopadhyay, 2021; Sheehan et al., 2021). Cognitive decline, functional impairment and challenging behaviours are more common when the care receiver has dementia (Basu & Mukhopadhyay, 2021). These factors have been linked to greater levels of stress and burden and lower levels of mental and physical health in informal caregivers (Blake et al., 2022; Secinti et al., 2021; Shin & Kim, 2022). As around half of the dementia population receives informal care, it follows that the number of informal dementia caregivers in New Zealand is also growing (Alzheimers New Zealand, 2012). As such, there is a growing need to understand the challenges experienced by this population. An improved understanding of the challenges will improve support that can be provided and can be used to help achieve the goals of the 2021 Improving Dementia Mate Wareware Services in Aotearoa New Zealand Action Plan (Croucher et al., 2021).

Informal Dementia Caregivers

There are a variety of terms used in the literature to describe those who provide unpaid support to individuals living with dementia, such as ‘carer’, ‘care partner’ and ‘caregiver’ (Prizer & Hudson, 2023). While ‘caregiver’ is the most used term, ‘care partner’ is being used with increasing frequency (Prizer & Hudson, 2023). ‘Care partner’ is used to highlight that the care relationship is a partnership where the person with the diagnosis contributes to their own care and, as this type of caregiving occurs within existing relationships, provides support to their care partner (Prizer & Hudson, 2023). The term ‘caregiver’ places the focus on the individual taking on the caregiving tasks or role (Castro et al., 2023). The term ‘informal caregiver’ is commonly used in the literature to distinguish between paid ‘professional’ caregivers and those who assume the role due to relationship and obligation (for example, family ties and cultural values; Castro et al., 2023), it includes a wide range of relationships (family member, friend or neighbour; Castro

et al., 2023). The focus of this research is on the caregiving role and tasks associated with supporting a person living with dementia. It includes anyone who is taking on these tasks in an unpaid/ non-professional capacity. In this study the term 'informal caregiver' is used to be inclusive to caregivers regardless of the relationship and to align with the focus on caregiver experiences, stressors and outcomes rather than shared experiences within the partnership.

Informal caregivers of people with dementia have a higher mean age than other caregivers (Alzheimer's Association, 2012). They are most often spouses or adult children, female and live with the person with dementia (Burholt et al., 2022). As a group, informal dementia caregivers spend more hours per week providing care than caregivers of other conditions (Sheehan et al., 2021). They help with a wide range of tasks, such as household tasks (gardening, shopping, cooking), personal care and dispensing medications (Lindeza et al., 2024; Maidment & Beddoe, 2016). They also provide emotional support, supervise behaviour, advocate, attend appointments and make decisions regarding respite and long-term care needs (Lindeza et al., 2024; Maidment & Beddoe, 2016).

The literature suggests that informal dementia caregivers have higher levels of stress and depression and lower subjective wellbeing than other caregivers, and age matched non-caregivers (Pinquart & Sörensen, 2007; Sheehan et al., 2021). This is associated with a greater risk of developing health problems (Sheehan et al., 2021). A third of caregivers in Sheehan and colleagues' (2021) study reported that their health was worse due to their caregiving role, this was partially attributed to the amount of care provided, or hours of care per week. In Watson and colleagues' (2019) systematic review of depression and anxiety symptoms in community dwelling older adults with dementia, they found that symptom severity and time since diagnosis were significantly associated with caregivers' depressive symptoms. As dementia caregiving

typically begins shortly after diagnosis this indicates that the duration of caregiving is linked to caregiver wellbeing (Basu & Mukhopadhyay, 2021).

Alongside the objective tasks of caregiving, caregivers report that they deprioritise their own needs which has the potential to compound health impacts by limiting engagement with relaxation and health related behaviours (Duplantier & Williamson, 2023; Vasileiou et al., 2017). Poor physical and mental health in the caregiver can reduce the quality of care they are able to provide, thus impacting the person with dementia (Richardson et al., 2013). Stress, that develops from the caregiving role is thought to drive these health outcomes (Blake et al., 2022; Secinti et al., 2021; Sheehan et al., 2021; Shin & Kim, 2022). The Stress Process Model (Pearlin et al., 1990) is a commonly used conceptualisation of the stress and health relationship in informal caregivers (Ruisoto et al., 2020; Sheehan et al., 2021; Whitlatch, 2001).

Cultural Aspects of the Caregiving Role

Aotearoa New Zealand is a bicultural nation, despite this, European ways of being and knowing have been privileged and the dominant systems in Aotearoa are shaped by these perspectives (Cooke et al., 2007; Heffernan et al., 2023). This has resulted in systems which prioritise autonomy, independence and consider illness from a Western framework (Heffernan et al., 2023). This does not align with Māori views which prioritise interdependence, including dimensions of whānau, culture and spirituality into views of illness and wellbeing (Rochford, 2004). There are differences in perspectives on dementia (mate wareware) and practices of caregiving between Māori and New Zealand European people, similar to differences seen between indigenous and non-indigenous in other colonised countries meaning that there are also differences in caring roles and challenges that may be faced (Racine et al., 2022).

Māori hold a holistic view of mate wareware (dementia), placing it within a social, historical and spiritual context (Dudley et al., 2019). In this way mate wareware (dementia) may be seen as a natural part of aging, where forgetting represents accumulated wisdom or a spiritual transition towards joining ancestors (Dudley et al., 2019). These views exist alongside feelings of stigma, fear and shame (Dudley et al., 2019). Dudley and colleagues (2019) found that Māori associated mate wareware (dementia) with social and cultural disconnection, suggesting an influence of colonisation in negative understandings of dementia. Dudley and colleagues (2019) suggest that for Māori, mate wareware (dementia) is both a medical condition and a manifestation of intergenerational trauma and cultural marginalisation.

For Māori, caregiving is a familial and social expectation, stemming from whānau values which emphasise obligation and reciprocity in relationships (Lapsley et al., 2020). It is typically shared across whānau (Dudley et al., 2019). For Māori, individual wellbeing is intertwined with the wellbeing of the group (Dudley et al., 2019). As such the wellbeing of the caregiver/s and person receiving care are part of whānau wellbeing. From this perspective caregiving is more than caring for the person with dementia, it also holds importance for the wellness of the whānau.

Caregiving among Māori can involve different tasks and priorities compared to non-Māori such as providing spiritual support and connection to community as well as acting advocates and interpreters (Dawes et al., 2022; Lapsley et al., 2020). Lapsley and colleagues (2020) found that Māori caregivers provide more hours of care than non-Māori, which may be due to these additional tasks. Māori caregivers face practical and systemic challenges. For example, caregiving costs for Māori were found to be higher than other groups (Lapsley et al., 2020). The New Zealand Carers' Strategy Action Plan for 2014 to 2018 (Ministry of Social

Development 2014) states that Māori caregivers report experiencing racism, negative experiences with providers and a lack of culturally safe services, these challenges can reduce help-seeking which may compound challenges for Māori caregivers. Less utilisation of support services can limit Māori caregivers' ability to participate in activities which may support them, for example Dyall et al. (2008) found that Māori caregivers (for people who have experienced a stroke) reported that their caregiving tasks interfered with participation in school and community activities.

The caregiving role sits alongside structural disadvantages due to systemic inequalities that are faced by indigenous populations worldwide which has contributed to poorer outcomes across multiple wellbeing indicators (Cooke et al., 2007). These systemic disadvantages experienced by indigenous peoples create a double-burden for indigenous caregivers (Cooke et al., 2007). Hill et al. (2011) found that indigenous caregivers in Australia were more likely than non-indigenous caregivers to experience unemployment, and as a consequence, lower income and fewer resources.

Chapter Two: The Stress Process Model as a Guide for Understanding the Development of Stress and Impact on Health in Informal Caregivers

The Stress Process Model was developed as a framework for understanding stress in live-in informal caregivers of people with dementia (Pearlin et al., 1990). It considers the interactions between background and context factors, primary stressors, secondary role strains, and outcomes (Pearlin et al., 1990). Background and context factors are said to influence the stressors caregivers are exposed to, along with personal resources for coping and reactions to stress (Pearlin et al., 1990). Primary stressors, which are specific to caregiving, are anchored in the needs of the person with dementia and generally increase in severity over time (Pearlin et al., 1990). They are split into two categories; objective (support with activities of daily living, managing challenging behaviour, and neuropsychiatric symptoms such as apathy and depression) and subjective (relational deprivation; Pearlin et al., 1990). In this model secondary role strains are said to develop as consequences of the primary stressors. Pearlin et al. (1990) state that once they develop, they can influence health outcomes to the same degree as the primary stressors. Therefore, gaining an enhanced understanding of secondary role strains, has the potential to enhance support and care for informal caregivers, in turn improving their quality of life.

Robison et al. (2021) reported that background factors (excluding gender) and stressors were significantly related to caregiver outcomes. Specifically, higher Activities of Daily Living (ADL) dependency predicted increased burden and greater help hours predicted reduced burden. Fredriksen-Goldsen et al. (2023) evaluated the Stress Process Model with sexually and gender diverse caregivers. Consistent with the model they found that health outcomes were related to age, income, type of care tasks (ADL support for example) and hours of care provided.

This research examines the associations between aspects of the of caregiving role and loneliness in informal caregivers of people with dementia and its relationship to health outcomes, conceptualised in this project as quality of life. Quality of life is a subjective representation of physical and mental health, which are the outcomes of caregiving stress according to the Stress Process Model (Pearlin et al., 1990; WHOQOL Group, 1994).

Culture and the Stress Process Model

As discussed above, the Stress Process Model is used to understand stress and health outcomes (Pearlin & Bierman, 2013; Pearlin et al., 1990). This model has been developed in and primarily applied in western contexts; the implication of this is the model emphasises the individual, potentially overlooking the shared nature and other culturally embedded aspects of caregiving in non-western contexts (Dudley et al., 2019). It is also important to consider that for Māori, and other indigenous caregivers, stress can develop from systemic barriers, such as racism or lack of culturally appropriate services which can be encountered as part of caregiving (Pitama et al., 2014; Thoits, 2010).

Research exploring ethnic differences in the context of the Stress Process Model has primarily been done in the United States. Hilgeman et al. (2009) explored ethnicity (Caucasian, African American and Hispanic/Latino) as a moderator in the SPM. They used structural equation modelling and found the model demonstrated good fit across groups which provides support for the use of the model in these contexts. They also found that ethnicity moderated the relationship between personal resources and strain. Caucasian caregivers reported higher levels of strain than the other groups even when resources were higher. This may suggest cultural differences in coping. Brown and colleagues (2020) report that this is a common trend in stress literature, minority groups are seen to report higher exposures to stress than majority

counterparts, but do not always report higher levels of psychological distress. This suggests a difference in both exposure and appraisal which may be related to cultural contexts. For example, systemic inequalities may add to stress exposure and intensity, while cultural norms and values may influence how stress is appraised and managed (Brown et al., 2020). Liu et al., (2021) found support for this notion in their systematic review and meta-analysis. They found that African American caregivers reported better wellbeing than Caucasian caregivers. It was suggested that this finding may be related to higher levels of religiosity and familism in African American culture.

Ice et al., (2012) applied the SPM to an indigenous population with Luo grandparent caregivers of orphans in Kenya. In their sample of 640, they found that caregivers had significantly higher levels of perceived stress when compared to non-caregivers. Caregiving burden was not associated with biomarkers of stress (blood pressure and cortisol). Their results were consistent with the Stress Process Model, perceived stress increased with caregiving intensity. Support was found for the role of background and context factors in the relationship, the presence of more adults in the household was associated with lower levels of perceived stress. This may indicate that caregiving responsibilities are shared by these adults which may be associated with lower perceived stress. This work found support for the utility of the model in an indigenous group with areas of similarity to the Māori context, with a collective approach to caregiving. In both contexts caregiving tasks are spread across a wide family network. This indicates that the SPM may have utility for use with Māori, however modifications may be necessary to fully capture the experience.

Many aspects of the caregiving role, explored in the SPM are core for caregivers of all backgrounds, like managing cognitive symptoms (Knight & Sayegh, 2010). It is established that there are additional roles that Māori caregivers take on, such as maintaining cultural connection (Lapsley et al., 2020). As these core aspects of the role are considered to be stressors in the context of the SPM these additional responsibilities may also be considered stressors. While some cultural differences may be captured through the background and context factors in the model, like socioeconomic status. The model does not include a wider lens which could account for issues such as institutional racism which are related to poor wellbeing for Māori (Pitama et al., 2014). These systemic barriers could arguably be considered role-specific strains as they are encountered directly in the caregiving role. Discrimination itself is a chronic stressor, it is independently associated with health outcomes, even when other stressors are accounted for (Thoits, 2010).

Another area which may not be appropriately addressed by the SPM are the cultural buffers to the impacts of stress. Differences in coping resources across cultural groups are influenced by cultural norms such as familism and filial piety (Knight & Sayegh, 2010). These differences were explored by McCleary and Blain (2013) who found that, consistent with the model, primary and secondary role strains arise from role task and additionally culturally based values were related to the caregiver's appraisal of potential stressors.

The available literature on the appropriateness of use of the SPM with indigenous cultures is sparse. It may be appropriate to use at the level of objective stressors as these are core components of the caregiving role which are shared across contexts (Knight & Sayegh, 2010). The literature highlights that that there are additional stressors to consider in work across cultures for example additional tasks that indigenous caregivers may consider core to their role, like

maintaining connection to culture (Lapsley et al., 2020), as well as structural inequalities in the system they are working with (Thoits, 2010). The literature suggests that the most pronounced differences in the stress process between cultures are in terms of appraisal and coping, as such caution should be taken if the intention is that the model is used to explore these aspects, and it may be more appropriate to use culturally specific models to achieve this.

Health Outcomes of Demographic, Background, and Context Factors in Informal Caregivers

Women are more likely than men to be informal caregivers (Yang, 2019). Navaie-Waliser et al. (2002) found that age, gender, and low income were associated with high levels of stress in a cross-sectional study of 1002 caregivers. Being female was associated with the greatest risk of developing caregiving related stress. Females were more likely to be the primary caregiver, aged over 65, married to the care receiver and in poorer emotional health. Women reported greater emotional challenges than men and these were related to balancing caregiving and social participation. This supported findings from Yee and Schulz (2000) who found that female caregivers described higher stress, depression, and anxiety than men. While the literature generally reports that women experience worse outcomes, these may not be solely due to gender differences. There is a suggestion that much of the time women spend caregiving is not reported in the literature, as some caregiving tasks (meal preparation, washing, for example) could be considered as part of a woman's role (Yang, 2019). Therefore, some of the gender differences seen may be related to amount of time spent caregiving.

In terms of the influence of other background and context factors on caregiver physical health (like hours per week providing care and duration of caregiving), findings have been mixed. Pinquart and Sörensen (2007) meta-analysis concluded that amount of caregiving (hours

per week and caregiving duration) was not associated with caregiver wellbeing. However, more recent research has found negative impacts on health outcomes from these factors. Litzelman et al. (2015) found that increased care hours per week, longer duration of caregiving and relationship to the care recipient were associated with higher levels of caregiver strain (measured by the Caregiver Strain Index) in their sample of 264 caregivers of all conditions. Their longitudinal study supported a 'chain of risk' model similar the Stress Process Model, suggesting that these contextual factors accumulate through strain to negatively impact health outcomes. A meta-analysis by Lindt et al. (2020), found that the duration of caregiving significantly predicted caregiver burden. Alfonzo et al. (2024) focussed on young, informal caregivers (under 25, n=8996) and reported a dose-response relationship, where increased caregiving hours correlated with negative impacts on mental health. These differences may reflect how our understanding of caregiving challenges has changed over time. They may also reflect of the lack of standardisation in the literature for reporting both time spent on caregiving tasks and duration of the relationship, this can make drawing conclusions difficult.

The impact of the amount of help caregivers receive on caregiver wellbeing has received less attention in the quantitative literature. More help has been associated with reduced burden, however this association was found in research evaluating help hours following return to informal care after a period of respite (Robison et al., 2021). This does not capture long term impacts, which are relevant to dementia caregiving, given the long-term nature of the role.

Dementia caregivers have described help as essential to their wellbeing in qualitative research (Hazzan et al., 2022; Oliveira et al., 2020). Hazzan et al. (2022) found that caregivers considered unpaid help from friends and family important for wellbeing. Oliveira et al. (2020) had similar findings in their research with 150 dementia caregivers over 60. Thematic analysis of

these interviews indicated that help was considered a crucial component, with participants expressing a need for time away, access to formal services and social support.

Primary Stressors in Informal Caregiving

Primary stressors include, managing challenging behaviour, supporting with ADLs, and relational deprivation (Pearlin et al., 1990). Challenging behaviours are symptoms of dementia and can include increased aggression, disinhibition, anxious and depressive behaviours, and hallucinations (Teri et al., 1992). These symptoms have a non-linear progression, can be unpredictable, difficult to manage and are said to have a large impact on the caregiver's daily life (Basu & Mukhopadhyay, 2021).

In a 2021 review, Basu and Mukhopadhyay found that prolonged exposure to challenging behaviours strongly influenced caregiver health. This supports research by Ervin, Pallant, et al. (2015) who found that these symptoms were reported as highly stressful by caregivers. Almost half (n=19) of the caregivers in their sample reported stress levels on the moderate to extremely severe range, on the Depression and Anxiety Stress Scale (DASS). Behavioural and psychological symptoms in the person with dementia (measured with the Neuropsychiatric Inventory Questionnaire) were associated with caregivers' scores on the DASS. Caregivers reported that anxiety, apathy, and agitation were related to higher levels of distress, these symptoms were reported by over 70% of caregivers. This relationship has been seen in informal caregivers of all conditions, in Pinquart and Sörensen (2007) meta-analysis of 228 studies, behavioural problems of the care receiver had the highest correlation to caregiver stress, these associations were more pronounced for dementia caregivers.

Increased functional impairment has also been described as stressful, with the potential to impact health (Basu & Mukhopadhyay, 2019; Clark & Bond, 2000). In cross-sectional research

with 134 caregivers Basu and Mukhopadhyay (2019) found that caregivers who provided greater ADL support experienced higher levels of stress and anxiety when compared to caregivers providing less support. Activity patterns have been shown to be associated with physical and mental health, links have been found between participation in satisfying activity, cognitive performance, psychological wellbeing and QOL (Clark & Bond, 2000). Clark and Bond (2000) found that caregivers were more active in domestic and service activities than non-caregiving peers and that this was related to the progression of dementia and thus amount of ADL support they were providing.

The qualitative literature also describes associations between challenging behaviour, ADL support and caregiving stress. Unson et al. (2015), conducted focus groups with informal dementia caregivers (n = 24). These caregivers reported that stress was related to a lack of personal boundaries, repetitive behaviours, hygiene, aggression, and the constant nature of providing care. They also discussed loss of free time, personhood, and their relationship with the person with dementia. Ervin, Reid, et al. (2015), also explored the experience of stress in informal caregiving and had similar findings. Participants reported that stress came from the struggle of balancing caregiving responsibilities with other aspects in their life and feeling like the job was never done. Participants described stress as stemming from behavioural and psychological symptoms. Loss was also described by participants who felt that their grief for the past relationship was related to stress.

Relational deprivation is a primary stressor in The Stress Process Model (Pearlin et al., 1990). It relates to the loss, through dementia, of a companion, confidant, or support person (Beeson, 2003). Kolodziej et al. (2022) found that relationship quality substantially decreased with the amount of care provided and increased concern that the person with dementia is well

cared for. Caregivers have reported that deterioration of the relationship occurs through caregiving challenges (Schulz et al., 2020). Beeson (2003) investigated relational deprivation, quality of the current relationship and distance felt due to caregiving, they found that caregivers who felt more distance from their relative due to caregiving experienced more relational deprivation. According to Pearlin et al. (1990) this loss of reciprocal exchange is related to increased stress for the caregiver.

Summary

The Primary stressors addressed in this research are, challenging behaviour, reaction to challenging behaviour, ALD dependency and relational deprivation. The literature has found these factors to be related to increased stress and poor health in caregivers supporting their role in the Stress Process Model (Basu & Mukhopadhyay, 2019, 2021; Ervin, Pallant, et al., 2015; Pearlin et al., 1990; Unson et al., 2015). Challenging behaviour has been reported to have the most severe impact on caregivers' lives (Basu & Mukhopadhyay, 2021). Increased ADL dependency has been described as stressful and time consuming, reducing time available for engagement in other activities (Basu & Mukhopadhyay, 2019). Although relational deprivation has received less attention in the literature, what is available supports its inclusion in the model as a primary stressor. Relational deprivation is thought to be associated with increased stress (Beeson, 2003; Pearlin et al., 1990). According to the Stress Process Model the cumulative impact of these factors can directly influence health for caregivers and indirectly through the development of secondary role strains (Pearlin et al., 1990).

Chapter Three: Loneliness

Definition and Theories of Loneliness

Loneliness is a subjective, unpleasant emotional state that occurs when an individual perceives a discrepancy between desired and actual levels of social connection and contact (Peplau, 1985). It occurs when an individual feels they have fewer social contacts than they would like, or when an individual feels that their current relationships lack quality (Peplau, 1985).

The definition of loneliness used in this research approaches loneliness from an interactionist perspective alongside the Weiss (1975) typology which separates loneliness into social and emotional components. A consideration of these dimensions of loneliness may be useful when considering interventions to alleviate loneliness in this population, as pathways to developing these loneliness types are different, as are perpetuating factors (Masi et al., 2011). There are four predominant theories of loneliness: psychodynamic, existential, cognitive, and interactionist approaches (Tzouvara et al., 2015).

Psychodynamic Approach

From a psychodynamic perspective, deficits in attachment from infancy result in shortages in social skills required to develop intimate relationships contributing to the development of loneliness (Singh & Kiran, 2013). Psychodynamic theory has contributed to current understanding by distinguishing the experience of being lonely from alone (Singh & Kiran, 2013).

This perspective has been criticised for its reliance on observations of people with mental illness, rather than taking a wider societal perspective (Tzouvara et al., 2015). Alongside this, it does not consider other factors related to loneliness like culture, age, and bereavement (Tzouvara

et al., 2015). It also does not address health related difficulties associated with loneliness (Singh & Kiran, 2013).

Existential Approach

The existential approach views loneliness as a reflexive and positive condition which allows individuals to build on their understanding of themselves (Victor et al., 2000). In this view loneliness can be 'true loneliness' or 'anxiety loneliness'. True loneliness relates to the realisation that humans are alone in life. Anxiety loneliness is characterised by a response mechanism that people develop to avoid facing the realisation of their lonely existence (Tzouvara et al., 2015).

The existential perspective on loneliness has been criticised for taking a positive stance on loneliness, when other theoretical perspectives consider it to be a solely negative experience (Weiss, 1975). It has also been criticised for not explaining predisposing, precipitating and perpetuating factors which can lead to difficulty in using this perspective to alleviate loneliness (Gallagher, 2023). Existential theories also lack the distinction between the subjective and objective notion of feeling alone, as existentialists view loneliness as an essential condition where people are perceived to be lonely rather than describing themselves as lonely (Gallagher, 2023). There is an acknowledgement in the literature that people can be alone without feeling lonely and that people who feel lonely are not always alone (Tzouvara et al., 2015).

Cognitive Approach

The cognitive approach focusses on the role of cognitive processes in the development and maintenance of loneliness (Peplau, 1985). It emphasises how an individual's thoughts, perceptions and interpretations of their social relationships influence their feeling of loneliness

(Peplau, 1985). It draws on cognitive biases, social cognition, and maladaptive thought patterns to show causes and maintaining factors but also targets for intervention.

From this perspective people who experience loneliness exhibit certain cognitive biases that can influence perceptions of social interactions for example, a tendency to interpret social cues as negative (Hawkley et al., 2010). Maladaptive thought patterns are though to create a cycle where loneliness leads to negative thoughts such as negative self-evaluations or pessimism about social situations and relationships which then reinforces negative feelings (Masi et al., 2011). The cognitive approach emphasises that cognitive processes are mediating factors between perceived loneliness and the intensity of negative emotions (Peplau, 1985). Like the other approaches it has been criticised for a lack of consideration of cultural effects on loneliness (Tzouvara et al., 2015).

Interactionist Approach

The interactionist perspective is based on Attachment Theory, which corresponds to the Psychodynamic Theory of loneliness. Bowlby (1973, as cited in Tzouvara et al., 2015) stated that secure attachment in early life positively influences later relationships. The interactionist approach suggests that loneliness is a result of the interaction of situational and personal factors, for example a lack of adequate social network and lack of intimate attachment figure (Singh & Kiran, 2013). This view contains elements of both cognitive and psychodynamic theory. The interactionist approach has been criticised for limiting its conceptualisation of loneliness to only negative factors, while evidence exists for the role of other neutral factors such as age, gender, and culture (Dahlberg & McKee, 2014).

Weiss (1975) loneliness typology of social and emotional loneliness represents the interactionist approach. Emotional loneliness relates to attachment, it is experienced when need

for attachment is perceived to be lacking (Ciolfi & Jimenez, 2017). This could be caused by not having close relationships with people to confide in (Ciolfi & Jimenez, 2017). Social loneliness relates to an individual's perception of social interactions and may not reflect how objectively isolated someone is (Ciolfi & Jimenez, 2017). Both are described as 'lonely', but the subjective experience is different, as is the method for relieving the distress caused. For example, relief from emotional loneliness may require the development of close relationships whereas social loneliness may be relieved by activities that promote social integration (Masi et al., 2011). As the probability of creating new close relationships decreases with age, this distinction is particularly relevant for studies of older adults (Luanaigh & Lawlor, 2008).

Dahlberg and McKee (2014) provided empirical evidence for the interactionist approach in a UK-based study. They found that emotional loneliness was significantly predicted by factors such as being widowed, while social loneliness was significantly predicted by low contact with friends. This research also found that the constructs shared limited variance, supporting research by Green et al. (2001) where loneliness types were only moderately correlated. Green et al. (2001) found that emotional loneliness was related to the presence of a romantic partner, while the average closeness of the individual's network predicted social loneliness in older adults. Recently, Wolters et al. (2023) supported the evidence for the separation of the constructs. In their research social loneliness was most strongly explained by isolation and emotional loneliness was most strongly explained by depression and anxiety.

Delineating Loneliness and Isolation

Isolation is often conflated conceptually and empirically with loneliness. Isolation is objective; it reflects an individual's contacts and relationships with others (Cornwell & Waite, 2009). It is a quantifiable reflection of reduced network size and thus lack of social contact

(Steptoe et al., 2013). Measurement of isolation varies across social contexts and research objectives, as such there is no gold standard measure for isolation (Zavaleta et al., 2017). It is important to select a measurement strategy that aligns with the conceptual definition of isolation and doesn't conflate loneliness and isolation for conceptual clarity.

Cultural aspects of Loneliness and Isolation

The definition of loneliness explored above as a subjective experience involving perceived deficiencies in the quality and quantity of relationships, separate from isolation has been applied across a variety of cultures including Māori (Morgan et al., 2020; Moeke-Maxwell, 2023; Van Staden & Coetzee, 2010; Wright-St Clair et al., 2017).Wright-St Clair et al. (2017) conducted a review of studies of loneliness for older people in Aotearoa New Zealand found that loneliness and isolation were typically examined separately, and that isolation was not necessarily considered to be a component of loneliness. The experience of loneliness can differ between cultures, as expectations for closeness, connection, and relationships are shaped by cultural meaning and vary between cultures (Van Staden & Coetzee, 2010; Waldegrave et al., 2020). Van Staden and Coetzee (2010) state that an additional feature of loneliness exists for non-majority migrant cultures, cultural loneliness, where worldview, identity and values are unrecognised in the person's context. This concept may be relevant for Māori, although indigenous to Aotearoa New Zealand, society is shaped by New Zealand European norms which may disrupt Māori identity and values potentially inducing loneliness.

Māori are disproportionately affected by loneliness compared to non-Māori (Lay-Yee et al., 2022; Wright-St Clair et al., 2017). This disparity has been attributed to the ongoing impacts of colonisation, urban migration, disruption to whānau structures, marginalisation and cultural disconnection (Lay-Yee et al., 2022; Morgan et al., 2020; Moeke-Maxwell, 2023; Waldegrave et

al., 2020; Wright-St Clair et al., 2017). Despite higher prevalence of loneliness among Māori compared to non-Māori, loneliness has been found to have a lesser association to health-related quality of life for Māori (Lay-Yee et al., 2022). As the links between loneliness and health outcomes are strong across a variety of populations (Holt-Lunstad et al., 2010) this may be due to a difference in the experience and expression of loneliness for Māori or indicate that there are aspects of Māori loneliness not captured in the study. It may also reflect difference in perspectives on wellbeing. Morgan et al. (2020) found that Māori participants described loneliness as both a lack of contact with others and a disconnection from cultural identity and place. Participants also placed importance on whānau relationships, with feelings of loneliness mitigated by knowledge of whānau activities even without regular contact. Participants also reported feelings of loneliness related to whānau not following tikanga (customs and traditions) by prioritising their nuclear family or work over maintaining connection with elders. The centrality of whānau in loneliness was also found by Waldegrave et al. (2020) who qualitatively explored the items on the de Jong Gierveld loneliness scale with Māori. Participants in this research reflected that closeness with whānau made more sense in the context of loneliness than closeness with a friend. Moeke-Maxwell (2023) discussed the importance of culturally embedded expectations for people's connection to whānau, place and cultural roles in loneliness, stating that even in the presence of social contact loneliness may be felt if these expectations are unfulfilled.

