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University of Southampton

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**Caregivers and Loneliness in the
English Longitudinal Study of Ageing**

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Thesis for the degree of Doctor of Philosophy

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UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF SOCIAL SCIENCES

School of Economic, Social and Political Sciences

Thesis for the degree of Doctor of Philosophy

CAREGIVERS AND LONELINESS IN THE
ENGLISH LONGITUDINAL STUDY OF AGEING

By Lisa Davison

Informal caregivers represent around 26% (13.6 million) of the UK population. Alongside the known health and wellbeing consequences of caregiving, caregivers have been identified as being at higher risk of loneliness. However, current research among caregivers is inadequate. Mostly, specific subgroups of caregivers are analysed in isolation (e.g. dementia caregivers or spousal caregivers), and therefore the diverse caregiving population is under-represented in the literature. Specifically, there is a lack of evidence on the determinants of loneliness among caregivers. What limited research that has been conducted, suggests that the typical determinants applicable to the general population are not consistent amongst caregivers. Therefore, because caregiving-specific risk factors are not clearly understood, support services and policy-makers cannot work to effectively prevent loneliness. Furthermore, individually, both caregiving and loneliness are associated with adverse health and wellbeing outcomes, but there is an absence of research investigating the impact on health and wellbeing for caregivers who are lonely. It is hypothesised that the combined impact of loneliness and caregiving could have worse health and wellbeing outcomes than either characteristic alone.

Using quantitative secondary data analysis of the English Longitudinal Study of Ageing, this thesis explored, both cross-sectionally and longitudinally, the effects of caregiving on loneliness. This thesis addressed the aforementioned research gaps by comparing a wide range of caregivers, including those providing care at different intensities, and to a variety of care recipients. Additionally, caregiving-specific determinants of loneliness were investigated, as well as examining how the health and wellbeing impacts of loneliness differed between caregivers and non-caregivers. The results indicated that caregiving was associated with loneliness, but depended on the loneliness measure used. As such caregivers were more likely to be lonely using the UCLA loneliness scale, but not a direct question. Additionally, the determinants differed for caregivers and non-caregivers: health appeared to play a larger role in non-caregivers' loneliness, whereas within caregivers, care provision to adult-children was a determinant of loneliness. Finally, as predicted, the combined impact of caregiving and loneliness was associated with worse health and wellbeing outcomes across a number of measures.

Overall, there was limited evidence of a long-term effect of caregiving on loneliness, which implies that the impact of caregiving is acute rather than chronic, highlighting a need for early intervention. Finally, the evidence suggests that caregiving may have more substantial effects on mental health and wellbeing than for physical health, which provides direction for policy development.

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Research Thesis: Declaration of Authorship

Print name: Lisa Davison

Title of thesis: Caregivers and Loneliness in the English Longitudinal Study of Ageing

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- None of this work has been published before submission.

Signature: 

Date: 06/08/2021

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Abbreviations

ADLs	Activities of Daily Living
BBC	British Broadcasting Corporation
BHPS	British Household Panel Survey
CASP19	Control Autonomy Self-realisation and Pleasure (19 item)
CCA	Complete Case Analysis
CES-D	Centre for Epidemiological Studies Depression Scale
CIT	Caregiver Identity Theory
CLS	Community Life Survey
CV	Cardiovascular
CVD	Cardiovascular disease
DCMS	Department of Culture, Media, and Sport
DD	Developmental disabilities
DEAS	German Ageing Survey
DF	Degrees of freedom
DHSC	Department of Health and Social Care
DJGLS	de Jong Gierveld Loneliness Scale
DV	Dependent variable
ELSA	English Longitudinal Study of Ageing
FINDS	Family and Individual Needs for Disability Supports
HPD	Hours per day
HPM	Hours per month
H/PP/Y	Hours per person per year
HPW	Hours per week
HRS	Health and Retirement Study
HSE	Health Survey for England
IADLs	Instrumental Activities of Daily Living
ICIM	Informal Caregiving Integrative Model
IV	Independent variable
LLTI	Limiting long-term illness
NHS	National Health Service
NICE	National Institute for Health and Care Excellence

Abbreviations

NSHAP	National Social Life, Health and Ageing Project
ONS	Office for National Statistics
OR	Odds ratio
QoL	Quality of life
RQ	Research question
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2
SD	Standard deviation
SDA	Secondary data analysis
SEM	Social Ecological Model
SES	Socioeconomic status
SET	Stereotype Embodiment Theory
SF-36	QoL Short Form
SHARE	Survey of Health, Ageing and Retirement in Europe
SWLS	Satisfaction with life scale
TILDA	The Irish Longitudinal Study on Ageing
UCLA-LS	University of California, Los Angeles Loneliness Scale
UK	United Kingdom
UKHLS	United Kingdom Household Longitudinal Study
US	United States (of America)
VIF	Variance inflation factor
WHO	World Health Organisation
95CI	95% Confidence Interval

Chapter 1 Introduction

Informal caregivers, hereafter referred to as caregivers, are an expanding, but largely undetected subgroup of the population, who play an essential role in supporting health and social care systems. Prior to the coronavirus (SARS-CoV-2) outbreak, there were an estimated 9.1 million caregivers across the United Kingdom (UK), representing as many as 17% of adults within the general population, although, due to the initial lockdown period beginning in March 2020, this increased by almost 50% to 13.6 million (Carers Week, 2020). Data from Understanding Society collected 2016-2018, indicated around 20% of the population were caregivers; 23% of females and 17% of males (Zhang and Bennett, 2019). Furthermore, caregiving is known to impact health and wellbeing. Schulz *et al.* (2020) highlight that evidence on negative outcomes are more prevalent than positive, listing psychological distress and poor physical health as common consequences. Moreover, caregiving has been linked to loneliness, particularly among dementia caregivers (Bramboeck *et al.*, 2020; Leszko *et al.*, 2020; Victor *et al.*, 2020). Caregivers are 37% more likely to report loneliness than non-caregivers (Pyle and Evans, 2018). It is considered that due to the increased time spent caregiving, social activity, interaction, and consequently, social networks may be reduced amongst caregivers (Vasileiou *et al.*, 2017). Alternatively, the loss of relationship between caregiver and care recipient may also contribute towards increased loneliness (Leszko *et al.*, 2020). However, it is not yet fully understood why the prevalence of loneliness is higher amongst caregivers, or whether the negative consequences of loneliness are greater for caregivers compared to non-caregivers.

The prevalence of loneliness is dependent on sociodemographic characteristics (Groarke *et al.*, 2020). Data from the Office for National Statistics (ONS) indicates that in 2016/17 amongst individuals in the general population (aged ≥ 16) in England, 5% were lonely often or always, and 16% sometimes (Pyle and Evans, 2018). Moreover, evidence from Victor and Yang (2012) suggests a U-shaped distribution of loneliness, highest among younger (aged < 25) and older (aged ≥ 55) adults. Using data from the English Longitudinal Study of Ageing (ELSA), the percentage of lonely people in England, aged ≥ 50 , was shown to be relatively stable over a decade (2006/07 to 2016/17); 6-9% were often lonely, and 24-26% were sometimes lonely (Age UK, 2018). These figures are slightly elevated in comparison to the aforementioned ONS data, but this is likely due to the reported U-shaped age distribution, it could reasonably be expected to see a higher prevalence of loneliness among a sample aged ≥ 50 .

The impact of loneliness on mortality risk is comparable to factors such as daily smoking, and excessive alcohol consumption; Holt-Lunstad *et al.* (2010) concluded that individuals with adequate relationships (i.e. not lonely) experience a 50% greater likelihood of survival than those with inadequate relationships. Furthermore, loneliness has previously been identified as a public health issue (Groarke *et al.*, 2020), but, since the outbreak of SARS-CoV-2, loneliness has become an increasing concern among policy-makers. Evidence suggests that risk factors for loneliness since the

Chapter 1

outbreak are virtually identical to beforehand; however those previously at risk of loneliness may be at higher risk (Bu *et al.*, 2020). Therefore, interventions should be aimed at groups already known to be vulnerable to loneliness (*ibid*). As such, the UK Government has identified caregivers as being a group vulnerable to loneliness (Department of Culture, Media, and Sport [DCMS], 2018; Victor *et al.*, 2020).

Although both caregiving and loneliness have been linked to adverse health and wellbeing outcomes, there is little research investigating the impact on health and wellbeing for caregivers who are lonely. Individually, loneliness is associated with physical and psychological morbidities (Ong *et al.*, 2016), and reduced wellbeing (Emerson *et al.*, 2020). Similarly, caregiving has been linked to negative health consequences (Caputo *et al.*, 2016), and detrimental effects on wellbeing (Dahlrup *et al.*, 2015). It is likely that the combined impact of loneliness and caregiving could have worse health and wellbeing outcomes than either characteristic alone. This is because, firstly, there is potential for overlap between the separate health and wellbeing consequences. As such, both caregiving and loneliness have been associated with a wide range of similar health and wellbeing outcomes, including, but not limited to, cardiovascular (CV) conditions (Friedler *et al.*, 2015; Bouchard *et al.*, 2019), depression (Caputo *et al.*, 2016; Ong *et al.*, 2016) and effects on wellbeing (Dahlrup *et al.*, 2015; Emerson *et al.*, 2020). Therefore, the presence of loneliness could further exacerbate depression, poor CV health, or reduced wellbeing amongst caregivers. Secondly, because loneliness is often reported as a consequence of caregiving (Beeson, 2003; Bramboeck *et al.*, 2020), there may be sequential or cumulative effects on health and wellbeing. Additionally, evidence has demonstrated that the impact of caregiving on physical health may affect older caregivers (aged ≥ 50) more than younger caregivers (Danilovich *et al.*, 2017). Therefore, to make appropriate policy recommendations to support and protect caregivers, it is essential to investigate how the caregiving population differs in relation to loneliness, health and wellbeing; particularly among older caregivers, where health outcomes may be more prominent.

The following sections outline the proposed aims, objectives, and research questions (RQs) (section 1.1). Subsequently, key concepts and relevant definitions for this thesis (section 1.2), including caregiving, loneliness, health, and wellbeing are introduced, before outlining the structure of the thesis (section 1.3).

1.1 Aims, objectives and research questions

This thesis examines the relationships between caregiving, loneliness, health, and wellbeing, for which the collective association is largely unknown. The subsequent aims, objectives, and research questions detail how this thesis investigates these areas, in order to disentangle the relationships.

The main aims are to investigate the association between caregiving and loneliness, identify the determinants of loneliness, and to evaluate the health and wellbeing consequences. From the analysis,

policy recommendations can be designed to support caregivers within England. In order to meet these aims, secondary analysis was conducted with ELSA to determine the relationship between caregiving and loneliness. Moreover, the available data were explored to ascertain the determinants of loneliness; this involved the analysis of sociodemographic characteristics, socioeconomic factors and health and wellbeing variables, contrasted between caregivers and non-caregivers. To investigate the impact of loneliness on health and wellbeing for caregivers and non-caregivers, different pathways of health were explored, namely physiological, psychological, and behavioural, alongside general physical health, mental health, and aspects of wellbeing. Primarily, this thesis contrasted caregivers and non-caregivers to determine the association between caregiving and loneliness, and in turn, the health and wellbeing impact. However, to progress the understanding of these associations, the effects of caregiving characteristics, the caregiving relationship, and the caregiving role were explored.

1.1.1 Research questions

1. How does loneliness differ for caregivers and non-caregivers?
 - a. Is caregiving associated with loneliness?
 - b. Are the determinants of loneliness different for caregivers and non-caregivers?
 - c. How does the interaction between caregiving and loneliness affect the relationships between loneliness and health and wellbeing?
2. How does caregiving affect loneliness, health, and wellbeing?
 - a. How does caregiving affect loneliness?
 - b. How does caregiving affect health?
 - c. How does caregiving affect wellbeing?
3. What are the longer-term effects of caregiving on loneliness?
 - a. Is caregiving in wave two associated with loneliness at wave eight?
 - b. Is caregiving at any wave associated with later loneliness?
 - c. How are the caregiving relationship, and role, associated with loneliness for short-term versus long-term, or intermittent caregivers?

1.2 Definitions and key concepts

1.2.1 Caregiving

An informal caregiver provides unpaid assistance to someone with disabilities, or chronic physical or mental health conditions (Vasileiou *et al.*, 2017; Gérardin and Zech, 2019). Recipients of care are typically family members, friends or neighbours (Vasileiou *et al.*, 2017). However, the circumstances of caregiving can differ considerably; as such, caregivers may cohabit with, or live separately from the recipient, and responsibilities may be regular, occasional or continuous (Brodaty and Green, 2002). The roles of a caregiver vary significantly, often categorised into activities of daily living (ADL) and instrumental activities of daily living (IADL), examples of which include: assistance using the toilet (ADL) and meal preparation (IADL) (Lyons *et al.*, 2015). Personal care, such as assistance with bathing (Bergman and Pulling, 2020), is provided by around one-third of caregivers across Europe (Broese van Groenou and de Boer, 2016). Provision of personal care can increase physical and mental demand on the caregiver (Hiel *et al.*, 2015). Additionally, more intimate personal care tasks have been linked to higher emotional burden (Schrank *et al.*, 2016). This is particularly relevant for caregivers of individuals with dementia, where care needs are typically more complex. In contrast to caregivers of older adults with physical limitations, dementia caregivers reported a lack of rest, higher irritability, and relationship difficulties (Sequeira, 2013). The physical and emotional effects of providing care are typically referred to as caregiver burden (section 1.2.1.4).

Caregiving, while central to this thesis, is also a recurring theme within Gerontological research, though research often overlooks care provided by older adults, fixating on care provided by younger or middle-aged adults (Phillips *et al.*, 2010). This thesis expands upon that criticism, focusing on caregivers aged ≥ 50 (middle-aged and older adults). Thomas (1993) and Phillips *et al.* (2010) advocate that care cannot be researched as a stand-alone term; as it is a multi-dimensional concept, several factors of care must be considered for a reliable analysis. Within this thesis, the factors of care are separated into three logical categories: caregiver characteristics, the caregiving relationship, and intensity of the caregiving role. Additionally, caregiving appraisal, including burden and satisfaction, is thought to mediate the relationship between caregiving and related outcomes (Gérardin and Zech, 2019). Moreover, burden and satisfaction are often shown to impact upon caregiver health and wellbeing (Chang *et al.*, 2010; Mochari-Greenberger and Mosca, 2012; Dahlrup *et al.*, 2015), therefore these aspects are also discussed.

1.2.1.1 Characteristics of caregivers

Thomas (1993) uses the term ‘social identity’ regarding the caregiver and recipient; under these circumstances, the identity of a caregiver can refer to the familial role (e.g. spouse) or the sex. Alternatively, Phillips *et al.* (2010) considers social identity to mean a ‘type’ of caregiver, including factors such as age or ethnicity. For the purpose of this thesis, sociodemographic and socioeconomic

characteristics are examined, aligning with Phillips *et al.* (2010) definition of identity. The familial role, as suggested by Thomas' (1993) definition, is examined as the caregiving relationship (section 1.2.1.2).

Some of the key caregiver characteristics identified within research (section 3.3.1) include age, sex, marital status, and socioeconomic status (SES). To illustrate, caregiving at older ages is linked to providing higher-intensity care (Dahlberg *et al.*, 2007) and poorer health outcomes (Danilovich *et al.*, 2017). Moreover, although females are more commonly associated with caregiving roles (van Campen *et al.*, 2013), 2011 England and Wales Census data shows that more older males than older females are caregivers (Milligan and Morbey, 2016); this suggests that the age and sex of caregivers are likely to impact outcomes such as loneliness, health, and wellbeing.

1.2.1.2 Caregiving relationship and co-residential care

The inter-personal relationship refers to the existing relationship prior to caregiving; typically, these would be familial (e.g. parent) but could also include friends and neighbours (Thomas, 1993; Phillips *et al.*, 2010). Another aspect of caregiving relevant to the relationship is whether the caregiver is paid, and if the care is considered formal or informal. The concept of care is substantially different for formal and informal caregivers; financial involvement can alter the dynamic of the relationship considerably (Thomas, 1993). Nevertheless, these concepts (financial involvement and formal care) are less relevant for this thesis, as the focus is solely on informal (unpaid) caregivers.

Furthermore, location is also important; caregiving usually takes place within the caregivers' or recipients' homes, although caregiving roles often continue if the recipient is hospitalised or institutionalised (Montgomery and Kosloski, 2009; Montgomery *et al.*, 2016). The location of the caregiving tasks may also influence intensity. To illustrate, co-residential care, whereby the care recipient lives with the caregiver, is more likely to be continuous or higher-intensity (Kumagai, 2017); whereas if the recipient lives separately from the caregiver (non-residential), caregiving can be carried out over fewer hours (e.g. visiting to assist with shopping or household chores). For this thesis, both the inter-personal relationship, and provision of co-residential care are investigated as factors related to caregiving.

1.2.1.3 Caregiving role: intensity of care

The caregiving role includes factors such as nature of care, duration, and intensity. Nature of care can denote the specific tasks of caregiving (Thomas, 1993), for example, assisting the recipient to dress. However, more broadly, the nature can refer to the type of support provided (Phillips *et al.*, 2010), such as personal care, or instrumental support. Nature of care is often associated with intensity, as more complex care may require longer caregiving hours.

Caregiving intensity can be classified by the number of ADL and IADL tasks the recipient requires support with, and the perceived difficulty of each task (Lyons *et al.*, 2015; Anthony *et al.*, 2017).

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However, there are weaknesses associated with this method. To illustrate, Lyons *et al.* (2015) categorise ≥ 2 ADL tasks, or ≥ 6 IADL tasks, as high-intensity; however, each task is equally weighted. Therefore, caregivers helping with two less complex ADL tasks would be categorised as high-intensity caregivers, alongside those aiding with more challenging tasks. Additionally, some caregivers might find the same task more difficult than others, for example, recipient cooperation could influence the intensity of the task. In contrast, duration could be considered a more consistent measure; difficult ADL or IADL tasks may take longer to complete, therefore longer durations would reflect higher-intensity caregiving.

Intensity is most commonly measured as the number of hours spent providing care per week, utilised in the Dutch National Population Survey (van Campen *et al.*, 2013), ONS Longitudinal Study (Robards *et al.*, 2015), ELSA (Clemens *et al.*, 2019) and UK Household Longitudinal Study (UKHLS) (Lacey *et al.*, 2018). The hours per week (hpw) method of measuring intensity is adopted in this thesis, because it is more comparable across individuals. To illustrate, caregiver A may find assisting the recipient to dress difficult due to limited mobility, whereas caregiver B might find this task simple, because the recipient is able to assist. Therefore, it would be illogical to classify this as the same level of intensity.