Loneliness and Isolation as Secondary Role Strains for Informal Caregivers

There has been a limited exploration of loneliness in the informal dementia caregiving literature. Based on the literature surrounding loneliness in other populations, primary stressors in the Stress Process Model have been identified as potential risk factors for the development of

loneliness and isolation in informal caregivers. Loneliness has yet to be measured as a specific secondary strain, arising from primary stressors. This is an important gap in the literature, as loneliness is a well-established risk factor for poor health (Holt-Lunstad et al., 2015; Quadt et al., 2020). Therefore, loneliness may mediate the relationship between caregiving stressors and poor health that has been evidenced in the informal caregiving population (Blake et al., 2022; Secinti et al., 2021; Sheehan et al., 2021; Shin & Kim, 2022).

Demographic factors may hold inherent risk for the development of loneliness and isolation (Menec et al., 2020), dementia most commonly affects older adults, as caregivers are often spouses or partners, they are commonly older themselves (Alzheimer's Association, 2012). The loss of a significant other is the most common risk factor for both loneliness and isolation for adults over 65 (Somes, 2021). Background and context factors such as time spent caregiving and duration of caregiving may also increase the risk of developing loneliness through their impact on free time. The association of these factors with greater progression of dementia potentially increases the likelihood of changes in the relationship between the caregiver and person with dementia, increasing the risk of emotional loneliness (Green et al., 2001; Litzelman et al., 2015). Primary stressors lead to changes social and recreational activities (Vasileiou et al., 2017) and emotional connection (Beeson, 2003). Informal dementia caregivers describe a lack of time for socialising arising from caregiving responsibilities as well as the loss of their relationship with the person with dementia (Ervin, Pallant, et al., 2015). Given the influence that primary stressors can have on the caregivers' ability to socialise and maintain relationships, it follows that loneliness may develop in informal caregivers and that they may become isolated. The development of loneliness may mediate the influences of caregiving stressors on informal caregivers' health (Blake et al., 2022; Secinti et al., 2021; Sheehan et al., 2021; Shin & Kim,

2022). Therefore, informal caregivers who develop loneliness due to caregiving may experience a compounded risk for low wellbeing.

Loneliness in Informal Caregivers

Qualitative literature has explored experiences of loneliness to a greater degree than quantitative research and both indicate that loneliness is experienced by caregivers. Greenwood and Smith (2019) conducted a thematic analysis on five focus groups with older caregivers (aged 70+). Loneliness, and loss featured prominently in the responses. Loneliness appeared to develop from isolation, relating to feelings arising from diminishing social circles and losing connection with friends who did not understand the health conditions informal caregivers were assisting with. Participants also described withdrawing from others due to uncertainty about the behaviour of the care recipient when socialising. Older participants were less likely to ask for support and more likely to describe themselves as lonely and isolated than their younger counterparts. Participants also commented that they had reduced energy for socialising. Importantly, participants described how loneliness had increased as caregiving progressed due to the change in the relationship with the person they are caring for. This was described as loneliness within the relationship. Loneliness was perceived as especially significant for housebound caregivers and those caring for someone with dementia.

Vasileiou et al. (2017) examined experiences of caregiving-related loneliness in informal caregivers of several conditions including dementia. Their thematic analysis highlighted that loneliness could develop out of reduced social interactions and personal space due to the caregiving role. Social interactions that did occur were also said to induce feelings of loneliness. Participants reported being unsatisfied with their social interactions as they felt the challenges of caregiving were misunderstood by their friends. Participants linked loneliness to loss of the

relationship with the care receiver. This was especially prevalent in the responses of spousal caregivers of people with dementia. Spouses described feelings of their previous relationship being lost due to the decline of care receiver's communication and ability to participate in activities previously enjoyed as a couple.

Research focusing solely on informal dementia caregivers has found similar themes. Loss was highlighted by Evans and Lee (2014) in their systematic qualitative review on the impact of dementia on marriage. Descriptions of the impact were characterised by the transition in roles and the relationship that occurred after onset of dementia and the loss of the self, partner, and relationship. Qualitative research provides the strongest evidence for the experience of loneliness within the informal dementia caregiving context and the connection between primary stressors and loneliness. Responses appear to capture both social and emotional loneliness. Relationships were discussed between the caregiving responsibilities and the limitations this puts on time for socialising and social relationships(Evans & Lee, 2014; Vasileiou et al., 2017). Also captured were themes of change within the relationship which may be indicators of emotional loneliness (Evans & Lee, 2014; Vasileiou et al., 2017).

Although there is limited exploration of the loneliness within the Stress Process Model in the quantitative literature, there is evidence that loneliness is a factor of the caregiving experience. Beeson et al. (2000), found that loneliness was significantly related to depression ($r = .66$, $p < .001$), relational deprivation ($r = .36$, $p < .001$), and quality of the current relationship ($r = .34$, $p < .001$) in their sample of 242 informal dementia caregivers. Beeson et al. (2003) also reported gender differences with loneliness, relational deprivation and quality of the relationship predicting depression for 41% of caregiving wives and 30% of husbands. This research used a single item to measure loneliness (do you feel lonely?) which is thought to under report

loneliness due to the stigma associated with the emotion (Shiovitz-Ezra & Ayalon, 2012). Beeson (2003) revisited the relationship between loneliness and depression using the UCLA loneliness scale (20-item) and found that loneliness explained 49% of the variance in Alzheimer's Disease caregiver depression. Caregiving spouses had significantly higher levels of both loneliness and depression (mean, 9.12; SD, 8.27) than non-caregiving spouses (mean, 3.77; SD, 4.05). The UCLA loneliness scale is a more robust measure of loneliness; however, it may lack the specificity to explore the experience of loneliness in this population. According to the Weiss typology loneliness consists of emotional and social factors (Weiss, 1975). The Stress Process Model points to possible deficiencies in both social and emotional relationship factors due to the stressors of informal caregiving. A multidimensional measure of loneliness which captures both social and emotional aspects, such as the de Jong-Gierveld Loneliness Scale (de Jong-Gierveld, 1987), could provide a clearer picture of the experience.

More recently quantitative findings have been mixed. Longitudinal research by Hajek and König (2019) found no association between informal caregiving and loneliness, despite finding that informal caregiving significantly impacted satisfaction with leisure activities. Zwar et al. (2020) also found no association between informal care and loneliness, in longitudinal panel data. Loneliness was reported in Liao and colleagues' (2024) systematic review and meta-analysis of loneliness among informal caregivers of people with dementia (27 papers involving 11,134 informal caregivers from 17 different countries) found the pooled prevalence of loneliness to be 50.8% (95% CI: 26.7% - 47.6%). Interestingly, they found that the factors that most influenced the prevalence between studies included were study design, data collection time and choice of assessment tools.

Isolation in Informal Dementia Caregivers

Isolation has also been found to feature in the informal caregiving experience, tending to increase with disease progression, largely due to symptom and disease related factors (Wawrziczny et al., 2017). Isolation is thought to occur when people around the caregiver retreat or the caregiver withdraws from those around them (Wawrziczny et al., 2017). People retreat for a variety of reasons for example, not knowing how to respond to symptoms, fear, lack of knowledge, stigmatization and a lack of understanding of the caregiving experience (Wawrziczny et al., 2017). Caregivers reportedly withdraw from others to avoid burdening them, difficulty with leaving the person with dementia and feeling distressed about their ability to manage behavioural symptoms (Wawrziczny et al., 2017).

Robert et al. (2017)found that while people in all stages of dementia caregiving reported increased psychological pressure and distress, those in later stages reported experiencing greater caregiving responsibilities and isolation with reports of feeling ‘tied to the house’. This supports findings from Greenwood and Smith (2016) whose thematic analysis found descriptions of isolation related to both disease and symptom progression. Participants described connections lost with friends who did not understand the condition, as well as withdrawal from others due to uncertainty about the behaviour of the care recipient when socialising. They also found that older caregivers were less likely to ask for support and hypothesised that this was related to the increased isolation that older caregivers also reported. Vasileiou et al. (2017) reported similar findings in their thematic analysis where caregivers reported that they did not have the ability to commit to plans because they needed to put the person with dementia’s needs first.

While caregivers qualitatively report indicators of isolation, quantitative literature is less conclusive. Robison et al. (2009) found that caregivers (of all conditions) were not more isolated than non-caregivers (measured by days they left the house) and Sibalija et al. (2020) analysed

data from the Canadian Longitudinal study of Aging and found that caregivers reported significantly higher levels of social participation than non-caregivers.

Qualitative research by Davies et al. (2019) may provide insight into this, their participants reported that while they experienced a loss of family and friends who were not involved in the caregiving, they developed new social connections specific to their caregiving needs. There is evidence to suggest that isolation changes depending on stage of dementia. Initial stages have been linked to expanded social networks as caregivers make new connections (Hajek et al., 2021; Lee et al., 2022). As different symptoms emerge caregivers are prompted to seek new knowledge and support which also has the impact of reducing isolation (Lee et al., 2022).

The theory of Sustaining Place provides an explanation for this process (Daly et al., 2013). It states that informal caregivers experience changes in their social interactions as they experience 'threats to place' in adapting to dementia's impact. This leads them to redefine themselves and their relationships by gaining knowledge, engaging professional supports, and joining support networks (Daly et al., 2013). Isolation can reoccur if the progression of dementia recomplicates these relationships (Daly et al., 2013).

Impacts of Loneliness and Isolation on Health Outcomes

Although research in the informal caregiving population is sparse, the wider literature has consistently linked loneliness and isolation to poor mental and physical health outcomes (Holt-Lunstad et al., 2015; Holt-Lunstad & Steptoe, 2022; Quadt et al., 2020). One of the most notable arguments for the health risks of loneliness and isolation was put forward by Holt-Lunstad et al. (2015). Their meta-analysis found that individuals who had satisfactory social relationships had a 50% greater chance of survival than those who did not. The magnitude of this effect was found to be comparable to smoking and greater than many other well recognised risk factors for

mortality such as obesity. These findings have been supported more recently in a review by Quadt et al. (2020), who found that loneliness is associated with negative impacts on physical and mental wellbeing as well as increased risk of morbidity and mortality. In their review Holt-Lunstad and Steptoe (2022) suggest that the presence of others (proximity and contact) are strong predictors of health, in some cases stronger than other aspects of relationships. The extent to which loneliness and isolation contribute independently to health outcomes is unclear, as much of the existing literature does not examine these constructs together, however growing evidence suggests that isolation predicts mortality independently of loneliness (Holt-Lunstad & Steptoe, 2022).

Loneliness, Isolation and Physical Health

Loneliness and isolation have been found to have significant impacts on physical health, cognitive function and mortality. Tilvis et al. (2012) followed a sample (n = 3858) of older adults (>75 years) for seven years. They found that 46.1% were socially isolated, 39.4% socially inactive and 37% lonely. The mortality rate for people in the lonely, inactive, and isolated group was 52.9%, compared to 29.9% in the neither lonely, nor inactive nor isolated group. Loneliness and inactivity were independent mortality risk factors while isolation was not a risk factor for mortality. Valtorta, Kanaan, Gilbody, Ronzi, et al. (2016) meta-analysis of longitudinal observational studies reported similar findings. Poor social relationships were found to be associated with a 29% increase in incidence of coronary heart disease and 32% increase in the incidence of stroke. The authors suggested that the size of this association was comparable to the effect of anxiety. Christiansen et al. (2021) conducted longitudinal research with Danish participants (n= 27,678) and found that loneliness and isolation were independently associated with cardiovascular disease and type-2 diabetes.

Steptoe et al. (2013) examined whether the health impacts of isolation were due to loneliness, using data from the English Longitudinal Study of Aging (n = 6500). After ruling out baseline health variables they found that isolation but not loneliness was associated with increased mortality. However, in this research loneliness was associated with higher baseline mental and physical health problems, than the isolation without loneliness cohort. This indicates that both loneliness and isolation are associated with higher mortality rates.

Cognitive function has also been associated with loneliness and isolation with the literature providing evidence for and against each relationship. Holwerda et al. (2014) assessed the relationship between loneliness, isolation, and dementia. Loneliness was associated with the onset of dementia at follow up (three years; odds ratio, 1.64, 95% CI [1.05 to 2.56]). Around thirteen percent of participants with feelings of loneliness at baseline developed dementia at follow up compared with 5.7% who did not have feelings at of loneliness baseline. Isolation was not associated with a higher dementia risk. Although this research is longitudinal, inferences regarding causality should be considered with caution. Neuropsychiatric changes can occur some years before a diagnosis of dementia (Bature et al., 2017). Loneliness is correlated with depression (Teo et al., 2013), which is thought to be an indicator of prodromal dementia (Bature et al., 2017), as such, measurements of loneliness in this sample may have been confounded by symptoms of the early stages of dementia. Penninkilampi et al. (2018) found that poor social engagement indices (poor social network and poor social engagement) were significantly associated with increased dementia risk in their systematic review and meta-analysis of case-control studies (pooling results from 2.3 million participants). Loneliness was non-significantly associated with increased risk for dementia.

More recently, Yu et al. (2021) analysed data from the China Health and Retirement Longitudinal study and found that loneliness was significantly associated with cognitive decline; however, this association did not remain significant after adjusting for presence of chronic disease, heath behaviour, disabilities and depressive symptoms. In contrast, isolation (measured by marriage, contact with others and participation in social activities) was significantly associated with decreased cognitive function, and it remained so after controlling for loneliness and above variables.

These findings were supported by Shen et al. (2022) who found that isolation (assessed by living alone, frequency of social contact and participation in social activities) was associated with a 1.26-fold increased risk of dementia (95% CI, 1.15–1.37) independently of various risk factors including loneliness and depression.

Loneliness, Isolation, and Psychological Health

Teo et al. (2013) found a relationship between depression, isolation and relationship quality at baseline and 10-year follow up. Risk of depression at follow up was highest for participants with greater negative aspects of social relationships, low social support, and low relationship quality at baseline. Quality of social relationships was significantly associated with risk of depression (adjusted odds ratio, 2.65; 95% CI, [1.86–3.76]), even after controlling for the effect of depression at baseline. Participants with the lowest relationship quality at baseline had double the risk of developing depression (adjusted odds ratio 14.0%; 95% CI, [12.0–16.0]; $p<.001$) compared to those with the highest relationship quality (adjusted odds ratio 6.7%; 95% CI, [5.3–8.1]; $p<.001$). This finding has been supported more recently by Menec et al. (2020) who assessed the influence of loneliness and isolation on psychological distress. Participants were classified into four groups (isolated, lonely, isolated and lonely, neither isolated nor lonely).

They found that the isolated and lonely group had an increased likelihood of psychological distress compared to the neither isolated nor lonely group. The lonely group had a greater likelihood of psychological distress compared to the isolated group.

Loneliness, Isolation and Health Behaviours

It has been suggested that lonely individuals have poor health beliefs and behaviours which in turn leads to poor health outcomes (Lauder et al., 2006). Loneliness and isolation have been associated with increases in substance use, poor sleep, reduced physical activity and poor diet (Hawkley et al., 2010). In a cross-sectional study (n = 1289) lonely individuals were more likely to smoke and have significantly higher BMIs compared to non-lonely individuals even when age, gender, employment, and marital status were controlled for (Lauder et al., 2006). These findings were expanded on by Nieminen et al. (2013) who compared social capital and health behaviours. They found that social participation was associated with smoking, drinking, physical activity, vegetable consumption and sleep. Participants with higher social capital were found to have higher feelings of mental and physical health. This relationship was primarily influenced by the participation domain of social capital. Higher levels of social participation were positively correlated to higher engagement in health behaviour, particularly leisure and physical activity. This association remained significant after controlling for sociodemographic characteristics.

Chapter Four: Quality of life

The outcomes of caregiving stressors can be seen in informal caregivers' mental and physical health (Pearlin et al., 1990). Quality of life (QOL) is a broadband outcome measure which allows for the consideration of the interrelationship of health factors (WHOQOL Group, 1994). Quality of life encompasses aspects that are shown to influence physical and mental health, such as perceptions of mood and energy, functional status, and health conditions (WHOQOL Group, 1994). The WHOQOL Group (1994), defines QOL as a dynamic interplay between an individual's perception of their position in life, in the context of their culture and values which influences their goals and standards. Broadly speaking QOL encompasses individual's perceptions of their position in life, influenced by their perceptions of physical and psychological health, level of independence, social relationships, and environmental satisfaction (WHOQOL Group, 1994). In the context of caregiving, QOL is a tool to understand physical, psychological, social, and environmental functioning, it has become a core construct used to measure the caregiver experience (Glozman, 2004).

There is an association between informal caregiving and caregiver QOL, this appears to be particularly significant for those caring for people with dementia. Martis et al. (2024) found that informal dementia caregivers reported higher levels of stress and significantly lower QOL (measured by the WHOQOL-BREF), than caregivers of other conditions. A significant association was also seen between hours spent caregiving and QOL. This supports findings from Karg and colleagues' (2018) cross sectional research (n = 386) which identified dementia diagnosis in the care receiver as a predictor of poor QOL in the caregiver. In this research dementia caregivers reported poorer health and QOL than caregivers of other conditions, this relationship was seen after controlling for sex, age and employment. Dementia caregivers have

also been found to have poorer QOL compared to the general population. Andreakou et al. (2016) found that caring for a relative with Alzheimer's Disease was associated with poor QOL scores across all domains, and increased depressive symptoms compared to the general population. This relationship was particularly significant for those providing support in the later stages of the disease as well as those providing more hours of care, living with the care receiver, poor financial status and personal illness.

Culture and Quality of Life

The application of the concept of quality of life across cultural groups rests on the assumption that definitions and components of wellbeing are common across cultures and contexts (Durie, 2006). There is a growing understanding that indigenous concepts of health and wellbeing are not the same as non-indigenous, and that they include additional aspects (Cram, 2014; Gall et al., 2021). A review by Gall et al. (2021) highlighted that a core feature of indigenous wellbeing is it's holistic, interconnected nature. They identified common themes to indigenous peoples such as connection to culture, tribe, family and community as well as the concepts of self-determination and the importance of balance in mental, physical, spiritual and emotional aspects of life. As such universal definitions and indicators may not fully capture wellbeing for indigenous groups (Cram, 2014; Durie, 2006). To add necessary complexity, it is also important to note that indigenous are not a homogenous group. Gall and colleagues(2021) review found similarities in conceptualisations in indigenous groups in Aotearoa, Canada and the United States but also highlighted that the Māori conceptualisation added concepts of whakapapa (genealogy), and connection to whānau (family), whenua (land) and tupuna (ancestors).

One of the most widely cited models of Māori wellbeing is Te Whare Tapa Whā, was developed from a hui of Māori health workers and described by Durie in 1994 (Cram, 2014;

Rochford, 2004). Wellbeing represented by a wharenui (meeting house), supported by four pillars, taha tinana (physical), taha hinengaro (psychological), taha whanau (family) and taha wairua (spiritual) (Rochford, 2004). The wharenui and its pillars are supported by the whenua (land), which symbolises the importance of connection to place and associated ties to identity and ancestry (Rochford, 2004). All areas are important to the wharenui, and difficulty in one area affects the whole, emphasising that for Māori wellbeing is the sum of the whole. The Meihana model expands on Te Whare Tapa Whā to include a consideration of the ongoing impact colonisation and systemic inequalities in Māori wellbeing (Pitama et al., 2014). These conceptualisations are reflected in the literature. Dyall and colleagues (2014) found that higher health related QOL was related to measures of cultural engagement (like frequency of visits to Marae), they also found that experiencing discrimination was linked to lower mental health QOL. While useful for providing empirical support to Māori specific aspects of QOL it is important to note that this research used the SF-12, which was developed for use in the general population and does not account for culturally important dimensions such as wairua (spiritual wellbeing; Sullivan et al., 2023).

The holistic and interconnected nature of wellbeing, as outlined in both Te Whare Tapa Whā and Meihana (Pitama et al., 2014; Rochford, 2004) is another aspect of wellbeing which may not be captured by generalist conceptualisations. Cram (2014) conducted interviews with Kaumatua, questions asked attempted explore QOL as separate components. They found that participants responses commonly combined areas, for example physical activity was included in discussions about mental wellbeing. This reflects a holistic perspective to wellbeing.

Primary Stressors and Quality of Life

The outcomes in the Stress Process Model are conceptualised in this research as QOL. Primary stressors such as the functional dependence and neuropsychiatric symptoms of the person with dementia have been found to be related to QOL of the informal caregiver. Although not directly measured, there is slight evidence for the role of loneliness in this relationship. Andrieu et al. (2007) found an overall negative correlation between care receiver dependency and caregiver QOL (measured with the SF-36). This research used a measure of QOL which provides information about perceived social functioning. The social functioning domain of the SF-36 showed a significant decrease in relation to level of dependency of the person with dementia. This indicates that dependency affects the caregiver's satisfaction with their social functioning. The level of dependency of the person with dementia was found to have a greater impact on the informal caregivers' QOL than disease severity, given the strong relationship between dependency and the social functioning domain, this could provide support for the importance of social relationships in QOL. These findings were supported by Nogueira et al. (2015) who found that functional status of the person with dementia was negatively correlated with caregiver QOL ($\rho = -0.27$, $p = 0.04$; measured with QOL-AD). The QOL-AD assesses satisfaction with friendships however individual domain scores were not reported in this research, so it is not known if this influenced the overall QOL score.

Lethin et al. (2017) found that informal caregivers who reported high psychological wellbeing also reported less caregiver burden compared with informal caregivers who reported low psychological wellbeing. They also found that informal dementia caregivers who supported someone with higher neuropsychiatric symptoms reported lower psychological wellbeing than informal dementia caregivers who supported someone with fewer of these symptoms. Psychological wellbeing was measured by the Global Health Questionnaire (GHQ-12) and

compared to QOL (EuroQoL). Quality of life was found to be higher in informal caregivers who also reported increased psychological wellbeing compared to informal caregivers reporting low psychological wellbeing. This research provides evidence for the relationship between primary stressors and QOL, however it does not include a consideration of social functioning. Measures such as the WHOQOL-BREF or the SF-36 contain a social functioning domain, the EuroQoL does not, as such we cannot infer how social functioning may have influenced this relationship. Contreras et al. (2021) found that challenging behaviour and psychological symptoms in the person with dementia had a weak but significant effect on caregiver QOL.

There is evidence to suggest that subjective variables have a stronger relationship to QOL than objective variables. Santos et al. (2014) found that objective variables, like functional status of the person with dementia, were less predictive of informal caregiver QOL than subjective variables like informal caregiver depression and burden. This indicates that factors associated with the informal caregiver's psychological wellbeing may be more important to QOL than factors associated with the care receiver. Oba et al. (2018), examined the direct and indirect relationships between the characteristics of people with dementia and their informal caregiver's QOL (n = 110 caregivers). Caregiver QOL (measured by the WHOQOL-BREF) was directly influenced by caregiver factors, such as caregiver burden and the depressive symptoms. Characteristics of the person with dementia, such as functional status, behavioural and psychological symptoms did not directly affect caregiver QOL. This suggests that subjective experiences of the caregiver may be stronger contributors to QOL than objective strains. These findings provide further insight into the relationship between primary stressors and QOL, they suggest that it is the effect the stressors have on the caregiver that influence QOL rather than the

stressors themselves. If loneliness is a consequence of primary stressors, this could provide evidence for its role in the relationship between caregiving stress and quality of life.

Loneliness, Isolation and Quality of Life

Loneliness and isolation in informal dementia caregivers have been examined in relation to quality of life. Ekwall et al. (2005) compared loneliness, social network, age, gender, and socioeconomic status in a population-based sample. Interestingly, these informal caregivers reported lower feelings of loneliness and larger social networks than non-caregivers. In this sample, there was a significant relationship between low psychological QOL (measured with SF-12), small social network and loneliness. For informal caregivers, loneliness was the most important predictor of low QOL. Fekete et al. (2019) used latent profile analysis to determine profiles of functioning among older informal caregivers in New Zealand (n = 336). Differences between profiles were driven by social support which was conceptualised as the quality and quantity of social relationships and measured by The Practitioner Assessment of Network Type, The Social Provisions Scale and the de Jong Gierveld Loneliness Scale. The optimally functioning profile had positive outcomes and low levels of depression. Those with a poorly functioning profile had extremely high levels of depression and extremely low levels of positive outcomes. A one standard deviation in loneliness was associated with 2.08 increase in the odds of being in the poorly functioning profile compared to the optimally functioning profile. The poorly functioning profile had the lowest value on all social support variables. This research suggests that social relationships are an important mediator between caregiving and health outcomes.

Research using more specific measurement of isolation has also found associations between isolation and QOL. Barnes et al. (2022) found that participants who were both lonely and isolated had lower QOL than those who were not. Their cross-sectional survey of adults aged

over 65 in the United States used the UCLA Loneliness Scale and the Social Network Index also found that isolated participants had lower physical QOL scores. Another cross-sectional study (n=1,252) using the Lubben Social Network Scale found that higher levels of isolation were associated with lower QOL after controlling for sociodemographic and health factors (Moreno-Tamayo et al., 2020). These cross-sectional studies support the relationship between isolation and QOL. However, as poor health can influence QOL and increase risk of isolation, longitudinal studies that measure isolation before the onset of health difficulties, can provide a more conclusive understanding of these relationships (Holt-Lunstad & Steptoe, 2022).

Summary

The outcome measure in this research is quality of life. This is an assessment of overall wellbeing as well as satisfaction with various aspects of life (Billington et al., 2010). Research conducted internationally has found that informal dementia caregivers are at a greater risk of poor physical and mental health than non-caregivers (Basu & Mukhopadhyay, 2021; Sheehan et al., 2021).

It is well established in the literature that informal caregiving leads to stress which can negatively influence physical and mental wellbeing (Goren et al., 2016; Lwi et al., 2017; Mohamad Asfia et al., 2022; Moreno et al., 2015; Roth et al., 2015; Schulz et al., 2020). The Stress Process Model (SPM) is a commonly used conceptualisation of caregiving stress and its health impacts (Ruisoto et al., 2020; Sheehan et al., 2021). Using the SPM, and robust literature regarding influences of the caregiving role on health outcomes as a guide we can see that many of these aspects are common to the drivers of loneliness (Goren et al., 2016; Holt-Lunstad et al., 2015; Lwi et al., 2017; Mohamad Asfia et al., 2022; Moreno et al., 2015; Roth et al., 2015; Schulz et al., 2020).

The informal dementia caregiving population is underrepresented in research exploring the prevalence of loneliness and the impact of the development of loneliness on health. Evidence to support this association is primarily found within the qualitative literature (Evans & Lee, 2014; Greenwood & Smith, 2016; Vasileiou et al., 2017). While findings from these studies cannot establish a correlation, they do report themes which indicate that there is a connection between the stressors in the SPM and the experience of loneliness. Quantitative research has found links between elements of the SPM and loneliness (Hajek et al., 2021; Menec et al., 2020), but loneliness has yet to be specifically explored within the SPM. This research seeks to further our understanding of how the informal caregiving role influences quality of life of caregivers by exploring the development of loneliness within the SPM.

Additionally, qualitative findings include descriptions of loneliness from both a social and emotional perspective (Greenwood & Smith, 2016; Vasileiou et al., 2017). Findings include reported limitations on time for socialising and difficulties maintaining social relationships; as well as themes of loss, change and grief in the relationship between caregiver and receiver (Greenwood & Smith, 2016; Vasileiou et al., 2017). The SPM points to possible deficiencies in both social and emotional relationship factors because of caregiving. The present research addresses this by using a multi-dimensional measure of loneliness (the de Jong-Gierveld Loneliness Scale; de Jong- Gierveld, 1987; see method for discussion). Matching interventions to the type of loneliness can increase their efficacy (Masi et al., 2011). A multi-dimensional measure of loneliness increases the ability of the research findings to be used to support our caregivers in New Zealand.

Chapter Five: Rationale for the Current Study

At least 50% of New Zealanders with dementia receive support from an informal caregiver, typically a spouse, partner, adult child, or friend (Cornwall & Davey, 2004). Within the New Zealand context, the prioritisation of informal community care and private care over formal social services, has placed a great responsibility on informal caregivers (Lay-Yee et al., 2017). Despite the essential work they provide, informal caregivers are reportedly poorly supported and undervalued by policy makers (Burholt et al., 2022). It is in New Zealand's best interest to grow our understanding of the health and wellbeing of this population. This aligns with the goals of the Improving Dementia Mate Wareware Services in Aotearoa New Zealand Action Plan, as findings may be used to improve support for people who care for people with demenita (Croucher et al., 2021).

The current study seeks to contribute to the existing literature by using a quantitative methodology to further our understanding of wellbeing in informal caregivers of people with dementia, conceptualised as quality of life. It also aims to explore loneliness in informal caregivers of people with dementia in the context of the SPM and associations between loneliness and the quality of life of these individuals in a New Zealand setting. The exploratory questions and hypotheses have been developed to address these aims.

Chapter Six: Research Questions and Hypotheses

Exploratory Questions

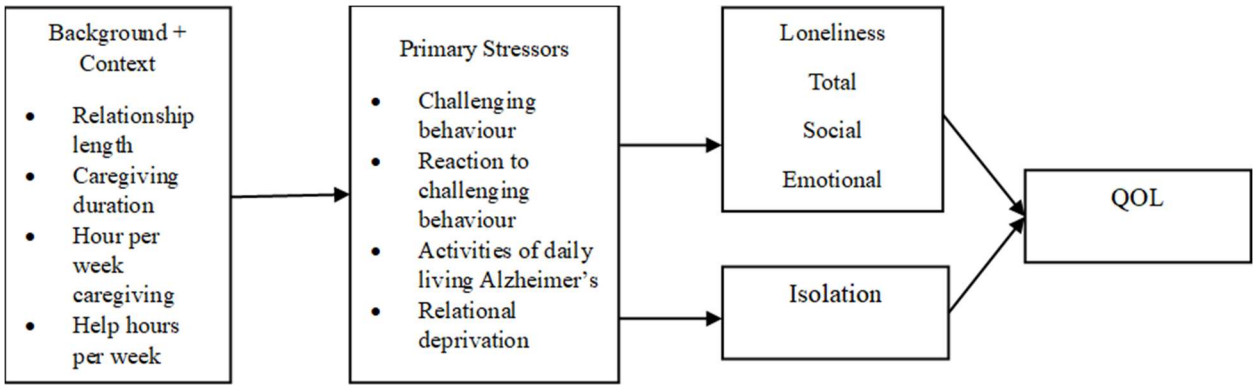
1. What is the quality of life profile of informal caregivers of people with dementia?
2. What is the prevalence of loneliness among informal caregivers of people with dementia?
3. To what extent is the quality of life of informal caregivers of people with dementia correlated to their loneliness profile?
4. Do emotional loneliness and social loneliness function as mediators in the relationship between caregiving stress and quality of life?

Hypotheses

The hypotheses focus on the relationship between primary caregiving stressors, total loneliness, emotional loneliness, social loneliness, isolation and quality of life in a New Zealand sample of informal caregivers of people with dementia.

Figure 1

Modified Stress Process Model of the Research Variables



H1. Background and Context Factors will be Correlated with Quality of Life (Figure 1)

The background and context factors included are relationship length, caregiving duration, hours per week caregiving and help hours per week. Quality of life reflects an individual's perspective on their health and wellbeing (WHOQOL Group, 1994). A longer caregiving history is expected to indicate a greater progression of dementia. Higher functional impairment has been linked to greater stress (Bom et al., 2018). More help hours may indicate more support, which may be related to QOL, by mitigating the amount of primary stressors. Thus, these factors in the caregiver's background and context will be correlated to their quality of life.

H2. Background and Context Factors will be Correlated with Primary Stressors (Figure 1)

Primary stressors (challenging behaviour, caregiver reaction to behaviour, ADL dependence, and relational deprivation) are directly related to the provision of care (Santos et al., 2014). Background and context factors are suggested to be key to the development of primary stressors by influencing the kind of stress caregivers are exposed to (e.g., caregiving duration), as well as their resources and reactions to stress (Pearlin et al., 1990). Experiences of stress have been found to differ between these background and context factors in a variety of populations (Thoits, 2013).

H3. Background and Context Factors will be Correlated with Loneliness and Isolation (Figure 1)

It is expected that background and context factors will be related to loneliness through their associations with leisure, social networks, and close relationships (Litzelman et al., 2015; Menec et al., 2020; Vasileiou et al., 2017). Caregiving duration and hours per week spent caregiving is expected to be related to the amount of other time caregivers have, limiting time for participation in and maintenance of social relationships (Vasileiou et al., 2017). A longer

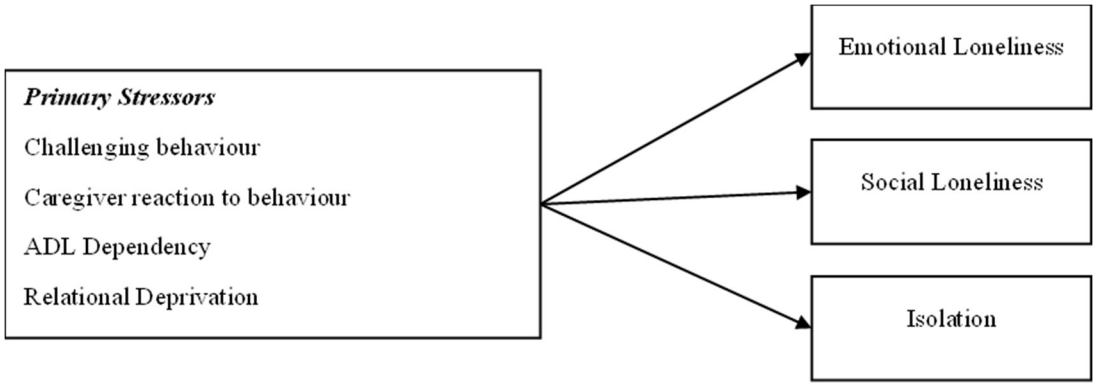
relationship length is expected to be related to greater feelings of loss with relationship changes that come with dementia (Beeson, 2003).

H4. Primary Stressors will be Correlated with Quality of Life (Figure 1)

Informal dementia caregivers have been found to report higher levels of stress and burden than caregivers of other conditions (Basu & Mukhopadhyay, 2021; Sheehan et al., 2021). This is thought to be related to stressors that are more prevalent in dementia care. Challenging behaviours, ADL dependency and involuntary loss of the relationship have been reported as the most stressful aspects of informal dementia caregiving (Basu & Mukhopadhyay, 2021; Pearlin et al., 1990; Sheehan et al., 2021; Watson et al., 2019; Wu-Chung et al., 2022). Challenging behaviour and ADL dependency have been found to be important predictors of caregiver burden (Bergvall et al., 2011). Greater stress is related to physical and mental health in the caregiving and general population (Farina et al., 2017; Thoits, 2010). It is expected that this will be related to the caregiver's subjective evaluation of their quality of life.

Figure 2

The Relationship Between Primary Stressors, Emotional Loneliness, Social Loneliness and Isolation

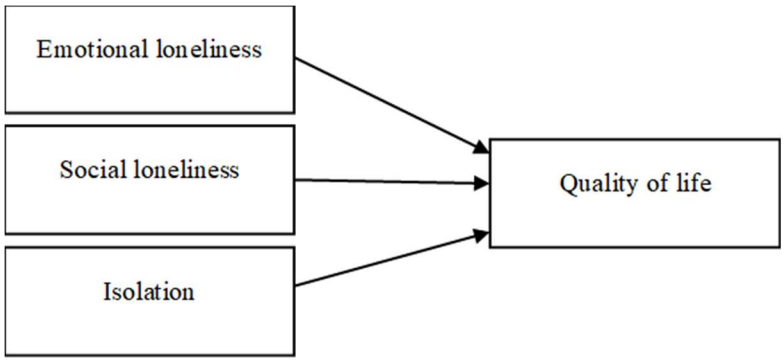


H5. Primary Stressors will be Related to Emotional Loneliness, Social Loneliness, and Isolation to Differing Degrees (Figure 2).

Primary stressors are expected to be associated with caregiver loneliness through restrictions on ability to socialise, time for socialising and loss of a close relationship. According to the Weiss typology of loneliness, these factors could lead to loneliness if the caregiver perceives their relationships to be deficient (Ciolfi & Jimenez, 2017). A greater amount of challenging behaviour and functional impairment may be linked to the caregiver's ability to socialise and maintain relationships. Greater relational deprivation may indicate that the caregiver is experiencing the loss of the relationship.

Figure 3

The Relationship Between Emotional Loneliness, Social Loneliness, Isolation, and Quality of Life



H6. Loneliness and Isolation will be Correlated with Quality of Life (Figure 3)

Loneliness and isolation have been linked to physical and mental health outcomes (Holt-Lunstad et al., 2015; Holt-Lunstad et al., 2010). If greater loneliness and isolation are related to

poor mental and physical health outcomes and quality of life is a measure of perceived wellbeing it follows that there will be a correlation between these factors.

It is theorised that emotional loneliness, social loneliness, and isolation are associated with health through different pathways (Coyle & Dugan, 2012). As the antecedents to each are different it is expected they will develop through separate deficiencies in the caregiver's circumstances. A multidimensional measure of quality of life will present domain scores which will highlight relationships between loneliness, isolation and each domain.

Chapter Seven: Method

Overview

This research was conducted on a New Zealand sample of informal caregivers of people with dementia. It investigated factors hypothesised to contribute to the development of loneliness as well as the association of loneliness and quality of life for these individuals. A cross-sectional survey design which utilised a structured questionnaire was used to explore the multiple variables under investigation: background, and context factors (caregiving duration, hours per week spent on caregiving tasks, relationship length and help hours per week), primary stressors (ADL dependency, behaviour frequency, caregiver reaction and relational deprivation), loneliness, isolation and quality of life.

Data were collected using an online survey, using Qualtrics, which includes functionality to prevent multiple responses from the same device and ensure all responses are anonymous. A Low-Risk Notification was made to the Massey University Ethics Committee.

Choice of Study Design

The cross-sectional survey design was chosen as it was considered the most feasible approach given access to participants and time and resource limitations of a doctoral project. An organisation with experience in engaging with caregivers and supporting with research was consulted in the planning stages. They agreed to promote the research to their database of 8000 members and recommended using an online survey to collect responses. This recommendation was based on their experience with research conducted in this way which typically collected high response rates. The use of a structured online survey enabled efficient data collection. Advice around engaging with Māori participants was sought from Dr Pita King. He advised that face-to-face approaches are more appropriate than online surveys. However, given the access to a large

database with a history of high response rates, the cross-sectional online survey was determined to be the most feasible to meet the aims of the research within the limitations. The impacts of COVID-19 (see limitations for a discussion) limited participant numbers, the limited sample led to the choice of path analysis which allowed for it allows for testing the hypothesised relationships within this constraint.

Pilot Study

A small pilot study was conducted to determine suitability of survey materials and data collection protocols. Participants were asked to provide feedback on the ease of access to the survey, any challenges using the online platform (Qualtrics) and comprehension of consent forms. The researcher used responses to determine if length of time to complete the survey was appropriate as well as pre-empt any challenges with data entry. Feedback from the pilot study indicated that the survey was suitable for use.

Recruitment

Individuals were eligible to participate if they were the primary informal caregiver for someone with a diagnosis of dementia at the time of completing the survey (March 2020 to March 2021). An informal caregiver is defined as an individual who provides support to someone with long term condition/s who lives at home (Greenwood & Smith, 2019). An informal caregiver may receive government assistance for providing care, but they are not employed by the care receiver (Greenwood & Smith, 2019).

Path analysis requires a sample size of 10 to 25 times the number of survey items, with a lower bound of 100 to 200 (Bentler & Yuan, 1999). Initial discussions with a community organisation who were supportive of the research indicated that this would be achievable based

on their previous experience with promoting research to their database of 8000. The organisation reported they typically saw a 10-15% response rate to survey research.

The research was initially agreed to be promoted to potential participants by a unique email to the organisation's database as advised by them to maximise participation. The email was planned to be sent in February 2020; the recruitment process was subsequently heavily impacted by COVID-19. With the growing uncertainty surrounding COVID-19 in early 2020 and subsequent lockdowns the organisation deprioritised the promotion of the research to deliver only essential information to their databases, and later to conduct their own research into the impacts of the lockdown at the time. Participant numbers were likely heavily impacted by this change, as well as the unique and challenging time that COVID-19 brought.

During 2020 other community organisations in New Zealand who supported informal caregivers of people with dementia were contacted to request support in promoting the research. Participants were recruited with assistance from Dementia Auckland, Dementia Canterbury, and Alzheimer's New Zealand. Dementia Auckland and Dementia Canterbury included information about the research and an anonymous link to the survey in their quarterly newsletter which was emailed to their database. Their email databases are primarily made up of people with dementia and their caregivers. However, as anyone can sign up to receive this information, the database is made up of a variety of interested people. Alzheimer's New Zealand advertised the research on their website and Facebook page. As with Dementia Auckland and Canterbury, Alzheimer's New Zealand's content is open to view, as such, this research was promoted to a range of individuals.

Steps were taken to ensure responses were only collected from the target population. The link included in electronic promotion took potential participants to a webpage which contained information about the research as well as eligibility criteria (see Appendix for participant

information sheet and survey). The survey targeted the primary informal caregiver of a person with dementia. This was defined as someone providing unpaid care to a person living with dementia at home. The intention was to identify participants most likely to be experiencing the primary stressors in order to observe associations between stressors, loneliness, isolation and quality of life. Participants were provided with information about how the study defined primary informal caregiver alongside examples of caregiving tasks (e.g. managing medication, providing personal care, organising respite). It was also stated that primary caregivers may receive help from others. It was assumed that in contexts where tasks were shared (like in the case of whānau caregiving) there would be individual/s who identified with this description and that it would be inclusive of whānau caregiving arrangements (limitations of this decision are discussed in the limitations section). Potential participants were able to click through to the consent form, only those who provided consent by checking a box were able to proceed to the screening question. One screening question required participants to confirm that they were an informal caregiver and that the person that they were caring for had dementia. Participants who either did not consent, or who did not self-identify as informal caregivers of people with dementia (as determined by the screening question) were directed to the final page of the survey and were not able to provide any answers to the survey items.

Online Survey Considerations

Data from internet service providers in 2017 indicated that 79% of New Zealanders have internet access in their homes, and others have access to the internet elsewhere (Lips et al., 2020). Collecting data online has advantages over mail-out and in-person questionnaires, overall time is reduced as are the costs (Remillard et al., 2014). Although internet use has been found to be lower among older adults (Remillard et al., 2014), this was not expected to be an issue in this

research. Participants were recruited from an email database, on advice from an organisation that frequently communicates with informal dementia caregivers, as such they were expected to have access to and basic proficiency with the internet.

Inclusion and Exclusion Criteria

The inclusion criteria required participants to be informal caregivers for a person with dementia. Exclusion criteria was as follows:

1. Participants who answered 'no' to the survey consent item were not permitted to continue the survey.
2. Participants who answered 'no' to being an informal caregiver of someone with dementia were not permitted to continue.

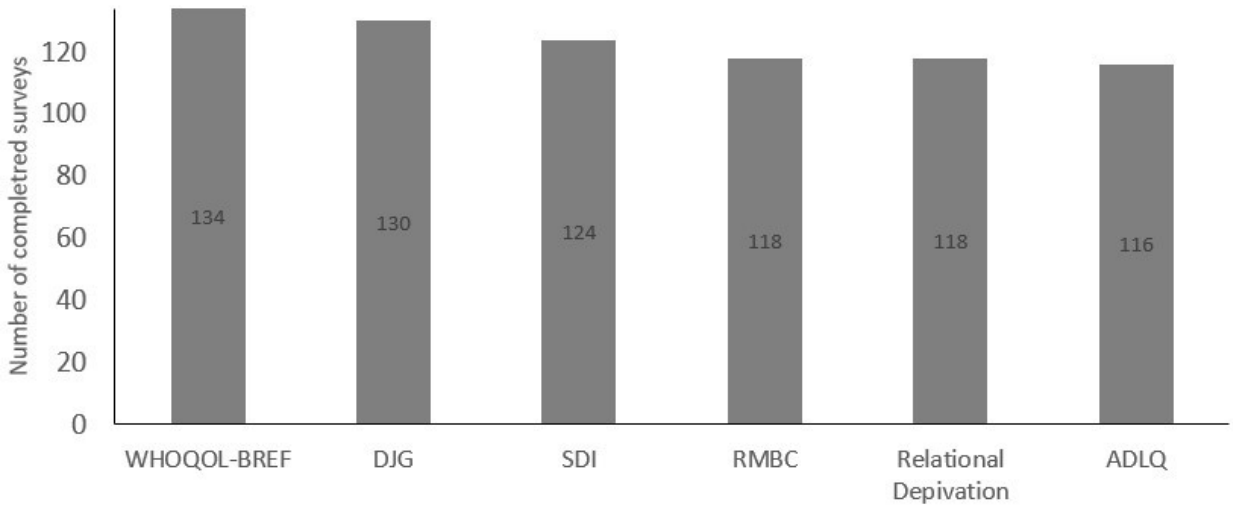
   The theoretical framework is specific to informal caregivers and the challenges faced in informal dementia caregiving, therefore it was important that responses from others; paid caregivers or people caring for other conditions or non-caregivers were not collected.
3. Participants who completed < 50% of the following items and scales were not included in the analysis.
   i. World Health Organisation Quality of Life Scale – Brief (WHOQOL-BREF; 26 item)
   ii. De Jong Gierveld Loneliness (DJG;11 item)
   iii. Relational Deprivation (6 item)
   iv. Social Disconnection Index (SDI; 20 item)
   v. Revised Memory and Behaviour Checklist (RMBC; 24 item)
   vi. Activities of Daily Living Questionnaire (ADLQ; 28 item)

Sample

A total of 241 participants consented to participating in this research. Of these, 62 participants indicated that they were not the primary informal caregiver, and no further data was collected. A further 45 participants did not complete any measures beyond screening question. The final sample size was 134 participants. The distribution of participants who completed each measure is displayed in Figure 4.

Figure 4

Total Number of Participants who Completed each Measure



Note. WHOQOL-BREF: World Health Organization Quality of Life – Brief, DJG: de Jong-Gierveld Loneliness Scale, SDI: Social Disconnection Index, RMBC: Revised Memory and Behaviour Checklist, ADLQ: Activities of Daily Living Questionnaire

The demographic characteristics of the sample are presented in Table 1. Most participants identified as female (n=118, 88%) and New Zealand European (n=111, 83%). The average age was 64.98 years (SD= 12.30). Most participants were married (n=90, 67%). In terms of education, all but one participant reported that they had a secondary education (n= 43, 32%) or

higher (n= 85, 63%). Participants tended to be retired (n= 64, 48%) or engaged in either full or part-time employment (n=13, 10% and n=31, 23% respectively). Approximately 41% of participants (n= 55) indicated that they were currently managing their own medical condition.

For caregiving roles, most participants were responsible for the care of their spouse (n= 72, 54%) or parent (n= 39, 29%) and were living with the individuals they were providing care for (n= 112, 84%). External assistance in caregiving was reported by 60% of participants (n= 80).

Table 1

Demographic Characteristics of the Sample

	N	%	M	SD	Min-max
Age			64.98	12.30	27-89
21-30	1	1%			
31-40	4	3%			
41-50	12	9%			
51-60	21	16%			
61-70	51	38%			
71-80	31	23%			
81-90	13	10%			
Missing	1	1%			
Sex					
Female	118	88%			
Male	16	12%			
Ethnicity					
NZ European	111	83%			
Māori	6	4%			
NZ European and Māori	3	2%			
Cook Island Māori	1	1%			
Niuean	1	1%			
NZ European, Māori and Chinese	1	1%			

NZ European, Māori and Cook Island Māori	1	1%
Samoan	1	1%
Missing	4	3%
Other	4	3%
Marital status		
Single	12	9%
Married	90	67%
Living as married	12	9%
Separated	1	1%
Divorced	7	5%
Widowed	5	4%
Partner/boyfriend/girlfriend not living together	4	3%
missing	3	2
Education		
Primary	1	1%
Secondary	43	32%
Tertiary	85	63%
Missing	5	4%
Employment		
Retired	64	48%
Part time	31	23%
Full time	13	10%
Unemployed	8	6%
Student	2	1%
Other	12	9%
missing	4	3%
Personal medical condition		
Yes	55	41%
No	79	59%
Who are you caring for?		
Spouse	72	54%
Parent	39	29%
Someone Else	7	5%
In-Law	4	3%
Partner/girlfriend/boyfriend	4	3%
Friend	2	1%
Grandparent	1	1%
Missing	5	4%

Length of the relationship (years)			46.08	17.39	.5 - 74
0-10	8	6%			
10-20	3	2%			
20-30	9	7%			
30-40	12	9%			
40-50	24	18%			
50-60	35	26%			
60-70	30	22%			
70-80	3	2%			
Missing	10	7%			
Do you have help?					
Yes	80	60%			
No	54	40%			
Living situation					
Lives with care receiver	112	84%			
Lives without care receiver	17	13%			
Missing	5	4%			
Years spent caregiving			3.85	3.86	0-24
1-2	42	31%			
2-4	47	35%			
4-6	19	14%			
6-8	10	7%			
8-10	6	4%			
10-12	5	4%			
12+	5	4%			
Hours per week spent caregiving			67.84	60.90	2-168
0-20	26	19%			
20-40	32	24%			
40-60	16	12%			
60-80	8	6%			
80-100	6	4%			
100+	34	25%			
Missing	12	9%			
Help hours per week			18.48	28.23	0-168
0-10	44	56%			
10-20	15	19%			
20-30	10	13%			
30-40	4	5%			
40+	5	6%			

Incomplete Responses

In cases where responses contained missed items the procedure for missing data points outlines in each survey manual was followed. For example, the WHOQOL-BREF manual recommends the following process: each survey should be checked for missing items and those with > 20% of data missing should be discarded (this did not apply to any participants). Following this, individual domains should be examined, if more than two items are missing from a domain, the domain score should not be calculated. Finally, where two or less items are missing from a domain, the mean of the other items in the domain is substituted (WHOQOL Group, 1995). For the WHOQOL-BREF it is important to note that the manual advises scoring the national items separately from the core 26-items, therefore any missing national items did not influence this procedure (WHOQOL Group, 1995).

The manual for the DGJ recommends a similar procedure, stating that in cases where a participant missed two or more items the case should be deleted from analysis (this did not apply to any participants). In cases where a participant has missed < 2 items, these values should be replaced by the mean (de Jong-Gierveld, 1987). Scoring instructions for The Social Disconnection Index stated that if more than two indicators were missing, the index should not be scored (Bassuk et al., 1999). The following did not have information for managing incomplete responses, Relational Deprivation, Revised Memory and Behaviour Checklist and Activities of Daily Living Alzheimer's.

Missing data considerations are important due to their potential to impact validity and reliability of findings (Baraldi & Enders, 2010). The percentage of missing data should dictate the management technique used and the framework recommended by Mirzaei et al. (2022) was

followed. In this study, there was 3.71% missing data. As the percentage is less than 5%, this can be considered negligible and likelihood methods are recommended (Mirzaei et al., 2022).

To address missing responses in this study, path analysis employed Maximum Likelihood Estimation (MLE; Baraldi & Enders, 2010). MLE uses all available information in the estimation process, even when some observations contain missing values. Unlike traditional techniques that involve imputing missing values, MLE identifies the parameter values that have the highest probability of producing the sample result (Baraldi & Enders, 2010). This approach produces unbiased estimates with both MCAR and MAR data, parameter estimates can be biased when data are MNAR, however the magnitude of this bias is far less than bias resulting from traditional techniques (Baraldi & Enders, 2010).

Measures

This research is concerned with several key areas: Primary Stressors, theorised to be Activities of Daily Living dependency (Activities of Daily Living Questionnaire; Johnson et al., 2004), frequency of and caregiver reaction to challenging behaviour (Revised Memory and Behaviour Checklist; Teri et al., 1992) and relational deprivation (Pearlin et al., 1990). Total, emotional and social loneliness (de Jong-Gierveld Loneliness scale; de Jong-Gierveld, 1987), isolation (Social Disconnection Index; Bassuk et al., 1999) and quality of life (World Health Organisation Quality of Life Scale – Brief, New Zealand Version, NZ WHOQOL-BREF; Billington et al., 2010). Self-report data was collected using a 115-item questionnaire (see Appendix for the survey). The questionnaire consisted of demographic questions and measures that were primarily widely used and well validated. In cases where questionnaires with limited validation information were used this was deemed necessary because of the consistency with the theoretical framework of the research.

The Questionnaire

1. Demographic information
2. Background and context
    a. Caregiving duration
    b. Hours per week spent on caregiving tasks
    c. Relationship length
    d. Help hours per week
3. Primary stressors
    a. Activities of Daily Living Questionnaire (Johnson et al., 2004)
    b. Revised Memory and Behaviour Checklist (Teri et al., 1992)
    c. Relational Deprivation (Pearlin et al., 1990)
4. Loneliness and isolation
    a. de Jong Gierveld Loneliness scale (de Jong-Gierveld, 1987)
    b. Social Disconnection Index (Bassuk et al., 1999)
5. Quality of life

    World Health Organisation Quality of Life Scale – Brief, New Zealand Version (NZ WHOQOL-BREF; (Billington et al., 2010)

Background and Context

These variables were selected to provide insight to each participant's caregiving experience. They are guided by Pearlin et al. (1990) conceptualisation of factors in the Stress Process Model as well as the literature to contextualise participants' reported primary stressors, loneliness, and quality of life.

Primary Stressors

The Activities of Daily Living Questionnaire (Johnson et al., 2004). The Activities of Daily Living Questionnaire is an assessment of functional abilities in people with dementia completed by an informant. In this research it is used as a proxy for support a caregiver may be providing with Activities of Daily Living (ADLs). It assesses functioning in six areas: self-care, household care, employment and recreation, shopping and money, travel, communication and includes a global impairment score. It is applicable to a wide range of dementia presentations (Johnson et al., 2004). Scores were calculated following instructions provided by Johnson et al., (2004). The total score was computed by using the formula: (sum of all ratings)/ (3x total number of items rated) x 100. Items rated as nine (never had responsibility for this activity/ don't know) were excluded from this calculation. This score was used for subsequent analyses. Participants were also classified into three groups: None to mild (0-33), moderate (34-66) and severe (>66) for descriptive purposes.

Instruments designed to assess ADLs have traditionally been designed for use in rehabilitation contexts, which prioritises physical capabilities. For people with dementia, impairments in ADL often arise from cognitive decline while physical abilities can remain relatively intact. The ADLQ was developed to address this limitation (Johnson et al., 2004). The ADLQ has shown concurrent validity with the Record of Independent Living, a previously validated measure of dependency in daily living activities (Johnson et al., 2004). It has high test-retest reliability (concordance coefficients of 0.86 or higher and lower concordance limits exceeding 0.73). Concurrent validity was assessed by Johnson et al. (2004) using a repeated-measures ANOVA to examine change in ADLQ, Mini-Mental State Examination (MMSE; a general measure of cognitive impairment) and Clinical Dementia Rating Scale (CDR; a rating of

dementia severity), all measures showed more impairment at one year follow up supporting the ADLQ as a measure of disease progression.

Revised Memory and Behaviour Checklist (RMBC; Teri et al., 1992). The Revised Memory and Behaviour Checklist (RMBC) is a 24-item measure of observable behavioural problems in people with dementia, reported by caregivers, designed for use in research settings. These problems include difficulties with personal care, depression, agitation, and aggression. It provides a total score and three subscale scores (memory-related, depression and disruptive behaviour). The RMBC uses objective scaling guidelines to assess occurrence of behaviour, items are rated zero (never) to four (daily or more) and provides an index of the impact of each behaviour and domain on the caregiver by asking the caregiver to rate their reaction (described as 'how much it bothered you' on a four-point scale, 0 not at all, 1 a little, 2 moderately, 3 very much, 4 extremely). Scores were calculated following instructions provided by Teri et al., (1992). Frequency and reaction scales were scored separately. For the frequency scale all items with scores ranging from zero to four were summed. Items scores as nine (don't know/ not applicable) were excluded. The frequency scores were computed by dividing the sum by the number of included items. For the reaction scale, only items with frequency scores of one or greater were included. The reaction score was computed by summing reaction scores and dividing this number by the number of items included. Internal consistency for frequency and reaction was established by Cronbach's alpha (.75 and .76, respectively), for memory-related problems, .82 and .77 for depression, and .62 and .70 for disruptive behaviours (Teri et al., 1992). The average reaction indicates how reactive a caregiver is on average to any behaviour problem, this is conceptualised by Roth et al. (2003) to represent the caregiver's stress appraisal. A caregiver may have a high reaction score but few reported problems. The total reaction score

is a measure of total burden or stress experienced by the caregiver, this score can be elevated through either high reaction ratings or a high number of problems reported (Roth et al., 2003).

Relational Deprivation. Relational Deprivation was assessed with six questions from Pearlin et al. (1990), as used in Beeson et al. (2000). These questions concern the caregiver's loss of relationship with the person with dementia. Questions are on a 4-point Likert scale from not at all (1) to completely (4), higher total scores indicate greater deprivation. The first three questions are related to loss of closeness in the relationship (ability to confide in the person with dementia, knowing the person with dementia as they once were, and the person with dementia knowing the caregiver well). Responses were summed with higher scores indicating greater relational deprivation as instructed in Pearlin et al., (1990).