However, in research, intensity categories are inconsistent. Low-intensity caregiving is typically recognised as 1-19hpw (Dahlberg *et al.*, 2007; Robards *et al.*, 2015; Vlachantoni *et al.*, 2016); though Lacey *et al.* (2018) divide this further into < 5 hpw and 5-19hpw. It is generally acknowledged that ≥ 20 hpw is high-intensity caregiving (Vlachantoni *et al.*, 2016; Lacey *et al.*, 2018); yet some studies introduce additional categories separating 20-49hpw and ≥ 50 hpw (Dahlberg *et al.*, 2007; Robards *et al.*, 2015). For context, a full-time job typically equates to 40hpw, and many jobs do not permit working in excess of 48hpw (Gov.UK, 2018). Therefore, caregiving for ≥ 50 hpw is comparable to roles such as emergency services (*ibid*). Overall, current research is largely unanimous that ≥ 20 hpw is high-intensity; however, this poses a certain inequity when comparing within high-intensity care. The total number of potential caregiving hours ranges between 0-168hpw. Thus, if the most common division of intensity was assumed, 1-19hpw (low-intensity) *versus* ≥ 20 hpw (high-intensity), all caregivers providing care for 20-168hpw would be grouped together. Despite providing over eight times as many hours of care, round-the-clock caregivers (168hpw), would be in the same classification as those providing 20hpw. For this reason, it is logical to separate round-the-clock caregivers into a discrete category for comparison with high-intensity and low-intensity caregivers. In this thesis, intensity is determined by caregiving hpw and classified as low-intensity (≤ 19 hpw) high-intensity (≥ 20 hpw), or round-the-clock (168hpw).

The duration of the caregiving role considers the time spent as a caregiver, i.e. short-term or long-term (Phillips *et al.*, 2010), but it is also important to consider whether caregiving is continuous over this period or intermittent. Evidence suggests the average duration of a caregiving role is over four-years (Boling, 2010). However, duration of care can differ depending on recipient care needs

(Barnhart *et al.*, 2020; Fuino and Wagner, 2020). For example, care provision to individuals with developmental disabilities (DD), such as Down syndrome, is typically over a longer duration than to older adults (Anderson *et al.*, 2018).

1.2.1.4 Caregiver burden and satisfaction

Early definitions considered burden to be negative consequences resulting from caregiving activities (Chou, 2000), but more recent definitions are more specific. As such, Chiao *et al.* (2015, p.341) define burden as “physical, psychological, emotional, behavioural and financial burden that may be experienced by informal caregivers”; although a flaw in this definition is that the term burden is used within. Alternatively, Lee *et al.* (2017a) suggest that burden is a multidimensional outcome of negative appraisal. Evidently, burden is a negative experience, which can be encountered in a variety of ways; it can affect the physical health, mental health, wellbeing, and social engagement of caregivers (*ibid*). However, it is important to note the criticisms of research into burden. Caregiving can be both emotionally demanding and rewarding (Dahlrup *et al.*, 2015), therefore it is plausible that most caregivers encounter a combination of negative and positive experiences. However, negative consequences of caregiving continue to be more extensively researched than positive ones (de Labra *et al.*, 2015; García-Mochón *et al.*, 2019).

Caregiver satisfaction may be perceived to contrast with burden, but this is not explicit (García-Mochón *et al.*, 2019), as caregivers can experience both feelings of burden and satisfaction simultaneously. Research is largely in agreement that satisfaction is derived intrinsically, for instance, strengthening relationships (Kietzman *et al.*, 2008), or personal growth (Ekwall and Hallberg, 2007); thus satisfaction could have beneficial effects on health, wellbeing, or loneliness. Additionally, evidence suggests that satisfaction has implications for both caregiver and recipient wellbeing (Kietzman *et al.*, 2008).

It is often speculated that increased time spent caregiving is linked to burden and satisfaction, as such caregiving ≥ 5 -hours per day (hpd) is linked to lower satisfaction among caregivers (Marcén and Molina, 2012). In contrast, interviews with adult-daughters providing care to their mothers (N=133) suggested that, in around half of the sample, caregiving was beneficial to their relationship, 57% of those attributed this to additional time spent together (Walker *et al.*, 1990). While these relationship improvements were correlated with satisfaction, the findings contradict the idea of higher-intensity caregiving equating to greater burden, as increased time resulted in increased satisfaction. This would suggest that burden is not only linked to caregiving intensity, but that there are other influential or mediating factors, such as the inter-personal relationship, or the nature of care.

1.2.2 Loneliness

There are several definitions and interpretations of loneliness, ultimately emphasising a lack of satisfaction with one’s relationships. Seminal definitions include that of Perlman and Peplau (1981,

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p.31), who delineate loneliness as an “unpleasant experience that occurs when a person’s network of social relations is deficient in some important way, either quantitatively or qualitatively”, and Weiss (1973, p.17), who articulates: “loneliness is not caused by being alone but by being without some definite needed relationship or set of relationships”. Overall loneliness is a discrepancy between actual and desired relationships, in that networks are smaller (quantitatively) or less satisfying (qualitatively) than desired. Moreover, these early definitions are still widely cited in contemporary research (Barreto *et al.*, 2020; Groarke *et al.*, 2020; Hajek and König, 2020).

Loneliness is a multidimensional concept, often categorised into social and emotional loneliness (Weiss, 1973; Dahlberg and McKee, 2014; Tiilikainen and Seppanen, 2017). Simply, social loneliness reflects a lack of socially inclusive relationships, whereas emotional loneliness manifests as the absence of significant emotional attachments (Weiss, 1973). The Weiss distinction suggests that social and emotional loneliness are separate; however, it could be argued that there is an overlap. As such, unmarried, childless, individuals may develop significant attachments within friendship groups, which may also constitute inclusive relationships. Among older, unmarried, childless women, relationships with siblings, friends, and neighbours were stronger than those who were married or with children (Wenger *et al.*, 2000). Therefore, the Weiss distinction may not be a distinction, but more of an identification of two possible sources of loneliness. Attachment theory suggests that new attachments may be established after loss (Lang and Fowers, 2019). Therefore, as people gain and lose relationships throughout their lifecourse, emotional loneliness is likely to occur, until significant attachments are re-established or transferred.

The definition of loneliness adopted within this thesis is a discrepancy between desired and actual relationships (Perlman and Peplau, 1981, Barreto *et al.*, 2020). However, different dimensions, including absence of significant attachment (emotional) and lack of inclusive relationships (social) are also acknowledged, alongside the notion that one can be lonely without being alone (Weiss, 1973).

1.2.2.1 Related terminology

Alongside loneliness, there are terms such as solitude, social isolation, and social exclusion. Often in literature, these are used synonymously with loneliness, but the definitions suggest that they represent individual constructs. Solitude refers to the experiences of being or feeling alone (Burger, 1995; Long *et al.*, 2003). Similarly, Galanaki (2004) defines solitude as a temporary state of voluntary, beneficial aloneness; in contrast to the aforementioned sources, this suggests solitude is exclusively positive. Nguyen *et al.* (2018) highlight that as solitude (the experience of being alone) is related to other psychological experiences, such as loneliness, there is little focus on solitude within research. Solitude is conceptualised as being alone without communication or other activities (*ibid*), therefore, is considered a deliberate action, rather than an emotional or psychological response.

In contrast, social isolation is an objective measure of aloneness, typically a quantification of relationships, inferring that fewer relationships result in isolation (Jopling, 2015). Tilvis *et al.* (2012) expand on this by separating the size of networks from the frequency of interactions within. Moreover, de Koning *et al.* (2017) specify that to be socially isolated, contact with friends or family should be less frequent than once per week. As an objective measure, a standardised value for social isolation should be employed to ensure consistency when monitoring individuals, and to promote comparability for research purposes. However, Victor *et al.* (2003) criticised this approach of quantifying weekly interactions, identifying that by determining social isolation using a specific value within a certain timeframe (e.g. once per week), this infers that all interactions are equal, and a greater number is always preferable, which may be inaccurate.

Victor *et al.* (2003) consider that social isolation could predict loneliness. However, as indicated when discussing the definitions (section 1.2.2), loneliness is not always the result of being alone (Weiss, 1973). The evidence on the association between isolation and loneliness is inconsistent (Smith and Victor, 2019), thus it is important to consider the possibility of having contact with individuals and still experiencing loneliness. This highlights the incongruity between social isolation and loneliness, whereby to be isolated, an individual must have infrequent social interactions, or a small social network, whereas loneliness reflects individuals' psychological response to a discrepancy between the relationships they want and currently have. Social isolation, which could be equated to reduced social networks (de Jong Gierveld and van Tilburg, 2016) has been linked to loneliness (Hawkey *et al.*, 2008; Domènech-Abella *et al.*, 2017a). However, small social networks do not necessarily cause loneliness; fewer relationships are often indicative of isolation, but not always loneliness (de Jong Gierveld, 1998). This highlights that social isolation and loneliness are separate phenomena. Within this thesis, social isolation is not measured as an outcome; but, measures of social networks (section 4.3.7), which arguably reflect isolation by determining the quantity of individuals' networks (Tilvis *et al.*, 2012; Jopling, 2015), are included within the conceptual framework (section 2.2) and analysed as a potential moderator between caregiving and loneliness.

Another concept is social exclusion. Similar to loneliness, social exclusion is subjective; Hajek and König (2017) differentiate between loneliness and social exclusion, indicating that the latter is a perception of not belonging within society. Social exclusion is also used to depict disadvantaged states experienced by marginalised groups, who perceive themselves to be removed from society (O'Donnell *et al.*, 2018). Exclusion is more commonly perceived than observed, i.e. individuals feel excluded from society, rather than being actively excluded by members of societal groups. Therefore, it could be considered that the perception of being left out could lead to loneliness, but the two are not automatically linked. For instance, if individuals feel excluded from one community, but accepted within another, this may alleviate feelings of loneliness, but would not reduce the exclusion from the initial community. Social exclusion involves detachment not only from relationships, but also institutions and groups (Hajek and König, 2017), additionally exclusion is influenced by health and resources (Kristensen *et al.*, 2019). **This suggests that, for social exclusion, larger emphasis**

would be placed on examining personal and community resources, rather than a responsibility such as caregiving. Overall, a larger body of evidence links caregiving to loneliness than to social exclusion, and one of the main aims of this thesis (section 1.1) is to determine the health and wellbeing consequences of loneliness among caregivers. For this reason, social exclusion is not investigated further within this thesis. Nevertheless, defining these key terms is essential prior to discussing the current literature, to enhance the clarity and comparability of the results from this thesis with other studies.

Identified within this section, the terms social isolation, solitude, and social exclusion, despite frequently being discussed in conjunction with loneliness, are all distinct. For the purpose of this thesis, loneliness is the focus. However, social isolation is included in the analyses as a covariate, determined using measures of familial and friendship networks. Given the circumstances of caregiving, caregivers' networks may reduce due to caregiving responsibilities (Vasileiou *et al.*, 2017), but caregivers are unlikely to be completely isolated due to connection with the recipient. For this reason, loneliness was considered more appropriate to research, while considering the effects of a reduced network. Additionally, there is a higher quantity of evidence supporting the link between social isolation and health, than between loneliness and health (Blazer, 2020), which emphasises a need for further research on loneliness, in relation to health and wellbeing.

1.2.2.2 Measuring loneliness: loneliness scales

The most common methods to measure loneliness are: single-item direct questions, the University of California Loneliness Scale (UCLA-LS), and de Jong Gierveld Loneliness Scale (DJGLS) (Campaign to End Loneliness, no date; ONS, 2018b). Single-item questions ask directly about loneliness, typically including the word 'lonely'; for example: 'how often do you feel lonely?' (ONS, 2018b). One of the main disadvantages of direct questions is the social stigma attached to loneliness, making individuals less likely to report feeling lonely (Shiovitz-Ezra and Ayalon, 2012). Indirect scale measures are an alternative approach, the questions do not include 'lonely' or 'loneliness', therefore are less likely to result in under-reporting (*ibid*).

The 20-item UCLA-LS contains positively (N=10) and negatively (N=10) worded items (Russell *et al.*, 1980). Despite this, the UCLA-LS is characterised as a global scale, not as two separate scales (Dodeen, 2015). There are several short-form versions, such as 3-item (Campaign to End Loneliness, no date), 4-item (Hays and DiMatteo, 1987), 6-item (Neto, 2014) or 8-item (Wu and Yao, 2008). However, the items used in each scale are not always reported, nor are they consistent. As such, the numbering of items in the 4-item scale reported by Hays and DiMatteo *et al.*, (1987) did not correspond with the numbering on the original 20-item UCLA-LS (Russell *et al.*, 1978). To illustrate, item 15 according to Hays and DiMatteo (1987) related to companionship, whereas originally this was reported as "No one really knows me well" (Russell *et al.*, 1978, p.292). The items in the 3-item UCLA-LS ask about companionship, isolation and feeling left out, and responses include 'hardly

ever or never’, ‘some of the time’, or ‘often’, scored as 1-3 respectively; the overall loneliness score is determined from the sum (ONS, 2018b).

In contrast, the 11-item version (DJGLS-11) of the DJGLS has been described as the most utilised loneliness instrument across Europe (Tomás *et al.*, 2017). Moreover, unlike the UCLA-LS, which emphasises social loneliness, DJGLS-11 incorporates the Weiss distinction (Penning *et al.*, 2014). Therefore, the DJGLS-11 can be used as an overall measure of loneliness, but also as individual, social (N=5) and emotional (N=6) loneliness subscales (de Jong Gierveld and van Tilburg, 2010). The 6-item version (DJGLS-6) was developed specifically for large surveys (*ibid*). Although most commonly used for older adults (Penning *et al.*, 2014), the DJGLS-6 is appropriate for all adults aged 18-99 (Leung *et al.*, 2008). As with the DJGLS-11, the DJGLS-6 can also be used as an overall loneliness measure, or two shorter social (N=3) and emotional (N=3) subscales (de Jong Gierveld and van Tilburg, 2006). Emotional loneliness indicators ask about emptiness, having people around and feelings of rejection, whereas the social indicators include relying on, trusting, and feeling close to others (*ibid*); responses include ‘yes’, ‘more or less’, and ‘no’.

In this thesis, initially, a direct loneliness question is compared with the UCLA-LS to identify any differences in reporting loneliness among caregivers and non-caregivers. However, for the majority of the analyses, the UCLA-LS is the primary loneliness measure. This is because firstly, shorter versions of scales are considered more appropriate in large surveys (ONS, 2018a), therefore, in large surveys such as ELSA, the UCLA-LS 3-item would be favoured over the DJGLS-6. Secondly, the UCLA-LS is well-established (*ibid*), widely used among older adults, and applicable in both questionnaire and interview scenarios (Campaign to End Loneliness, no date).

1.2.3 Health and wellbeing

Health and wellbeing are distinct but connected; health influences wellbeing, but health is also impacted by wellbeing (Department of Health, 2014). Therefore, it is difficult to distinguish between the two and often, in research, they are combined without clear distinction between the concepts. Nevertheless, it is important to recognise the similarities and differences between health and wellbeing, and to identify clear definitions to guide the interpretation of the findings. Previous research on wellbeing is founded on descriptions of wellbeing, as opposed to a coherent definition (Dodge *et al.*, 2012); this diverse approach has fostered ambiguity and broad definitions (Forgeard *et al.*, 2011). The following sections discuss common definitions for both health and wellbeing, identifying which are the most relevant for this thesis. To aid clarity, key indicators, quality of life (QoL) and life satisfaction (which are often used interchangeably with wellbeing), are also defined.

1.2.3.1 Health

The World Health Organisation (WHO) published a definition of health in 1948, which is still widely used: “a state of complete physical, social and mental wellbeing, and not merely the absence of

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disease or infirmity” (WHO, 1998, p.1; McCartney *et al.*, 2019, p.23). Although WHO (1998) contended that the most comprehensive understanding of health involves collective health and wellbeing, the lack of clarity surrounding the constitution of ‘social wellbeing’ (as opposed to physical or mental wellbeing) contradicts this. Alternatively, Card (2017) proposed a definition whereby health was not defined by presence of disease or disability, but considered on a spectrum from more to less healthy, determined by physical and psychological wellbeing. However, this definition is still largely weighted on wellbeing. In contrast, health status, a measurement of individual or population health compared to specific criteria (WHO, 1998), may be a more appropriate perspective. Health status can be determined by using either professional diagnoses or self-reported measures (Ngamaba *et al.*, 2017). A significant positive association was observed between health status and subjective wellbeing, highlighting that health and wellbeing are distinct components, but inevitably influence one another (*ibid*).

The medical model of health – health as absence of disease – is an objective measure where an individual must meet specific parameters (Victor, 2005). Similarly, health as functional normality, as proposed by Tengelnd (2007), focuses on areas of limited function, such as disabilities. These perspectives are particularly reductionist, considering solely medical diagnoses, irrespective of how individuals feel. For example, people can be healthy, whilst living with disability or chronic conditions (McCartney *et al.*, 2019). In comparison to the medical model and WHO definition, the sociological perspective adopts a more person-centred approach (Victor, 2010). The sociological perspective – health as absence of illness – allows an individual to determine their physical and mental health status (Victor, 2005; 2010). Alongside perceived health status, the presence of any pain or self-reported disabilities are acknowledged (Victor, 2005). Although this method is entirely subjective, it may be a more accurate way of determining an individual’s health. To clarify, the individual can offer a conclusive overall health status, incorporating specific conditions that they have been diagnosed with, but also any acute or undiagnosed problems that may be directly affecting their health. One limitation of this definition is the subjective nature; self-rated health status may fluctuate significantly depending on personal circumstances and may not necessarily follow an expected pattern.

The definition of health, for the purpose of this thesis, is a combined approach, considering both the medical model (absence of disease, e.g. diagnosed conditions) and sociological perspective (absence of illness, e.g. self-rated health and the individuals’ perceptions of health). Furthermore, a key component to defining health is the recognition that health is multidimensional (McCartney *et al.*, 2019), this will be further applied within the thesis by including both physical (e.g. reported illnesses) and mental health measures (e.g. depressive symptomatology). The thesis also measures health expectations, behavioural health, and physiological health conditions by incorporating specific health pathways derived from theory (chapter 2).

1.2.3.2 Wellbeing

Wellbeing is a broad concept: “wellbeing encapsulates how we are faring, in all domains of life, including financial, health, social, personal and the local environment” (Green *et al.*, 2017, p.3). Alternatively, national wellbeing includes individuals’ perceptions of their wellbeing, external factors which impact wellbeing (e.g. health or education), and contextual influences, such as the economy (Beaumont, 2011). These two perceptions incorporate an extensive range of factors, and the lack of clarity has resulted in a disorganised approach to measuring wellbeing. As such, researchers use contrasting approaches to assess wellbeing (Forgeard *et al.*, 2011). This ultimately impacts comparability of research and limits the understanding of the concept.