Pearlin et al. (1990) reported an alpha level of .77 for the first three questions, and .67 for the remaining three. The last three questions relate to loss of goals and activities that were shared within the dyad. Pearlin et al. (1990) reported a score range from 6-24 with higher scores indicating greater feelings of relational deprivation. Beeson et al. (2000) reported a Cronbach's alpha of .87 when using all six questions in a sample of informal caregivers of people with Alzheimer's Disease, aged between 31 and 90 years old.

Loneliness

De Jong-Gierveld Loneliness Scale (DJG; de Jong-Gierveld, 1987). The DJG scale was used to assess current feelings of loneliness. The DJG scale contains emotional (6-item, negatively worded) and social (5-item, positively worded) loneliness subscales as well as providing an overall loneliness score. The 11-item version is recommended when loneliness is a key variable in the research (de Jong Gierveld & Van Tilburg, 2010). There are five response categories (yes!, yes, more or less, no and no!). Analysis by Penning et al. (2014) supported the

bi-dimensionality of the scale. Items do not specifically ask about ‘loneliness’ which avoids the issue of participants underreporting loneliness due to the associated stigma (Shiovitz-Ezra & Ayalon, 2012). Instructions in the test manual were followed to compute scores for use in analyses and to classify participants’ loneliness. Participants with two or more missing values were excluded from the analysis. Item six was reversed, and all items coded one to five (five indicating greater loneliness). The five category responses were transformed into dichotomous responses where responses indicating any feeling of loneliness were coded as ‘one’ and responses with did not indicate any loneliness were coded as ‘zero’. The ‘more or less’ responses were treated as indicators of loneliness. The maximum possible loneliness score was 11 and the minimum was zero. This scale was used for subsequent analyses. For descriptive purposes participants were also placed in the following categories, not lonely (score of 0-2), moderate loneliness (score of 3-8), and strong loneliness (score of 9-11).

The DJG scale has been used in large scale research projects (Fekete et al., 2019), with a variety of populations including research in New Zealand (Fekete et al., 2019; Wright-St Clair et al., 2017). A scale reliability in the range of .80 - .90 is typically observed (de Jong Gierveld & Van Tilburg, 2010). More recently, research by Thompson and Pollet (2024) found the reliability of the global scale to be excellent (α = 0.92) and internal reliability for the subscales to be good (emotional α = 0.89 and social α = 0.88). Research conducted by de Jong-Gierveld (1987) showed sufficient reliability and construct validity across five research projects, finding that method of administration did not impact the mean score of the scale (interview versus self-administered). It has been found to be reliable and valid for use with older adults (de Jong Gierveld & Van Tilburg, 2010) and is appropriate for use in electronic data collection (de Jong Gierveld & van Tilburg 1999).

Isolation

Social Disengagement Index. The Social Disengagement Index (Bassuk et al., 1999) captures the operational definition of isolation by reporting objective counts of social contact and network size (Bassuk et al., 1999). It measures six constructs known to be related to isolation: marital status, monthly visual contact with friends and family, annual nonvisual contact with friends and family, attendance at religious services, membership in groups and participation in social activities (Bassuk et al., 1999). It does not contain a direct measure of network diversity; however greater network diversity may be inferred if an individual participates in a range of groups (Bassuk et al., 1999).

Care was taken to select a measure that would capture this research's operational definition of isolation, in line with the theoretical framework regarding conceptual differences between loneliness and isolation. To achieve this, it was important to capture only objective isolation. Valtorta, Kanaan, Gilbody and Hanratty (2016) framework for classifying and comparing tools of loneliness, social isolation and social relationships was consulted, three scales were identified as measures of network structure with a low degree of subjectivity. Wenger Support Network Typology (Wenger, 1991), Litwin Support Network Type (Litwin & Landau, 2000) and Berkman-Syme Social Network Index (Berkman & Syme, 1979). The Wenger and the Litwin were determined to be inappropriate in this instance as they categorise participant responses into network type rather than providing a metric for isolation.

The Berkman-Syme Social Network Index (Berkman & Syme, 1979) allows individuals to be categorised into four levels of isolation, from socially integrated to socially isolated.

However, the measure includes five questions about subjective experiences of connection to contacts such as *"Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?"* subjective satisfaction with social contact is classified as social loneliness under the operational definitions used in this research and is measured with the DJG loneliness scale. Due to this aspect the Berkman-Syme Social Network Index was deemed inappropriate for use.

The Social Disconnection Index is based on the Berkman-Syme Social Network Index (SDI; Bassuk et al., 1990). The SDI is an objective measure of social connection (Bassuk et al., 1999), it was chosen for use in this research because it includes only objective elements of isolation, in keeping with the operational definitions. While psychometric data is not available for this measure it has been used primarily in health research with older adults. For example, a mixed methods study of older adults with diabetes (Lucas, 2013), longitudinal research on social disengagement and cognitive decline in community dwelling older adults (Bassuk et al., 1999) and research investigating cognitive impairment and mortality in community dwelling older adults (Bassuk et al., 2000). It has also been used in research alongside loneliness, Brady et al. (2020) used the SDI as a measure of isolation in their quasi-experimental study evaluating the impact of membership in a group fitness programme on isolation, loneliness and health of older adults using path analysis.

Index scores were calculated in accordance with the author's instructions. The isolation score was calculated from six indicators, the presence of a spouse (spouse), monthly visual contact with three or more relatives or close friends (visual), yearly non-visual contact with three or more relatives and close friends (non-visual), attendance at religious meetings, membership in social groups and social activity. The isolation score was based on the number of indicators

endorsed from zero to six. These were then transformed so that higher values indicated increased isolation aligning them with the direction of the other variables for ease of interpretation. This was used for subsequent analyses. The number of indicators could be coded into number of ties, allowing participants to be described as between one (most engaged) and four (socially disengaged) .

Quality of Life

World Health Organisation Quality of Life Scale, New Zealand Version (WHOQOL-BREF NZ; Billington et al., 2010). The measurement of QOL captures an individual's satisfaction with multiple areas of their life (Theofilou, 2013). The WHOQOL-100 was the first measure to be produced, fifteen international field centres were involved in the development leading to a measure with cross-cultural applicability (Skevington, Lofty & O'Connell, 2004). The 100-item scale was condensed into a 26-item version (WHOQOL-BREF) for use in research and large clinical trials (Skevington et al., 2004). The WHOQOL-BREF contains two comprehensive questions to capture QOL and health satisfaction. These sit alongside the four-domain QOL profile (Table 2). This allows for expression of the individual's perception of QOL, while highlighting areas which may benefit from intervention. Items are scored on a 5-point Likert scale from one (the most negative option) to five (the most positive option). The questions assess 'how much', 'how satisfied' or 'how completely' the respondent felt in relation to the domain. The WHOQOL-BREF is reported as having good to excellent psychometric properties of reliability and validity (Skevington et al., 2004). The WHOQOL-BREF has been used in research regarding stress in caregivers of people with Alzheimer's Disease (Oba et al., 2018).

Table 2

Areas Assessed by the NZ WHOQOL-BREF

	Number of items	Areas addressed
Overall quality of life	1	Quality of life
Health satisfaction	1	Health satisfaction
Physical domain	7	Capacity for work, reliance on medicine, activities of daily living, mobility, sleep and rest, fatigue, energy as well as pain and discomfort.
Psychological domain	6	Positive feelings, spirituality/religion/personal beliefs, thinking and concentration, body image and appearance, self-esteem, and negative feelings.
Social relationships domain	3	Social relationships, sexual activity, and social support.
Environment domain	8	Physical safety and security, physical environment, financial resources, opportunities for acquiring new information and skills, participation in and opportunity for leisure activities and home environment

Krägeloh et al. (2013) tested the WHOQOL-BREF for use in New Zealand with a random sample from the electoral roll (n = 808, mean age = 49.69 years, SD = 17.85, female = 469, 140 participants answered, 'yes' to the question 'are you currently ill?'). They found Cronbach's alpha to be at an acceptable level for the overall scale (0.91), and each domain physical (.80), psychological (.82), social (.71) and environment (.81). Criterion related validity was assessed with Pearson's correlation coefficients by comparing domain scores to the responses to the two general items. All domain scores were significantly correlated (p >.01) with item 1 (r ranged from .45 - .60) and item 2 (r ranged from .31 - .64).

Using an online survey has been established as a viable method for collecting data with the WHOQOL-BREF (Chen et al., 2009). Chen et al. (2009) used crossover self-controlled trials to compare web and paper versions of the WHOQOL-BREF. Correlations of domain scores between online and paper versions ranged from 0.71 to 0.85. Dependent t tests showed no significant differences in domain scores between these two versions (Chen et al., 2009). Multiple

regression models indicated good concurrent reliability for the online version, Confirmatory factor analysis supported the construct validity of the online version.

Scores were calculated following guidelines from the World Health Organisation. Items one and two were scored individually. The remaining 24 items were grouped into four domains, physical health, psychological health, social relationships and environment. Negatively worded items were reverse-coded. Domain scores were computed as the mean of the item scores the multiplied by four to align with the WHOQOL-100 scale. This results in domain scores ranging from four to 20, with higher scores indicating greater quality of life. (World Health Organization, 1996).

The World Health Organisation (1996) recommends analysing the national items separately to allow data to be compared across studies. The five New Zealand items (four items in the psychological and one in the social relationships domain) were removed from the main analyses. Hence the analysis included the 26 individual items of the NZ WHOQOL-BREF and the domain scores.

Cultural Considerations for Measurement Tools

The appropriateness of using the measures described above in a culturally diverse context like Aotearoa New Zealand should be considered. In the Aotearoa New Zealand context, practices of caregiving and perspectives of the included concepts can differ between New Zealand European/ Pakeha and Māori, and other non-Pakeha communities. For example, Māori views of wellbeing encompass individual, collective and spiritual domains (Rochford, 2004).

The measures described above were selected based on psychometric properties and theoretical alignment to the Stress Process Model. Where possible measures that had been validated or used in New Zealand were selected. The WHOQOL-BREF and the DJG have been

used in New Zealand research with older adults (Krägeloh et al., 2013; La Grow et al., 2012; Lay-Yee et al., 2022; Thompson et al., 2022; Waldegrave et al., 2020). The WHOQOL-BREF demonstrated acceptable psychometric properties in a sample from the electoral roll (Krägeloh et al., 2013). Waldegrave and colleagues (2020) explored the relevance of items on the DJG for Māori loneliness, through a hui process with Kaumatua. While the DJG items were found to be generally aligned with Māori experiences of loneliness, additional items were discussed by participants in this research indicating that participants felt there were aspects not captured by the scale. Quantitative analyses found statistically significant correlations between these items and the DJG. This suggests that the DJG has utility but may not capture the full picture of loneliness for Māori.

The ADLQ and RMBC have not been validated in a New Zealand setting. However objective counts of ADLs through a variety of methods are commonly used in the literature in a variety of contexts(Chan et al., 2021; Fredriksen-Goldsen et al., 2023; Robison et al., 2009). These measures are symptom checklists included to quantify the stressors experienced by informal caregivers through counts of functional impairment and memory, behavioural and psychological symptoms. While they may achieve this purpose, they may overlook cultural differences in elements of the caregiving role, for example the responsibility of the caregiver to support the person with dementia to maintain culturally meaningful roles and connections (Lapsley et al., 2020). The culturally embedded nature of responsibility and interdependence (e.g. sharing of caregiving tasks) may mean there are differences in what ADLs are considered essential as well as how limitations in function are experienced by the person completing the survey.

In terms of the remaining measures, the SDI and the relational deprivation measure, may not adequately reflect these concepts for those from a collectivist culture. For example, the

importance of connection and relationship to wairua (spirituality) and whenua (land; Gall et al., 2021, Rochford, 2004) However, there were limited options in the literature for measuring these concepts. While these tools provide an estimate of concepts of interest and caregiving demands within the Stress Process Model their limitations in culturally diverse populations must be acknowledged. Findings should be interpreted with these limitations in mind.

Data Analysis

Data analysis was completed in IBM SPSS Statistics (version 23) and AMOS (version 29). IBM SPSS Statistics is a comprehensive software package widely used for statistical analysis in a variety of fields including psychology and health care (Field, 2024). AMOS is an add-on module for SPSS with advanced capabilities for modelling complex relationships between variables. AMOS allows for specification and testing of path models, estimate parameters, assess model fit and conduct mediation analysis (Barnidge & De Zúñiga, 2017). SPSS Statistics was used for descriptive analyses and correlation analyses. AMOS was used to conduct confirmatory factor analyses, path analyses and mediation analyses.

The selection of analytic methods in this study was informed by the structure of the variables under investigation. For example, quality of life, the main outcome variable is measured on an ordinal scale. Ordinal scales are widely employed in Psychology, they enable ranking phenomena, however, do not guarantee equal distances between ranks (Field, 2024). This inherent property of ordinal scales has implications for the assumptions of linearity and continuity, failure to account for the ordinal nature of variables can introduce bias (Field, 2024). As such it is important to be reflexive the structure of the data when selecting analytical techniques.

Preliminary Analysis

Descriptive Analyses. Descriptive analyses were used to provide basic summaries of the data. They included measures of central tendency, standard deviations, normality, and confidence intervals where appropriate. Descriptive analyses were used to address Exploratory Questions One and Two. Exploratory Question One was concerned with the quality of life profile of informal caregivers in the sample and was addressed with a combination of descriptive statistics, correlational analyses and differences between groups analyses. Exploratory Question Two aimed to understand the prevalence of loneliness in this sample and was addressed with the descriptive analysis, no statistical significance tests were performed.

Correlational Analysis. Pearson's and Spearman's correlations were used in this research, Pearson's correlations were used for continuous variables with a linear relationship, determined via visual inspection of scatterplots. Spearman's correlations were used with ordinal variables, or where the relationship was nonlinear as the assumption of monotonicity needed for Spearman's correlations is less restrictive than the assumption of linearity required for Pearson's correlation (Field, 2024). Two tailed significance tests were used as is the convention in psychological literature (Field, 2024). Correlational analyses were used to address hypotheses one to three.

Differences in WHOQOL-BREF responses. Between groups analysis was conducted to explore participants' responses to the WHOQOL-BREF. It aimed to identify if variations in subjective QOL and domain scores among the study participants were statistically significant using Wilcoxon Signed Ranks tests and within subjects' one-way ANOVA. Mauchley's test of sphericity was used to test the sphericity assumption. Maxwell et al. (2017) recommend using a Greenhouse-Geisser correction regardless of the outcome as the assumption of sphericity is

difficult not to violate and due to the sensitivity of the ANOVA to departures from sphericity. A post hoc Bonferroni correction was applied as it is recommended for the purpose of testing all possible pairwise combinations (Maxwell et al., 2017).

These analyses provided context for Exploratory Question One. Wilcoxon signed-ranks tests were used to compare differences between items one and two of the WHOQOL-BREF as these items are ordinally scaled. Within subjects' one-way ANOVA was used to compare differences between domain scores as these scores are on an interval scale.

Confirmatory Factor Analysis. Confirmatory Factor Analysis (CFA) is used to assess the fit between observed data and an hypothesised measurement model (Collier, 2020). This provides information about how well observed variables align with the latent construct they are theorised to represent. Fit indices and parameter estimates provide insight into the adequacy of the measurement structure (Collier, 2020). In the present study CFA was used to evaluate the theoretical framework underlying the measures used. Factor models were specified according to the author's frameworks, with each observed variable loading onto its observed factor. Parameters were estimated using Maximum Likelihood Estimation. Model fit was assessed using Chi-square (Kline, 2023), the Comparative Fit Index (CFI; Kline, 2023), and the Root Mean Square of Approximation (RMSEA; Kline, 2023).

Path Analysis. Path analysis was used to explore the relationships between variables. Path analysis is a commonly used method of statistical analysis in social and behavioural sciences (Collier, 2020). It is a method for obtaining empirical evidence for theoretical constructs through statistical testing (Collier, 2020). Path analysis uses a path diagram which seeks to represent hypotheses about structural relationships within a theoretical model (Nachtigall et al., 2003). The objectives of using a path analysis are to view relationships between variables based

on an a priori model, calculating the effect of exogenous variables on endogenous variables (Nachtigall et al., 2003). The model considers relationships between variables simultaneously through a system of regression equations (Nachtigall et al., 2003).

Prior to data collection the measurement model and structural models were defined. Primary stressors were hypothesised to be associated with levels of loneliness and isolation. Loneliness and isolation were hypothesised to be associated with quality of life. Primary stressors were also hypothesised to show an association with quality of life. Rather than conducting individual regression analyses, path analysis considers these equations simultaneously (Nachtigall et al., 2003). Through this method the total association of primary stressors and quality of life can be separated into a direct association of primary stressors on quality of life and the indirect association , mediated by loneliness.

The decision to use path analysis over structural equation modelling was due to sample size. Path analysis is less computationally demanding making it suitable when sample sizes are limited, it allows for testing the hypothesised relationships effectively within these limitations (Kline, 2023). Total scores from each measure were used as observed variables, this is a common approach in psychological research (Kelcey, 2019).

For this analysis technique it is recommended that the sample size should be approximately 10 times the number of parameters in the model (Kline, 2023) with a lower bound of 100 (Bentler & Yuan, 1999). The largest model tested had 10 parameters and the sample size for the main analyses was 116 participants which satisfies this requirement. Parameters were estimated using Maximum Likelihood Estimation. Maximum Likelihood Estimation has been found to be relatively robust to violations of assumptions and is typically suitable for most uses (Hu & Bentler, 1999). Model fit was assessed using the Chi-square statistic, Normed Chi-square

(CMIN/DF), Comparative fit index (CFI) and Root Mean Square Error of Approximation (RMSEA), fit indices are discussed in greater detail below.

Composite variable: Primary Stressors. To represent the overall exposure to primary stressors, a composite variable was created for use in the path analysis. This used the sum of z-scores of the individual stressors. Total scores were first standardised into z-scores then summed to create the composite variable. The composite variable was used to reduce complexity of the model, satisfying sample size requirements for path analysis.

Mediation Analysis. Mediation Analysis is concerned with understanding the mechanisms that underlie relationships between variables, it is a widely used approach in the psychological literature (Schuler et al., 2024). This method explores how an independent variable influences a dependent variable by passing through an intermediate variable known as a mediator (Schuler et al., 2024).

This research used a bootstrap sample of 5,000 as recommended by Collier (2020). Mediation can be full or partial. Full is where the indirect effect is significant in the context of nonsignificant direct effects and partial is where the indirect effect is significant in the context of significant direct effects (MacKinnon et al., 2007).

Mediation Analyses were conducted to address Exploratory Question Five: Does loneliness function as a mediator in the relationship between primary stressors and quality of life? Both models were multiple mediation models, the first used loneliness and isolation as mediators. The second used emotional and social loneliness as mediators in the relationship between primary stressors and QOL. Mediation analyses were conducted in AMOS, the ‘estimands’ function was used to allow measurement of individual mediators instead of the indirect effect from the independent to dependent variable through all possible mediators.

Model Fit. Fit indices provide information about the fit of the proposed model to the observed data (Collier, 2020). Path analysis does not provide straightforward statistic of model fit; therefore, it is recommended to examine multiple indices, consider the model's complexity as well as the context of the research (Smith & Mc Millan, 2001). Each statistic used provides a different perspective of the fit of the model to the observed data. The cut-points for fit indices (Table 3), are guidelines and caution should be taken to make decisions based on these alone (Marsh et al., 2005). Marsh et al. (2005) advise a nuanced approach that considers issues such as model complexity, sample size and research context. Fit statistics were used to provide information about each tested model; however, they were not used to determine if the hypotheses were supported as the hypotheses are concerned with testing the significance and direction of the paths between variables specified by the theoretical framework, rather than assessing the overall fit or adequacy of the entire model.

Table 3

Fit Indices Used to Evaluate Model Fit and Description of Each

Measure	Description
Chi-square ($\chi 2$)	The Chi-square tests a null hypothesis that the model being tested perfectly fits the population. It is sensitive to large sample size and non-normally distributed data (Smith & McMillan, 2001). A nonsignificant *p* value ($p > .05$) suggests that the model is a good fit for the data.
Normed Chi-square	The normed Chi-square provides a measure of discrepancy between the observed covariance matrix and the model-implied covariance matric adjusted for the complexity of the model. It is calculated by dividing the chi-square by the degrees of freedom (Kline, 2023). While values that are close to one suggest good fit, values below three are considered acceptable (Smith & McMillan, 2001).
The Comparative Fit Index (CFI)	The CFI Compares the fit of the hypothesised model to a null model, assuming no relationship between the observed variables. It ranges from zero to one with values above 0.90 suggesting acceptable fit (Kline, 2023).

Root mean square error of approximation (RMSEA)	The RMSEA evaluates the discrepancy between the observed covariance matrix and the model's covariance matrix (Kline, 2023). Values greater than 0.08 are suggested to indicate less than optimal fit. The associated confidence interval increased precision of the estimate while the pclose value describes the probability that RMSEA value would be equal to or smaller than the observed value if the model were true. Pclose values greater than 0.05 suggest the model fits the data well (Kline, 2023).

Hypotheses

Hypotheses addressed the criteria for accepting or considering the hypothesis supported are presented in Table 4.

Table 4

Hypotheses and Acceptance Criteria

	Predictor variable/s	Outcome variable/s	Criteria for acceptance
Hypotheses addressed with correlations			
Hypothesis 1	Background and context factors	Quality of Life	Statistically significant *p* values of less than 0.05 (2-tailed).
Hypothesis 2	Background and context factors	Primary Stressors	Statistically significant *p* values of less than 0.05 (2-tailed).
Hypothesis 3	Background and context factors	Loneliness and Isolation	Statistically significant *p* values of less than 0.05 (2-tailed).
Hypotheses addressed with path analysis			
Hypothesis 4	Primary Stressors	Quality of Life	Negative standardised regression coefficients Statistically significant *p* values of less than 0.05 (2-tailed).
Hypothesis 5	Primary Stressors	Loneliness Isolation Emotional Loneliness and Social Loneliness	Negative standardised regression coefficients Statistically significant *p* values of less than 0.05 (2-tailed).

Hypothesis 6	Loneliness and Isolation	Quality of Life	Negative standardised regression coefficients Statistically significant *p* values of less than 0.05 (2-tailed).

Note: Background and context factors (care hours, help hours, care length, relationship length) Primary Stressors (Activities of Daily Living Dependency, Relational Deprivation, Behaviour Frequency and Caregiver Reaction). Primary stressors is the primary stressors composite variable

Chapter Eight: Results

Descriptive statistics are reported followed by correlational analysis, confirmatory factor analysis (CFA) and path analysis. All variables in path analysis are observed variables. Fit statistics are reported for each CFA and path analysis, these statistics are used to provide information around the estimates of parameters, rather than determine the validity of the hypothesis. Poor fit may indicate uncertainty around these estimates. Standardised regression coefficients are reported for results of path analyses.

Descriptive Results

Descriptive statistics for the main variables of the study are presented in Table 5. The internal consistency reliability of each scale was assessed using Cronbach's alpha, findings suggested robust internal consistency for all measures.

Table 5

Descriptive Statistics for Survey Scales (World Health Organisation Quality of Life – BREF, de Jong Gierveld Loneliness Scale, Social Disconnection Index, Relational Deprivation, Activities of Daily Living Alzheimer's, Revised Memory, and Behaviour Checklist) and Background and Context Factors.

	%	Min-max	Median	Mean	SD	Kurtosis	Alpha
Background and Context Factors							
Care hours		2-168	40.00	67.84	60.90	-.97	
Care duration		0-24	2.80	3.85	3.86	11.39	
Relationship length		0.5-74	50.00	46.08	17.39	.29	
Help hours		0-168	2.50	9.97	22.59	11.39	
WHOQOL-BREF							.93
Overall QOL		1-5	3	3.26	1.00	-.57	
Health Satisfaction		1-5	3	3.07	1.09	-1.01	
Domain Scores							
Physical		7.43-20	13.75	13.75	2.68	-.47	.80
Psychological		6.67-19.33	12.51	12.51	2.95	-.47	.86
Social Relationships		4-20	13.50	13.50	3.42	-.19	.74

	%	Min-max	Median	Mean	SD	Kurtosis	Alpha
Environment		8.5 -20	13.40	13.40	2.28	-.16	.79
DJG Loneliness							
Total	81%	0-11	9	7.37	3.59	-8.6	.93
Moderate	33%						
Severe	28%						
Subscale							
Social	2%	0-5	5	3.28	1.99	-1.35	.91
Emotional	18%	0-6	4	4.14	1.89	-.38	.88
SDI							
Total		1-3	2.00	2.03	.61	-.27	.81
0 ties (socially disengaged)	0%						
1-2 ties (socially disengaged)	19%						
3-4 ties	63%						
5-6 ties	18%						
Primary Stressors		-5.57-7.31	.01	.000	2.59	-.168	.93
Relational Deprivation		6-24	19.00	17.83	4.43	-.21	.85
ADLQ							
Total		6.41-100	71.72	68.57	20.36	-.01	.92
Impairment	8%						
Moderate Impairment	37%						
Severe Impairment	56%						
Subscales							
Self-care		5.56-100	44.44	48.57	27.44	-1.04	.78
Household		6.67-100	88.89	80.11	22.79	1.12	.88
Employment		16.67-100	77.78	73.96	18.77	.99	.08
Shopping		0-100	100	84.77	23.94	.99	.78
Travel		0-100	88.89	79.38	24.19	.98	.57
Communication		8.33-100	60	62.35	21.63	-.65	.72
RMBC							
Total (FREQ)		1-3.89	2.71	2.69	0.57	-.17	.89
Total (REAC)		1-4	1.85	2.05	0.66	.52	.95
Subscales							
Depression (FREQ)		1-4	1.87	2.03	0.74	.11	.81
Disruption (FREQ)		1-4	2.00	2.15	0.74	.45	.77
Memory (FREQ)		1-4	3.71	3.43	0.79	.31	.81
Depression (REAC)		1-4	2.00	2.08	0.84	.67	.93
Disruption (REAC)		1-3.67	2.00	1.94	0.72	.94	.92
Memory (REAC)		1-4	1.80	1.99	0.85	-.13	.89

Background and Context Factors

The mean duration of the caregiver's relationship with the care receiver was 46.08 years (SD= 17.39). The average duration of caregiving was 3.85 years (SD= 3.86), and participants reported spending an average of 67.84 hours per week on caregiving duties (SD= 60.09). Caregivers reported receiving an average of 18.48 (SD= 28.23) help hours per week.

Primary Stressors

The scores for the primary stressors variable are presented as z-scores. Scores indicate that most participants experience levels near the average. The standard deviation indicates that some participants experience high and low levels of stressors.

Individual Stressors

Primary stressors were, activities of daily living dependency (ADLQ; Johnson et al., 2004), challenging behaviour (RMBC; Teri et al., 1992) caregiver reaction to challenging behaviour (RMBC; Teri et al., 1992) and relational deprivation (RD; Pearlin et al., 1990). Descriptive statistics for the ADLQ describe the ADL dependency of the people participants are caring for. Most reported that the person they were caring for had severe (56%) or moderate (37%) impairment in their activities of daily living. The RMBC describes the weekly frequency of challenging behaviours and caregiver reaction to these behaviours. On average, the weekly frequency of all behaviours was 2.68 (SD= 0.57). The average reaction score was 2.05 (SD= 0.66) indicting caregiver's typical reactions (assessed by the question "how much did these behaviours bother you") were between 'moderately' and 'very much'. Memory related behaviours were the most frequent, followed by depressive behaviours. The reaction score for these behaviours was similar. Disruptive behaviours were the least commonly reported and

elicited the lowest level of distress. Moderate levels of relational deprivation were seen in the sample.

Loneliness

Loneliness was assessed with the de Jong-Gierveld Loneliness scale (de Jong-Gierveld, 1987). Eighty-one percent of participants were classified as lonely. Of those classified as lonely, 60% were categorized as both socially and emotionally lonely, 18% were classified as only emotionally lonely, and 2% as only socially lonely. In terms of loneliness severity, 28% of participants were classified as moderately lonely and 33% were classified as severely lonely.

Isolation

Isolation was assessed with the Social Disconnection Index (Bassuk et al., 1999). Most participants were not classified as socially disengaged (82%), indicating that they were not isolated. Reported participation in social activities was low, with 88% reporting they did not engage regularly, 77% did not attend religious services and 52% were not part of a group.

Quality of Life

Quality of life was assessed with the WHOQOL-BREF (WHOQOL Group, 1994). On average, participants rated their quality of life as between 'neither good nor poor' and 'good', indicating a moderate overall QOL in this sample. Health satisfaction was also rated moderately, mean ratings falling between 'neither satisfied nor dissatisfied' and 'satisfied'. Results of Wilcoxon Signed Ranks tests and one-way repeated measures ANOVA are presented here for clarity as both descriptive statistics and the ANOVA address exploratory question one.

The relationship between gender and overall QOL and health satisfaction was assessed with Wilcoxon Signed Ranks tests (results displayed in Table 6). Significant differences were found between males and females for both. Gender differences in domain scores were also

assessed, no significant differences were found. Potential differences in age and each of these variables was assessed, no significant differences were found.

Table 6

Results of Wilcoxon Signed Ranks Test Comparing Quality of Life and Health Satisfaction

	Male			Female			
	n	M	SD	n	M	SD	z
QOL	16	3.06	.85	118	3.29	.85	9.84***
Health Satisfaction	16	3.13	.96	118	*3.07*	*1.12*	9.69***

Note: p values are two-tailed. *p <.05, ** p<.01, ***p<.001

A one-way repeated measures ANOVA was conducted to examine differences in QOL domain scores within the sample. Mauchley's test indicated that the assumption of sphericity had been violated $\chi^2(5)$ 32.92, p <.001. Epsilon (ε) was 0.84, as calculated according to Greenhouse and Geisser (Maxwell et al., 2017) and was used to correct the one-way repeated measures ANOVA. Domain scores were statistically significantly different from each other, F(2.53, 336.92) = 11.99, p < .001, partial η2 = .083. Post-hoc pairwise comparisons with a Bonferroni adjustment indicated that there were significant differences between the physical and psychological domain (M = 1.24, 95% CI [0.69, 1.79] p <.001). Psychological and social relationships domain (M = -.99, 95% CI [-1.60, 0.39] p <.001) and the psychological and environmental domain (M= -.89, 95% CI [-1.38, -.39] p <.001).

Exploratory Questions Addressed by Descriptive Statistics

Exploratory Question One: What is the Quality of Life Profile of Informal Caregivers of People with Dementia in this Sample? Overall QOL was rated moderately by participants, between 'neither good nor poor' and 'good'. Health satisfaction was also rated

moderately. Overall QOL and health satisfaction varied significantly between genders, with females reporting lower scores. The psychological domain was rated significantly lower than all other domain scores.

Exploratory Question 2: What is the Prevalence of Loneliness in this Sample? These findings indicate a high prevalence of loneliness within this sample, with the majority classified as both emotionally and socially lonely.

Confirmatory Factor Analysis

Confirmatory Factor Analyses (CFA) were carried out to test the hypothesised factor structure of each measure as well as assess the fit of the path analyses (Table 7). The CFA for the measures returned mixed findings. The Social Disconnection Index was the only measure to demonstrate good fit. Fit indices were mixed for the WHOQOL, DJG and RD measures. The RMBC had poor fit. These measures are well validated and widely used (Beeson, 2003; Brady et al., 2020; de Jong Gierveld & Van Tilburg, 2010; Fekete et al., 2019; Johnson et al., 2004; Roth et al., 2003), suggesting they are appropriate for use.

For the path analyses, all models were assessed to have acceptable to good fit, except for the models assessing the relationship between loneliness (and loneliness type) and QOL (Table 7). The results of the CFA for these models were mixed. This suggests that most models captured the overall structure of the relationship between the variables. In situations of mixed results, the chi-square and RMSEA indicated poor fit (as indicated by a significant chi-square and RMSEA over 0.08; Kline, 2023) while the CFI suggested adequate fit (>.90; Kline, 2023). This discrepancy can occur for reasons related to sample size and model complexity (Kline, 2023). Mixed fit statistics do not automatically imply a poor model, the inconsistency may arise because fit indices evaluate fit from different perspectives and ‘good fit’ is not well defined in the current

literature (Lai & Green, 2016). Kline (2023) argues that cutoffs for fit indices do not distinguish between sampling error and true evidence against the model. Fit statistics can be sensitive to sample size, model complexity, and data distribution, which can produce conflicting results and lead to difficulty drawing conclusions. Reliance on fit statistics alone may overlook the broader context of model evaluation including theoretical coherence and practical utility. For this study poor fit was interpreted as suggesting uncertainty around parameter estimates.

Table 7

Fit Statistics for Confirmatory Factor Analysis and Path diagrams

						RMSEA				Kurtosis (CR)
	X^2	df	NPAR	CMIN/DF	CFI	RMSEA	LO90	HI90	PCLOSE	
Confirmatory Factor Analysis										
WHOQOL	493.08**	246	78	493.08	.79	.093	.08	.10	.000	51.35
De Jong Gierveld loneliness	102.6**	43	34	2.38	.93	.110	.08	.14	.000	17.10 (5.44)
Relational Deprivation	55.05**	9	18	55.04	.84	.21	.16	.27	.000	
SDI	15.043	9	12	1.67	.932	.076	.000	.142	.230	90.74 (49.97)
RMBC (FREQ)	521.61***	249	75	2.09	.766	.98	.86	.109	.000	102.43 (15.61)
RMBC (REAC)	639.94***	249	75	2.57	.751	.117	.106	.128	.000	115.86 (17.66)
ADLQ	622.72***	335	99	622.72	.798	.86	.07	.09	.000	67.65 (8.89)
Path Diagrams										
Primary Stressors to loneliness, isolation and QOL	19.32	13	22	19.32	.96	.06	.000	.122	.31	4.46 (2.14)
Loneliness and isolation to QOL	5.51*	1	5	5.51	.93	.19	.06	.37	.04	-.53 (-.52)
Mediation Analysis										
Primary Stressors to QOL through Loneliness and isolation	2.24	1	13	2.24	.98	.104	.00	.29	.189	-1.32 (-1.026)
Primary Stressors to QOL through emotional and social Loneliness	57.92**	1	13	57.92	.66	.070	.56	.86	.000	-1.30 (-.944)

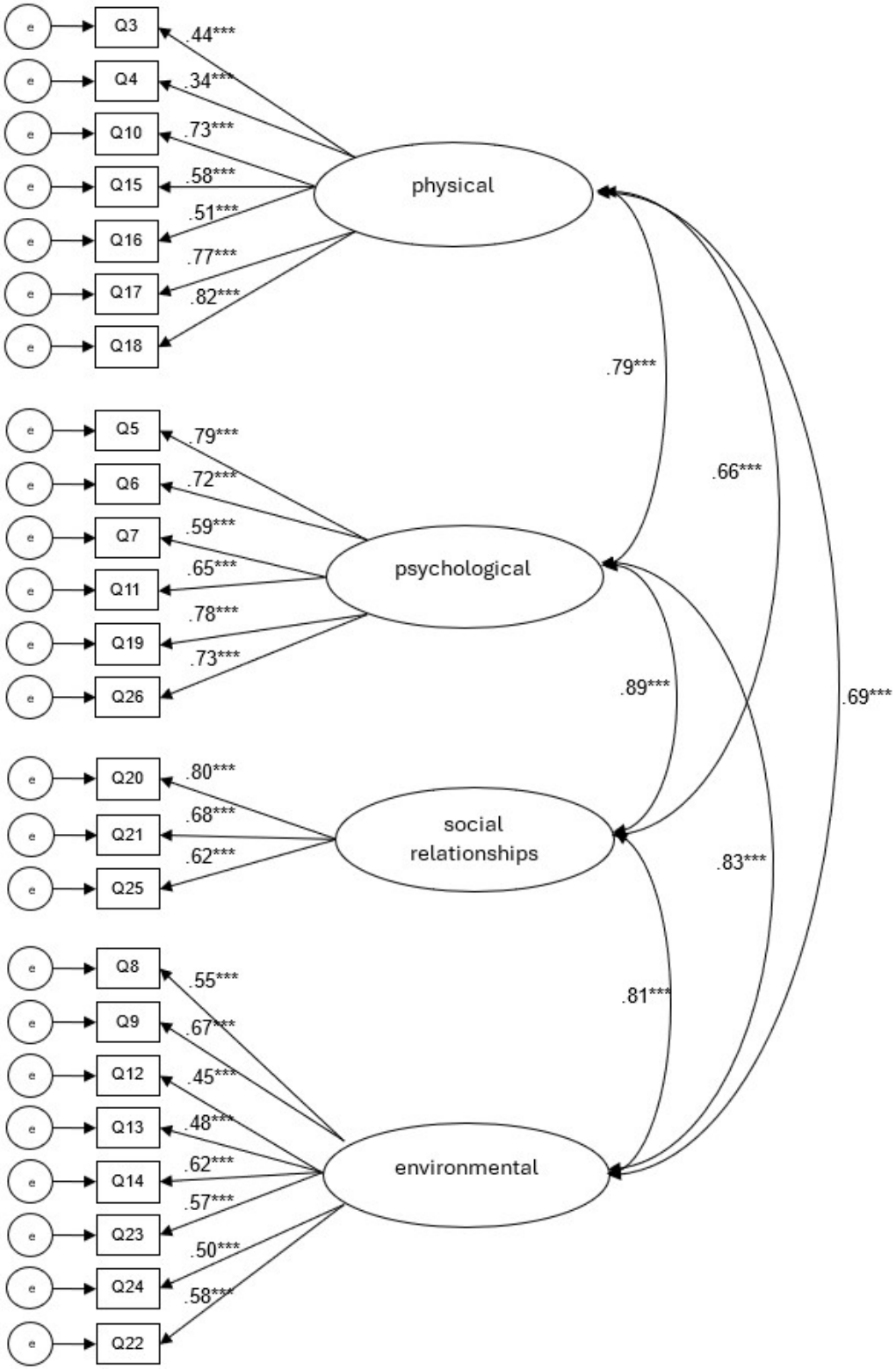
Note: p values are two-tailed. *p <.05, ** p<.01, ***p<.001.
PS: Primary Stressors composite variable, ADLQ: Activities of Daily Living Alzheimer's, RD: Relational Deprivation, FREQ: Revised Memory and Behaviour Checklist Behaviour Frequency, REAC: Revised Memory and Behaviour Checklist, Lone: de Jong Gierveld Loneliness, Emot: de Jong Gierveld Loneliness emotional loneliness subscale, Soc: de Jong Gierveld Loneliness social loneliness subscale SDI: Social Disconnection Index (isolation), QOL: Quality of Life.

WHOQOL-BREF

The path diagram (Figure 5) displays the relationships between the latent QOL domains' observed indicators. Factor loadings for each indicator are standardised and displayed as path coefficients. Fit indices for the model returned mixed results, with a chi-square statistic of $\chi^2(246) = 493.079$, $p < .001$, Comparative Fit Index (CFI) = .792, Root Mean Square Error of Approximation (RMSEA) = .093 (90% CI [.081,.105]). CFI indicates low to acceptable fit. Assessing the confidence intervals of the RMSEA indicates it may be in the range of acceptable fit. All standardised coefficients between indicators and latent variables were significant and moderate to strong (ranging from .337 - .816, $p <.001$). Strong correlations were observed between all domains (ranging from .662 to .895, $p <.001$).

Figure 5

Four Factor Structure for the WHOQOL-BREF



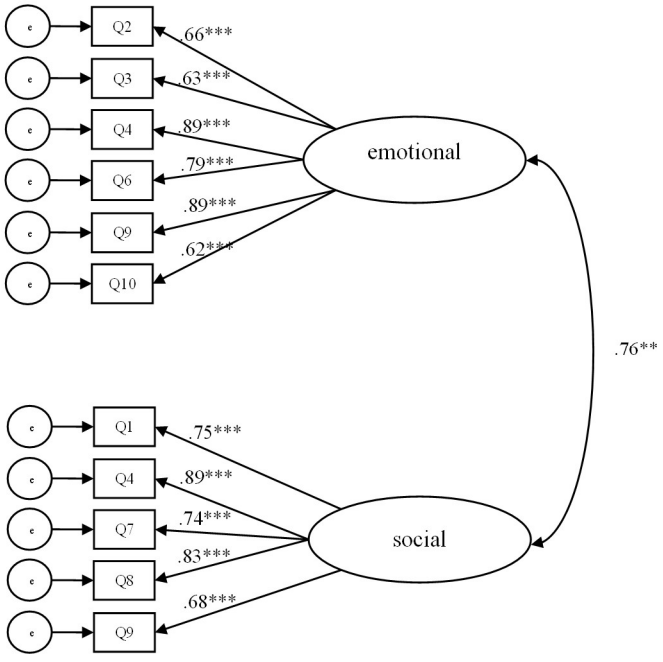
Note: Standardised coefficients reported. *P* values are two-tailed, *p <.05, ** p<.01, ***p<.001

DeJong Gierveld Loneliness Measure

Figure 6 displays the path diagram for the relationships between the latent factors in the DGJ measure. The standardised coefficients ranged from .62 to .89 indicating relatively strong relationships. All coefficients were significant (p <.001), showing that the observed indicators contributed significantly to the measurement of the latent variables. The factor correlation between social and emotional loneliness was .76 (p = .02) suggesting a strong positive association, which may indicate some conceptual overlap in the constructs and that they are not entirely distinct. The model's fit indices were mixed with a with a Chi-square statistic of $\chi^2(43)$ = 102.58, p < .001, and RMSEA = .110 (90% CI [.083,.137]) suggesting that the model does not fit the data well. On the other hand, the CFI = .931 suggests a relatively good fit.

Figure 6

Two-factor Structure of the DeJong Gierveld Loneliness Measure



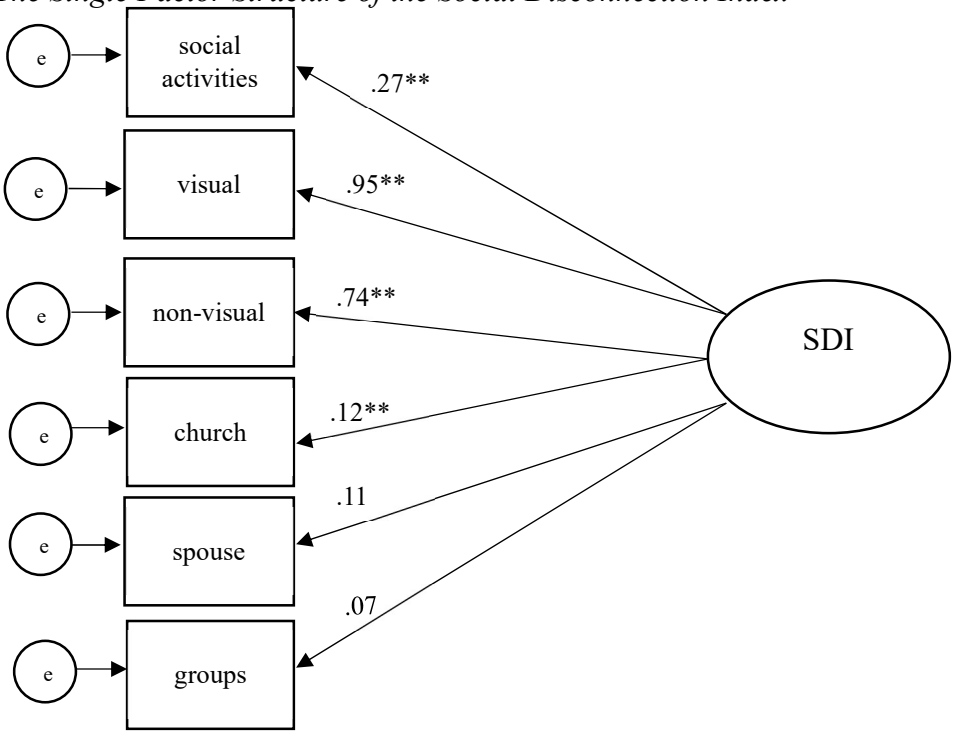
Note: Standardised coefficients reported. *P* values are two-tailed, *p <.05, ** p<.01, ***p<.001

Social Deprivation Index

The visual and non-visual indicators had strong relationships with the latent factor, indicating a strong contribution to the underlying construct of isolation (results of analysis presented in Figure 7). In contrast, church attendance (church) and participation in social activities showed weaker, significant correlations. Being married (spouse) and being a member of a group (groups) did not show statistically significant contributions to isolation. The model fit was considered acceptable, $\chi^2(9) = 15.04$, $p = .09$, and RMSEA = .076 (90% CI [.000,.142]), CFI = .932. The Chi-quare and CFI indicated good fit and the RMSEA suggested reasonable fit.

Figure 7

The Single Factor Structure of the Social Disconnection Index



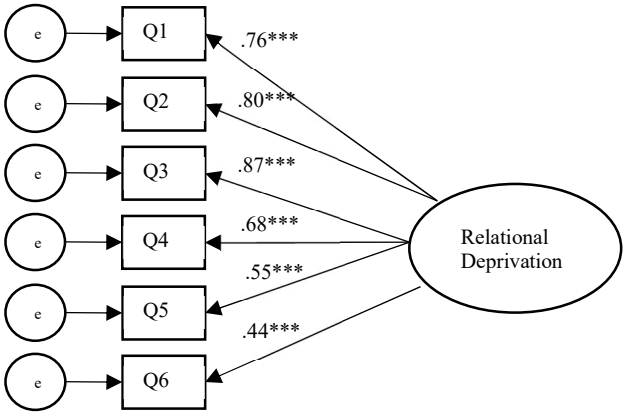
Note: Standardised coefficients reported. *P* values are two-tailed, *p <.05, ** p<.01, ***p<.001

Relational Deprivation

The relationships between the indicators and the latent variable were moderate to strong with coefficients ranging from .44 to .87, all of which were significant (p <.001; Figure 8). The fit indices for the model were mixed with a Chi-square statistic of $\chi^2(9) = 55.049$, $p < .001$, RMSEA = .211 (90% CI [.159,.266]) and CFI = .844.

Figure 8

Single Factor Structure of the Relational Deprivation Measure



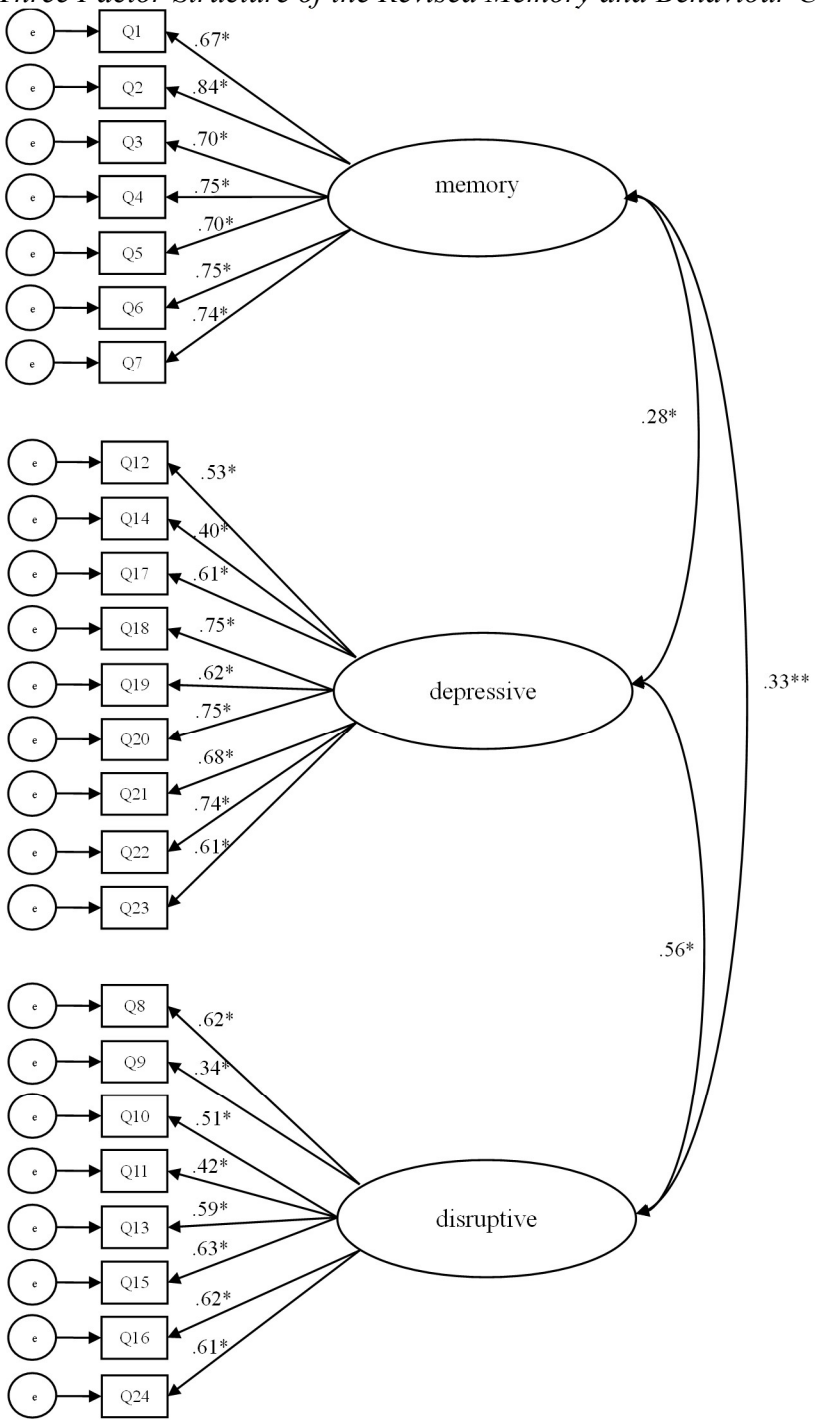
Note: Standardised coefficients reported. *P* values are two-tailed, *p <.05, ** p<.01, ***p<.001

Revised Memory and Behaviour Checklist

Figure 9 presents the CFA for the Frequency scale of the RMBC. The factor loadings ranged from .34 to .85, indicating moderate to strong relationships between the observed variables and RMBC subscales, all statistically significant (p <.05). There were moderate to strong correlations between the disruptive behaviour subscale and the other two subscales (depression and memory). However, the fit statistics suggested the model may not adequately fit the data. $\chi^2(249) = 521.61$, $p < .001$, RMSEA = .98 (90% CI [.086, .109]) and CFI = .766.

Figure 9

Three Factor Structure of the Revised Memory and Behaviour Checklist – Frequency

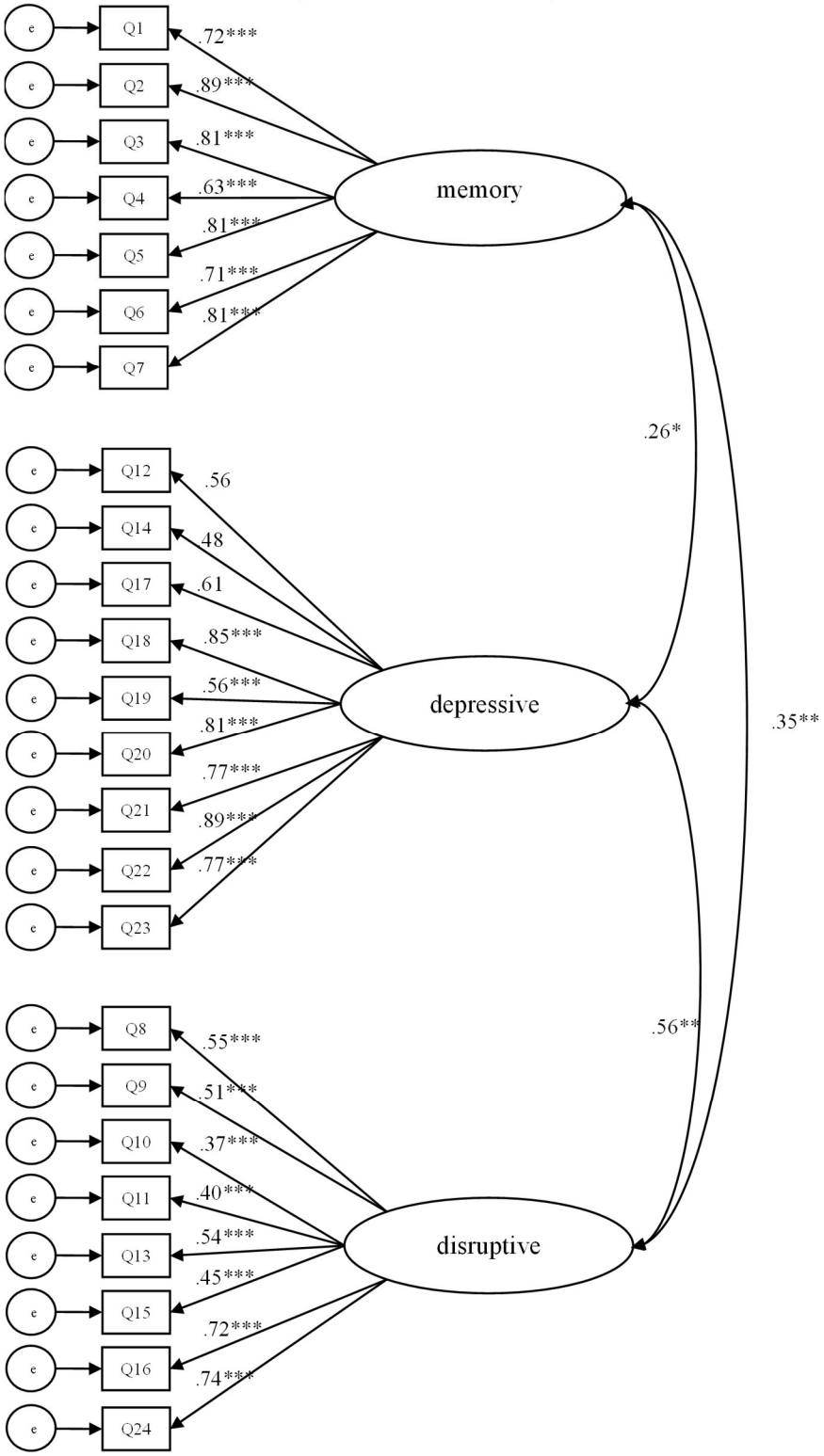


Note: Standardised coefficients reported. *P* values are two-tailed, *p <.05, ** p<.01, ***p<.001

Figure 10 presents the results of analysis of the Reaction scale of the RMBC. The factor loadings ranged from .34 to .84, indicating moderate to strong relationships between the observed variables and their corresponding latent factors all statistically significant (p <.05). There were moderate associations between disruptive behaviour and depression as well as disruptive behaviour and memory, a weak association was seen between memory and depression (all p <.05). Fit statistics suggest the model does not fit the data well $\chi^2(249) = 639.94$, $p < .001$, RMSEA = .117 (90% CI [.106,.128]), and CFI = .75.

Figure 10

Three Factor Structure of the Revised Memory and Behaviour Checklist – Reaction



Note: Standardised coefficients reported. *P* values are two-tailed, *p <.05, ** p<.01, ***p<.001

Correlational Analysis

Spearman's correlations were conducted to explore the relationships between background and context factors and the main study variables (results presented in Table 8). Relationships between individual primary stressors, loneliness, loneliness type, isolation and QOL were also assessed. Correlations were used to address hypothesis one to three and to provide additional context to the path analyses which were conducted to address hypotheses four to six.

In terms of significant findings between background and context factors and the main study variables, the number of months spent caregiving showed a moderate positive correlation with isolation (r_s =.23, p < .014, 95% CI[.042, .398]), relational deprivation (r_s =.21, p < .024, 95%CI [.023, .384]), and ADL dependency (r_s =.38, p < .001, 95% CI [.206, .532]). This suggests that longer duration of caregiving is associated with greater isolation, relational deprivation, and higher levels of ADL dependency in the care receiver. Additionally, hours per week spent caregiving (r_s = 26, p = .002, 95%CI [.109, .469]) and help hours received per week (r_s =.36, p < .001, 95%CI [.129, .472]) had a weak positive correlation with ADL dependency, indicating that caring for people with higher functional impairment requires more time and that caregivers receive more help to manage this.

ADL dependency was significantly correlated with isolation ((r_s =.24, p <=.009, 95%CI [.059, .415]), but not loneliness or QOL. Both behaviour frequency (r_s = -.39, p <.001, 95%CI [-.474, -.132]) and caregiver reaction (r_s = -.45, p =.001, 95%CI [-464, -.117]) demonstrated negative moderate significant correlations with QOL and positive correlations with loneliness (freq r_s = .32, p < .001, 95%CI [.142, .482]; reac r_s = .31, p <.001, 95%CI [.137, .480]) indicating that greater levels of challenging behaviour and caregiver reaction to behaviour are associated with lower QOL and higher loneliness. Relational deprivation demonstrated moderate significant

with QOL (r_s = -.27, p = .002 95% CI [-.445, -.097]) and loneliness ((r_s = .24, p <.010, 95%CI [.054, .410]) indicating that greater relational deprivation is associated with lower quality of life and higher loneliness.