The two main domains are subjective and psychological wellbeing; but, similarly to the definitions of overall wellbeing, there are several interpretations for both. Subjective wellbeing is expressed as a balance between positive and negative emotions (Dolan *et al.*, 2011). However, that is a simplistic definition; Diener *et al.* (1999) define subjective wellbeing differently, advocating three components: pleasant affect (e.g. happiness), unpleasant affect (e.g. stress) and life satisfaction. Moreover, subjective wellbeing reportedly contains hedonic (feeling good) and eudaimonic (functioning well) aspects (Chanfreau *et al.*, 2013). Correspondingly, psychological wellbeing is also considered to comprise hedonic and eudaimonic perspectives (Winefield *et al.*, 2012). Therefore some ambiguity surrounds the contrast between subjective and psychological wellbeing, although Linley *et al.* (2009) argue that subjective wellbeing is hedonic, whereas psychological wellbeing is eudaimonic.

An alternative, and arguably clearer, distinction of psychological wellbeing is provided in Ryff’s six-dimension wellbeing model (Ryff, 1989). The dimensions are: self-acceptance, personal growth, purpose in life, positive relations with others, environmental mastery, and autonomy (*ibid*). In a more recent evaluation of the model, correlations were identified between specific dimensions (e.g. purpose in life) and conditions such as dementia, highlighting the link between health and wellbeing (Ryff, 2014). Moreover, although ‘positive relations with others’ could be compared to social loneliness, arguably, the perspectives differ significantly. To clarify, loneliness focuses on a lack of relationships (negative outlook), whereas the eudaimonic perspective of psychological wellbeing adopts a positive approach. Therefore, social loneliness and ‘positive relations with others’ are contrasting perceptions on a similar experience, and reasonably, this may make them compatible with one another.

Finally, QoL is frequently used synonymously with wellbeing. However QoL reflects the degree to which an individual feels their needs are met and, if they have adequate opportunities to achieve fulfilment (WHO, 1998). This definition highlights that QoL is closely linked to areas of psychological wellbeing (e.g. self-acceptance), identified in the psychological wellbeing model (Ryff, 1989). In contrast, life satisfaction is an aspect of subjective wellbeing linked closely to

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happiness (Diener *et al.*, 1985). Life satisfaction is a cognitive process involving an overall judgement about one's life. However, the criteria are vague and rely on individuals to compare their lives to an ideal standard (*ibid*). Within this thesis, the division of subjective and psychological wellbeing is adopted, utilising measures of QoL and life satisfaction to determine wellbeing within the sample. See section 4.3.4 for further discussion on QoL and life satisfaction scales.

1.3 Thesis structure

The first chapter has introduced the main concepts relevant to the thesis, and clarified definitions. The discussion on loneliness also introduced key measurement tools and details of the UCLA-LS used within this thesis. Moreover, the aims, objectives and research questions were explicated.

Chapter two: theoretical understanding

In the second chapter, key theories are discussed in relation to caregiving motivation, and the impact of caregiving. Furthermore, the theoretical, and conceptual knowledge from chapters one and two are combined to formulate a conceptual framework for this thesis.

Chapter three: literature review

This chapter is divided into sections discussing the determinants of loneliness, caregiving literature, and loneliness in relation to health and wellbeing, for both the general population and within a caregiving context. Determinants of loneliness are addressed with consideration to the demographics of this thesis' sample (aged ≥ 50), looking particularly at studies that examine middle-aged or older adults. Caregiving-specific literature examines characteristics of caregivers, the caregiving relationship, the caregiving role, and burden and satisfaction. The final literature review section recognises that the relationship between loneliness, health, and wellbeing is multidimensional, therefore literature is examined on the associations in multiple directions, and within the caregiving context.

Chapter four: methodology

The methodology outlines the research strategy, including cross-sectional and longitudinal research design and an overview of the research materials, which are the ELSA dataset. The chapter outlines the key variables from ELSA that are analysed within the thesis, and variables computed for the follow-up analysis. Finally, the statistical techniques applied within the thesis are outlined.

Chapter five: cross-sectional results

Chapter five reports on the cross-sectional results, carried out on ELSA wave eight. This chapter addresses research questions one and two, as outlined previously (section 1.1.1). The methods applied are primarily binary logistic regressions, with additional multinomial logistic regressions and

linear regressions where appropriate. Initially, caregivers are compared with non-caregivers, using variables relevant to both groups; subsequently, research question two builds on this by adding caregiving-specific variables.

Chapter six: twelve year follow-up

Follow-up analyses are conducted on a sample of respondents who provide data from waves two to eight of ELSA, the results of which are reported in chapter six. Binary logistic regressions are used to determine if caregiving at wave two, caregiving in any wave, or changes to the caregiving relationship and role between waves two and eight, are linked to loneliness.

Chapter seven: discussion

The final chapter elaborates on the interpretations of each research question, in relation to the theoretical and conceptual framework, and published evidence. The limitations of the thesis are also outlined, and to conclude, a statement of original contribution is made alongside recommendations for policy and further research.

Chapter 2 Theoretical understanding

The application of Gerontological theory connects current findings to previous observations, and encourages new perspectives (Biggs *et al.*, 2003). Theoretical and conceptual frameworks in Gerontology provide structure for interpreting new ideas, which can prevent ageism within research, aid policy development, and enhance practical applications of the findings (Hasworth and Cannon, 2015). In social Gerontology, and more specifically family Gerontology, a division of social Gerontology focused on ageing families (Humble *et al.*, 2020), it was identified that stress and coping theories were commonly applied in research over the past few decades (1990-2018) (Roberto *et al.*, 2006; Alley *et al.*, 2010; Humble *et al.*, 2020). These theories are relevant to this thesis on loneliness among caregivers because, predominantly, caregivers within these analyses are providing care to a family member, thus representing family Gerontology. The following sections discuss caregiving-relevant theories, alongside the key concepts (section 1.2), will formulate a suitable conceptual framework for this thesis (section 2.2).

2.1.1 Caregiving theories

It is important to discuss caregiving-specific theory because, as outlined previously, theories are used to interpret research findings (Biggs *et al.*, 2003). Therefore, to develop and address caregiver-focused research questions, a deeper understanding of current knowledge of the caregiving role is beneficial. As such, historical evidence suggests caregiving may be an evolutionary characteristic, due to its long-standing and multi-cultural nature (Lang and Fowers, 2019).

The lifecourse perspective is fundamental to social theories of ageing, assuming occurrences throughout the lifecourse have a cumulative effect (Hasworth and Cannon, 2015). The lifecourse has multiple pathways that involve experiences, lifelong development, and sociocultural contexts (Elder Jr., 1994; Crosnoe and Elder Jr., 2015). The lifecourse can be analysed using either a two-stage or a three-stage model, the latter separates the lifecourse into childhood, adulthood, and older age, whereas two-stage models contrast older age with the rest of the lifecourse (Vincent *et al.*, 2006). A fundamental aspect of the lifecourse perspective is linked lives (Elder Jr., 1994; Crosnoe and Elder Jr., 2015; Hasworth and Cannon, 2015). Linked lives are direct and indirect effects of resources across multiple generations within a family (Gilligan *et al.*, 2018); resources are not limited to tangible items such as money but can also include knowledge and social networks. As the nature of change throughout one's life can vary considerably, lifecourse perspective encompasses several factors, for example biological, developmental, or geographic. Therefore, it is applicable to a diverse range of research topics (Hendricks, 2012).

The less diverse, more caregiving-specific, theories tend to focus on understanding the motivation behind caregiving, or the impact of caregiving (Lang and Fowers, 2019). Theoretical explanations,

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such as the aforementioned linked lives or other exchange theories (e.g. reciprocity), are common in research examining why caregivers provide care; whereas the popular stress, coping and appraisal theories are more relevant for caregiving impact (section 2.1.1.2).

While theoretical frameworks on caregiving motivation are important for understanding caregiving as a concept, they are less relevant to the work within this thesis, which is largely interested in the outcomes of caregiving. That is exploring the ‘how’, not the ‘why’. Motivation to care will not be analysed within this thesis; the intention of this thesis is to consider the impact of caregiving on loneliness, health and wellbeing, thus the following section highlights relevant theories on the impact of caregiving.

2.1.1.1 *How does caregiving impact the caregiver?*

Stress, coping and appraisal theories are prevalent in underpinning research into the impact of caregiving (Gérain and Zech, 2019). Caregiving appraisal, defined as the cognitive and emotional evaluation of stressors and coping (Wang *et al.*, 2020a), was introduced to expand the understanding of caregiver burden, by establishing that not all caregiving appraisal is negative (Lawton *et al.*, 1989). Moreover, appraisal is multifaceted and represents satisfaction, impact, mastery, ideology, and burden (*ibid*). Despite this conceptualisation, burden is still frequently used synonymously with appraisal. Therefore, in response to these inconsistencies, Wang *et al.* (2020a) proposed three levels of a Social Ecological Model (SEM): individual (caregiver and recipient factors), interpersonal (family function and support), and community (social support or pressure), which arguably provides a clearer approach to understanding appraisal. A similar approach was adopted by Gérard and Zech (2019), through the development of the Informal Caregiving Integrative Model (ICIM). Similar to SEM, ICIM includes factors inside and outside of the caregiving context and considers appraisal to be a key component. However, ICIM largely reflects the negative bias of appraisal, by focusing on burnout (*ibid*). That said, the structure of ICIM is more detailed than SEM, including appraisal and relationships as mediators of burnout.

Alternatively, Caregiver Identity Theory (CIT) depicts the dynamic process of adaptations throughout the caregiving role, for example, accommodating the recipient’s changing health status (Montgomery *et al.*, 2016). To clarify, adaptations may include increasing caregiving hours, or new, caregiving tasks. Caregiver identity can refer simply to whether individuals consider themselves caregivers, but also the extent to which they associate with the role. For example, although caregiving tasks are recognised, many people may not identify as caregivers, due to stigma surrounding the terms ‘carer’ or ‘caregiver’ (Hughes *et al.*, 2013). Montgomery and Kosloski (2009) detail the identity change process using the example of a spousal caregiver (Figure 1); however, the process is not exhaustive, individuals may not experience all phases, or phases may occur in different orders (Montgomery *et al.*, 2016).

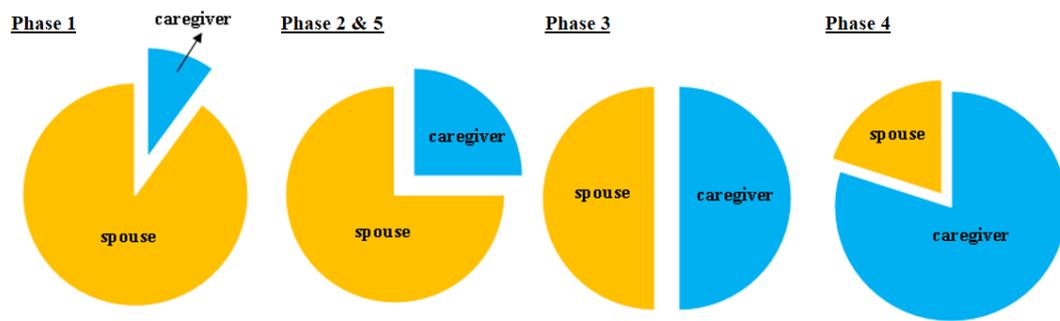


Figure 1: **Caregiver Identity Theory: phases of caregiver identity change**

Source: author's adaptation from Montgomery and Kosloski, 2009, p.51; Montgomery *et al.*, 2016, p.454

Transitions between phases may relate to changes in both the caregiving context and caregiver identity (Montgomery, 2007; Montgomery and Kosloski, 2009). Using the example of a spousal dementia caregiver, identity may change as the dementia progresses. In phase one, caregiving tasks are less noticeable, such as assisting with shopping. Often, caregivers may not identify as a caregiver until phase two, when tasks surpass typical family roles (Montgomery *et al.*, 2016). Phase three commonly involves the introduction of personal care, as dementia severity is likely to have increased: caregiving now forms a substantial part of the relationship. Within the fourth phase, caregiving is dominant as care needs have considerably increased, and here, the caregiver often identifies with the caregiver role more than as a spouse. The fifth phase (repeat phase two) may reflect a transition to formal care, or institutionalisation, which often occurs in advanced stages of dementia, but informal care roles frequently continue at reduced intensities.

CIT outlines the process of adaptations that a caregiver may experience, highlighting how identity and caregiving behaviours can change throughout the role. This is particularly relevant when researching loneliness among caregivers; for example, identity change from spouse to caregiver could contribute to reduced relationship quality, which is known to influence loneliness (Hsieh and Hawkey, 2018; Leszko *et al.*, 2020). However, aspects of SEM and ICIM are also relevant to this thesis, highlighting the importance of factors both within, and external to, the caregiving role, and the mediating impact of appraisal.

2.1.2 Stereotype embodiment theory

Stereotype embodiment theory (SET) demonstrates that as people age, age-stereotypes become increasingly relevant (Kornadt, 2016). Although age-stereotypes can be positive, they are predominantly negative, for example, considering physical decline a normal part of ageing. Internalised negative age-stereotypes result in self-fulfilling prophecies, such as frailty or memory-loss (Levy, 2009; Meisner and Levy, 2016).

Perceptions of ageing are determined through personal experience and societal influences. Moreover, often the most vulnerable to negative age-stereotypes are children, because of limited exposure to older adults, or older adults being portrayed as frail in the media (Levy, 2009). A large portion of

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societal influence is drawn from culture; the UK was found to have among the strongest negative age-stereotypes, whereas China demonstrated stronger neutral and positive age-stereotypes (Meisner and Levy, 2016). Negative age-stereotypes are linked to poorer health outcomes in older adults (Levy *et al.*, 2000; Levy and Myers, 2004; Levy *et al.*, 2009). However, negative age-stereotypes can also influence whether individuals obtain medical advice or treatment; older adults who consider pain and illness as a typical age-related component may not seek medical attention, assigning their symptoms to age as opposed to illness or injury (Hasworth and Cannon, 2015).

Although SET appears to relate predominantly to individuals' expectations, SET operates through multiple pathways: psychological, behavioural and physiological (Levy, 2009; Meisner and Levy, 2016). The psychological pathway relates to expectations; negative age-stereotypes are linked to lower self-efficacy, whereas positive age-stereotypes are linked to higher self-efficacy (Meisner and Levy, 2016). An earlier study demonstrated the effect of age-stereotype priming on memory in individuals from the United States (US), aged 60-90 (Levy, 1996). Individuals were exposed to twelve negative (e.g. senile) or twelve positive (e.g. wise) words prior to completing memory tasks. Those exposed to positive age-stereotypes performed significantly better than the negative terminology group.

The second SET pathway is behavioural, related to healthy practices (Meisner and Levy, 2016). As most individuals consider health decline as unavoidable (Levy, 2009), engagement in healthy practices is often limited. Individuals with positive age-perceptions were found to engage in more preventative health behaviours (e.g. regular exercise), than those with negative perceptions (Levy and Myers, 2004).

Thirdly, the physiological pathway is connected to the autonomic nervous system (Levy, 2009), specifically stress and CV activity (Meisner and Levy, 2016). Negative age-stereotypes are associated with increased CV response to stress, which increases likelihood of CV events (Levy *et al.*, 2000). Negative age-stereotypes can also inhibit recovery from acute CV events (Levy *et al.*, 2006). Comparison of cardiac recovery patients (mean age 71) showed that physical performance of the positive age-stereotype group was significantly greater than the negative group at follow-up.

Within this thesis expectations for both future loneliness and health are analysed, thus SET is highly relevant. The psychological pathway aids the interpretation of the results and connects the findings from this thesis with current understanding on expectations. Additionally, SET is applicable to other areas within this thesis, as by mapping out behavioural, physiological, and psychological pathways, this gives structure to how the health and wellbeing consequences of loneliness are examined among caregivers and non-caregivers.

2.2 Theoretical and conceptual framework

The main theories underpinning this thesis are CIT and SET. CIT demonstrates that caregiving is adaptive and shows transitions between the pre-caregiving relationship and the caregiver-recipient relationship. The phases represent how the caregiver identifies with the role but could also be attributed to evolving care needs. While changes in identity are not explicitly measured in this thesis, the understanding that perhaps more complex care needs (higher-intensity roles) could reflect less of a connection to the pre-caregiving relationship, would highlight potential connections to loneliness. As suggested by Weiss' (1973) social and emotional loneliness, identifying more as a caregiver than, for example a spouse, caregivers may feel the significant emotional attachment is lost, or weaker, or the relationship is less inclusive because they are responsible for more of the marital tasks (e.g. finances) which may have previously been shared. Furthermore, to provide a more structured approach to the health aspect of the thesis, a health-related theory was deemed important. SET identifies three pathways of health, which implements a specific structure for interpreting health impacts. Providing evidence on the association between caregiving, loneliness and, for instance, a self-rated general health measure would identify if caregiving and loneliness were broadly connected to health. However, there would be limited detail into which particular aspects of health were most affected. A more specific approach, through the application of theoretical knowledge, can provide more comprehensive results, and detailed policy recommendations.

Additional theories (caregiving appraisal, SEM and ICIM) have guided the formulation of the conceptual framework. SEM and ICIM identify the importance of factors inside, and outside of the caregiving role, which have been integrated into the proposed framework. Moreover, certain aspects of appraisal are relevant to this research. This thesis focuses on the impact of caregiving on loneliness, health, and wellbeing, so satisfaction and burden (shown to be linked to health and wellbeing, section 3.3.4), are likely to play integral roles **in the observed relationships.**

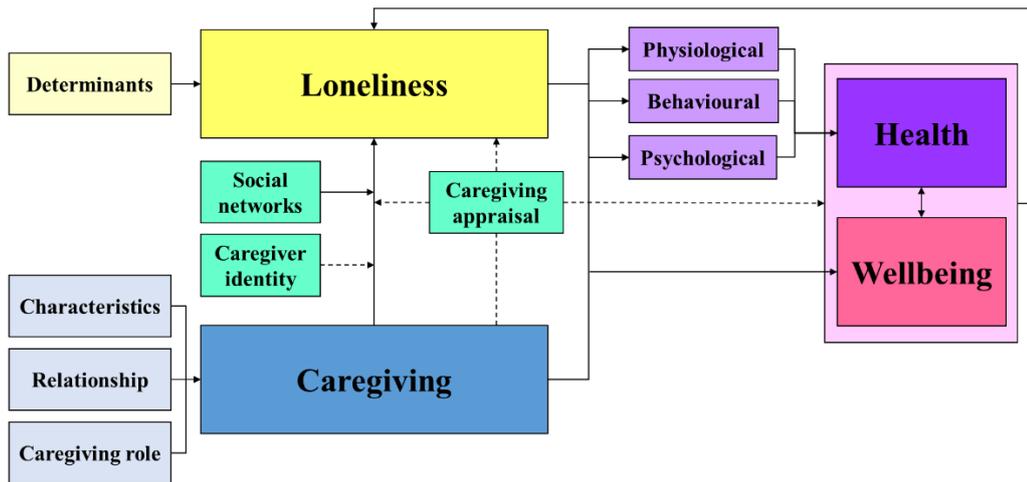


Figure 2: Conceptual framework

Source: author's own

The conceptual framework (Figure 2) depicts a consolidation of the aforementioned theories and concepts, whereby factors related to caregiver characteristics, the caregiving relationship and role shape the caregiver, and in turn, contribute to caregiving outcomes. While there is likely to be an overlap between the determinants of loneliness and the characteristics of caregivers (e.g. sociodemographic characteristics), this is not exclusive. For example, there is contrasting evidence on the association between sex and loneliness (section 3.2.1), and sex and caregiving (section 3.3.1.2) therefore, sex may be a determinant of both caregiving and loneliness, either caregiving or loneliness, or neither caregiving nor loneliness. Moreover, factors such as reduced social networks of caregivers, identification with the role (CIT), and appraisal are likely to moderate the impact of caregiving on loneliness. For example, adequate social support through networks may buffer the impact of caregiving on loneliness. The pathways to health, as identified by SET, also form an integral part of the framework, encouraging investigation into specific health outcomes to form more precise policy recommendations.