Table 8

Spearman's Correlations of Background and Context factors to Study Variables

	PS	ADLQ	FREQ	REAC	RD	Lone	Emot	Soc	SDI	QOL
Background and context factors										
Care hours	.18*	.26**	.04	.09	.13	-.04	-.01	-.06	-.07	-.04
Help hours	.17	.36**	.13	-.04	-.02	.04	-.02	.08	.06	-.10
Caregiving duration	.23*	.38**	.03	.05	.21*	-.10	-.10	-.05	.23*	-.15
Known length	-.08	-.01	-.12	-.08	.05	.08	.09	-.01	.08	-.01
Primary Stressors		.52**	.76**	.66**	.61**	.36**	.39**	.25**	.23*	-.50**
ADL dependency			.16*	.02	.26**	.08	.07	.05	.24**	-.17
Frequency of challenging behaviour				.66**	.20*	.32**	.35**	.24**	.16	-.39**
Caregiver Reaction					.11	.31**	.31**	.27**	.18*	-.45**
Relational deprivation						.24**	.28**	.15	.07	-.27**
Loneliness							.90**	.88**	.18	-.60**
Emotional loneliness								.62**	.27**	-.54**
Social loneliness									-.05	-.51**
Isolation										-.30**

Note: p values are two-tailed. *p <.05, ** p<.01,

PS: Primary Stressors composite variable, ADLQ: Activities of Daily Living Alzheimer's, RD: Relational Deprivation, FREQ: Revised Memory and Behaviour Checklist Behaviour Frequency, REAC: Revised Memory and Behaviour Checklist, Lone: de Jong Gierveld Loneliness, Emot: de Jong Gierveld Loneliness emotional loneliness subscale, Soc: de Jong Gierveld Loneliness social loneliness subscale SDI: Social Disconnection Index (isolation), QOL: Quality of Life.

Hypotheses Addressed by Correlational Analysis

Hypothesis One: The Relationship Between Background and Context Factors and Quality of Life. No significant relationships were seen in Spearman's correlations (Table 8). Hypothesis one was not supported.

Hypothesis Two: The Relationship Between Background and Context Factors and Primary Stressors. Hypothesis two is partially supported. The analysis found that care hours per week and caregiving duration were both positively correlated to primary stressors (at the $p < .05$ level). This suggests that a higher number of care hours per week and a longer duration of caregiving are associated with a higher amount of primary stressors. In terms of the individual stressors, help hours per week, caregiving duration and caregiving hours per week were all positively and significantly associated with higher levels of ADL dependency. This suggests that more caregiving and help hours, as well as a longer caregiving duration were linked to greater ADL dependency (Table 8).

Hypothesis Three: The Relationship Between Background and Context Factors and Loneliness and Isolation. Findings partially support the hypothesis. Caregiving duration showed a significant association with isolation suggesting that longer caregiving durations were linked to increased isolation among caregivers (Table 8).

Path Analysis

Path analyses were conducted to address hypotheses four to six. Mediation analyses were conducted to address exploratory question three. The first path analysis assessed the relationships

between primary stressors and loneliness, isolation and QOL (Figure 11). The fit indices for the model suggested good fit $\chi^2(9) = 19.32$, $p > .05$, RMSEA = .06 (90% CI [.000,.122]) and CFI = .96. The results of this analysis are used to address hypothesis four, and five. The second path analysis assessed relationships between loneliness and isolation and QOL (Figure 12). The fit indices for the model were mixed $\chi^2(1) = 5.51$, $p < .05$, RMSEA = .19 (90% CI [.06,.37]) and CFI = .93. Results of this analysis were used to address hypothesis six.

Mediation Analysis

Two mediation models were tested; the first assessed the mediation of loneliness and isolation between primary stressors and QOL (Figure 13). The second assessed the mediation of loneliness type on the relationship between primary stressors and QOL (Figure 14). Fit statistics (Table 7) for the first model, suggested the model fit the data reasonably well $\chi^2(1) = 2.24$, $p = .134$, RMSEA = .104 (90% CI [.00 ,.29]) and CFI = .98. Fit statistics for the second model were mixed $\chi^2(1) = 57.92$, $p < .001$, RMSEA = .070 (90% CI [.56, .86]) and CFI = .66.

Hypotheses Addressed by Path Analysis

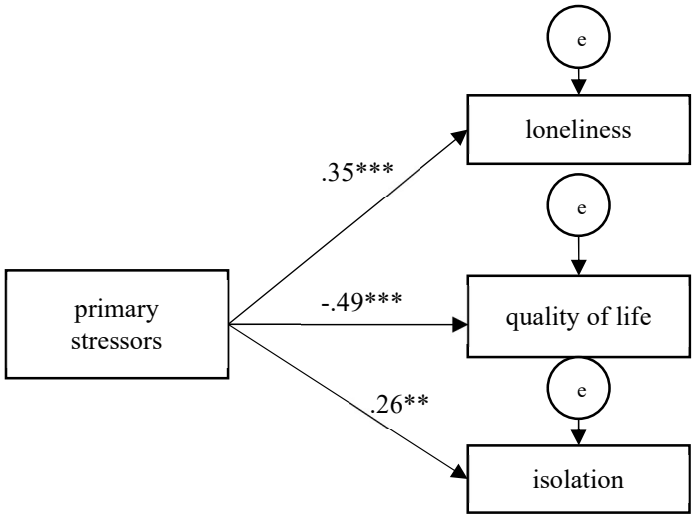
Hypothesis Four: The Relationship Between Primary Stressors and Quality of life. Hypothesis four was supported. Primary stressors had a significant negative path to QOL (β -.49, $p = .001$, 95%CI [-599, -.351]; Figure 11) indicating that higher levels of primary stressors are associated with lower QOL. This indicates that when considering all types of stressors combined there is a statistically significant negative relationship with QOL. In terms of individual stressors, all demonstrated significant negative correlations with QOL (Table 8). This suggests that higher levels of each stressor were associated with lower QOL. The only exception was the correlation between ADL dependency and QOL which was not significant, indicating that ADL dependency was not significantly associated with QOL in this study.

Hypothesis Five: Primary Stressors Will be Related to Loneliness, Emotional Loneliness, Social Loneliness and Isolation to Differing Degrees. Hypothesis five was supported. Path analysis showed primary stressors was significantly associated with higher levels of loneliness **(**β .35, p <.001, 95% CI [.177, .501; Figure 11**)** and isolation **(**β .26, p = .006, 95%CI [.085, .412**]**; Figure 11**)**. The relationship between primary stressors and loneliness was stronger than between primary stressors and isolation. Significant positive correlations were also seen between primary stressors and emotional (r_s = .39, p <.001 95% CI[.220, .539**]**) and social loneliness (r_s = .25, p =.006, 95%CI[.070, .421**]**). This suggests that higher levels of primary stressors were associated with higher levels of loneliness and isolation.

In terms of individual stressors, significant positive correlations were observed between total loneliness, emotional loneliness, and all stressors except for ADL dependency (Table 8). Indicating that most stressors were associated with higher levels of total and emotional loneliness. Significant positive correlations were also seen between social loneliness and frequency of challenging behaviour (r_s = .24, p =.007, 95%CI[.065, .420]) and caregiver reaction (r_s = .27, p =.003, 95%CI [.097, .448]). This indicates that higher levels of challenging behaviour and greater caregiver reaction to these behaviours were associated with higher levels of social loneliness. Significant positive correlations were seen between isolation and ADL dependency (r_s =.24, p =.009, 95%CI [.059, .415]) and caregiver reaction to challenging behaviour (r_s = .18, p =.051, 95%CI [-.006, . 362]). This indicates that supporting with greater amounts of ADLs and having greater reactions to challenging behaviour was associated with isolation for the caregivers in this research.

Figure 11

Path Diagram: The Relationships Between Primary Stressors and Loneliness, Isolation and Quality of Life

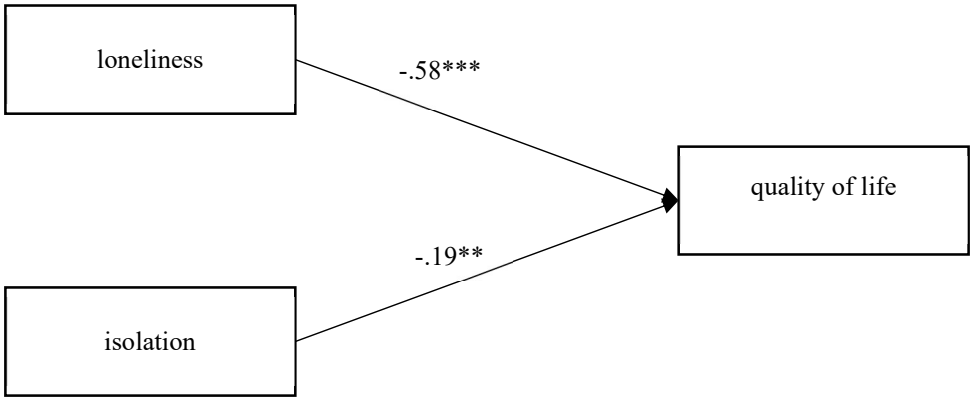


Note: Standardised coefficients reported. P values are two-tailed, *p <.05, ** p<.01, ***p<.001. Solid lines show significant paths.

Hypothesis Six: The Relationships Between Loneliness and Isolation and Quality of Life. Hypothesis six was supported. There was a moderate negative association between loneliness and QOL, showing that higher levels of loneliness were associated with lower QOL (β -.58, p <.001, 95% CI[-708, -.423]; Figure 12). Similarly, a weak association was seen between isolation and QOL, suggesting that higher levels of isolation are associated with lower QOL (β-.19, p = .009, 95%CI [-.353, -.027]).

Figure 12

Path Diagram: The Relationships Between Loneliness, Isolation and Quality of Life



Note: Standardised coefficients reported. P values are two-tailed, *p <.05, ** p<.01, ***p<.001. Solid lines show significant paths.

Exploratory Question Addressed by Mediation Analysis

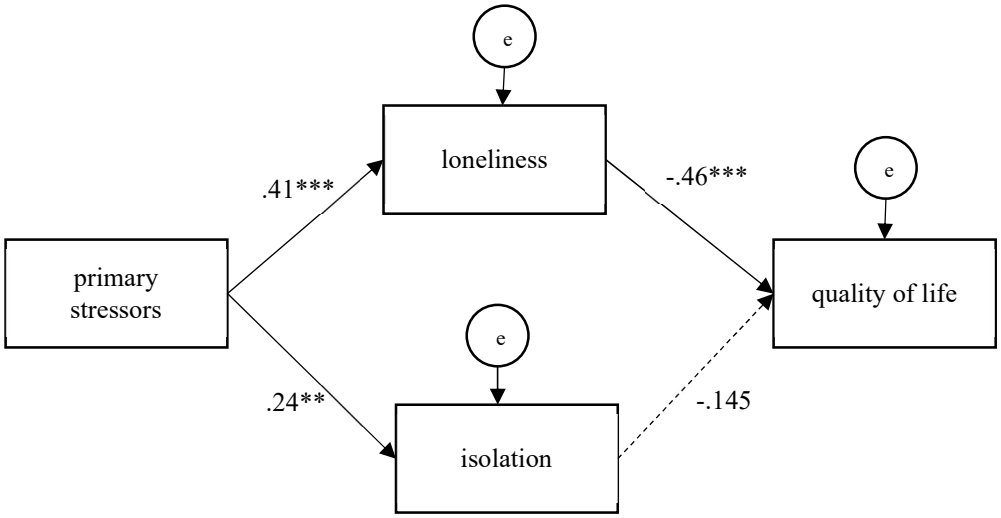
Exploratory Question Three: Does Loneliness Function as a Mediator in the Relationship Between Primary Stressors and Quality of Life? Two mediation analyses were carried out to address this question. The first assessed total loneliness and isolation as mediators between primary stressors and QOL. The second assessed loneliness type as mediators in the relationship between primary stressors and QOL.

Total Loneliness and Isolation as Mediators Between Primary Stressors and Quality of Life (Figure 13). The results showed insignificant indirect association between primary stressors on QOL through isolation (b = -.041, t = 1.24, p = 0.51) and a significant indirect association through loneliness (b -.221, t = 2.77 p = .001). The direct association of primary stressors on QOL remained significant (b -.36, p = .002), indicating that loneliness is a partial mediator (MacKinnon et al., 2007). The summary of the analysis is presented in Table 9. These results suggest that loneliness but not isolation mediates the relationship between primary stressors and QOL. Given the nature of the data and limitations in the analysis method, these findings should not be interpreted as evidence of causal relationships. Primary stressors were

directly associated with QOL. Findings suggest that primary stressors may be related to QOL through loneliness, however causal inferences cannot be made from this data. A discussion of assumptions required for causal inference is included in the discussion section.

Figure 13

Path Diagram: Loneliness as a Partial Mediator in the Relationship Between Primary Stressors and Quality of Life



Note: Standardised coefficients reported. P values are two-tailed, *p <.05, ** p<.01, ***p<.001. Solid lines show significant paths. Dotted lines show insignificant paths.

Table 9

Results of Mediation Analysis: Loneliness as Mediator Variable Between Primary Stressors and Quality of Life

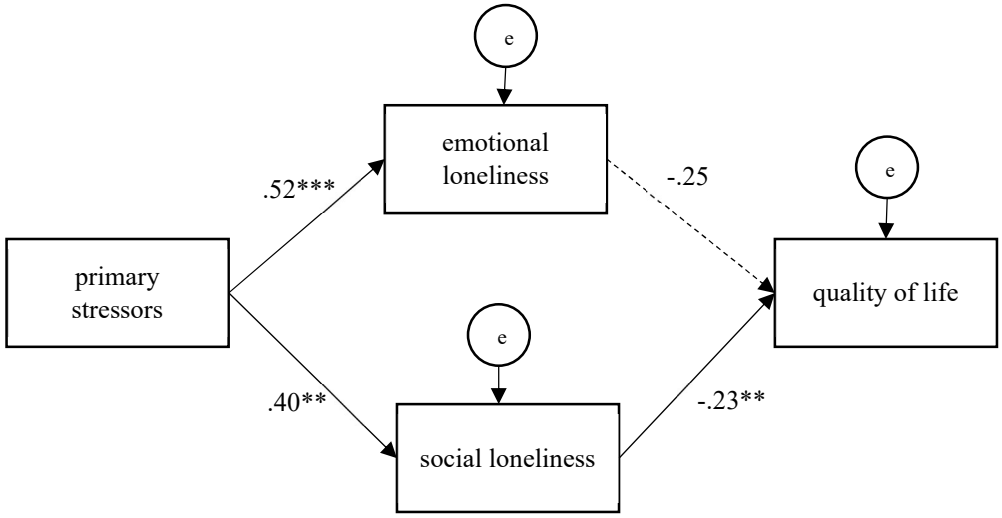
Relationship	Direct effect	Indirect effect	Confidence interval		Conclusion
			Lower bound	Upper bound	
Primary Stressors -> loneliness -> WHOQOL	-.36**	-.22***	-.41	-.11	Partial mediation
Primary Stressors ->		-.04	-.14	-.03	No mediation

isolation ->
WHOQOL

Loneliness Types as Mediators Between Primary Stressors and Quality of Life (Figure 14). The results showed an insignificant indirect association of primary stressors on QOL through emotional loneliness (b= -.16, t = -0.06, p = .062) and a significant indirect association through social loneliness (b = -0.11, t = -0.15, p = 0.037). The direct association between primary stressors and QOL remained significant (b = -.44, t = -3.07 p = 0.004), indicating that the loneliness is a partial mediator (MacKinnon et al., 2007). The summary of results is presented in Table 10, they suggest that social loneliness may mediate the relationship between primary stressors and QOL and emotional loneliness may not. Primary stressors were associated with lower QOL, both directly and indirectly through associations with greater loneliness. Again, these findings should not be interpreted as evidence of causal effects. The study uses cross-sectional data and contains potential breaches of the assumptions required for causal inference in path analysis (discussed in chapter 9).

Figure 14

Path Diagram: Test of Loneliness Types as Partial Mediators Between Primary Stressors and Quality of Life



Note: Standardised coefficients reported. *P* values are two-tailed. *p <.05, ** p<.01, ***p<.001. Solid lines show significant paths, dotted lines show insignificant paths.

Table 10

Results of Mediation Analysis: Emotional Loneliness and Social Loneliness as Mediator Variables Between Primary Stressors and Quality of Life

Relationship	Direct effect	Indirect effect	Confidence interval		Conclusion
			Lower bound	Upper bound	
Primary Stressors -> emotional loneliness -> WHOQOL	-.44**	-.16	-5.94	.31	No mediation
Primary Stressors -> social loneliness -> WHOQOL		-.11*	-.60	-.03	Partial mediation

Note: Standardised coefficients reported. Bootstrap sample = 5,000. *P* values are two-tailed. *p <.05, ** p<.01, ***p<.001.

Chapter Nine: Discussion

Using the Stress Process Model (SPM) as a framework, this study used a quantitative methodology to examine associations between factors related to the caregiving role (primary stressors), loneliness, isolation and QOL. Existing research indicates that dementia caregivers face higher risks of poor physical and mental health compared to caregivers of other conditions and non-caregivers (Basu & Mukhopadhyay, 2021; Sheehan et al., 2021). The Stress Process Model is commonly used to conceptualise caregiving and its health impacts (Ruisoto et al., 2020; Sheehan et al., 2021). Despite the connections between loneliness and health outcomes observed in other populations (Holt-Lunstad et al., 2015), the informal caregiving population is underrepresented in this research. Qualitative research describes themes which indicate a place for loneliness as a secondary role strain in the SPM, and quantitative research links elements of the SPM to loneliness (Hajek et al., 2021; Menec et al., 2020). Loneliness has not been specifically considered within the SPM framework.

Qualitative findings also suggest both social and emotional aspects of loneliness in the caregiving experience (Vasileiou et al., 2017), while primary stressors in the SPM may lead to deficiencies in both social and emotional aspects of relationships due to caregiving. Interventions that target loneliness type can be more effective than an approach targeting 'overall loneliness' (Masi et al., 2011). This study used a multidimensional loneliness measure to enhance the ability of findings to be used to support caregivers in New Zealand.

The QOL profile indicated that participants viewed their QOL in the moderate to positive range. A large number of participants were classified as lonely, fewer were classified as isolated. Hypothesis testing supported the direct negative association of primary stressors with loneliness, isolation and QOL. Loneliness and isolation were found to be associated with caregiver QOL.

Mixed results were seen in the pathways between primary stressors, loneliness and isolation and QOL. Associations between loneliness, primary stressors and QOL were consistent with loneliness as a partial mediator in the relationship between these variables. In terms of loneliness type associations between variables were consistent with social loneliness as a partial mediator, but not emotional loneliness. Isolation also did not show associations consistent with a mediating effect. This suggests that in this sample, caregiver's perception of social connection plays a more important role in wellbeing than physical proximity. Due to the nature of data and analysis methods used in this research these findings should not be interpreted as evidence of causal relationships, a discussion of assumptions required for causal inferences is included below.

While most of the relationships were more or less expected, and functioned in accordance with the Stress Process Model, few significant relationships were seen between background and context factors and the other variables in the model.

Assumptions Required for Causal Inferences

This research used path analysis to test theoretically informed associations. Drawing causal inferences from these associations would require several strong assumptions to be met, which is not possible in the current study. For causal inferences to be made from the estimates of direct effects it must be assumed that there is no reverse causality (Rohrer et al., 2022). For example, QOL must not influence loneliness. There must also be no unmeasured confounding variables and effects are assumed to be linear and additive (for example a one-unit change in primary stressors would be associated with the same change in loneliness across all participants). The design of this research cannot rule out reverse causality, this would require temporal ordering which cannot be achieved by a cross-sectional design (Rohrer et al., 2022). There are also

confounding factors which could influence the included variables (for example, individuals may interpret social cues negatively due to cognitive biases leading to feelings of loneliness; Hawkley et al., 2010), meaning that this assumption may not hold.

Mediation is interpreted as the product of two causal effects with both paths meeting the assumptions discussed above along with these additional assumptions. (Rohrer et al., 2022; VanderWeele, 2016). Firstly, that the effects are linear and additive, for example the effect of loneliness on QOL would be assumed to be consistent across all levels of primary stressors (Rohrer et al., 2022). Second, effects are assumed to be independent, meaning that the effect of primary stressors on loneliness must be unrelated to variability in the effect of loneliness on QOL (VanderWeele, 2016). Third that all covariates must be correctly modelled and not interact with the primary stressors or loneliness (VanderWeele, 2016).

For causal inferences to be made, confounders across the exposure-outcome, mediator-outcome and exposure-mediator relationships should be controlled for (VanderWeele, 2016). Also important is that confounders of the mediator-outcome relationship are not themselves affected by the exposure. In this research potential confounding variables were not measured or controlled for (VanderWeele, 2016). As a result, estimates of direct and indirect effects may be biased, and causal conclusions cannot be drawn from the models.

There are also assumptions about the measurement model which must hold for causal inferences to be drawn from the estimated relationships. As path analysis does not explicitly account for error, it must be assumed that the constructs are measured without error (Cole & Preacher, 2014). While efforts were taken to use reliable and valid measures, psychological constructs can contain measurement error, which can bias results. For causal inference the model must also assume that the constructs are meaningfully distinct and do not influence each other

(Cole & Preacher, 2014). There may be overlap in some concepts such as loneliness and isolation. These assumptions cannot be verified in the current study and therefor the findings should be interpreted only as associations.

Quality of Life Profile of Informal Caregivers in this Research

Participants rated their QOL between 'neither poor nor good' and 'good' indicating that participants' perception of their quality of life is better than neutral but does not reach a 'good' rating. There were significant gender differences in QOL ratings with females reporting lower QOL than males. In terms of domains, the psychological domain was rated significantly lower than all other domain scores, reflecting caregivers' perceptions of their negative feelings, satisfaction with cognitive function or body image and meaning or purpose in life. These findings suggest that, in general, the caregivers in this sample are, not dissatisfied with their QOL, contrasting with studies reporting that caregivers have poor QOL (Andreakou et al., 2016; Martis et al., 2024). Due to the nature of cross-sectional research, it cannot be determined if this is a change for caregivers related to taking on the caregiving role.

The mean age of caregivers in this sample was 64.5 years, which may point to the impact of life stage on QOL. Adults aged 65 to 84 are often referred to as the young old and have fewer demands on their time (such as work and childcare) while remaining in relatively good health (Ortman et al., 2014). The caregivers in this research are older than the caregivers in the research documenting poor QOL (58 years old in Andreakou et al., 2016 and 46 years old in Martis et al., 2024 for example). The difference in both QOL and age may reflect age related differences in how people appraise and respond to emotional stimuli. Socioemotional Selectivity theory suggests that older adults prioritize emotional goals, leading them to regulate their responses to

challenging events more effectively than younger adults (Wirth et al., 2023). Given the interpersonal nature of the challenges the caregivers are responding to, it may be that participants are more effective at regulating their responses, reducing the potential associations with their QOL.

A related aspect may be the links between well-being and positives in the caregiving experience (Quinn et al., 2024). Caregiver satisfaction and QOL have been found to relate to caregivers perception of their personal growth, sense of duty and feelings of making a difference (Quinn et al., 2024). Identifying positive experiences in caregiving is also associated with better well-being and life satisfaction, although not with lower personal stress (Lindeza et al., 2024). This indicates that wellbeing can improve independently of stress.

Domain Score Differences

The rating of the psychological domain as significantly lower than other domains indicated that caregivers were less satisfied with their emotional QOL than physical, relationships or environment. Mental health domains have been reported as the most affected in caregivers of all conditions (Gammie et al., 2016). This finding indicates that without consideration of other factors, interventions to improve the psychological well-being of dementia caregivers would have the greatest impact on over all QOL.

The Prevalence of Loneliness and Isolation in this Sample of Caregivers

A significant proportion of participants were classified as lonely with most experiencing both emotional and social loneliness. Despite the high numbers of lonely participants, the majority (81%) were not classified as isolated, suggesting they had adequate social contact. This supports the distinction between loneliness and isolation, where loneliness can occur in the presence of social interactions (Cacioppo et al., 2006). Twenty-eight percent of participants rated

their loneliness as severe aligning with other research showing moderate or severe loneliness in caregivers (Victor et al., 2021).

The isolation measure, the Social Disconnection Index (Bassuk et al., 1999), measured isolation through counts of visual and non-visual contact with friends, and relatives as well as group and church membership. It does not include interactions with formal help, such as healthcare providers, or home help. The types of social connections that are included are typically those which would be targets for improving loneliness, e.g. Making friends, or joining groups. This supports the idea that social contact alone does not alleviate loneliness. This is an important consideration as many intervention studies synonymously include loneliness and isolation which has the potential to confound results (Dickens et al., 2011). When addressing loneliness, interventions with a clear theoretical basis have been shown to be most effective (Jarvis et al., 2020). The lack of isolation indicates that interventions to increase social contact alone are unlikely to adequately address the issue. It also indicates that the caregivers in this study are not satisfied with their existing social connections or are unable to leverage these connections in a way which reduces their loneliness.

This is an important finding for those interested in treating loneliness in caregivers. It shows that isolation does not need to be a precursor to loneliness. Caregivers may already have the social resources to reduce loneliness, support could be directed towards increasing the caregiver's ability to receive support and increase satisfaction in these existing relationships. Interventions should go beyond increasing social contact and focus on enhancing the quality of social interactions and ability to receive support from these connections.

The high prevalence of loneliness in this sample and the current understanding in the literature of the links between loneliness and poor emotional and physical health indicates that

loneliness is a worthwhile intervention target (Holt-Lunstad et al., 2015; Quadt et al., 2020). Given these findings, psychological interventions may be a highly appropriate tool for reducing loneliness in this population. Psychological interventions target mental processes, such as negative interpersonal thoughts and responses. It has been suggested that changing these processes can lead to change in social behaviour, which has the potential to reduce loneliness over time (Hickin et al., 2021). Cognitive Behaviour Therapy (CBT) is a commonly used intervention for loneliness, it targets the cognitive biases that influence the interpretation of social information (Hickin et al., 2021). CBT aims to decrease loneliness by helping individuals to seek out disconfirming evidence to reframe these maladaptive cognitive biases to assist them to change behaviour (Hickin et al., 2021). This may support caregivers by assisting them to enhance existing connections. These findings also indicate that psychologists working with caregivers should be aware that loneliness may feature in the experience, even in the case of apparent social connections.

Primary Stressors and Quality of Life

Primary stressors demonstrated a significant negative association with QOL. The fit indices for this model indicated good fit, supporting the reliability of these findings. Individual stressors (except for ADL dependency) demonstrated significant negative correlations with QOL. These findings support the framework of the Stress Process Model, where primary stressors directly impact caregiver wellbeing (Pearlin et al., 1990). The significant negative relationship seen between primary stressors and QOL supports the model, showing that the cumulative effects of the stressors are associated with mental and physical health outcomes.

The results indicate that QOL in caregivers may be related to the type and intensity of stressors caregivers are managing. Findings showed significant correlations between challenging

behaviour, caregiver reaction, relational deprivation and QOL. Surprisingly, ADL dependency did not have a significant association with QOL. The relationship found between behaviour difficulties and QOL are consistent with the literature. The stress of managing challenging behaviour has been related to poor physical and mental health, (Basu & Mukhopadhyay, 2021; Sheehan et al., 2021; Watson et al., 2019). Perceptions of physical and mental health are quality of life indicators (WHOQOLGroup, 1994), and perceived stress has been directly linked to life satisfaction (Peavy et al., 2022).

The lack of association between ADL dependency and caregiver QOL appears to be inconsistent with the wider literature. Basu and Mukhopadhyay (2019) found that supporting with a higher number of ADLs is physically and emotionally exhausting for caregivers, as well as time consuming, all of which are linked to poor wellbeing. A possible explanation for this discrepancy is the increased likelihood of support that may coincide with increase ADL needs. Hvidsten et al. (2020) suggested that greater functional impairments in care recipients necessitate more formal and informal support which might alleviate some of the burden on caregivers. There are reported difficulties with caregivers accessing support from formal services in New Zealand (O'Sullivan et al., 2014), with these challenges being more pronounced for Māori and Pacific Island populations (Ma'u, 2021). Participants in this research were recruited from support organisations indicating that they may not have these difficulties and the sample in this research was 88% New Zealand European. Access to support may help to explain why higher ADL dependency was not associated with QOL in this study.

This study found a relationship between relational deprivation and QOL, which contributes to the existing literature. There is currently limited evidence for the relationship between relational deprivation and QOL. Beeson (2003) highlighted that emotional support is

key for caregiver health, suggesting that relational deprivation can lead to poorer QOL. This finding supports the position of relational deprivation as a primary stressor in the Stress Process Model.

Despite the negative association of primary stressors with QOL, caregivers did not rate their QOL poorly. While primary stressors were associated with lower QOL scores, , their intensity or frequency in this sample may not have been high enough to correspond to QOL scores in the 'poor QOL' range. . Other factors such as coping mechanisms, access to support (participants were primarily recruited through support services) or other protective factors might have buffered the impacts of these stressors, resulting in the neutral to slightly positive QOL ratings. The relationships between individual primary stressors and QOL were tested with correlations. It could be beneficial to explore these relationships with a larger sample and a causal identification strategy to provide a better understanding of at what threshold they significantly reduce QOL.