2.3 Chapter summary

Chapter two has discussed relevant caregiving theories and introduced the conceptual framework. One of the main aims of this thesis is to identify the impact of caregiving upon loneliness, health and wellbeing, thus theories on motivation to care are less applicable. Moreover, the long-term effects of caregiving are considered, including changes to the caregiving role, therefore CIT aids the understanding of how caregivers adapt to changing caregiving circumstances. Finally, the application of SET allows a structured interpretation of health consequences, to promote more specific health policy recommendations. The next chapter critically discusses current literature in relation to the key concepts caregiving, loneliness, health and wellbeing. Specifically, the literature review addresses the determinants of loneliness, caregiving-specific literature, and loneliness, health and wellbeing in the context of both the general population and amongst caregivers.

Chapter 3 Literature review

3.1 Chapter outline

This chapter critically discusses relevant literature on the determinants of loneliness (section 3.2), considering which predictors may be the most relevant to a caregiving population. Moreover, caregiving-specific literature (section 3.3), in addition to literature on burden and satisfaction, will be discussed. Finally, the relationship between loneliness, health and wellbeing is known to be complex, whereby bi-directional associations have been reported. Section 3.4 disentangles this literature and discusses evidence in a caregiving context. The summary of the literature is presented in section 3.5, where fundamental research gaps are outlined, clearly addressing how this thesis augments the current knowledge on caregiving and loneliness.

The literature search was conducted using several databases including Elsevier's ScienceDirect® and Scopus®, Clarivate analytics' Web of Science, EBSCOhost's APA PsycINFO, and DelphiS which is specific to the University of Southampton (also powered by EBSCOhost). Searches were conducted using key terms, and combinations of key terms using Boolean operators such as 'caregiving AND loneliness', and 'caregiving AND (health OR wellbeing)'. Initially articles from the search results were excluded based on the relevance of their titles and abstracts, and any duplicates were removed before articles were fully-reviewed. Supplementary literature was sourced from the reference lists of reviewed articles and additional searches to provide evidence for specific definitions, policy documents or publications from third sector organisations. Finally, additional literature searches were conducted towards the end of writing up the thesis to obtain any new evidence published since the initial literature review. These searches involved the aforementioned databases alongside the use of Google Scholar to locate specific articles.

3.2 Determinants of loneliness

A determinant of loneliness is a factor deemed to have an influential connection to loneliness. De Jong Gierveld (1998) suggests that the exact identification of loneliness determinants is unattainable due to their extensive and interdependent nature. As such, it would be inaccurate to assume that determinants act separately; for example, health may have direct effects on loneliness, but also indirect, by affecting social activity, capacity to work, and wellbeing, which in turn could impact loneliness. Victor *et al.* (2020) identifies and addresses a key research gap, highlighting that evidence on prevalence and predictors of caregiver loneliness is largely inadequate. Few studies have addressed loneliness among caregivers, but focus instead on outcomes, rather than understanding the determinants. Typically, studies investigating the determinants of loneliness in the general population identify similar factors, including sociodemographic and socioeconomic characteristics,

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social networks and resources, and aspects of physical and mental health (Honigh-de Vlaming *et al.*, 2014; de Jong Gierveld *et al.*, 2015; Hajek and König, 2020). Less commonly, neighbourhood factors such as public transport use have been linked to loneliness (Kemperman *et al.*, 2019). Moreover, Victor *et al.* (2020) investigated the determinants of loneliness among dementia caregivers, the most influential factors were: social isolation and networks, living arrangements, depression, life satisfaction and QoL.

The forthcoming sections discuss literature on sex (section 3.2.1), relationships (section 3.2.2), social networks (section 3.2.3), and SES (section 3.2.4) as determinants of loneliness. These factors were selected due to their relevance for older caregiving populations. As such, a larger proportion of caregiving roles are fulfilled by females (Rutherford and Bowes, 2014), except among older adults (aged ≥ 65) whereby England and Wales 2011 Census data revealed a higher percentage of older male caregivers, compared to older females (Milligan and Morbey, 2016). However, due to the gendered nature of the caregiving role, whether actual or stereotypical, it could be expected that sex should play a large role in the loneliness of caregivers, as sex is well-reported as a predictor of loneliness in the general population. Moreover, evidence suggests that caregiving is linked to a reduction in social activities; caregiving responsibilities often restrict caregivers' availability for social interaction, impacting relationships and social networks, which, subsequently, lead to loneliness (Vasileiou *et al.*, 2017). Care provision is also known to impact employment, due to demands of the caregiving role, often caregivers cease paid work, or substantially reduce working hours (Ciccarelli and van Soest, 2018). Other known associations such as caregiving burden, satisfaction, health, and wellbeing are addressed subsequently (sections 3.3.4 and 3.4.2).

3.2.1 Are females lonelier?

It is commonly conceived that females are lonelier, or more likely to report loneliness, than males (Pinquart and Sörensen, 2001; Nicolaisen and Thorsen, 2014a). However, some evidence argues being female does not predispose an individual to loneliness (Borys and Perlman, 1985; Barreto *et al.*, 2020), therefore inconsistencies within the literature must be addressed. Females are more likely to experience widowhood and undertake a caregiving role, compared to men (Pinquart and Sörensen, 2001), both of which are linked to loneliness. Therefore, it is also important to consider other contextual or sociodemographic factors that may mediate the significant relationship between sex and loneliness. When Norwegian middle-aged individuals, aged 40-59 (N=1,882), were compared with older individuals, aged 60-80 (N=1,181), sex was not significantly associated with loneliness in the middle-aged group. However, females were significantly more likely to report loneliness in the older group (Nicolaisen and Thorsen, 2014a). As sex was not significant across both age groups, this highlights that the relationship between sex and loneliness is likely influenced by other characteristics. Using a lifecourse perspective, childhood events were used to predict loneliness; significant differences were observed across age groups and between sexes. This further

emphasises the importance of contextual factors in relation to sex differences, but also suggests that age may mediate the relationship between sex and loneliness.

The literature provides limited evidence to definitively conclude that females are lonelier than males. Often, sources cited for higher prevalence of loneliness among females are quite dated, typically using data from the 1980/90s. More contemporary evidence advocates inconsistent sex differences. A meta-analytical review found that the magnitude of sex differences was smaller in more recent literature (Pinquart and Sörensen, 2011); publications ranged from 1948-1999, although sex differences were still present in the 'recent' studies (1995-1999), a declining trend was evident. This suggests that contemporary literature (>2000s) comparing male and female loneliness should observe fewer sex differences, however evidence remains inconsistent. From early 2000s data, in a sample of 999 individuals aged ≥ 65 (53% female), females were more likely to be lonely than males; however, after adjusting for age, marital status and household composition, sex was not significantly associated with loneliness (Victor *et al.*, 2005). Loneliness was more stable among males, 75% reported no change in loneliness over the past decade, compared to 60% of females (*ibid*). However, this was not a longitudinal comparison, only based on individuals' recall of the 10-year period, therefore subject to recall bias. Furthermore, 2006 data on UK individuals (N=2,393), indicated females were more likely to report loneliness across all ages (15-97 years), although the magnitude varied dependent on age and loneliness frequency (always *versus* sometimes) (Victor and Yang, 2012). This evidence also supports the hypothesis that factors such as age may mediate the relationship between sex and loneliness.

In contrast, recent evidence from the British Broadcasting Corporation (BBC) Loneliness Experiment found that males were lonelier than females across all ages (N=46,054, aged 16-99), but the effect of sex was weaker among older ages (Barreto *et al.*, 2020). This finding contradicts most other evidence, for example, 2016/17 ONS data aligned with aforementioned research suggesting a higher prevalence of female loneliness (Pyle and Evans, 2018). It is argued by Barreto *et al.* (2020) that the context of an online survey, as with the BBC experiment, is likely to reduce perceived stigma, therefore males may feel more able to report loneliness. However, if this were the case, whereby reduced stigma contributed towards a male majority, this should also have been evident in ONS data (Pyle and Evans, 2018), as the Community Life Survey (CLS) 2016/17 was administered in online and paper formats only (DCMS, 2017).

Alongside contextual factors, sex differences may also be attributable to the method of measuring loneliness. Often, studies that employ indirect scale measures report no significant sex differences, alternatively, studies using direct loneliness measures generally report higher female prevalence (Heinrich and Gullone, 2006; Pinquart and Sörensen, 2011). Similarly, Nicolaisen and Thorsen (2014a) found that females (aged 60-80) were more likely to report loneliness, than age-matched males using a single-item measure of loneliness; thus this may have contributed towards the observed

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sex differences. Overall, evidence suggests that the prevalence of loneliness may not necessarily be higher among females, but that females may face fewer barriers to directly report loneliness.

In conclusion, the literature is inconsistent in reporting sex differences in loneliness. Loneliness appears to be mediated by several factors, including the measurement tool (direct *versus* indirect), or contextual factors (e.g. age). Overall, females appear more likely to report loneliness, therefore it could be expected that, when using single-item measures, sex differences may be observed. Arguably, methods which do not require interviews or directly-reported loneliness, challenge the stigma of loneliness, thus using self-completion questionnaires and scale measures may give a more accurate depiction of loneliness prevalence. Finally, despite the indication that females were more likely to be lonely and to undertake caregiving roles, there was little discussion in the reviewed literature comparing loneliness between male and female caregivers. Victor *et al.*, (2020) attempted to address this by comparing loneliness predictors among dementia caregivers, but no significant association was found between sex and loneliness. Those findings may be limited to dementia caregivers, however, the lack of evidence among alternative caregiving samples (e.g. non-dementia), and the inconsistency in the general population literature, makes it difficult to hypothesise whether sex differences would be observed among other caregiving groups.

3.2.2 Relationships as a protective factor

Conceptually, relationships cover a broad spectrum and can be measured through marital status, living arrangements, or factors such as relationship quality. Marital status is frequently reported as an important predictor of loneliness (de Jong Gierveld *et al.*, 2015; Hajek and König, 2020) with emphasis on cohabitation or living arrangements among caregivers (Victor *et al.*, 2020). As definitions of loneliness frequently refer to both qualitative and quantitative aspects of relationships (section 1.2.2), it is likely that different aspects of relationships are influential on loneliness.

3.2.2.1 Marital status

Marriage is considered a protective factor against loneliness (Hsieh and Hawkey, 2016; 2018), although Dafoe and Colella (2016) argue that simply being married does not prevent loneliness, marital quality and satisfaction are highly influential. Moreover, using data from the US-based National Social Life, Health and Ageing Project (NSHAP), higher-quality marriages were indicative of lower loneliness (Warner and Kelley-Moore, 2012). Additionally, previous marriage was positively associated with loneliness, suggesting that those married multiple times were more likely to be lonely. This might be interpreted that longer (first) marriages equate to higher-quality relationships, and therefore less loneliness. However, the majority of the respondents were in long-term first marriages (average 44-years), which therefore suggests that the quality of the marriage is more influential than the duration on loneliness, but that longer marriages do not necessarily reflect higher-quality.

In studies that compare marital status, never married, divorced, and widowed respondents are frequently grouped as unmarried (Victor and Bowling, 2012; Dahlberg *et al.*, 2018b), which makes it particularly difficult to differentiate between the effects of widowhood and divorce on loneliness. The experience of being single is different to being widowed, both of which are contrasting experiences to divorce. It is unlikely that, collectively, these respondents would experience loneliness in the same way. Some studies focus particularly on widowhood, for example, Cavallero *et al.* (2007) compare widowed and married Italian older adults (N=956), reporting that married individuals were significantly less lonely than widowed. No divorced or never married respondents were included, so further comparison cannot be made. Alternatively, Ben-Zur (2012) contrasted married, divorced, and widowed Israeli individuals (N=196). Loneliness was significantly higher among widowed than married respondents, but no significant difference was observed between widowed and divorced, or divorced and married. Arguably, the mean loneliness score used within this study is unreliable; the scoring system for the UCLA-LS was not designed to quantify loneliness, thus the scale should only be used to categorise as lonely or non-lonely (Campaign to End Loneliness, no date).

Interviews with 'often or always' lonely, older Finnish adults (N=10, aged 70-83) revealed that the interviewees considered loneliness unavoidable, attributing this to age-related health declines which limit social interaction (Tiilikainen and Seppanen, 2017). This would suggest that loneliness was an internalised stereotype; SET conveys that this perception is likely to be a contributing factor towards their experiences of loneliness. One of the key themes identified from the interviews was the loss, or lack of, a partner (*ibid*); however, all but one of the respondents were without a partner (divorced N=4, widowed N=4, never married N=1, married N=1). Although this was identified as a substantial **determinant** of loneliness among the sample, and is supported by additional evidence indicating that widowhood and divorce are predictive of loneliness (Pinquart and Sörensen, 2011; Ben-Zur, 2012), arguably, a sample skewed towards those who have lost, or are without, a partner would be expected to produce such a strong result. The key themes arising in the interviews may have been largely different among a predominantly married sample, or a mixed sample of married, widowed, and divorced individuals.

Longitudinal analysis of loneliness among older adults is much less common; Victor and Bowling (2012) compare 1999 ONS omnibus data (N=999) with follow-up postal questionnaires in 2007/08 (N=287). Bivariate analysis demonstrated that marital status and living arrangements at follow-up were associated with change in loneliness; overall, 12% experienced a reduction in loneliness, but over twice as many (25%) showed an increase in loneliness. Changes in marital status, but not living arrangements, were significant in predicting loneliness change (*ibid*). It is possible that individuals experiencing a change in marital status (e.g. married to widowed), simultaneously experience a change in living arrangements, unless living with other family members, therefore it is plausible that the significant association between marital status and loneliness accounts for change in living arrangements.

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The literature search revealed an absence of evidence examining the relationship between marital status and loneliness among caregivers. However, Smith *et al.* (2020) analysed changes to the psychosocial status of caregivers (N=777) using ELSA waves 1-5. Over the eight-year period, prevalence of loneliness increased to a greater extent for caregivers than non-caregivers (N=1,463). Simultaneously, the proportion of married and cohabiting relationships significantly reduced among the caregiving sample. However, although both trajectories were statistically significant (i.e. different for caregivers and non-caregivers), there was little consideration into whether they were linked. This raises the question of whether the reduction in marital relationships contributes towards increased loneliness among caregivers.

3.2.2.2 *Relationship quality*

Hsieh and Hawkey (2018) also analysed NSHAP data, categorising marriages as aversive, indifferent, ambivalent, and supportive. Compared to those in supportive marriages, females in indifferent or aversive marriages were more likely to be lonely; whereas among males, only aversive marriages were significantly lonelier than supportive. Descriptive data identified that more males reported being in ambivalent marriages, whereas females most commonly reported supportive marriages. Given that the sample was dyadic, this suggests that females were less likely to report marital strain, or that males over-reported marital strain, which could have contributed to the gender differences. The sample comprised 953 heterosexual couples, limiting the generalisability of the results only to heterosexual relationships. This is a common theme within the literature, where there is little evidence on marital status, or quality of marriages, among same-sex couples. It is therefore unknown whether the gender differences identified within marital literature would be relevant. Relationships outside of marriage were also considered, but, regardless of quality, relationships with family and friends did not influence the direct effect of marital quality on loneliness (*ibid*). This suggests individuals with poor quality marriages are likely to be lonely, even if other relationships are high-quality. One explanation for this might be: marriages are potentially more intense relationships, and therefore could be expected to have a larger weighting on loneliness. As such, couples are likely to be cohabiting and therefore spend more time together than with friends or other relatives; moreover, exposure to a higher-quality relationship over a short time-period (e.g. visiting friends) is unlikely to counteract a poor quality relationship over a longer period (e.g. living with spouse).

Additional research on marital quality was conducted by de Jong Gierveld *et al.* (2009), among a sample of 755 respondents (60% male, aged 64-92) from the 2001/02 wave of Longitudinal Ageing Study Amsterdam. Many marital quality factors were investigated for associations with loneliness; larger social networks, infrequent contact with children, and lack of spousal emotional support were associated with higher incidence rates of loneliness. Furthermore, instrumental support provided to someone other than a spouse was associated with lower incidence of loneliness; the tasks reported as instrumental support included helping with daily chores or around the house, which could

be likened to some caregiving tasks. Therefore, this implies that caregiving may be linked to lower loneliness.

Overall, the literature appears to support aforementioned claims that being married is protective of loneliness (Hsieh and Hawkley, 2016; 2018). It is evident that factors such as relationship quality play an important role, thus the presence or absence of a spouse alone may not determine loneliness. Additionally, it is difficult to draw comparison between most other categories of marital status, as they are commonly aggregated. Due to the lack of evidence, it is unknown whether caregiving would impact the relationship between marital status and loneliness. Evidence from Smith *et al.* (2020) implies an association between marital status and caregiver loneliness, but this was not tested.

The main research gaps, other than the dearth of research on the impact of relationships on caregiver loneliness, is research focusing on the impact of, for example, divorce in comparison to widowhood. Particularly, when evidence suggests that being unmarried is related to loneliness, additional evidence comparing the different classifications of ‘unmarried’ would augment this conclusion. Moreover, alternative aspects of relationships, such as quality, or cohabitation, appear to be largely influential on loneliness. Additional research emphasising the importance of relationship features outside of marital status would largely expand the current knowledge.

3.2.3 Social networks

Reduced networks have been linked to social isolation (de Jong Gierveld and van Tilburg, 2016) and loneliness (Domènech-Abella *et al.*, 2017a). Additionally, evidence from a National Institute for Health and Care Excellence (NICE) quality standard suggests that increasing or maintaining social participation can prevent loneliness in older adults (NICE, 2016). Diminished social networks, often through reduced social participation, are common with age (Böger and Huxhold, 2018); moreover, due to caregiving responsibilities, social networks of caregivers are at particular risk of disruption (Davies *et al.*, 2019).

Social networks can be measured in many ways, most commonly: network size, relationship quality, or satisfaction with social connections. Among a sample of Spanish adults aged ≥ 50 (N=3,535), several aspects of social networks, including size, frequency of contact, and quality, were associated with loneliness at bivariate level (Domènech-Abella *et al.*, 2017a). However, in the multivariate analyses, only network size remained significant, those with larger networks displayed lower odds of loneliness (*ibid*). These results appear contradictory to other published evidence, which tend to favour network satisfaction or quality, over size as **determinants of loneliness**.

By illustration, in a sample of Dutch older adults (N=182, aged ≥ 65), network satisfaction was directly associated with loneliness (Kemperman *et al.*, 2019). In contrast, network size was only significantly associated with loneliness when mediated by satisfaction. Network satisfaction was derived from three items (social contacts, network quality and network size), therefore provided a

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multifaceted approach. Conversely, Domènech-Abella *et al.* (2019) used a social network index to assess loneliness within the Irish Longitudinal Study on Ageing (TILDA), they reported significant loneliness differences between the most isolated and most integrated respondents. However, this association attenuated after controlling for other covariates. The index encompassed a combination of closer and wider network aspects, including marriage, cohabitation, close friends and relatives, volunteering or club memberships, and frequent church attendance. Respondents were categorised as integrated or isolated, based on these variables, although arguably, these may be restricted to a specific context and not applicable to everyone. As such, non-religious individuals would score lower due to not attending church, but may be integrated in other ways.

There appears to be no standardised measure for quality of social networks; Böger and Huxhold (2018) compared distressing and pleasant relationships, whereas Štípková (2019) considered that individuals who list their partner in their close network demonstrate high-quality relationships. Analysis of the German Ageing Survey (DEAS) (N=10,900) found that quantity of distressing and pleasant relationships, alongside relationship satisfaction, were indicative of loneliness among adults aged 40-84 (Böger and Huxhold, 2018). More pleasant relationships, and less distressing relationships, were associated with lower levels of loneliness, these relationships were not significantly different for middle-aged and older adults. This suggests that regardless of age, lower-quality relationships are linked to loneliness. Alternatively, Štípková, (2019) did not directly measure the quality of social networks; but Czech data from wave six of the Survey of Health, Ageing and Retirement in Europe (SHARE) included the size and composition of respondents' (N=3,949) networks. The majority (>80%), mentioned their partner within their network. The author suggests that this was indicative of a high-quality relationship, and regression analysis revealed that loneliness was lower for those with high-quality relationships (partner mentioned in network). This evidence on the quality of social networks corresponds with evidence on marital quality (section 3.2.2), thus implying that regardless of whom the relationship is with, quality is still an influential factor for loneliness.

There was a lack of substantive evidence demonstrating the relationship between social networks and caregiver loneliness. In a review examining the social consequences of caregiving, only two of the reviewed studies (N=66) referred to loneliness (Keating and Eales, 2017). The first indicated that the changing relationship between spouse and caregiver contributed towards loneliness among Swedish male caregivers. This relates to the adaptations outlined by CIT (section 2.1.1.1), whereby caregivers begin to identify more as a caregiver than a spouse. The second suggested that reduced social engagement was particularly difficult for caregivers reporting high levels of burden, depression, and loneliness. Overall, neither gave insight into the impact of social networks on loneliness among caregivers, but suggested that reduced networks, or changes to relationship quality, were linked to loneliness.

Focus groups, conducted with older adults on the causes of loneliness, proposed that caregivers experience isolation due to lack of conversation with others outside of the caregiving situation (Cohen-Mansfield *et al.*, 2016). This would suggest that an external support network (e.g. non-family members), might be advantageous to caregivers. However, qualitative evidence from Davies *et al.* (2019) posed contradictory results on support groups as part of a social network, many of the caregivers perceived this as being separate from their typical network. Caregivers were able to talk freely about caregiving within the group, whereas conversations within their friendship network rarely included caregiving. Moreover, some did not engage with the group, as they found it depressing and did not wish to be burdened with other people's problems (*ibid*). This evidence would suggest that how individuals engage with, or perceive, their network is more important than the presence of a network. Additionally, aligning with aforementioned evidence from Keating and Eales (2017), relationship losses (e.g. family members, care recipients and their own identity), were represented through social isolation and loneliness.

Overall, there is evidence to suggest that multiple aspects of social networks: size, satisfaction, and quality, are linked to loneliness. However, the methods used to determine social networks vary substantially, assessing either overall social network (size and satisfaction), or just the closest individuals within a social network (living arrangements or relationship quality).

3.2.4 Socioeconomic status

SES can be represented by one, or a combination of factors, including education, income, and employment (Braveman *et al.*, 2005). Arguably, due to the multifaceted disposition of SES, a single measurement (e.g. only education) would not capture an accurate picture of an individual's socioeconomic activity. Different aspects of SES are likely to have varying influence at different life stages, as such, income may be less valid among retirees, and thus wealth may be a more reliable criterion among retired older adults. Measurement of SES also differs across countries; occupation is common across Europe, whereas in the US, income and education are more common (*ibid*).

Within the literature, there is evidence that lower SES is linked to loneliness. A meta-analytical study highlighted income and education as the most common SES indicators of loneliness (Pinquart and Sörensen, 2001). The association between loneliness and SES was stronger for single-item measures (N=73) compared to the UCLA-LS (N=40), and among income as opposed to education, although both were significant (*ibid*). Arguably, education is a weaker measure of SES among older adults, compared to wealth (Darin-Mattsson *et al.*, 2017). Education is less likely to be affected by health (Smith and Goldman, 2007), and in previous decades, the majority of UK and European older adults reportedly left school with few or no qualifications, and at younger ages than later birth cohorts (Grundy and Holt, 2001). When comparing cohort studies (birth cohorts: 1958, 1970, 1980 and 1990), early entry into the labour market declined across the cohorts (Anders and Dorsett, 2017). Simultaneously, accumulation of human capital (i.e. continuing education) substantially increased

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across the cohorts. This implies that older adults are likely to report lower education, therefore education should be considered in addition to other SES measures, rather than in isolation.

Loneliness was more prevalent in deprived Danish neighbourhoods, than in the general population (Algren *et al.*, 2020). Within the deprived population, loneliness significantly differed by employment status, highest among those unable to work due to disability, and lowest among the employed. However, loneliness did not significantly differ by education. Alternatively, data from a representative sample of Spanish individuals aged ≥ 50 (N=971), demonstrated that among lonely individuals (N=100) loneliness differed by SES (Domènech-Abella *et al.*, 2017b). Individuals with higher SES were significantly less likely to be lonely than those with lower SES. The measure of SES in this study was computed using combined education and household income, and is therefore less comparable with other studies using education and income separately. The authors argue that occupation-based methods were not used because they have different meanings for different birth cohorts, but as discussed previously, this argument is also applicable to education (Anders and Dorsett, 2017).

Wealth was the primary measure of SES in a study analysing wave five of SHARE (Niedzwiedz *et al.*, 2016); among the respondents (N=29,795), prevalence of loneliness was highest in the poorest quintile, more so for females than males. The logistic regressions indicated that, for both males and females, all wealth quintiles demonstrated lower odds of loneliness in comparison with the poorest. Whereas, medium or high education were only negatively associated with loneliness among females. Similar to Domènech-Abella *et al.* (2017b), Niedzwiedz *et al.* (2016) measured loneliness using the UCLA-LS, which suggests that SES is also linked to loneliness when using scale measures, not just direct questions.

The review of evidence on SES and loneliness emphasises the importance of selecting an appropriate context-specific variable, education is reportedly most common in particular populations (Pinquart and Sörensen, 2001; Braveman *et al.*, 2005) but, as identified above, across a range of contexts, the relationship between education and loneliness was frequently non-significant (Niedzwiedz *et al.*, 2016; Domènech-Abella *et al.*, 2017b; Algren *et al.*, 2020). Overall, the use of education as a measure of SES appears complex, the relationship between education and loneliness is variable, with little evidence supporting a link.

Research with caregivers (N=70) found education to be negatively associated with loneliness (McRae *et al.*, 2009); respondents were predominantly female (74%) and spousal caregivers (N=67), average education level was 14-years, ranging from 8-18 and 23% were employed alongside caregiving. The authors suggest that higher education equated to greater resources to deal with the challenges of a caregiving role, thus protective of loneliness. No other socioeconomic factors were included in the analysis, such as wealth or income, therefore it is difficult to generalise to SES as a whole. The overwhelming evidence would suggest that the relationship between education and loneliness is largely inconsistent. Alternatively, wealth is considered an appropriate measure of SES,

particularly among older, retired populations (Demakakos *et al.*, 2016; Niedzwiedz *et al.*, 2016) as it is reflective of accumulated assets. Wealth may be considered more appropriate among caregivers aged ≥ 50 , as caregivers are shown to have lower levels of employment, often due to their caregiving commitments (Hendricks-Lalla and Pretorius, 2020), which, correspondingly, reduces income. Wealth has also been shown to have strong links to health and mortality (Torres *et al.*, 2016). The connection between loneliness, health and wellbeing is discussed in section 3.4.

3.2.5 Summarising the literature on determinants of loneliness

Largely, the highlighted evidence is quantitative and identifies recurring predictors of loneliness, such as sex, marital status, poor social networks, and SES. However, there was limited research discussing the determinants of loneliness among caregivers. From the research that has been conducted, typical loneliness determinants do not appear to be consistent for caregiving populations. For example, Victor *et al.* (2020) found no significant association between sex and loneliness among caregivers. Additionally, over a period of eight-years, it was demonstrated that for a sample of English caregivers, the proportion of married individuals reduced more substantially than among non-caregivers. Meanwhile, the prevalence of loneliness increased more for caregivers than non-caregivers, yet there was no evidence in the study to confirm the two occurrences were linked (Smith *et al.*, 2020). This may suggest that the established determinants of loneliness are not necessarily applicable to caregivers. Alternatively, qualitative evidence from focus groups with older adults suggested that caregivers may experience loneliness and isolation, as they have no one else to talk to besides the care recipient (Cohen-Mansfield *et al.*, 2016). This aligns with evidence from Victor *et al.* (2020) which highlights social networks and isolation being among the most influential factors for caregiver loneliness. Due to the lack of research into the predictors of loneliness among caregivers, and the indication that traditional predictors may not apply, further research is needed to identify which determinants are applicable to caregiving and non-caregiving populations. Furthermore, if there are different predictors of loneliness for caregivers, the identification of these are highly relevant for policy-makers to implement prevention and support services.

3.3 Caregiving literature

The literature discussed in the previous section examined the determinants of loneliness, and although this was largely within the general population, reference was made to caregivers where available. The following sections examine literature exclusively in caregiving samples, to address sociodemographic characteristics associated with caregiving, and factors related to the caregiving relationship and role. Furthermore, in the conceptual framework, several factors were identified that could impact the relationship between caregiving and loneliness; these included caregiver burden, satisfaction, social networks, and identity. Caregiver burden and satisfaction are discussed in more depth in section 3.3.4. However, literature on social networks was addressed previously as a

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determinant of loneliness (section 3.2.3), as this was deemed applicable to loneliness in general, not just among caregivers. Finally, the identity of a caregiver shifts continuously, as described by CIT (section 2.1.1.1). This topic is not well-researched, and typically, identity has been determined by a respondent categorising themselves as providing care. For this reason, it was challenging to address the impact of caregiver identity on loneliness.

3.3.1 Caregiver characteristics

Conceptual literature identified caregiver characteristics as a key area for caregiving research. This section discusses age, sex, marital status, and SES as characteristics of caregivers. The literature addresses the peak age of caregiving and care provision among older adults, in addition to discussing the stereotypical assumption that caregivers are mostly female. Marital status is likely to form a large part of the caregivers' networks and has previously been linked to loneliness. Therefore, it is important to understand the marital demographic of caregivers, identifying if being married, or unmarried, is associated with likelihood to provide care. Finally, other characteristics influential to caregiving are socioeconomic factors such as education or employment, which are likely to restrict availability to provide care and the intensity in which it is delivered.

3.3.1.1 Age

The peak age for caregiving across the UK is 50-years old. In 2001 UK Census data, caregiving was most common between ages 45-59 (Dahlberg *et al.*, 2007). In comparison, the largest percentage of caregivers were aged 50-59 (Nomis, 2018a) or 50-64 (Nomis, 2018b) in 2011 England Census data. However, discrepancies between 2001 and 2011 are likely due to inconsistencies when dividing the age groups. Similarly, Vasileiou *et al.* (2017) indicates that across Britain, the peak age for caregiving is 50-64 years. In a geographically-stratified sample of caregivers from the 2001 UK Census (N=182,664) caregiver age was significantly associated with higher-intensity caregiving; approximately 50% of male and 45% of female caregivers aged 80-89 provided ≥ 50 hpw of care. Therefore, those aged ≥ 70 spend the most time caregiving due to increasing intensity. Furthermore, data from the Carers Trust indicated that 13% of individuals aged ≥ 75 were caregivers, rising to 19% among ages ≥ 85 (Greenwood and Smith, 2016).

The age of caregivers appears to differ by sex, whereby female caregivers are, on average, younger than males. Nevertheless, by age 50, half of people in England will have provided care (Zhang and Bennett, 2019). Stratified by sex, 50% of females are assumed to have provided care by age 47 and by age 57 for males (*ibid*). The trend of older male caregivers is present in other countries too, in a sample of Spanish caregivers (N=6,923), the majority of female caregivers were aged 45-64, whereas the largest proportion of male caregivers were aged ≥ 65 (Abajo *et al.*, 2017). Further sex differences in caregiving are discussed in the next section.

3.3.1.2 *Sex*

Caregiving is most commonly associated with females (Dahlberg *et al.*, 2007; van Campen *et al.*, 2013); analysis of 2016-2018 Understanding Society data indicated that 58% of current caregivers were female (Zhang and Bennett, 2019). However, evidence from 2011 England and Wales Census data highlights that of those aged ≥ 65 , 15% of males and 14% females identified as caregivers (Milligan and Morbey, 2016). These figures suggest a greater prevalence of male caregivers, compared to female among those aged ≥ 65 , although it could be considered that these males are more likely to identify as caregivers, compared to older females. To clarify, due to the stereotypical nurturing disposition of females, they may consider helping a spouse as an extension of roles they have had throughout the lifecourse, such as childcare. Familiarity with the tasks may act as a buffer for recognising their caregiving role. Alternatively, this could be due to greater longevity of females. In other words, due to discrepancies in life expectancy, females are more likely than males to be widowed and therefore less likely to have a spouse to care for (Pinquart and Sörensen, 2011).

It is possible that the prevalence of male caregivers may be higher than reported. As such, due to the female caregiving stereotype, males may be deterred from identifying as caregivers. Sanders and Power (2009) interviewed only male caregivers for wives with dementia (N=17). Two themes emerged from the interviews: adapting roles from a marital to caregiving relationship, and changes to the inter-personal relationship. The adaptation of roles aligns with CIT, suggesting that, as dementia progresses, care needs change and simultaneously, the caregiving role changes, including tasks such as personal care. No comparison was drawn with female caregivers, but the authors propounded that the caregivers identified with their male “protective role” (Sanders and Power, 2009, p.44). This could be linked to SET, whereby stereotypes about protective males influenced their marital and caregiving relationships. Caregiving was considered to pose an unnecessary challenge to male caregivers’ masculinity (Milligan and Morbey, 2016), with many justifying the role by highlighting manual tasks. A qualitative investigation with caregiving husbands (N=9) reported a similar methodical approach in the way males provided spousal care (Calasanti and King, 2007), for example, by blocking emotions or exerting force, which could be considered stereotypical male traits. These articles suggest males focus only on the physical tasks of caregiving, and not the emotional aspects (Swinkels *et al.*, 2017); but also emphasise the relevance of CIT and SET.

3.3.1.3 *Marital status*

Unlike section 3.2.2.1, where there was a range of evidence to suggest significant associations between marital status and loneliness in the general population, there is limited research evaluating the effects of marital status among caregivers. However, there is evidence of marital status differences among the caregiving population. Among a sample aged 40-59 in England and Wales (N=110,464), non-married individuals were the most likely to report caregiving, compared to married, remarried, separated or divorced, and widowed (Young and Grundy, 2008). The evidence

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was drawn from the ONS Longitudinal Study in 2001, so these figures may not be reflective of the current population. Moreover, the authors include only caregivers providing high-intensity care (≥ 20 hpw) which represents 5% of the total sample, an additional 14% reported providing care for < 20 hpw. Marital status may affect an individual's availability to provide care. As such, if they have responsibilities to uphold within their own family, they may be more likely to provide lower-intensity care, therefore larger proportions of the caregivers providing < 20 hpw may have been married. Evidence from Finch and Mason (1991) suggests that obligation to care tends to be stronger among close family than other relatives, but females tended to have stronger obligation to care than males. For example, regardless of the direct relationship with the recipient, more people expected females to cease employment for care responsibilities than males (i.e. daughter-in-law instead of a son). This could also be extended to marital status, where obligation to care may be higher among unmarried family members, but that married daughters may be more likely to provide care than unmarried sons due to the gendered stereotypes of care. This is supported by evidence from Pillemer and Suitor (2014), who compared 537 adult-children within 139 families. The analyses showed that competing responsibilities (marital status, employment or parenthood) were not significantly associated with care provision, suggesting that among filial caregivers, marital status has little influence on the decision to provide care. However, odds of caregiving were twice as high for females, compared to males, indicating that sex was a stronger determinant of care than marital status or other responsibilities. Marital status data were collected in 2001-2003, whereas care provision occurred within the two-years preceding the follow-up interview (2008-2011). Therefore, it is possible that baseline marital status may have differed to marital status during care provision (e.g. unmarried individuals may have married). Arguably, current marital status would be expected to have greater influence on the uptake of caregiving responsibilities than marital status recorded several years previously.

Among filial caregivers, marital status may impact co-residential caregiving. When comparing married (N=38) and unmarried (N=10) male filial caregivers, a substantially larger percentage of non-married caregivers provided co-residential care than married caregivers (Campbell, 2010). This suggests that marriage introduces additional responsibilities, which may supersede the responsibilities that individuals feel towards older parents. Some respondents expressed that their single status meant they were more available than married siblings, and therefore assumed the caregiving role. In contrast, evidence from Bauer and Sousa-Poza (2015) found no association between the caregivers' marital status and the likelihood of co-residential care provision to a parent. However, marital status did influence the location of the care; for married respondents, co-residential care typically occurred within the caregivers' home, whereas for non-married respondents, this would more often occur in the care recipients' home. As highlighted by Campbell (2010), unmarried children may have greater availability, this is reflected by unmarried caregivers moving in with their parents to provide care (Bauer and Sousa-Poza, 2015). Alternatively, being married does not make an adult-child less likely to provide care, but there may be greater time limitations. This may reduce

availability for caregiving hours, or, as Wong and Shobo (2017) depict, reduce time spent on leisure activities outside of the caregiving role.

3.3.1.4 Socioeconomic status

It could be considered that those with higher education levels would be more likely to be in higher levels of employment (e.g. managerial) and therefore receive higher incomes. This would imply greater financial stability, with disposable income to pay for formal care, or alternatively, they may rely on other family members to provide care. Low-wage workers, or those providing a smaller proportion of overall household income are considered more likely to cease paid employment for care responsibilities (Carr *et al.*, 2018). Furthermore, Finch and Mason (1990) suggest that family responsibilities have become weaker over time and may take less precedence than other commitments such as employment. A stronger presence in the labour market, particularly among women, suggests less assistance is available to family members.