The Association Between Primary Stressors, Isolation, Loneliness, and Loneliness Type

Path analysis showed that primary stressors were significantly associated with higher levels of loneliness and isolation, a stronger relationship was observed for loneliness. Correlation analysis indicated that primary stressors were significantly related to both emotional and social loneliness. This suggests that caregiving stressors are related to the caregivers' ability to maintain intimate and social connections. The significant path between primary stressors and isolation, considering the relatively low number of participants being categorized as isolated, suggests that for those who were isolated, higher levels of caregiving stress may be linked to greater isolation.

The stronger association between primary stressors and loneliness compared to isolation suggests that primary stressors have a stronger relationship with feelings of satisfaction with relationships than objective social contacts. Findings align with the theoretical framework of the Stress Process Model, where primary stressors can lead to secondary role strains (Pearlin et al., 1990), loneliness being an hypothesized secondary role strain. Stressors in the model were thought to be related to both social and emotional aspects of relationships, which is evidenced by the findings of the correlational analysis in this research.

Relationships Between Individual Primary Stressors, Loneliness, Isolation, and Loneliness Type

Differences were seen in significant relationships between individual stressors, loneliness, isolation, and loneliness type. Frequency of challenging behaviour correlated to loneliness but not isolation. Activities of Daily Living dependency correlated to isolation but not loneliness and relational deprivation correlated with loneliness and emotional loneliness, but not social loneliness or isolation. The relationship between frequency of challenging behaviour and loneliness suggests that supporting with greater challenging behaviour was associated with the caregiver's perception of the quality and/or quantity of their relationships. This is consistent with existing literature indicating that caregiving for individuals with dementia, with greater amounts of challenging behaviour leads to increased feelings of loneliness (Greenwood & Smith, 2019; Vasileiou et al., 2017). The lack of correlation with isolation indicates that it is not associated with the amount of social contact caregivers have. It may be that caregivers feel unsupported in dealing with these specific behaviours as they are unique and perhaps misunderstood by others (Perissinotto et al., 2012; Vasileiou et al., 2017), potentially leading to dissatisfaction with personal relationships.

Activities of Daily Living dependency can be time intensive for caregivers taking time away from ability to maintain relationships, face to face or over other forms of communication, resulting in isolation. Clark and Bond (2000) found that severity of dementia and behaviour demands were correlated with lower social activity. However, if caregivers do not feel deficient in their relationships due to this, they would not experience loneliness (Ciolfi & Jimenez, 2017). These findings suggest that while functional impairment of the person with dementia is associated with the caregiver's ability to see and communicate with others, challenging behaviour is associated with the caregiver's satisfaction with their relationships. Supporting with ADLs is not specific to dementia caregiving, it can look like the general support one might provide to a family member, such as doing the grocery shopping for an elderly parent. The ability of others to understand to these tasks might enable them to relate to the caregiver, potentially mitigating feelings of loneliness. The association between caregiver reaction and isolation but not loneliness suggests that caregivers who find these behaviours challenging limit interactions with others, as discussed in qualitative research (Greenwood & Smith, 2019). However, caregivers might feel emotionally supported by friends who understand and support the 'stress' even if they cannot fully relate to the specific challenges of dementia caregiving (Victor et al., 2005). Thus, it may not be associated with satisfaction with relationships, as evidenced by the lack of significant association with loneliness.

Relational deprivation refers to the feelings of loss of a close companion as the dementia progresses, which aligns with the definition of emotional loneliness (a feeling of absence of close, emotional connections (Ciolfi & Jimenez, 2017). The relationship between relational deprivation and emotional loneliness, but not total or social loneliness highlights importance of multidimensional loneliness measurement. A unidimensional measure may not be sensitive

enough to detect this relationship. As relational deprivation is an important consideration for the dementia caregiving population (Beeson, 2003) missing this association could lead to insufficient understanding of the experience.

The Relationship Between Loneliness, Isolation and Quality of Life

A significant relationship was seen between loneliness and isolation and QOL. The stronger relationship between loneliness and QOL compared to isolation suggests that, in this sample, perception of relationship quality and quantity may have a stronger connection to wellbeing than social contact. Improving quality of interactions connections might be more important for improving QOL than increasing social contact. While a significant negative relationship between loneliness and QOL was seen, it is interesting to note that despite the high percentage of participants classified as lonely, the majority of these being classified as moderately or severely lonely, QOL was not rated poorly in this sample. This suggests that there may be other factors contributing to the participants' QOL rating. Findings align with the existing literature, where loneliness and isolation both impact mental and physical health outcomes (Holt-Lunstad et al., 2015; Holt-Lunstad & Steptoe, 2022; Quadt et al., 2020).

The relationship between loneliness and QOL is likely influenced by a range of factors outside the scope of the current research. Although there is evidence of an association between loneliness and QOL , it is not the sole determinant. This research only examined aspects that may exist due to the caregiving role. Of course, people exist in a much wider context. It is likely that there are intrinsic and extrinsic factors at play in this relationship; engagement in meaningful activities, good health, effective coping and personal resilience as well as access to resources, and appropriate living conditions can all positively contribute to QOL (Lee & Oh, 2020; Marquez et al., 2020; Owen et al., 2022; Palacio et al., 2020).

Loneliness as a Mediator Between Primary Stress and Quality of Life

Loneliness partially mediated the relationship between primary stressors and QOL. Including loneliness in the model reduced the strength of the association between primary stressors and QOL, though this path remained significant. In terms of loneliness type, social loneliness partially mediated the relationship between primary stressors and QOL and emotional loneliness did not. The partial mediation of loneliness suggests that the caregivers' perception of the quality and quantity of their relationships are associated with a greater likelihood of a negative relationship between caregiving stressors and QOL. This aligns with the Stress Process Model where secondary role strains exacerbate the impact of caregiving stress on caregiver wellbeing. While this aligns with the SPM it is important to note that due to limitations in the design of the research as they relate to causal inferences (as discussed above), the findings are only able to show an association between primary stressors, loneliness and quality of life.

The partial mediation of social loneliness (and not emotional loneliness) suggests that the caregiver's satisfaction with their social connections has an important role in the relationship between primary stressors and QOL. Reinforced by the context of this finding in a primarily non isolated sample.

The lack of associations consistent with mediation effects from emotional loneliness, could reflect true differences in the constructs. It may also be due to the variables included in the model. Relational deprivation was included as it is in the Stress Process Model and the literature indicated it was a stressor for caregivers (Pearlin et al., 1990). It was the only included stressor which was primarily hypothesised to be associated with emotional loneliness. The other stressors could influence social and emotional relationship satisfaction. Furthermore, relational

deprivation may be an incomplete conceptualisation, measurement of this concept could be improved by including a measurement of relationship quality which is shown to be associated with loneliness (Victor et al., 2021).

These findings align with the existing literature on the relationship of loneliness to health and QOL(Goren et al., 2016; Holt-Lunstad et al., 2015). Findings contribute to the literature by supporting the conceptualisation of this relationship within the Stress Process Model, where primary stressors are related to secondary role strains, loneliness in this instance. There is substantial evidence for the relationship between loneliness and physical and mental health in other populations (Holt-Lunstad et al., 2015), this mediation analysis provides evidence for loneliness in the caregiving population and an association between loneliness and QOL. Given the design of this research, and inability of this study to meet assumptions required for causal inference (discussed above), these findings should only be considered as evidence for associations.

These findings support loneliness as an intervention target for caregivers. Loneliness is a treatable aspect of the caregiving experience and may be more appropriate for intervention than primary stressors which may not be able to be changed. Psychological treatments for loneliness, like CBT target processes such as avoidance and cognitive biases (Hickin et al., 2021) which may help caregivers reduce loneliness by increasing their satisfaction with existing connections.

The Limited Role of Background and Context Factors in the Relationship Between the Caregiving Role and Quality of Life

According to the literature review and framework of the Stress Process Model it was expected that background and context factors would correlate to primary stressors, loneliness,

isolation and QOL (Bom et al., 2018; Santos et al., 2014; Vasileiou et al., 2017). While some correlations were seen they were fewer than anticipated. No relationships were seen between the background and context factors and QOL, indicating that the development of primary stressors, loneliness and isolation have a greater relationship to QOL than these factors alone.

Relationships Between Background and Context Factors and Primary Stressors

In this study the average duration of caregiving was 3.85 years and caregivers reported spending 67.84 hours per week on caregiving tasks. Higher caregiving durations and hours per week spent caregiving were associated with higher cumulative primary stressors. This is consistent with the existing literature where longer caregiving duration indicates greater progression of dementia with associated levels of functional decline linked to a more challenging caregiving role (Bom et al., 2019; Greenwood & Smith, 2019; Litzelman et al., 2015).

Findings indicate that interventions to support caregivers experiencing high care demands may reduce the cumulation of primary stressors. Supports such as respite care may be beneficial (Oliveira et al., 2020). However, it should be noted that help hours per week did not show a correlation to primary stressors indicating that the help caregivers in this sample are receiving may not be sufficient or appropriate for an association with primary stressors to be found. Care should be taken to ensure that help provided for or accepted by caregivers is appropriate for their needs.

Relationships Between Background and Context Factors and Loneliness and Isolation

In terms of the relationship between loneliness, isolation and background and context factors, the only correlation was between caregiving duration and isolation. This was consistent with the literature which suggests that longer durations of caregiving are associated with decreases in social engagement (Brodaty & Donkin, 2009). This was the only background and

context factor associated with any relational deficiency, suggesting a link between duration of caregiving and isolation.

Relationship Length Did Not Correlate to any Outcome Variables

Over time, caregiving responsibilities can alter relationship dynamics which may impact emotional wellbeing and QOL (Beeson, 2003). It was expected that there would be correlations between relationship length, relational deprivation, loneliness and QOL. Relationship length was the only background and context factor to not correlate to any of the outcome variables. This suggests that there might be other factors that better explain associations between care relationship and QOL.

The average duration of the relationship in this study was 46 years. Twenty-nine percent of participants were caring for their parent. Participants caring for their parents stated that their relationship length was their age. The average age of participants was 64.98 years with largest relationship length brackets 40-50 years (18%), 50-60 years (26%) and 60-70 years (22%). Most participants stated they were married (67%) or living as married (9%) therefore individuals caring for their parent in this sample are likely to be married. Although relational deprivation has been seen in caregiving daughters (Beeson, 2003) it could be theorised that relational deprivation more commonly develops with the loss of a spouse as that is typically the closest relationship for adults (Beeson, 2003).

It may be that the length of the relationship was not a suitable predictor of relational deprivation. Research from Beeson (2003) found that relational deprivation was significantly correlated to perceived quality of current relationship which this research did not measure. The literature suggests that the quality of the relationship might be more impactful that its duration.

Kotwal et al. (2024) found that partners who were highly satisfied with their relationships experienced more loneliness when their partner developed dementia compared to those in lower quality relationships; a long relationship isn't necessarily close or good. Victor et al. (2021) also found that better quality of the relationship was associated with a lower risk of reporting loneliness (using the DJG scale) this agrees with findings that better relationship quality is associated with greater well-being in family caregivers of people with dementia (Quinn et al., 2009; Rippon et al., 2020).

Implications

The results of the study indicate that loneliness may be prevalent among informal caregivers of people with dementia, with 88% of participants reporting loneliness. This suggests that interventions aimed at addressing loneliness could be beneficial to informal caregivers, given the strong links between loneliness and physical and mental health seen in the literature (Holt-Lunstad et al., 2015; Holt-Lunstad et al., 2010). This is an important as loneliness is a potentially modifiable issue.

Frequency of challenging behaviour and relational deprivation showed significant relationships with loneliness. Loneliness, and both subtypes, showed significant relationships with QOL and its domains (except for social loneliness and the physical domain). While results showed an association between loneliness and QOL, it is important to note that the cross-sectional observational design of this study cannot provide evidence for causal conclusions to be made. Therefor targeting loneliness with the aim of improving QOL should be treated as a starting point for future research.

There are a range of approaches employed to address loneliness such as leisure activities, educational approaches, befriending and social and community interventions (Victor et al.,

2021). As well as, social skills training, social and emotional support, community projects and therapies (Hickin et al., 2021). There are challenges in assessing the effectiveness of interventions within the literature because of methodological issues with study design. For example, loneliness is typically not clearly defined and sometimes conflated with isolation creating uncertainty in what the interventions are addressing (Fakoya et al., 2020). Additionally, the theoretical underpinnings of studies are not often stated which it makes it difficult to understand the mechanisms through which the interventions may be operating and in what contexts the interventions would be appropriate (Fakoya et al., 2020). It is often unclear if the interventions themselves are impacting loneliness or if it is simply the act of bringing people together (Bessaha et al., 2020).

A review of befriending and peer support programmes aimed specifically at caregivers of people with dementia reported that these were largely ineffective at both reducing loneliness and improving mental health (Smith & Greenwood, 2014). Veronese et al. (2021) conducted an umbrella review of systematic reviews and meta-analyses and found three interventions were statistically significant for reducing loneliness: mindfulness/meditation, social cognitive training, and social support. However, the researchers applied a GRADE (Grading of Recommendations Assessment, Development and Evaluation) criteria for evaluating the strength of the evidence and found them to be low. Velloze et al. (2022) reviewed interventions for addressing loneliness in older adult caregivers. Five main intervention types emerged: mindfulness, computer applications, music therapy, peer support and community programmes. Peer support was the most frequently utilised intervention, commonly employing strategies such as emotional support, expanding the social network, supplying psychoeducation materials. Most studies did not report significant results and those that did reported small effect sizes.

As the current research found social loneliness to partially mediate the relationship between primary stressors and QOL, this may point to social loneliness as an intervention target. However, it is important to note that this would rest on the inference that loneliness has a causal role in this model which is not able to be established by the results of this research. Therefor the implications of the role of social loneliness as an intervention target should be considered tentative. Interventions should focus on an individual's satisfaction with the quantity of their relationships; thus, group interventions may be effective. However, it is important that participants are screened for loneliness type before applying the intervention. For a group intervention to be effective against emotional loneliness the participant would need to form close and satisfying relationships within the group rather than increase their satisfaction with the number of social connections. An individual experiencing primarily emotional loneliness would be better supported individually to identify barriers to forming meaningful relationships (Masi et al., 2011).

An issue identified in this research is that while social loneliness mediated the relationship between primary stressors and QOL, most participants were not isolated. This suggests that participants may have difficulty engaging with their social connections in a satisfying way. If the reasons for this are not addressed, there may be limited benefit to an intervention that seeks solely to increase the quantity of social contacts. Psychological interventions that target individual factors influencing social behaviour can help to reduce loneliness (Hickin et al., 2021). These interventions are designed to support cognitive change, addressing the maladaptive cognitions which can maintain loneliness, they also encourage behavioural change which could increase quality of interactions (Hickin et al., 2021).

Group interventions can be useful for treating social loneliness (Masi et al., 2011). They should focus on hobbies or skills and not explicitly be aimed at reducing loneliness. Lonely people may avoid a 'loneliness' group due to perceived stigma or discomfort (Masi et al., 2011). Activities provide a natural way for people to form bonds with one another. Caregivers could be well suited to skills-based groups as they are managing a challenging role and learning new skills could be seen as valuable to them. Caregivers are also known to put the needs of the person they are caring for first, portioning time away from themselves (Vasileiou et al., 2017). Such groups could fulfil a dual purpose of enhancing opportunities for the caregiver's social interaction and supporting the care receiver through upskilling the caregiver.

Limitations

Impact of COVID-19 Lockdown on Recruitment and Study Variables

Data was collected during New Zealand's COVID-19 lockdown. This impacted participant numbers due the organisation, which was planned to promote the research, no longer prioritising promotion of the research during this time. Findings may have been influenced as the effects of the lockdowns could have interacted with existing risk factors for loneliness. New Zealand implemented strict measures in 2020 to attempt to reduce the spread of COVID-19. This included border closures, physical distancing mandates and a nationwide lockdown (Baker et al., 2020). The first lockdown occurred on 19 March 2020, during this time individuals were confined to their homes. Interaction was limited to designated 'bubbles' and people were advised avoid non-essential activity outside of the home. Individuals who were thought to be more vulnerable to the virus, such as those over 70 or with underlying health conditions were advised to strictly isolate themselves (Cheung et al., 2020). These measures had a profound impact on daily routines and social interactions, potentially leading to feelings of loneliness and distress

(Every-Palmer et al., 2020). Research conducted in the third week of the lockdown asked respondents various questions about their emotional wellbeing including how often they had felt lonely in four weeks prior, 10.6% reported that they felt lonely most of the time (Walker, 2020). In contrast research done in 2018 in the General Social Survey, 3.5% reported feeling lonely most of the time in the past four weeks (Walker, 2020). While these results are not directly comparable due to survey and sampling differences, they do suggest that there was an increase in self-reported loneliness during the lockdown.

Research on informal caregivers during the lockdown conducted in New Zealand found that on average informal caregivers reported slightly higher and increased symptoms of depression but not anxiety compared to other older adults (Allen et al., 2022). Caregivers also reported a higher rate of significant symptoms of depression compared to non-caregivers (26.6% vs. 20.7%). Similar trends were seen in research conducted in Italy where informal caregivers of people with dementia reported increased symptoms of depression but not anxiety during Italy's initial pandemic lockdown (Altieri & Santangelo, 2021). A systematic review of qualitative research conducted by Ervin et al. (2024) on the impact of informal caregiving on mental health during the COVID-19 pandemic found that participants reported stress and loneliness during the pandemic. Themes of a rise in caregiving demands, negative emotions such as fear and uncertainty exacerbated by new knowledge of things such as transmission risk emerged (Ervin et al., 2024).

Omission of Socio-Economic Status in Demographic Information

Another limitation of this study is not collecting socioeconomic status (SES) information alongside other demographics. Although identified as a factor in the literature review, SES was not included due to an error in the survey. Research has found that caregivers from lower SES

backgrounds have higher levels of stress and poorer mental health (Pinquart & Sörensen, 2007). This may be due to decreased financial and social resources to cope with the demands of caregiving (Schulz & Martire, 2004). Financial restraints can also limit access to formal supports such as respite care (Chappell & Dujela, 2008). Not including SES in this research may have overlooked an important dimension in the factors that contribute to health outcomes for dementia caregivers. Future research should incorporate a consideration of SES.

Methodological limitations

There are several methodological limitations within this research. This research was not preregistered. Pre-registration involves registering the planned hypotheses, methods and analyses prior to data collection (Lakens, 2019; Rubin, 2020; Simmons et al., 2021). The aim is to increase transparency and prevent questionable research practices such as HARKing (hypothesising after results are known) and p-hacking (Simmons et al., 2021). Hypotheses, methods and analyses used in this research were guided by theory and the current literature, including preregistration may have increased credibility of the findings (Rubin, 2020; Simmons et al., 2021).

Sample size was likely constrained due to COVID-19 (discussed above) and practical time limitations. The final sample was judged to be appropriate for path analysis as it fit within the recommendations of the sample being ten times the number of parameters in the model with a lower bound of 100 (Bentler & Yuan, 1999; Kline, 2023). However, an *a priroi* power analysis was not conducted which would have determined the sample size necessary to detect hypothesised associations (Lakens, 2022). The lack of power analysis can increase the likelihood of type I and type II error, which can limit the confidence in the robustness of the reported findings and is a limitation of this research (Lakens, 2022).

There are also certain limitations to the use of path analysis. Path analysis does not explicitly account for measurement error (Cole & Preacher, 2014). The assumption that data does not contain error is unlikely to hold in this research given the self-report data and constructs measured (Cole & Preacher, 2014). Unaccounted for measurement error can attenuate the strength of the relationships between variables and lead to biased or undervalued parameter estimates (Cole & Preacher, 2014). This could lead to incorrect conclusions about the existence of associations (Cole & Preacher, 2014). Future research should consider using structural equation modelling (SEM) which explicitly accounts for measurement error by using latent variables which could improve the validity of the results (Cole & Preacher, 2014).

Path analysis also relies on several assumptions, for example that relationships between variables are linear, residuals are independent and normally distributed, no multicollinearity and that variables are correctly ordered (Streiner, 2005). These assumptions may not hold in this research. For example, given the cross-sectional data it is not possible to establish the ordering of variables meaning that reverse or reciprocal effects cannot be ruled out. Estimates and model fit can be impacted by violations of these assumptions which could limit the accuracy of the results (Streiner, 2005).

Another limitation of this research is the lack of a causal identification strategy. A causal identification strategy involves methodological steps such as specifying hypotheses, identifying potential confounders, using an appropriate estimation method and conducting sensitivity analysis (Grosz et al., 2020). A lack of a causal identification strategy can result in conflating association with causation (Grosz et al., 2020). This research was observational and cross sectional and, as such, cannot establish causation. However, there is some debate in the literature about avoiding causal inferences based on non-experimental evidence (Grosz et al., 2020).

Hernán (2018) states that ruling out causal assumptions in non-experimental literature is unhelpful as causal inference is a core job of research. They state that ultimately the result is researchers avoiding explicit statements about causality. Additionally, readers may still interpret findings as causal and subsequent publications may refer to them as such (Grosz et al., 2020). Hernán (2018) argue that explicit discussion about causal objectives improves data analysis and discourages excesses in interpretation of results.

The directional nature of path diagrams can give the illusion of a causal structure (Bollen & Pearl, 2013). The use of path analysis in this research may have inadvertently implied causal inference. Path analysis does not establish causality unless supported by a causal identification strategy and appropriate data (Bollen & Pearl, 2013). Given the study design and lack of a causal identification strategy and potential breaches of assumptions the findings of this research cannot support causal claims.

Cultural Limitations and Reflections

There are several limitations within the design, methodology and theoretical framing of this research which may have not only limited participation from Māori, but also, it's relevance and applicability to Māori caregivers. The design was chosen as it was determined to be the most feasible for time and resource limitations, but it may have been a factor in the low number of Māori participants. This limits the generalisability of findings. The survey was concerned with the 'primary caregiver', the intention was to target participants who were supporting with caregiving stressors which would demonstrate observable connections between primary stressors, loneliness, isolation and quality of life. This approach may have unintentionally excluded Māori as the concept of a 'primary caregiver' may not align with the shared nature of Māori care (Dyall et al., 2008). As such Māori may not have thought of themselves as meeting

the eligibility criteria and not completed the survey. This may have been mitigated by offering culturally grounded examples of caregiving tasks or explicitly acknowledging Māori caregiving arrangements.

While the Stress Process Model has shown utility in diverse populations (Hilgeman et al., 2009; Ice et al., 2012), it may not be fully appropriate for use with Māori. The model's linear progression from objective stressors to wellbeing may fail to capture the interaction in these areas, which means it fails to account for the holistic and interdependent aspects of Māori wellbeing (Pitama et al., 2014; Rochford, 2004). While there is evidence that the objective caregiving tasks included in the model are core across caregivers (Knight & Sayegh, 2010) the model was not adapted to include additional stressors unique to Māori.

The core concepts of loneliness, isolation and quality of life were operationalised using standardised tools. Preference was given to tools used in an Aotearoa New Zealand context, but they may not fully reflect Māori understandings of these contexts. For example, loneliness for Māori includes aspects of connection to whānau, whenua and culture in addition to elements in the de Jong Gierveld measure (Waldegrave et al., 2020). Similarly, while QOL was used as a measure of 'wellbeing', it may not fully capture 'wellbeing' for Māori. Models like Te Whare Tapa Whā frame wellbeing holistically (Rochford, 2004). Although the WHOQOL-BREF does include some of these aspects it frames them separately as domains which may miss the interaction of the whole. As these conceptualisations lacked cultural grounding, they may have limited the relevance and validity of findings for Māori.

As a Pakeha I acknowledge that my approach to this work was likely shaped by my culture. While it was my intention to explore the experiences broadly, I did not fully account for the cultural specificity of the framework, concepts and tools used. While the design was practical it

may have limited participation and not fully captured key constructs for Māori participants. Future work should incorporate these additional cultural dimensions to provide a picture of these associations that are relevant to Māori caregivers.

Directions for Future Research

The current study added to the existing literature by providing a quantitative description of caregiver QOL. It sought to contribute to our understanding of loneliness in informal dementia caregivers, a group otherwise underrepresented in the literature investigating loneliness and health outcomes. It did this by using a multidimensional measure of loneliness and exploring how loneliness, loneliness type and isolation function as mediators between primary stressors and QOL. Social and emotional loneliness are brought about by different caregiving factors and influence health in different ways. This study contributes this evidence to the literature with the aim of improving outcomes of interventions intended to improve health, by proposing loneliness as an intervention target and highlighting the importance of correctly identifying loneliness type before recommending the intervention.

It would be valuable to repeat an investigation into these variables outside of the context of COVID-19 lockdown. The unique condition of the pandemic likely influenced reported loneliness. Post-pandemic research could provide an understanding of loneliness, that is more specific to the caregiving context. The cross-sectional design of this research limits the ability to make statements of causality. Future research using a longitudinal design would allow for a temporal ordering of variables to determine causality in the relationships. A larger, more representative sample should also be an aim of future research to allow for a more detailed analysis of subgroups (such as high versus low loneliness). It would also enhance the

generalizability of findings. Socioeconomic status should be considered in future research exploring these relationships.

As discussed, this research does not fully capture the conceptualisations of these concepts from a Māori viewpoint which limits its ability to be relevant to caregivers in Aotearoa New Zealand. Future research should explore these factors and relationships through a culturally grounded approach, using culturally appropriate conceptualisation and measurement approaches.

As evidenced by the findings of this research, future research among the informal caregiving population should use a measure that includes both social and emotional loneliness. As well as considering additional cultural dimensions in the loneliness experience. Reliance on unidimensional or single-item measures may not provide the necessary specificity for this population. A comprehensive approach to measurement will provide much needed consistency in the literature and better inform intervention recommendations. The impact of loneliness type on efficacy of intervention should be explored.

Conclusion

This research contributes to our understanding of the associations between loneliness and quality of life in the informal dementia caregiving population and offers practical insights for targeting loneliness through interventions.

This study highlights loneliness as a significant issue in the informal dementia caregiving population. It used the Stress Process Model as a guide to examine connections between the caregiving role, loneliness, and quality of life. Existing knowledge indicates that loneliness is a major risk factor for poor health outcomes, evidenced by extensive research in various populations. Evidence is limited in the dementia caregiving population. Informal dementia caregivers thought to be at increased risk for loneliness due to factors intrinsic to the caregiving

role, as described in the Stress Process Model and conceptualised in this research as primary stressors. There has been a limited exploration of the role of loneliness in this relationship.

The high prevalence of loneliness in this research suggests that caregivers should be screened for loneliness, with a focus on correct identification of loneliness type before interventions are recommended. A ‘lonely/not lonely’ classification may not be specific enough for this population. Interventions should be matched to loneliness type and future research should explore the efficacy of this approach.

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Appendix A

Participant Information and Survey

Project Description and Invitation

I am interested in understanding how informal caregiving influences the development of loneliness and, in turn, how this influences the quality of life of informal caregivers. I would like to invite people who are the primary, informal (unpaid) caregiver of someone with dementia to participate in this research. You will be asked to answer some questions about your experiences as an informal caregiver. It will take approximately 20 - 30 minutes to complete the survey. Please be assured that your responses are anonymous and will be kept confidential. Data from the survey will be used for my Doctoral thesis and stored securely.

If you wish to receive a summary of the research findings, please provide your email address on the last page of the survey. This information will only be used for the purpose of providing the research summary. Your survey responses will be kept anonymous and will not be connected to your address.

Participation is voluntary, you are under no obligation to complete this survey. You have the right to decline to answer any question by leaving it blank. If you decide you no longer wish to participate, at any stage, please do not return the survey.

If you would like to discuss this research, please e-mail Brieonie Jenkins, brieonie.jenkins.1@uni.massey.ac.nz

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"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Professor Craig Johnson, Director (Research Ethics) email humanethics@massey.ac.nz".

Screening Questions:

These questions will determine if you are eligible to participate in the research.

Are you the primary informal caregiver of someone with dementia?

For this survey we are interested to hear from people who are primary informal caregivers of someone with dementia. Please read through the following information to determine if this is you.

A primary informal caregiver, in this case, is a person who provides regular ongoing care and assistance, without pay, to someone with dementia who lives at home.

There is no single job description for a primary informal caregiver. There are a large variety of tasks and responsibilities that can be involved in the role.

Some examples of things they help with are:

Household tasks, personal care, organising medication, supervising behaviour, advocacy and making respite decisions.

The primary caregiver is the person with the main responsibility for care. They may receive paid and unpaid help from others.

Informal caregivers are sometimes called family caregivers, care partners or caregivers. While informal caregivers may receive government support, they are not employed by the person they are caring for.

With this in mind, are you the primary informal caregiver of someone with dementia?

- ○ Yes
- ○ No

Does the person you care for have another condition that requires support?

If yes, please specify

- ○ Yes _____
- ○ No

Survey

About you

Are you:

- ○ Female
- ○ Male
- ○ Other

What year were you born in?

_____

Which ethnic group do you belong to?

Select the options that most apply to

you.

- [ ] NZ European
- [ ] Chinese
- [ ] Cook Island Māori
- [ ] Indian
- [ ] Niuean
- [ ] Samoan
- [ ] Tongan
- [ ] Māori
- [ ] Other _____

What is the highest level of education you have completed?