Largely, it appears the connection between SES and caregiving differs across countries. Full-time paid work was indicative of lower likelihood of informal activity (e.g. care provision) in Denmark, France, Italy and England, whereas **part-time work was only negatively associated with** care provision in England (Di Gessa and Grundy, 2017). This analysis was conducted cross-sectionally, therefore it is unknown whether the employment causes lack of informal activity, or informal activity is taken up because of lack of employment. When investigated longitudinally, ceasing employment was linked to increased likelihood of undertaking a caregiving role at follow-up (2-years later) in Italy and England but not Denmark or France (*ibid*). This further suggests country differences, but also that uptake of care provision could be due to availability.

Among Japanese females aged 40-60, caregivers (N=1,417) had lower levels of education and were less likely to be in full-time employment, but more likely to work part-time or be unemployed than non-caregivers (Tokunaga and Hashimoto, 2017). In the full sample, those with a high school education, in contrast to university graduates, were more likely to be caregivers, and both full-time and part-time workers were less likely to provide care than unemployed. This evidence suggests that less educated individuals and those not in employment are more likely to provide care. Similarly, pooled 1991-2005 data from the British Household Panel Survey (BHPS), demonstrated among 8,652 males and 13,983 females, **that care provision** was more likely among unemployed or low-wage employees (Carmichael *et al.*, 2010).

In contrast, in a Chinese sample of filial caregivers, divided into low-intensity (N=586), high-intensity (N=450), and non-caregivers (N=1,705), caregivers were more highly educated and reported higher incomes than non-caregivers (Wang *et al.*, 2020b). The evidence also suggests that SES is associated with caregiving intensity, among those with high school or university degrees, there was a higher likelihood of high-intensity care provision, but not low-intensity care, compared to non-caregiving. The authors suggest this provision of filial care was related to the repayment of

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their upbringing and education. Arguably, the division of intensity is not comparable with other studies, as ≥ 10 hpw was classified as high-intensity. Chen *et al.* (2017) examined the association between caregiving intensity, labour force participation, and working hours; when intensity was defined using 10hpw (< 10 hpw or ≥ 10 hpw), no significant differences in labour force participation or working hours were observed. Alternatively, significant differences were observed in labour force participation when intensity was divided at 15hpw or 20hpw. To illustrate, caregiving overall was associated with lower labour force participation, but caregivers of ≥ 15 hpw or ≥ 20 hpw were significantly less likely to be in the labour force (*ibid*). Typically high-intensity caregiving is recognised as ≥ 20 hpw (Vlachantoni *et al.*, 2016; Lacey *et al.*, 2018). Therefore, the evidence from Chen *et al.* (2017) may be more reflective of the high-intensity caregivers in other contexts, than those from Wang *et al.* (2020b).

Furthermore, within a representative US sample aged ≥ 55 (N=3,005), data suggests that caregivers (N=413) were more highly educated than non-caregivers: 55% of female and 63% of male caregivers reported receiving college education, compared to 50% (female) and 59% (male) of non-caregivers (Wharton and Zivin, 2017). Contradictorily, household income trends did not match. Female caregivers reported considerably lower income than female non-caregivers, whereas male caregivers reported higher income than male non-caregivers. This income discrepancy may be due to differences in care provision, i.e. those providing lower-intensity care may work part-time, which would be reflected in their income. Additionally, higher percentages of males were married, which would increase average household income, compared to single households.

Discrepancies between age ranges in the sample may explain why the literature appears to show contrasting evidence. For example, Tokunaga and Hashimoto (2017) suggest caregivers have lower education levels (aged 40-60), whereas, Wharton and Zivin (2017) (aged ≥ 55) and Wang *et al.* (2020b) (aged < 52) found that caregivers were more highly educated. This could also be due to cultural differences, as the three studies were conducted in Japan, America, and China, respectively. Moreover, both Tokunaga and Hashimoto (2017) and Wang *et al.* (2020b) analysed female-only samples, therefore there may be educational differences due to sex. Additionally, the direction of relationships between care provision and employment is largely unclear, i.e. were working hours reduced, or did employment cease, due to caregiving responsibilities? Or, did fewer working hours or unemployment make the individual more readily available than other family members to provide care? Evidence from Tokunaga and Hashimoto (2017) suggests that employment level is **linked to** care provision.

Within the UK context, the main predictor of ceasing full-time employment, for both male and female caregivers (aged 50-75), was the provision of co-residential care (Carr *et al.*, 2018). Amongst female caregivers, the provision of spousal care, and the uptake of a new caregiving role of > 10 hpw were **positively associated with** ceasing employment, although these factors were not significant for male caregivers. Conversely, intensity of a current caregiving role was not significantly associated with

an exit from the labour force (*ibid*). This implies that if a routine is established, for example balancing care and work responsibilities, the caregiver is likely to continue, perhaps using work as a respite from care responsibilities. Ceasing employment due to a new higher-intensity care role, but not a current one, could also suggest that if caregiving needs have increased over time (i.e. low- to high-intensity), the caregiver may feel able to cope and thus less likely to stop working, but initiating a high-intensity role without previous caregiving may feel overwhelming while working, and thus prompt an exit from the labour market.

3.3.2 Caregiving relationship

The caregiving relationship can refer to the inter-personal relationship between caregiver and recipient, but also differentiates between co-residential caregivers, and caregivers to recipients in other households. The following sections highlight comparisons between caregivers based on the relationship with the recipients, and contrast evidence on co-residential and non-residential caregivers.

3.3.2.1 *Inter-personal relationship between caregiver and care recipient*

Inter-personal relationship depicts the relationship outside of the caregiving context (e.g. spouse, rather than care recipient). Predominantly, research has been conducted with female caregivers, typically the recipients' wife or daughter. A review of 56 research papers on dementia caregivers identified that, although limited, research involving male caregivers was predominantly on spousal caregivers, with little focus on filial care (McDonnell and Ryan, 2013). Comparison between spousal, filial, and other (sibling, friend, or neighbour) caregivers from the Netherlands (N=660) suggested that, typically spousal caregivers were older, male, less educated, and more commonly co-residential caregivers, compared to the other groups (Oldenkamp *et al.*, 2018b). Parental caregivers were excluded, indicating this type of care was different; although arguably, all caregiving differs, as spousal care is unlikely to be a similar experience to caregiving for a neighbour. Qualitative evidence among spousal caregivers suggests that experiences of caregiving may be linked to the quality of previous relationships (Shim *et al.*, 2012). For example, those with negative relationships with the recipient prior to care provision reported negative current relationships and negative overall experience. Although this was only examined among spousal caregivers, it is likely that a prior negative relationship with another relative would also result in negative relationships during care provision.

Alternatively, Yu *et al.* (2020) compared parental (N=151) and spousal (N=114) caregivers in China. On average, spousal caregivers were younger, male, highly educated, employed, and provided care for longer durations, than parental caregivers. This contradicts previous evidence, which suggests that providing care to a child, often with DD, is a lifelong role (Weeks *et al.*, 2008; Byram, 2018; Barnhart *et al.*, 2020). However, parental caregivers in this sample were providing care to individuals

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with schizophrenia (average age 38), for an average of 14-years (Yu *et al.*, 2020), thus much shorter than caregivers to a child with DD. Multivariate analyses demonstrated that, compared to spousal caregivers, parental caregivers experienced higher levels of burden, depression, and anxiety. Despite the lack of consistency with other literature, overall this evidence would suggest that spousal caregivers differ significantly from all other caregiving subgroups. Furthermore, it has previously been reported that spousal caregivers demonstrate distinct characteristics, greater levels of burden, and often higher-intensity roles (Friedemann and Buckwalter, 2014). Comparison between US spousal (N=208) and filial (N=325) caregivers also indicated that spousal caregivers, regardless of sex, experienced a significantly higher obligation to care, compared to filial caregivers (*ibid*). This is consistent with Finch and Mason (1991), which indicates obligation is highest among closest family (e.g. spouse). Therefore, spousal caregivers may often experience the most negative health effects (Bédard *et al.*, 2005; Pinquart and Sörensen, 2011).

Additionally, care can be provided to multiple generations simultaneously. Falkingham *et al.* (2020) demonstrate from the China Health and Retirement Longitudinal Study that of the sample aged 45-64 (N=12,552), 33% were at risk of ‘sandwich’ caregiving (caring concurrently for a grandchild and older parent), but only 15% of those reported providing care to both. Most commonly, the respondents reported providing grandchild care only, or no care provision. Care to grandchildren contrasts to typical informal care, it is usually non-custodial and more representative of childcare. Schmidt *et al.* (2016) indicate that care to grandchildren is lower-intensity and comparable to social engagement. Evidence from Quirke *et al.* (2019) supports this, demonstrating that among German grandparent caregivers (N=1,125), care to grandchildren was associated with increased network size and reduced social isolation. For the purpose of this thesis, individuals reporting providing care to a grandchild were excluded. Moreover Falkingham *et al.* (2020) indicate that individuals aged ≥ 65 are increasingly less likely to have surviving parents; therefore, as the ELSA sample includes both middle-aged and older-adults, and with the exclusion of grandchild care, the relevance of ‘sandwich’ caregiving to this thesis is negligible. In contrast, ‘compound’ caregiving, which also reflects multiple caregiving roles, involves undertaking an additional caregiving role, while already providing care to a dependent child with DD (Perkins, 2009). This differs from ‘sandwich’ caregiving, because the additional role is not always a parent, and could be a spouse or sibling (*ibid*); caregivers within the ELSA sample reporting care to a child and another recipient are likely to be ‘compound’ caregivers.

3.3.2.2 *Provision of co-residential care*

Typically, co-residential caregivers are compared with caregivers of recipients in other households (non-resident). Caregiving intensity is considerably higher among co-residential caregivers, which has been linked to detrimental health consequences (Kumagai, 2017). To illustrate, Mentzakis *et al.* (2009) report data from BHPS: co-residential caregivers (N=7,212) most commonly provided care for >100hpw, whereas the majority of non-residential (N=17,366) caregivers reported providing

<5hpw. Co-residential care may also be linked to the caregiving relationship; Bédard *et al.* (2005) highlighted 98% and 97% of spousal caregivers respectively lived with the recipient, compared to 11% of son and 19% of daughter caregivers.

However, co-residential care was negatively correlated with role burden, and positively correlated with personal burden (Bédard *et al.*, 2005). These results indicate that co-residential care may reduce the demands of caregiving to some extent. For example, within the same household, caregivers do not have to travel to the recipients' homes for a specific time, this is therefore less demanding, as tasks can be carried out when appropriate with less scheduling required. Alternatively, co-residential care contributed to increased levels of personal burden (*ibid*), this may be due to increased intensity. Living with the recipient could indicate that care might be required 24hpd, with the caregiver available at all times. Moreover, US caregivers of recipients who lived within 20 minutes of the caregivers' home, were less likely to report negative health consequences, compared to co-residential caregivers (Danilovich *et al.*, 2017). Aligning with the interpretation above, this suggests that the caregiver did not have substantial travelling to organise, and therefore tasks could be performed more conveniently, also as the caregiver was not with the recipient all of the time, it was less demanding and less likely to negatively impact health.

3.3.3 Factors relating to the caregiving role

The nature of care, alongside the duration and intensity are the main factors related to the caregiving role. These factors substantially alter the caregiving dynamic, as such, personal care may be more physically and emotionally demanding for caregivers, compared to providing financial assistance. Moreover, long-term, and higher-intensity care often requires the largest adjustments from caregivers, such as reducing paid employment, or ceasing hobbies and social activities; therefore, it is likely that these factors have considerable impact on loneliness, health, and wellbeing.

3.3.3.1 Nature of care

Informal care can involve a range of tasks from more physical aspects, to psychological (Zwar *et al.*, 2018). Provision of personal care, which typically involves assistance with tasks such as dressing, or bathing, is considered to be more physically and mentally demanding than other aspects of care (Hiel *et al.*, 2015). In a study on the provision of personal care in SHARE (N=997 caregivers), caregiving was linked to poorer physical and mental health outcomes over an eight-year follow-up (*ibid*).

Types of care are inconsistent within the literature. When analysed within DEAS (Zwar *et al.*, 2018), caregiving was divided into: 'helping around the house' (e.g. cleaning), 'looking after' (e.g. emotional support), and 'nursing care' (e.g. personal care). Among caregivers aged ≥ 65 , 'looking after' someone was positively associated with cognitive function, but once stratified by sex, this association remained significant only for females. This suggests that females experienced greater cognitive benefit from caregiving and could be linked to [previous](#) evidence (section 3.3.1.2) which

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suggests males focus on physical tasks and not emotional (Calasanti and King, 2007; Swinkels *et al.*, 2017). Arguably, emotional aspects of caregiving may require further cognitive processes than physical tasks, which may be more familiar, thus promoting cognitive benefits. Zwar *et al.*, (2018) reported no data on the frequency or intensity of caregiving, but ‘looking after’ could be considered lower-intensity than ‘nursing care’; lower-intensity care has previously been reported as beneficial to caregiver health (Vlachantoni *et al.*, 2016; Lacey *et al.*, 2018).

Alternatively, in a Dutch study, caregiving was divided into personal and emotional care; Hwang *et al.* (2010) contrasted spousal caregivers of individuals with heart failure and spouses of individuals without. Significant sociodemographic and health differences were identified between the groups at baseline; therefore, it could be questioned how comparable the two groups were throughout the study. Personal and emotional care were more common in the heart failure group. A key difference between the groups was that a substantially higher percentage of heart failure caregivers were required to provide 24 hour care (41%), compared to 9% of healthy spouses (*ibid*). However, it could be considered among the healthy spouses, many may be non-caregivers. Nevertheless, this implies that the presence of a specific medical condition alters the nature and intensity of care required. Caregiving types identified within a UK study were ‘visible’ and ‘invisible’ care (Clark *et al.*, 2008). This separates behaviours (visible), such as personal care, from observations (invisible), such as symptom monitoring (*ibid*). The caregivers identified both types of care as essential, and despite being a constant task, even throughout the night, ‘invisible’ care was rarely recognised by recipients or external parties. This research highlights how personalised care provision is, with regard to recipients’ needs. However, similarities arose with the results of Hwang *et al.* (2010), whereby more advanced medical conditions required increased levels of personal care. Although no comparable studies were found on caregivers for recipients with conditions other than heart failure, thus, little comparison can be drawn. Additionally, Clark *et al.* (2008) identified that as care needs increased among the heart failure recipients, adaptation was required to increase the level of care. Therefore, as care needs increase, care provision may change; this aligns with CIT whereby the caregiving role, and therefore the caregiving identity, change over time.

3.3.3.2 *Duration of care*

Informal caregiving is the most common source of long-term care (Ciccarelli and van Soest, 2018). However, within literature, the total duration of caregiving is not as widely researched as caregiving intensity (section 3.3.3.3). This may be because where research **is** conducted with current caregivers, care provision is ongoing, and thus total duration of care is unknown. Additionally, in situations where caregivers have provided care intermittently, it would be difficult to determine total duration of the caregiving role. Moreover, because duration of care is collected retrospectively, typically as self-reported data, there may be recall errors, and caregivers are reported to often overestimate (Bremer *et al.*, 2017).

Duration of care has been shown to differ depending on the care recipient. Caregiving for individuals with DD was associated with longer caregiving durations than caregivers to individuals with mental illnesses; 69% of DD caregivers provided care for >5-years, compared to 48% of caregivers to those with mental illness (Barnhart *et al.*, 2020). Moreover, evidence from US-based Family and Individual Needs for Disability Supports (FINDS) and Caregiving in the US surveys indicated large percentages of caregivers providing longer-term care. Twenty-four percent of caregivers in Caregiving in the US were providing care >5-years, whereas in FINDS 35% had provided care for >25-years (Anderson *et al.*, 2018). However, the comparability of the two surveys is debateable; FINDS exclusively interviewed caregivers of those with DD, whereas Caregiving in the US included caregivers of older adults, physical disabilities, and dementias. Additionally, the age ranges of the care recipients differed substantially: a large percentage of the care recipients in FINDS (44%) were aged ≤ 21 , compared to Caregiving in the US which included no recipients aged <18, and only 14% of the sample were aged below 50.

Similarly, when considering the comparison between caregivers of recipients with DD or mental illnesses, DD included congenital conditions such as autism and Down syndrome, which are most commonly diagnosed at birth or in early childhood, whereas examples of mental illness were schizophrenia or depression, which typically do not occur at such early ages and are acquired during a person's lifetime (Barnhart *et al.*, 2020). Therefore, the potential care duration would likely always be longer for DD, because the caregiving occurs throughout the recipients' lives as opposed to later onset conditions. Overall, the evidence suggests that caregiving for individuals with DD is associated with longer duration of care, compared to that of older adults (Anderson *et al.*, 2018) and those with mental illness (Barnhart *et al.*, 2020). Care is typically provided to individuals with DD for the duration of the recipients' life. Conversely, care to older adults occurs later in life, typically after the onset of physical or mental health conditions, thus expected to be of a shorter duration than for a lifelong caregiving scenario.

3.3.3.3 *Intensity of care*

As outlined in section 1.2.1.3, caregiving intensity is typically determined by care provision in hpw. Evidence suggests females provide higher-intensity care, through both an increased number of caregiving hours, and more caregiving tasks than males (Cook and Cohen, 2018; Asi and Williams, 2020; Schulz *et al.*, 2020). Estimated from US data, on average, caregivers aged <65 provide around 53-hours per person per year (h/pp/y), compared to those aged ≥ 65 , providing on average 90h/pp/y (Chari *et al.*, 2015). Limitations of these estimates are that they are based only on US caregivers (N=1,383) who had provided care within 24-hours prior to the survey. Equivalent data on caregiving hours was not available with UK samples, so little comparison can be made. However, using 2011 England and Wales Census data, Milligan and Morbey (2016) demonstrate that male caregivers aged ≥ 65 provide more caregiving hours than females of the same age. This contrasts with the US evidence, whereby aged ≥ 65 , females provided a greater number of caregiving hours than males

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(Chari *et al.*, 2015). However, it is reported that caregivers are often undetected within the population (Carers UK, 2018), and are largely under-represented in population-based surveys, because many do not recognise their responsibilities as caregiving and therefore may not identify as caregivers.

In some studies, care is recorded in hours per month (hpm), rather than hpw, as per the majority. As such, 92 Swedish dementia caregivers (78% spousal) reported spending on average, 299hpm providing care (Wimo *et al.*, 2002). When divided into activities, the majority of hours (51%) were spent surveilling (e.g. preventing falls). It could be considered that for non-dementia caregivers, the proportion of time spent on surveillance may be considerably less, and additional time may be spent supporting with ADL/IADLs. Additionally, data from the National Study of Caregiving reports average caregiving intensity, for filial caregivers (N=993), at 85hpm (Cohen *et al.*, 2019). No division of high- or low-intensity is made within the study, but Schulz *et al.* (2020) suggest that >100hpm is a risk factor for adverse outcomes. Therefore, the hpm measure does not appear directly comparable to hpw, as ≥ 20 hpw has been linked to poor health (Asi and Williams, 2020), which would equate to approximately 80hpm.

Costa *et al.* (2013) reviewed 21 studies for caregiving time across different age-related dementias. The majority (N=15) involved Alzheimer's disease, so little comparison could be drawn between dementia types, although severity of dementia was compared. Time spent caregiving ranged from 1-56hpw for mild, 12-77hpw for moderate, and 21-120hpw for severe dementia. Although there appears to be a clear increase in intensity relative to dementia severity, the studies used different instruments to measure caregiving time (e.g. diary methods or activity surveys). The authors suggest that diary methods are preferred and typically yield fewer errors due to shorter recall periods (*ibid*). Nevertheless, there is additional evidence to support that caregiving intensity is related to the care needs of the recipient. Caregivers to individuals with DD were significantly more likely to provide >40hpw, compared to caregivers to individuals with mental illness (Barnhart *et al.*, 2020). Moreover, Wang *et al.*, (2020b) found that providing care to individuals aged ≥ 50 (compared to <50) was associated with a higher likelihood of providing both low- and high-intensity care. However, high-intensity in this study was classified as ≥ 10 hpw, therefore not reflective of the same high-intensity (e.g. ≥ 20 hpw) in other studies.

Caregiving intensity may also differ due to caregivers' circumstances. As such, among employed filial caregivers (N=333), those with organised caregiving arrangements (e.g. care leave or reduced hours) were able to provide higher-intensity care, than those without workplace arrangements (Oldenkamp *et al.*, 2018a). Caregiving hours ranged from 1-25hpw, on average, those with workplace arrangements provided 4hpw, and those without, 3hpw; although a minor difference, it was statistically significant. Moreover, the low-intensity care and the small difference in caregiving hours may be explained by both caregiving groups being in employment; as demonstrated by Chen *et al.* (2017) when comparing <10hpw caregiving *versus* ≥ 10 hpw, no significant difference was

found in labour force participation, suggesting that lower-intensity caregivers can manage both work and caregiving responsibilities.

3.3.4 Burden and satisfaction

Caregiving is most commonly portrayed as a negative experience, resulting in emotional distress, poor health, and reduced QoL (Casado and Sacco, 2012). The result of stress from the caregiving role is termed as caregiver burden (Lee *et al.*, 2017a). Studies have investigated the link between caregiver burden and recipient loneliness (Iecovich, 2016), or researched caregiver burden and caregiver loneliness within the same study (Bramboeck *et al.*, 2020) but there is an absence of research examining the association between caregiver burden and caregiver loneliness. Moreover, negative aspects of caregiving are more widely researched than positive aspects (de Labra *et al.*, 2015; García-Mochón *et al.*, 2019). Satisfaction represents a positive aspect of caregiving: a subjective measure of perceived gains from caregiving (de Labra *et al.*, 2015). Amongst caregivers, Kietzman *et al.* (2008) relates satisfaction to intrinsic feelings (e.g. pride), and growth within the relationship (e.g. closeness to the recipient).

3.3.4.1 Caregiver burden

A key caregiver characteristic shown to impact burden is sex. Telephone interviews conducted with US caregivers (N=1,002, 54% female) suggested that females were more likely than males to experience difficulties providing care (Navaie-Waliser *et al.*, 2002). However, due to the nature of data collection, it is essential to consider under-reporting of these difficulties, especially from male caregivers. The results highlighted that males were more likely than females to be employed alongside caregiving, and less likely to be primary caregivers (*ibid*). These factors would suggest lower-intensity care, and, combining caregiving with other activities has been linked to higher satisfaction (van Campen *et al.*, 2013).

Moreover, Akpinar *et al.* (2011) found overall burden to be significantly higher in females, in addition to all sub-scales of burden, except emotional burden. The absence of differences in emotional burden contrasts with research that suggests males are less emotionally attached within the caregiving role (Calasanti and King, 2007), as this would imply that males and females experience similar levels of emotional burden. Notably, intensity within this study was extremely high: 21hpd for females, and 19hpd for males. Therefore, the high-intensity may have influenced burden, alongside the caregivers' sex.

The caregiving relationship is also an important factor contributing towards caregiver burden. A study comparing Korean-American spousal caregivers (N=47) and other relatives (N=8) with filial caregivers (N=91) reported significantly higher burden among spousal caregivers, than filial (Casado and Sacco, 2012). No significant difference was observed between other relatives and filial, although this may have been due to the substantially smaller sample of caregivers to other relatives. Similar

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comparison was made amongst Finnish caregivers: whereby perceived burden was highest among spousal caregivers (N=660), than filial (N=143) and parental (N=259) caregivers (Juntunen *et al.*, 2018). However, differences in burden were only reported for the female caregivers within the sample (72%), which was foreseeable because there was little male representation for filial and parental in comparison with spousal caregivers. Nevertheless, there is evidence to suggest there are sex differences in caregiver burden.

In contrast, comparison was drawn between spousal (N=12) and filial (N=12) dementia caregivers in Australia (Tatangelo *et al.*, 2018). Although the interviews did not contain burden-specific questions, 'feeling overwhelmed' was commonly cited by filial caregivers arising from physical burden, emotional strain, and isolation. A greater percentage of filial caregivers identified unmet mental health needs compared to spousal caregivers, which would suggest higher levels of burden among filial caregivers. Moreover, concerns raised by spousal caregivers were related to worrying about recipients, rather than self-directed, which could be indicative of emotional burden. The authors conveyed that greater adjustments are often made by filial caregivers, as they are most likely to be employed, with their own family responsibilities, in addition to the caregiving role (*ibid*). Additionally, spousal caregivers tended to be older (aged 62-89), compared to filial (aged 36-70), which would suggest they may be retired, and are unlikely to have additional responsibilities (e.g. childcare), alongside their caregiving role. Overall, the quantitative evidence suggests spousal caregivers experience higher levels of burden than other caregiving groups. The qualitative study from Tatangelo *et al.* (2018) did not directly explore burden in the interviews, and therefore the findings are not considered robust enough to directly contradict what previous studies have found.

Finally, factors associated with the caregiving role, (e.g. caregiving intensity), have been shown to influence burden. Caregivers to cancer patients experienced similar levels of burden to dementia caregivers (Bevans and Sternberg, 2012). This suggests that additional care needs associated with chronic illness or cognitive impairments result in increased burden, compared to caregivers of older adults without chronic conditions. This could also be related to the relationship with the recipient. As such, when caregivers of children (N=100) were compared with equal groups of caregivers of adults, and older adults, using the Zarit Caregiver Burden Interview, caregivers of older adults provided the lowest intensity care at 15hpd, but exhibited significantly higher burden than caregivers of children and adults (de Oliveira *et al.*, 2015). Alternatively, caregivers of children provided the highest intensity care (20hpd), but burden was significantly lower than that of older adults. Participants were recruited from a Brazilian medical centre, meaning care recipients were likely to have complex health needs. Thus, contradictory to the evidence from Bevans and Sternberg (2012), factors other than medical conditions may be differentiating caregiver burden. Additionally, although caregiving to older adults was identified as the lowest intensity, typically high-intensity is classified as ≥ 20 hpd, so if they were providing care over multiple days, all caregivers in the sample were high-intensity caregivers. It is likely that caregiving intensity contributed towards the burden scores, but that daily hours are less influential than the overall impact of high-intensity (≥ 20 hpd) care.

3.3.4.2 *Satisfaction with caregiving*

Satisfaction (defined in section 1.2.1.4) is often perceived as the opposite to burden. However, it is more accurate to articulate that caregivers experience burden and satisfaction simultaneously, as the role can be both difficult, but fulfilling (Dahlrup *et al.*, 2015). Iecovich (2016) reported that the correlation between caregiver satisfaction and burden was non-significant; the lack of association suggests the two may not be directly related. In contrast, García-Mochón *et al.* (2019) suggest that burden and satisfaction are related, but with distinct interpretations, and typically lower burden scores are indicative of higher satisfaction. However, it is possible to experience burden and satisfaction together, individually, or not at all.

As with burden, there is evidence of sex differences in the experience of satisfaction. Amongst Spanish caregivers (N=610), significant sex differences were recorded for certain domains of satisfaction (e.g. self-esteem), but not for general satisfaction (García-Mochón *et al.*, 2019). However, in separate male (N=265) and female (N=345) analyses, differences in the predictor variables were apparent. Age and location were significantly associated with male satisfaction but not female, and among females but not males, education and use of social care services were significant predictors of satisfaction. However, males were older than females (mean age 62 *versus* 58), thus could have skewed the results. Evidence on Swiss caregivers (N=118) reported that females (N=86) experienced lower levels of satisfaction than males (Tough *et al.*, 2017). This aligns with the literature on burden, which suggests females experience higher levels of burden (Akpınar *et al.*, 2011) and supports the conclusion by García-Mochón *et al.*, (2019) that higher burden is linked to lower satisfaction. Similarly to the discussion on burden, caregiving relationships were significantly associated with satisfaction. Caregivers with shared ancestry (e.g. filial or sibling) experienced greater satisfaction than those without (e.g. spousal or in-laws), after controlling for factors such as the caregiving relationship, burden, and dementia severity (de Labra *et al.*, 2015). This aligns with previously discussed research that suggests spousal caregivers experience higher levels of burden, which could be indicative of lower role satisfaction.

Among Spanish caregivers (N=1,107) providing care <2hpd, 3-5hpd, and >5hpd, higher-intensity care was significantly associated with reduced odds of satisfaction, but only once controlled for other factors such as sociodemographic characteristics (Marcén and Molina, 2012). In contrast, when intensity was the only predictor, there was no significant association. Typically, caregiving intensity is measured in hpw, as opposed to hpd, which limits the comparability with other studies. Additionally, the authors speculate that caregiving tasks are based on the division of hours, but give little explanation about the significance of two, or five hours of care.

Overall, research investigating burden and satisfaction is largely focused on the caregiving relationship and role. Moreover, there is often a large female bias in the studies. Thus, it is not always clear what impact is due to caregiver characteristics (e.g. sex). There is evidence to suggest that male

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and female caregivers experience different levels of burden, but much less focus on age differences, for example. Additionally, there is considerably more literature discussing burden than satisfaction, which arguably, may strengthen negative perceptions and stereotypes surrounding caregiving. Iecovich (2016) found associations between burden, satisfaction, and loneliness, but this referred to care recipient loneliness. As highlighted, there is little evidence to clarify the relationship between burden, satisfaction, and caregiver loneliness.

3.3.5 Summary of caregiving literature

Overall, the literature identifies that caregivers are most commonly aged around 50-years old (Vasileiou *et al.*, 2017; Zhang and Bennett, 2019), and are typically female, but with a higher percentage of male caregivers at older ages (Milligan and Morbey, 2016). There is limited evidence suggesting a direct relationship between marital status and care provision, but evidence suggests that marital status might influence the type of care provided (i.e. co-residential) or the recipient. Finally, the association between SES and caregiving appears to differ across countries; in a UK context, provision of co-residential care was an important factor linked to caregivers ceasing employment (Carr *et al.*, 2018).

Evidence suggests that spousal caregivers provide higher-intensity care (Oldenkamp *et al.*, 2018b) and are more likely to provide co-residential care, compared to filial caregivers (Bédard *et al.*, 2005). However, the literature review revealed that, largely, research is conducted with spousal caregivers, and there are few studies comparing spousal caregivers with other caregiving subgroups. Further research is therefore needed to compare caregiving subgroups; thus, this thesis contributes towards this gap by comparing spousal, parental, filial, and other caregivers. There is a larger body of evidence comparing intensity of care than its nature, or duration. For instance, research is typically conducted with current caregivers, therefore total duration is unknown. Nevertheless, periods of caregiving have been shown to be longer among caregivers to individuals with DD, compared to older adults, or individuals with mental illness (Anderson *et al.*, 2018; Barnhart *et al.*, 2020). Additionally, nature of care is not always clearly defined or is inconsistent within the literature. Care has been categorised as helping, looking after, or nursing (Zwar *et al.*, 2018), or referred to as 'visible' and 'invisible' (Clark *et al.*, 2008). Arguably, 'visible' care would cover all three delineations outlined by Zwar *et al.* (2018), making comparison difficult. Moreover, evidence suggests caregiving intensity is dependent on other factors, such as sex (Schulz *et al.*, 2020), employment (Oldenkamp *et al.*, 2018a), and recipients' needs (Costa *et al.*, 2013).

Finally, caregiver burden is more widely researched than satisfaction. The literature suggests that both burden and satisfaction are influenced by caregiver characteristics, caregiving relationships and factors relating to the caregiving role. For example, burden was shown to differ by intensity and care recipient (de Oliveira *et al.*, 2015).

Literature would suggest that caregiving is not limited to one particular scenario. Caregivers differ by sociodemographic and socioeconomic characteristics, provide care to a range of recipients with variable needs, and can be high- or low-intensity. The aforementioned variations were also shown to influence perceived caregiver burden and satisfaction. Overall, when researching caregiving populations, these multiple factors should be considered. Accordingly, within this thesis, controls were included for caregiver characteristics, the caregiving relationship, and factors relating to the caregiving role to account for potential influences on caregiver loneliness, health and wellbeing.

3.4 Loneliness, health, and wellbeing

There is a vast range of literature reviewing the impact of loneliness on physical and/or mental health. However, the relationship between loneliness and health is complex. Evidence suggests loneliness influences health and wellbeing, but also that health and wellbeing are determinants of loneliness. Within this section, the relationship between loneliness, health and wellbeing are critically discussed. The aim is to disentangle whether loneliness contributes to poor health and wellbeing, if poor health and wellbeing leads to loneliness, or the extent to which simultaneity¹ occurs.

3.4.1 Associations between loneliness, health, and wellbeing

Loneliness has been linked to increased morbidity of several chronic diseases, for example, hypertension, heart disease and stroke (Friedler *et al.*, 2015; Ong *et al.*, 2016), which reflect physiological pathways (see SET, section 2.1.2). Research across 52 countries suggests that psychosocial risk factors (e.g. loneliness) contribute to over 32% of cardiovascular disease (CVD) risk (Dafoe and Colella, 2016). In comparison, CVD risk from smoking is around 36%. However, more commonly, research investigates loneliness in relation to more general health measures.

There are several review articles examining the relationship between loneliness and health, identifying a large range of health outcomes. Alongside being a risk factor for mortality, loneliness is linked to psychological and physical morbidity, depression, functional limitations, poor physical health, and cognitive decline in older adults (Ong *et al.*, 2016). Additionally, a review on loneliness among the general population, not just older adults, reported associations between loneliness and depression, dementia, alcoholism, chronic stress, suicide, sleep disturbance and physical health

¹ Simultaneity: “the fact of something happening or being done at the same time as something elsewhere” (Oxford University Press, 2020) for example, both loneliness and health influence each other at the same time, loneliness contributes towards poor health, but poor health also impacts loneliness.

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(Mushtaq *et al.*, 2014). However, in a review on loneliness, social isolation and health in which 68 articles (53%) focused on loneliness in relation to health, results were inconclusive (Courtin and Knapp, 2017). Several articles found loneliness, but not social isolation, to be significantly associated with increased mortality risk in older adults, while others reported both loneliness and social isolation as mortality risk factors. Examples of these associations have also been investigated in large representative studies across a range of countries. In Denmark, loneliness had different effects for middle-aged and older adults, whereby greatest impacts on physical ability was observed for middle-aged individuals (Jessen *et al.*, 2017). Once controlled for sociodemographic characteristics and SES, lonely middle-aged individuals showed the greatest risk of limited physical ability, compared to non-lonely individuals of the same age. Moreover, results from the Swiss National Survey indicate that the highest risk of poor health was for lonely individuals aged 30-59, but the association was also significant for ages 15-29 and ≥ 60 (Richard *et al.*, 2017). This would indicate that loneliness has greater impact on health among middle-aged rather than older adults, and the reasoning for this may be relevant to the health measures employed. Many older adults consider illness or health decline to be a normal part of ageing (Hasworth and Cannon, 2015), which therefore may reduce their likelihood to report poorer health in self-report measures. Associations between loneliness and poor health were also present in a sample of older New Zealanders (N=332); separated into three groups (non-lonely, moderately lonely and severely lonely), both physical and mental health were worse among the severely lonely (La Grow *et al.*, 2012). A limitation of this cross-sectional study is that the loneliness and health data were obtained at the same time-point. Therefore, it is unclear whether loneliness may have resulted in poor health, or whether poor health was a factor for increasing loneliness severity. Alternatively, Losada *et al.* (2012) focused solely on mental health implications of loneliness for community dwelling, Spanish older adults. The results followed a similar pattern to other literature, whereby loneliness was negatively associated with mental health.

3.4.1.1 Simultaneity: the impact of health on loneliness

A review by Ong *et al.* (2016) highlighted key research on loneliness and health. Its focus was predominantly on the impact of loneliness on health, however, it was identified that accumulation of chronic illness, mobility impairments, and poor physical health are risk factors for loneliness. Cacioppo *et al.* (2002) conducted two US-based studies, one with undergraduate students (aged 18-24), the other with middle-aged and older adults (aged 53-78). In both studies, health behaviours (e.g. alcohol consumption) were not significantly different among lonely and non-lonely respondents. This would suggest that loneliness has little influence on the behavioural SET health pathway. However, blood pressure was significantly higher in the lonely-older (aged 65-78), compared to lonely-younger group (aged 53-64). These results suggest, particularly among older adults, CV activity (physiological pathway) was associated with loneliness, but this may be accounted for by age differences. Analysis of TILDA also supported the link between health and loneliness: in a large, nationally representative sample of Irish older adults (N=6,613), the direct

effect of poor health on loneliness was significant (Burholt and Scharf, 2014). However, the association was stronger when variables such as depression and social resources were included. This indicates health directly affects loneliness, but it also has indirect effects, as the combined impact of health and other variables was stronger than health alone. Contrasting evidence from a large representative US sample (N=2,261) suggested that health was not significantly associated with changes in loneliness (Hawkley and Kocherginsky, 2018). Longitudinal evidence demonstrated that self-reported health was not significantly predictive of loneliness, but functional limitations were. However, further analysis indicated that functional limitations were only significant predictors of becoming lonely, not recovering from loneliness. Therefore, difficulty with ADLs can lead to loneliness in older adults but improving functional health does not significantly reduce loneliness. It could be interpreted that poor health leads to irreversible loneliness outcomes, perhaps suggesting that the link between health and loneliness is stronger than that between loneliness and health.

Furthermore, expectations and stereotypes about loneliness (SET psychological health pathway) have been linked to loneliness outcomes. In a sample from ELSA (N=4,465), negative stereotypes and expectations about future loneliness collected in wave two were **positively associated** with loneliness in later waves (3-6) (Pikhartova *et al.*, 2016). Self-rated health and depression were also indicative of developing loneliness. Lonely respondents at baseline were excluded, this clarified the direction of the relationship, in that poor health led to loneliness, as opposed to loneliness negatively affecting health. This emphasises the importance of the psychological health pathway.