- ○ None at all
- ○ Primary school
- ○ Secondary school
- ○ Tertiary

How many people (including yourself) live in your household?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6+

What is your relationship status?

- ○ Single
- ○ Separated
- ○ Married
- ○ Living as married
- ○ Divorced
- ○ Widowed
- ○ Partner/ boyfriend/ girlfriend (not living together)

What is your current employment status?

- ○ Full-time work
- ○ Part-time work
- ○ Unemployed
- ○ Student
- ○ Retired
- ○ Other _____

Are you currently ill or do you have a medical condition?

- ○ Yes
- ○ No

If yes, what is the diagnosis? OR What do you think the condition is?

_____

_____

_____

Who is the person you are the primary informal caregiver for?

- ○ Spouse
- ○ Partner/ boyfriend/ girlfriend
- ○ Friend
- ○ Parent
- ○ Someone else _____

How long, in years and months, have you been the primary informal caregiver for the person you are currently caring for?

e.g. 1 year 2 months

_____

How long have you known the person you have been caring for?

(if you are caring for your parent please put your age)

_____

Do you live with the person you are caring for?

- ○ Yes
- ○ No

How many hours, on average, per week do you spend caring for this person?

(caregiving tasks include household tasks, personal care, organising medication, supervising behaviour, advocacy, making respite decisions etc.)

_____

Does anyone else help you care for this person?

You may select more than one.

- ☐ Yes, paid caregiver/s
- ☐ Yes, a family member or friend (unpaid)
- ☐ Yes, someone else (please write who it is) _____
- ☐ No

Approximately how many hours per week do these people help you for?

- ☐ Paid caregiver _____
- ☐ Family member or friend _____
- ☐ Other _____

Please read these instructions before proceeding to the rest of the survey

The following questions ask how you feel about your quality of life, health, and other areas of your life.

Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

For example, thinking about the last two weeks, a question might be:

	Not at all	A little	A moderate amount	Very much	An extreme amount
How much do you worry about your health?	○	○	○	○	○

You select the response that best fits how much you have worried about your health over the last two weeks. So you would select "very much" if you worried about your health “very much”.

	Not at all	A little	A moderate amount	Very much	An extreme amount
How much do you worry about your health?	○	○	○	◉	○

Please read each of the following questions, assess your feelings, and select the option for each question that fits best for you.

Please read the question, assess your feelings **over the last two weeks** and select the response for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
How would you rate your quality of life?	○	○	○	○	○

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	○	○	○	○	○

The following questions ask about **how much** you have experienced certain things in the **last two weeks.**

	Not at all	A little	A moderate amount	Very much	An extreme amount
To what extent do you feel that physical pain prevents you from doing what you need to do?	○	○	○	○	○
How much do you need any medical treatment to function in your daily life?	○	○	○	○	○
How much do you enjoy life?	○	○	○	○	○
To what extent do you feel your life to be meaningful?	○	○	○	○	○
How well are you able to concentrate?	○	○	○	○	○
How safe do you feel in your daily life?	○	○	○	○	○
How healthy is your physical environment	○	○	○	○	○

The following questions ask about **how completely** you have experienced **or** were able to do certain things in the **last two weeks**. Select your best answer.

	Not at all	A little	A moderate amount	Very much	Extremely
Do you have enough energy for everyday life?	○	○	○	○	○
Are you able to accept your body appearance?	○	○	○	○	○
Have you enough money to meet your needs?	○	○	○	○	○
How available to you is the information you need in your day to day life?	○	○	○	○	○
To what extent do you have the opportunity for leisure activities?	○	○	○	○	○
How well are you able to get around physically?	○	○	○	○	○

The following questions ask about **how good or satisfied** you have felt about aspects of your life over the **last two weeks**.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sleep?	○	○	○	○	○
How satisfied are you with your ability to perform your daily living activities?	○	○	○	○	○
How satisfied are you with your capacity for work?	○	○	○	○	○
How satisfied are you with yourself?	○	○	○	○	○
How satisfied are you with your personal relationships?	○	○	○	○	○
How satisfied are you with the support you get from friends?	○	○	○	○	○
How satisfied are you with the conditions of your living place?	○	○	○	○	○
How satisfied are you with your access to health services?	○	○	○	○	○
How satisfied are you with your transport?	○	○	○	○	○
How satisfied are you with your sex life?	○	○	○	○	○

The following question refers to **how often** you have felt or experienced certain things in the **last two weeks**.

	Never	Seldom	Quite often	Very often	Always
How often do you have negative feelings such as blue mood, despair, anxiety or depression?	○	○	○	○	○

The following question asks about **how good or satisfied** you have felt about various aspects of your life over the **last two weeks**.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you that you are able to meet the expectations placed on you?	○	○	○	○	○

The following questions ask about **how completely** you have experienced **or** were able to do certain things in the **last two weeks**.

	Not at all	A little	A moderate amount	Very much	Extremely
To what extent do you feel respected by others?	○	○	○	○	○
To what extent are you able to manage personal difficulties?	○	○	○	○	○

The following questions ask **how much** you have experienced certain things in the **last two weeks**.

	Not at all	A little	A moderate amount	Very much	Extremely
To what extent do you have feelings of belonging?	○	○	○	○	○
To what extent do you feel you have control over your life?	○	○	○	○	○

For each of the following 11 statements, please indicate the extent to which they apply to your situation; the way you feel now.

	None of the time	Rarely	Some of the time	Often	All of the time
There is always someone I can talk to about my day-to-day problems	○	○	○	○	○
I miss having a really close friend	○	○	○	○	○
I experience a general sense of emptiness	○	○	○	○	○
There are plenty of people I can lean on when I have problems	○	○	○	○	○
I miss the pleasure of the company of others	○	○	○	○	○
I find my circle of friends and acquaintances too limited	○	○	○	○	○
There are many people I can trust completely	○	○	○	○	○
There are enough people I feel close to	○	○	○	○	○
I miss having people around me	○	○	○	○	○
I often feel rejected	○	○	○	○	○
I can call on my friends whenever I need them	○	○	○	○	○

Caregivers sometimes feel that they lose important things in life because of their relative's illness.

To what extent do you feel that you personally have lost the following?

How much have you lost:

	Completely	Quite a bit	Somewhat	Not at all
Being able to confide in the person you are caring for	○	○	○	○
The person that you used to know	○	○	○	○
Having someone who really knew you well	○	○	○	○
The practical things they used to do for you	○	○	○	○
A chance to do some of the things you planned	○	○	○	○
Contact with other people	○	○	○	○

The following is a list of problems patients sometimes have.

Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

Frequency ratings:	Reaction ratings:
0 = never occurred	0=not at all
1= not in the past week	1= a little
2= 1-2 times in the past week	2= moderately
3= 3-6 times in the past week	3=very much
4= daily or more often	4= extremely
9= don't know/not applicable	9= don't know/ not applicable

Please answer all the questions below. Please circle a number from 0-9 for both *frequency* and *reaction.*

	Frequency	Reaction
Asking the same question over and over	1 2 3 4 9	1 2 3 4 9
Trouble remembering recent events (e.g. items in the newspaper or on TV)	1 2 3 4 9	1 2 3 4 9
Trouble remembering significant past events	1 2 3 4 9	1 2 3 4 9
Losing or misplacing things	1 2 3 4 9	1 2 3 4 9
Forgetting what day it is	1 2 3 4 9	1 2 3 4 9
Starting, but not finishing, things	1 2 3 4 9	1 2 3 4 9
Difficulty concentrating on a task	1 2 3 4 9	1 2 3 4 9
Destroying property	1 2 3 4 9	1 2 3 4 9
Doing things that embarrass you.	1 2 3 4 9	1 2 3 4 9
Waking you or other family members up at night	1 2 3 4 9	1 2 3 4 9
Talking loudly and rapidly	1 2 3 4 9	1 2 3 4 9
Appears anxious or worried	1 2 3 4 9	1 2 3 4 9
Engaging in behaviour that is potentially dangerous to self or others.	1 2 3 4 9	1 2 3 4 9
Threats to hurt oneself	1 2 3 4 9	1 2 3 4 9
Threats to hurt others	1 2 3 4 9	1 2 3 4 9
Aggressive to others verbally	1 2 3 4 9	1 2 3 4 9
Appears sad or depressed	1 2 3 4 9	1 2 3 4 9
Expresses feelings of hopelessness or sadness about the future (e.g. "nothing worthwhile ever happens", "I never do anything right")	1 2 3 4 9	1 2 3 4 9
Crying and tearfulness	1 2 3 4 9	1 2 3 4 9
Commenting about death of self or others (e.g. "Life isn't worth living," "I'd be better off dead).	1 2 3 4 9	1 2 3 4 9
Talking about feeling lonely	1 2 3 4 9	1 2 3 4 9

Comments about feeling worthless or a burden to others	1 2 3 4 9	1 2 3 4 9
Comments about feeling like a failure or about not having any worthwhile accomplishments in life	1 2 3 4 9	1 2 3 4 9
Arguing, irritability, and/or complaining	1 2 3 4 9	1 2 3 4 9

The following questions ask about the amount of contact with your children.

When answering please consider, biological and adopted children including children you have raised.

If you do not have any children, please leave this set of questions blank.

How many children, if any have you had (including adopted children or children you have raised)?	
How many are presently living?	
How many of your children do you see at least once a week?	
Of the others, how many do you see every month?	
How many of your children do you talk to on the phone or correspond with weekly?	
Of the others, how many do you talk to on the phone or correspond with monthly?	
Of the others, how many do you talk to on the phone or correspond with several times a year?	

The following questions ask about your relatives, apart from your children, who you feel close to. People that you feel at ease with, can talk to about private matters, and can call on for help.

In general, how many other relatives do you have that you feel close to?	
How many of these relatives do you see at least once a month?	
How many of these relatives do you talk on the phone to, or correspond with a few times a year?	

The following questions items ask about close friends, these are people you feel at ease with, can talk to about private matters and call on for help.

In general, how many close friends do you have?	
How many of these friends do you see at least once a month?	
How many of these friends do you talk on the phone to, or correspond with a few times a year?	

How often do you go to religious meetings or services?

- ○ Never or almost never
- ○ Once or twice a year
- ○ Every few months
- ○ Once or twice a month
- ○ Once a week
- ○ More than once a week

Do you participate in any groups, such as senior centre; social or work group; church-connected group; self-help group; or charity, public service or community group?

- ○ Yes (please specify) _____
- ○ No

Here is a list of things people do in their free time. In the last month, how often have you done each of these things?

	Never	Sometimes	Often
Active sports or swimming	○	○	○
Take walks	○	○	○
Work in the garden or yard	○	○	○
Do physical exercises	○	○	○
Prepare your meals	○	○	○
Work at a hobby	○	○	○
Go out and do shopping	○	○	○
Go out to a movie, restaurant, or sporting event	○	○	○
Read books, magazines, newspapers	○	○	○
Watch television	○	○	○
Day trips, overnight trips	○	○	○
Unpaid community or volunteer work	○	○	○
Paid community work	○	○	○
Regularly play cards, games or bingo	○	○	○
Any other activities (please specify)	○	○	○

These questions ask about activities of daily living.

Please select the response that best represents the ability of the person you care for.

Eating

- ○ No problem
- ○ Independent, but slow or some spills
- ○ Needs help to cut or pour, spills often
- ○ Must be fed most foods
- ○ Don't know

Dressing

- ○ No problem
- ○ Independent, but slow or clumsy
- ○ Wrong sequence, forgets items
- ○ Needs help with dressing
- ○ Don't know

Bathing

- ○ No problem
- ○ Bathes self, but needs to be reminded
- ○ Bathes self with assistance
- ○ Must be bathed by others
- ○ Don't know

Elimination

- ○ Goes to the bathroom independently
- ○ Goes to the bathroom when reminded; some accidents
- ○ Needs assistance for elimination
- ○ Has no control over either bowel or bladder
- ○ Don't know

Taking pills or medicine

- ○ Remembers without help
- ○ Remembers if dose is kept in a special place
- ○ Needs spoken or written reminders
- ○ Must be given medicine by others
- ○ Don't know

Interest in personal appearance

- ○ Same as always
- ○ Interested if going out, but not at home
- ○ Allows self to be groomed, or does so on request only
- ○ Resists efforts of caretaker to clean and groom
- ○ Don't know

Household care
Preparing meals, cooking

- ○ Plans and prepares meals without difficulty
- ○ Some cooking, but less than usual, or less variety
- ○ Gets food only if it has already been prepared
- ○ Does nothing to prepare meals
- ○ Never did this activity OR don't know

Setting the table

- ○ No problem
- ○ Independent but slow or clumsy
- ○ Forgets items or puts them in the wrong place
- ○ No longer does this activity
- ○ Never did this activity OR don't know

Housekeeping

- ○ Keeps house as usual
- ○ Does at least half his/her job
- ○ Occasional dusting or small jobs
- ○ No longer does this activity
- ○ Never did this activity OR don't know

Home maintenance

- ○ Does all tasks usual for him/her
- ○ Does at least half of usual tasks
- ○ Occasionally rakes or some other minor job
- ○ No longer does any maintenance
- ○ Never did this activity OR don't know

Home repairs

- ○ Does all the usual repairs
- ○ Does at least half of usual repairs
- ○ Occasionally does minor repairs
- ○ No longer does any repairs
- ○ Never did this activity OR don't know

Laundry

- ○ Does laundry as usual (same schedule, routine)
- ○ Does laundry less frequently
- ○ Does laundry only if reminded; leaves out detergent, steps
- ○ No longer does laundry
- ○ Never did this activity OR don't know

Employment and recreation
Employment

- ○ Continues to work as usual
- ○ Some mild problems with routine responsibilities
- ○ Works at an easier job or part-time; threatened with loss of job
- ○ No longer works
- ○ Never worked OR retired before illness OR don't know

Recreation

- ○ Same as usual
- ○ Engages in recreational activities less frequently
- ○ Has lost some skills necessary for recreational activities (e.g. bridge, golfing); needs coaxing to participate
- ○ No longer pursues recreational activities
- ○ Never engaged in recreational activities OR don't know

Organisations

- ○ Attends meetings, takes responsibilities as usual
- ○ Attends less frequently
- ○ Attends occasionally; has no major responsibilities
- ○ No longer attends
- ○ Never participated in organisations OR don't know

Travel

- ○ Same as usual
- ○ Gets out if someone else drives
- ○ Gets out in wheelchair
- ○ Home or hospital bound
- ○ Don't know

Shopping and money
Food shopping

- ○ No problem
- ○ Forgets items or buys unnecessary items
- ○ Needs to be accompanied while shopping
- ○ No longer does the shopping
- ○ Never had responsibility in this activity OR don't know

Handling cash

- ○ No problem
- ○ Has difficulty paying proper amount, counting
- ○ Loses or misplaces money
- ○ No longer handles money
- ○ Never had responsibility in this activity OR don't know

Managing finances

- ○ No problem paying bills, banking
- ○ Pays bills late; some trouble writing checks
- ○ Forgets to pay bills; has trouble balancing checkbook; needs help from others
- ○ No longer manages finances
- ○ Never had responsibility in this activity OR don't know

Travel
Public Transportation

- ○ Uses public transport as usual
- ○ Uses public transport less frequently
- ○ Has gotten lost using public transport
- ○ No longer uses public transport
- ○ Never used public transport regularly OR don't know

Driving

- ○ Drives as usual
- ○ Drives more cautiously
- ○ Drives less carefully; has gotten lost while driving
- ○ No longer drives
- ○ Never drove OR don't know

Mobility around the neighbourhood

- ○ Same as usual
- ○ Goes out less frequently
- ○ Has gotten lost in the immediate neighbourhood
- ○ No longer goes out unaccompanied
- ○ This activity has been restricted in the past OR don't know

Travel outside familiar environment

- ○ Same as usual
- ○ Occasionally gets disoriented in strange surroundings
- ○ Gets very disoriented but is able to manage if accompanied
- ○ No longer able to travel
- ○ Never did this activity OR don't know

Communication
Using the telephone

- ○ Same as usual
- ○ Calls a few familiar numbers
- ○ Will only answer telephone (won't make calls)
- ○ Does not use telephone at all
- ○ Never had a telephone OR don't know

Talking

- ○ Same as usual
- ○ Less talkative; has trouble thinking of words or names
- ○ Makes occasional errors in speech
- ○ Speech is almost unintelligible
- ○ Don't know

Understanding

- ○ Understands everything that is said as usual
- ○ Asks for repetition
- ○ Has trouble understanding conversations or specific words occasionally
- ○ Does not understand what people are saying most of the time
- ○ Don't know

Reading

- ○ Same as usual
- ○ Reads less frequently
- ○ Has trouble understanding or remembering what he/ she has read
- ○ Has given up reading
- ○ Never read much OR Don't know

Writing

- ○ Same as usual
- ○ Writes less often; makes occasional spelling errors
- ○ Signs name but no other writing
- ○ Never writes
- ○ Never wrote much OR don't know

Final Page

Thank you very much for completing the survey.

If you would like to receive a summary of the results, please write your email address below.

If you do not wish to receive a summary of results, please leave this blank

_____

_____

Appendix B

Research Case Study

Research outline

Family or informal caregivers are the cornerstone of support for people with dementia in New Zealand, providing an estimated $7.3 - $17.6 billion dollars of care per year (Alzheimers New Zealand, 2012). It's estimated that 170,000 New Zealanders will be living with dementia by 2050 (Swarbrick, 2012). In New Zealand at least 50% of people with dementia are informally supported, often by a spouse, partner, adult child or friend which significantly increases the number of New Zealanders directly affected by dementia (Cornwall & Davey, 2004). Although this provision of care is not new, there is growing recognition that caregiving will become a major issue in the future. Demographic shifts towards an aging population and a shift in the epidemiology of illness from acute to chronic suggests that New Zealanders are likely to spend their retirement needing or providing care.

Informal caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically and physically taxing (Schulz & Martire, 2004). Informal dementia caregivers are older than other caregivers, they are most likely to be spouses or adult children, female and live with the person needing care. As a group they spend the most hours per week providing care compared to caregivers of other conditions. Dementia caregiving is more demanding than caring for other conditions, as such, these caregivers are under the most strain (Pinquart & Sörensen, 2007).

Stress, arising from caregiving responsibilities has consistently been linked to poor mental and physical health. The Stress Process Model is the most commonly used conceptualisation of this relationship in informal dementia caregivers (Whitlatch, 2001). The model considers the influences of the informal caregiver’s background and context, and

specific caregiving stress on their mental and physical health. Loneliness is believed to be associated with a cluster of life events commonly experienced in old age such as grief, change in living conditions and lifestyle, loss of close relationships and other life events (Dykstra, 2009). Caregiving is an activity that can precipitate the onset of these changes.

Background and context factors like age, gender and life transitions, like the transition into the caregiving role are associated with loneliness (Dykstra, 2009). Specific caregiving stress may increase the risk of loneliness by creating deficiencies in social and emotional relationships. The time commitment of caregiving can limit time for socialising and, as the illness progresses the emotional attachment between the care dyad can change often resulting in the loss of a close relationship (Pearlin et al., 1990). Although loneliness has been established as an important health risk in other populations (Luo et al., 2012) research in the informal caregiving population is sparse.

Defining Loneliness

We can trace the development of the concept of loneliness, as we understand it today, through literature. One of the earliest records of loneliness in the western world appears in a 1674 glossary of infrequently used words compiled by John Ray (Worsley, 2020). At this time loneliness was a physical separation and was used to describe the danger of being away from others. This dangerous connotation was capitalised on by early sermon writers who described hell as 'lonely'. This had the effect of moving hell from an abstract concept to the 'real world'. At the time being away from others, truly was dangerous and the idea was frightening to the congregation. Better to be in heaven with others, where it is safe. An example of this definition is seen in Milton's epic poem Paradise Lost, where Satan treads 'lonely steps', these steps are not a reference to Satan's emotional state they are a space of physical vulnerability where no other being has gone before (Worsley, 2020). In these days

loneliness had an easy cure, simply stay in the company of others while you're alive and stay faithful to God to avoid loneliness in death.

Moving forward to 1798, Rime of the Ancient Mariner by Samuel Taylor Coleridge explores an expanded definition of loneliness. Initially he is physically alone, after his peers ostracise him for killing the albatross. Interestingly, the Mariner finds that this loneliness allows him to appreciate his world. This facet of loneliness has largely fallen out of modern usage, but it exists throughout literature as something writers have sought to fuel their creativity. Now, we might refer to this state as solitude keeping 'loneliness' to describe unpleasant experiences only. The Mariner also experiences emotional separation from others, and here we see Coleridge expanding on early definitions. Although the Mariner is with other people he carries with him experience and knowledge and finds it difficult to relate to them, experiencing a painful state of internal isolation.

When Mary Shelley wrote Frankenstein in 1818 the experience of loneliness was not commonly discussed in literature. Shelley's loneliness is emotional, socially disconnected and alienated. By the 1950s it was commonly used to mean emotional as well as physical isolation. In The Bell Jar, Sylvia Plath explores the painful feeling of loneliness that coming from feelings of difference or swimming against the tide of societal expectations.

Now loneliness is commonly thought of as an emotional state of feeling apart from others without necessarily being so. Colloquially the terms loneliness and isolation tend to be used somewhat interchangeably to describe deficiencies in social relationships. While they are related concepts, the scientific literature generally acknowledges them to be distinct experiences.

Isolation is objective; it reflects an individual's contacts and relationships with others i.e. family, friends, neighbours, professionals and acquaintances. Loneliness is a subjective and negative experience, most commonly explained by the discrepancy theory, where

loneliness comes from a perceived discrepancy between the quantity or quality of relationships a person has (Marangoni & Ickes, 1989). Our perceptions of our social lives, our resources and relationships may not reflect how objectively social we are, which leads to an inconsistency in our desired and actual level of interaction.

Weiss (1975), classified loneliness into two types, emotional and social. Emotional loneliness relates to attachment, it is experienced when need for attachment is perceived to be lacking. This could be caused by not having close relationships with people to confide in (Ciolfi & Jimenez, 2017). Social loneliness can be thought of as the perception of social interactions and may not reflect how objectively social we are. This creates a discrepancy in our desired and actual level of interaction (Ciolfi & Jimenez, 2017). It is possible to feel one without the other, both, or neither. Each is described as 'lonely', but the subjective experience is different as is the method for relieving the distress caused. For example, relief from emotional loneliness may require a new intimate relationship whereas social loneliness may be relieved by activities that promote social integration. As the probability of finding a new intimate attachment figure decreases with age, this distinction is particularly relevant for studies of older adults (Luanaigh & Lawlor, 2008).

Loneliness and Health

Loneliness continues to be portrayed as something to be feared, headlines worldwide warn of a 'loneliness epidemic' (Ortiz-Ospina, 2019). The health risks of loneliness and isolation have been consistently established in the literature. One of the most notable arguments was put forward by Holt-Lunstad et al. (2010). Their comprehensive meta-analysis found that individuals with adequate social relationships have a 50% greater chance of survival than those who do not. The magnitude of this effect was found to be comparable with smoking and greater than many other well recognised risk factors for mortality such as obesity and inactivity.

It is theorised that isolation and loneliness will impact health and wellbeing in different ways. The stress buffering hypothesis states that social relationships can buffer negative effects of stress on health by lessening the impact of stressful events (Holt-Lunstad et al., 2010). Social relationships can also promote healthy behaviours like seeking medical treatment and adhering to treatment plans. These behavioural processes have a direct impact on health outcomes. The health effects of loneliness are thought to occur through psychological and biological channels. Loneliness is negative and distressing feeling. This distress can activate the hypothalamic-pituitary-adrenal (HPA) axis which produces cortisol. Consistent distress, like loneliness, creates dysfunction. The wear and tear hypothesis states that a consistent production of cortisol can damage internal processes, which is linked to poor physical and mental health (Cacioppo et al., 2003).

Although not a disorder in the DSM-5, assessing for and supporting an individual to overcome loneliness is highly relevant to psychological practice. As loneliness is strongly connected to physical and mental health, achieving relief from feeling of loneliness may lead to improvements in other areas. Crucially loneliness is determined by an individual's subjective experience of their social environment, similar to other dysphoric states firmly in the DSM like anxiety and depression. Loneliness has been considered to be an aspect of depression, now there is growing evidence that they are separate experiences and can both influence the development of each other (Luanaigh & Lawlor, 2008).

The role of the Psychologist in treating loneliness

Psychological interventions can be effective at reducing loneliness (Hickin et al., 2021). It is suggested that psychological interventions which are affective for reducing mental health difficulties through cognitive change may also be effective for loneliness (Hickin et al., 2021). Framing loneliness in a transdiagnostic perspective, an individual's perceived discrepancy between actual and desired connection can be triggered by the

interplay of interpersonal experiences and individual perceptions of the worth of relationships (Käll et al., 2020). This creates a bias towards negative appraisals of interpersonal interactions, resulting in maladaptive behaviour such as avoidance, negative self-focus and cognitive biases. This leads the individual to avoid social contact creating feelings of loneliness (Käll et al., 2020). Randomised comparison studies have found that more successful interventions for loneliness address maladaptive cognition which highlights the role of the therapist in supporting a lonely client (Masi et al., 2011). Addressing maladaptive cognitions has been shown to have a larger effect size than interventions that addressed social support, skills and intervention (Masi et al., 2011). More recent research indicates that mindfulness may have efficacy in the improvement of loneliness through improving an individual's ability to be aware of the present without judgement, while more research is needed it is hypothesised that this is an effective mechanism as mindfulness may improve an individual's awareness of their emotional reactions to social cues (Masi et al., 2011).

Other interventions described in the literature have varying degrees of efficacy and which is possibly accounted for interventions being applied without an intimate understanding of loneliness type. Group based support activities, for example, have shown mixed results (Masi et al., 2011); this could be due to poor identification of loneliness type before prescribing a group intervention. An individual experiencing emotional loneliness may not experience improvement from a group, unless it led to a meaningful friendship. Groups may be effective for supporting people experiencing social loneliness, with an important caveat. Research has consistently shown stigma attached to the experience of loneliness (Beach, 2014). This may deter people from taking part in groups when their purpose is explicitly presented as reducing loneliness. More effective are groups with stimulating activities based on shared interests for example, exercise, art and choir (Beach, 2014).

Treating loneliness in caregivers

It is unclear if the current research on effective loneliness interventions is relevant to a caregiving context. As interventions that have shown good effect sizes in the general populations have aspects which may not be helpful for caregivers. As described above interest groups can be useful in providing social encounters however qualitative research also tells us that socialisation can create deeper feelings of loneliness for caregivers as they can feel that others don't understand their experience (Vasileiou et al., 2017).

The caregiving role has fixed restrictions the effects of which may not be improved by cognitive restructuring. Caregivers report putting their needs second and finding themselves too busy to address their own health needs. Part of the issue is the difficulty in arranging care for the person they are supporting. Qualitative research has found that caregivers avoid taking time away because it's too difficult to arrange respite care (Vasileiou et al., 2017). If this is such a challenge for caregivers, how will they be able to find time to participate in group or individual treatment for loneliness? The literature tells us that therapy is most effective when individuals can practice the skills they are learning out of session. A caregiver might be giving up their only 'alone time' to come to attend individual or group therapy, how useful will this be if this is also their only opportunity to practice? More caregiver specific research is needed to understand how to provide useful support within their context.

For caregivers, it is possible that psychological support is secondary to structural changes needed in society when addressing loneliness. Caregivers may not need formal support if they were simply able to socialise more or did not have to make choices between using their free time practically (e.g. grocery shopping) or socialising. Increased availability and flexibility of respite services could be a step towards supporting this need. Perhaps the Psychologist can be most useful as an advocate.

COVID-19 and a growing need for effective treatments

Lockdowns across the world have meant that most of us have been isolated over the past year. During lockdowns the concerns about the impact of this isolation on mental health was covered by the media. In my internship I have seen clients who trace their current difficulties back to the loneliness and isolation they experienced over lockdown. As the literature is clear on the health impacts of loneliness and health, it is possible that we are on the precipice of another 'wave'. Not of COVID-19 but of mental and physical implications, the cost of 'staying safe'.

It is possible that our mental health system will not be prepared. A recent article by Dr. Paul Skirrow (2021) reported that currently many people in New Zealand can't access therapy. He reports that Psychologists are increasingly working in private practice, treating those who can afford it, leaving the public service with lengthy waitlists. How can the current system, which is struggling to meet current demand, cope with the aftermath of our collective isolation? Even before the impacts of COVID-19 lockdowns on mental health began to be felt by the system, it lacked capacity to expand the services to include care for the caregiver. Caregivers are not typically the identified client in their interactions with health services. They devote a great deal of time to the needs of those they are caring for, putting their own aside. Caregivers, already at risk for loneliness due to the nature of their role have now undergone a prolonged period of isolation compounding their risk. The physical and mental health of caregivers is factor in their ability to continue the caregiving role. If a caregiver's health reaches a point where they are not able to continue, the demand for institutional care for people with dementia will increase. Can we afford to continue to not actively support caregivers in all interactions with health services, identified client or not?