In summary, a greater body of evidence investigates the directional relationship between loneliness and health, compared to health and loneliness. However, there are many inconsistencies within the results. One reason could be the different measurement tools used to quantify health and loneliness: validity of measurement tools differs among populations (e.g. older adults). It is evident in the literature that mediating factors, such as sociodemographic characteristics, significantly affect relationships, in many cases strengthening the association. For this reason, it is important to consider any factors that may contribute towards loneliness and/or health.

3.4.1.2 Wellbeing and loneliness

Largely, in loneliness literature, aspects of physical health and mental health are more broadly researched than wellbeing. Despite this, evidence on the association between loneliness and wellbeing is consistent in reporting that loneliness is **negatively associated with** wellbeing (Tough *et al.*, 2018; Emerson *et al.*, 2020).

Loneliness appears to have similar effects on wellbeing regardless of sociodemographic characteristics (e.g. age). Data from three waves of CLS demonstrated loneliness was more strongly related to personal wellbeing (including life satisfaction) among ages 16-64 (N=17,723) than social interaction or perceived social support (Emerson *et al.*, 2020). Similarly, for a sample of Irish older adults (N=1,299, aged ≥ 65), loneliness was linked to lower happiness and life satisfaction. Another

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common theme was that loneliness and wellbeing were strongly linked to disability (Golden *et al.*, 2009; Emerson *et al.*, 2020). Moreover, Arslantas *et al.* (2015) measured the impact of loneliness on QoL for Turkish older adults (N=4,170, aged ≥ 65), where loneliness was significantly associated with all subscales of the QoL Short Form (SF-36) including general health perceptions, social functioning, and mental health. Respondents with chronic disease or physical disability reported higher loneliness scores, which would imply lower QoL, given the significant negative association.

In contrast Gerino *et al.* (2017) found no significant direct effect of loneliness on wellbeing, as measured by the WHO Quality of Life Instruments. Loneliness was significantly associated with QoL, but only through mediators, such as mental health and resilience. This suggests that the relationship between loneliness and wellbeing is complex and interrelated with other factors, such as health. However, it must be considered that a key issue with wellbeing research is a lack of uniformity in wellbeing measures. Both measures and content vary substantially, some including subscales on health-related aspects, such as physical functioning and mental health (e.g. SF-36, Arslantas *et al.*, 2015), others focusing more on life satisfaction and happiness measures (Tough *et al.*, 2018; Emerson *et al.*, 2020), while others measure QoL (Gerino *et al.*, 2017). As there is little clarity over the definition of wellbeing (section 1.2.3.2), it is therefore difficult to compare wellbeing studies. Nevertheless, loneliness is consistently reported as detrimental to a range of wellbeing measures.

3.4.2 Loneliness, health, and wellbeing in a caregiving context

The following sections discuss caregiving literature, in relation to loneliness (section 3.4.2.1), health (section 3.4.2.2), and wellbeing (section 3.4.2.3) outcomes. The review considers different aspects of caregiving (i.e. characteristics, relationship, or role) reported to influence loneliness, health, and wellbeing and, where the health literature permits, relate this to the SET pathways.

3.4.2.1 Caregiver loneliness

Previous research suggests that females are more likely to experience loneliness or other difficulties associated with caregiving (Navaie-Waliser *et al.*, 2002; Vitaliano *et al.*, 2003). Moreover, evidence from Beeson (2003) highlights that loneliness and depression are significantly higher among female than male caregivers, aligning with the evidence suggesting that females are more susceptible to negative experiences of caregiving. However, male and female caregivers did not differ in relation to negative relationship changes with the recipient, or in experiencing loss of identity (*ibid*). Therefore, as outlined by CIT, changes that occur to the caregiver-recipient relationship, and adaptations to identity due to the caregiving role do not appear to discriminate by sex. Similarly, female caregivers were lonelier in samples of Turkish caregivers (N=100) of recipients with cancer (Soylu *et al.*, 2016) and British dementia caregivers (N=1,283) (Victor *et al.*, 2020). Soylu *et al.* (2016) reported significantly higher loneliness scores for female compared to male caregivers, married compared to single caregivers, and among the lowest educated compared to high school and

university educated caregivers. Qualitative investigation on loneliness among English caregivers (N=16, 69% female) would also suggest that loneliness was more common among the female caregivers (Vasileiou *et al.*, 2017). When discussing the key themes, issues arose around reduced personal space, relational losses, social interactions, and sole-responsibility. However, it is important to note that there were a greater number of female caregivers, and all male caregivers were spousal, whereas female caregivers included **spousal, filial, and parental**. Therefore, as discussed below, relationship type may have influenced their caregiving experiences and loneliness level.

Moreover, Bramboeck *et al.* (2020) measured loneliness using UCLA-LS and German Multidimensional Loneliness Questionnaire (MEF). Both measures were associated with caregivers' age, sex, and living circumstances. In contrast to previous findings, among the caregivers (N=40) of people with Alzheimer's disease, male caregivers experienced higher levels of loneliness than females. Little is known about the caregiver-recipient relationship, other than that they were related, and sociodemographic information was not reported by sex; therefore, it is not possible to determine whether other relevant factors, were contributing towards the higher loneliness scores. Overall, the majority of the evidence suggests that female caregivers typically experience greater loneliness than male caregivers. Research conducted with non-caregiving populations report mixed findings (section 3.2.1), whereby significant sex differences often rely heavily on contextual factors, such as the loneliness measure, or other sociodemographic characteristics. This could be relevant among caregiving populations too, whereby in addition to sociodemographic discrepancies, caregiving relationship and role differences may contribute towards observed sex differences in loneliness.

Alternatively, there is evidence to suggest that factors related to the care recipient contribute towards caregiver loneliness. Longitudinal research from France investigating daughters (N=557) providing care to widowed parents suggests that care recipients' health **was linked to** caregiver loneliness, but that care provision was not significantly associated with caregiver loneliness (van den Broek and Grundy, 2018). It could be argued that health limitations of the care recipients (parent) means a lower likelihood of support provided to their adult-children (*ibid*), ensuing stress and increased need for a support network, thus resulting in feelings of loneliness. Other factors shown to contribute towards caregiver loneliness include those linked to the relationship and role. For example, co-residential caregivers were lonelier than non-residential caregivers (Bramboeck *et al.*, 2020), and spousal caregivers were lonelier than caregivers to other family and friends (Victor *et al.*, 2020).

Bramboeck *et al.* (2020) recruited their sample from an inpatient ward, thus the prevalence of co-residential care was much lower than typically reported in other studies (section 3.3.2.2). Nevertheless, the results showed that co-residential care was associated with increased loneliness compared to non-residential care. Moreover, the experience of loneliness may have been greater than usual for those providing co-residential care: because at the time of the study, the care recipients were hospital inpatients, therefore not residing at home with the recipient, which may have influenced feelings of loneliness. Furthermore, qualitative interviews with Polish spousal caregivers (N=30)

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indicated that behavioural changes linked to the recipients' Alzheimer's disease, contributed towards breakdown in communication and reduced relationship quality (Leszko *et al.*, 2020). Consequently, the caregivers reported experiences of loneliness due to the loss of the friendship and partnership. Additionally, the caregivers suggested that as the condition progressed, care needs and time spent caregiving increased accordingly, which exacerbated feelings of loneliness by reducing the caregivers' ability to socialise outside of the caregiving role.

Victor *et al.* (2020) found significant associations between factors such as depression, stress, life satisfaction and wellbeing and caregiver loneliness. Higher levels of depressive symptoms and stress were associated with greater loneliness severity, whereas lower life satisfaction and wellbeing were linked to more severe loneliness. The evidence would suggest that similar to the non-caregiving population, loneliness among caregivers is linked to poorer health and wellbeing. For example, loneliness among caregivers has been linked to frailty, which has been shown to predict other health outcomes in older adults (dos Santos-Orlandi *et al.*, 2019). In a sample of predominantly spousal caregivers (aged ≥ 60) who had been caregiving for an average of 6hpd over 10-years, odds of frailty among lonely caregivers were over four times higher than non-lonely caregivers (*ibid*). However, there were very few studies that examined the link between loneliness, health and wellbeing among caregivers, therefore, currently little comparison can be drawn with other findings. Largely, the concepts have been investigated in isolation. However, as discussed in the subsequent sections (3.4.2.2. and 3.4.2.3), caregiving has been linked to many health and wellbeing consequences. Therefore, further research is needed to investigate loneliness, health, and wellbeing measures simultaneously to aid the understanding within a caregiving context. This thesis therefore aims to help fill that knowledge gap. The subsequent section discusses literature on further health implications of caregiving.

3.4.2.2 Caregiver health

Health consequences of caregiving have been shown to differ by age. Among US caregivers, caregivers aged 18-64 experienced significantly more mental distress and reported lower life satisfaction compared to caregivers aged ≥ 65 (Anderson *et al.*, 2013); however, caregivers aged ≥ 65 reported poorer self-rated health and more frequent physical distress. The different outcomes suggest that caregiving has a greater impact on physical aspects of health in older caregivers, but appears to have greater psychological impact on younger caregivers. Similarly, Danilovich *et al.* (2017) found that US caregivers aged 50-64 were 65% more likely to perceive that caregiving had a negative impact on self-rated health, compared to younger caregivers (aged 18-49), also suggesting that the physical consequences of caregiving are more pronounced as caregivers age.

Alternatively, Tosi and Grundy (2019) hypothesised that career breaks to provide care to family would benefit the health of women, compared to those not working and those working continuously, however their results provided no support for this. The latent class analysis highlighted two groups

of women likely to have taken breaks to provide family care (>5-years): (i) those categorised as being in a lower socioeconomic position who started an early (aged <20) large family (≥ 3 children), and (ii) those categorised as being in a low socioeconomic position who took work breaks and provided family care. Of the two groups, the percentage providing family care was 58% and 93% respectively. The physical and mental health of the second group with the larger percentage of caregivers did not differ significantly from the reference group (women in a low socioeconomic position with a long working life and two children), but those in the first group demonstrated significantly lower physical and mental health, compared to the reference group. The results suggest that the negative effect on health was not necessarily due caregiving, as there were a lower percentage of caregivers in the first group compared to the second, or the lower socioeconomic position given that all three aforementioned groups shared this characteristic. This therefore suggests caregiving during an individual's working life had little impact on health in later-life, which would imply that the effect of caregiving on health is short-term rather than long-term.

In addition, caregiver health has been linked to the caregiving relationship and role. As such, significant differences in depressive symptoms and mortality were reported between co-resident, non-resident, and non-caregivers in the US (Caputo *et al.*, 2016). All co-residential caregivers, regardless of recipient (spouse, parent, or other), experienced significantly higher levels of depression than non-caregivers. In comparison, non-resident caregiver depression scores were not significantly different to non-caregivers. However, mortality did not reflect the same pattern: the mortality rate for non-resident caregivers was significantly lower than non-caregivers, and only co-residential caregivers of 'other' recipients experienced significantly higher mortality rates, compared to non-caregivers. The results infer that non-residential caregiving may be protective against mortality; however, it is important to consider that low-intensity caregiving has been linked to health benefits among caregivers, in comparison with higher-intensity care (Vlachantoni *et al.*, 2016; Lacey *et al.*, 2018), and non-residential care is typically indicative of lower-intensity care, than co-residential care.

Increased duration of caregiving roles has previously been linked to psychological morbidities, such as depression (O'Reilly *et al.*, 2008). Conversely, a comparison drawn from UK Censuses over a 10-year period suggest that those in long-term, high-intensity caregiving roles were less likely to report poor health, compared to persistent non-caregivers (Vlachantoni *et al.*, 2016). Upon reflection, it could be considered that poorer health is reported by non-caregivers, compared to long-term caregivers, due to their capacity to care. To clarify, caregivers consistently provide care because they are physically able to do so, and if a caregiver experiences poor health, they may need to cease their caregiving role due to their own health limitations. As shown by Vlachantoni *et al.* (2016), those transitioning from high-intensity caregiving roles to non-caregiving were more likely to report poor health, than persistent non-caregivers. Similarly, in a sample of US caregivers, duration of caregiving role was associated with poorer self-reported health (Danilovich *et al.*, 2017), compared to caregivers who had provided care for <6 months. Caregiving for 1-4 years, 5-9 years and ≥ 10 years significantly

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increased the risk of caregivers reporting worse health. It is noteworthy that this relationship only appears to take effect after a year of caregiving, as caregiving for 6-12 months, compared to <6, was not significantly associated with an increased risk of poorer health. This suggests that short-term caregiving roles <12 months have little impact on the health of caregivers, neither positively or negatively.

Finally, Lyons *et al.* (2015) evaluated stress and depression among a sample of 992 US females. Perceived stress was significantly higher among high-intensity caregivers, compared to low-intensity and non-caregivers, who exhibited similar scores. Additionally, depression scores were lowest among low-intensity caregivers in comparison with non-caregivers and high-intensity caregivers (*ibid*). These studies correspond with previously discussed research that low-intensity caregiving is beneficial to the health of caregivers. Vlachantoni *et al.* (2016), and Lacey *et al.* (2018) argue that caregiving for ≥ 20 hpw resulted in poorer health outcomes compared to fewer caregiving hours. Similarly, Northern Irish Census data highlighted that male caregivers providing ≥ 50 hpw were more likely to report a limiting long-term illness (LLTI), compared to non-caregivers (O'Reilly *et al.*, 2008). Further analysis considering self-rated general health indicated that high-intensity caregivers were more likely to report poorer health, compared to non-caregivers regardless of sex. This evidence would suggest that caregiving intensity has a more substantial effect on caregiver health, after accounting for sociodemographic characteristics.

Stereotype embodiment theory: pathways to health

Little research focuses on caregiving and health in relation to SET pathways, although Bevans and Sternberg (2012) highlight the importance of recognising the effects of physiological, psychological, and behavioural health outcomes among caregivers to prevent more serious health conditions and premature mortality.

Caregiver stress has been linked to increased risk of heart disease and stroke among females (Bouchard *et al.*, 2019). The impact of caregiving on physiological health was reportedly similar for both spousal and parental caregivers. Compared to caregivers reporting low or no stress, strained spousal and parental caregivers more likely to experience fatality as a result of CVD. Moreover, using pooled data from Swedish and UK-based surveys, high-intensity caregiving (>20hpw) was linked to increased CVD risk among caregivers (Mortensen *et al.*, 2017). When combined with working hours, a combination of higher-intensity care (>8hpw) and part-time work (≤ 40 hpw) was found to significantly increase CVD risk, compared to lower-intensity care and part-time work. In contrast, full-time working (>40hpw) regardless of caregiving intensity was not significantly associated with CVD. This suggests that stressors associated with caregiving may have a more substantial impact on physiological health than work-related stressors (*ibid*). Within the UK sample, longer-term care (caregiving at both time-points three-years apart) was associated with increased CVD risk for caregivers providing high-intensity care (>20hpw), compared to ≤ 8 hpw. Risk was not significantly different for short-term caregivers at any intensity, or long-term caregivers providing

9-20hpw care. These results suggest that high-intensity care over a prolonged period may contribute to higher levels of caregiver stress, and therefore increase the risk of poor physiological health among caregivers. As discussed previously, the evidence of the relationship between the caregiving role and health is largely inconsistent, which suggests that other contextual variables, such as differences in the caregiver relationship, or caregiver characteristics, may moderate the relationship between caregiving role and physiological health.

With regard to the psychological pathway, stereotypes about competence in ageing can act as a self-fulfilling prophecy (Fernández-Ballesteros *et al.*, 2016). As such, caregiving experiences have been shown to influence planning future care needs. Among Canadian respondents (N=180 non-caregivers, N=74 caregivers, N=92 caregivers with experience transferring their recipient to formal long-term care), both groups of caregivers were significantly less likely to avoid planning their own care needs, in comparison with non-caregivers. However, caregivers with formal care experience were also significantly less likely to avoid planning their own future care, than caregivers without formal care experiences. This indicates that personal experience with formal long-term care influences the decision to plan for future care needs more so than informal caregiving experience, perhaps due to the increased complexity of the recipient care needs for those transferred to formal care facilities. Evidence suggests that caregiving experiences, particularly involvement with formal care transfers, influence the caregivers' own health perceptions and increase the likelihood of expecting to require care.

Finally, caregiving has also been associated with behavioural health outcomes. World Health Survey data across 38 low- and middle-income countries (N=204,315) in 2002-04 indicated that caregivers were more likely to be physically active than non-caregivers (Jacob *et al.*, 2020). This was consistent with evidence from Gottschalk *et al.* (2020) who reported from a large US sample of caregivers (N=12,044) and non-caregivers (N=45,925) that caregivers were significantly less likely to be physically inactive compared to non-caregivers. Arguably, the level of physical activity among caregivers may be directly related to the caregiving role, in that they may consider manual caregiving tasks to form the majority of this activity, rather than exercising outside of the caregiving context. Nevertheless, caregiving appears to have a positive impact on behavioural health when measured by physical activity. Similarly, caregivers consume alcohol more responsibly than non-caregivers (*ibid*). Within the literature, the body of research mainly concentrates on the consequences of over-drinking, with less research on the positive aspects, such as the release of endorphins and increased functionality in social situations (Dunbar *et al.*, 2017). Moreover, there is evidence to suggest that moderate consumption of alcohol, particularly those who drink in a community atmosphere at a 'local' may be more socially engaged, happier and have higher life satisfaction. A simultaneous link may also exist between life satisfaction and drinking, in that those with higher satisfaction are more likely to visit a pub, and thus experience the social benefits (*ibid*). However, it is important to consider that the aforementioned study was not conducted with caregiving populations, and caregivers are less likely to have leisure time alongside their caregiving role to drink in pubs, so are

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less likely to experience the social benefits outlined in the study. Studies suggest that alcohol consumption among lonely individuals may be a coping mechanism (Wilson and Moulton, 2010), and among caregivers, burden was linked to problematic drinking (Rospenda *et al.*, 2010).

In contrast, other aspects of behavioural health, such as obesity and smoking were more common among caregivers (Gottschalk *et al.*, 2020). However, factors pertaining to the caregiving relationship and role had significant effects on the behavioural health of caregivers. Compared to spousal caregivers, care to parents, children, grandparents, grandchildren, and other relatives were associated with higher likelihood of obesity and excessive alcohol consumption. Additionally, high-intensity care (≥ 40 hpw) was linked to greater likelihood of obesity and smoking compared to caregivers of < 9 hpw. Principally, the literature suggests that caregiving positively influences the physical activity levels of caregivers, but this does not necessarily equate to good behavioural health, because negative health behaviours such as smoking, alcohol consumption, and obesity are prevalent within the caregiving population. This would emphasise a need for a multifactorial approach to measuring behavioural health to determine an overall effect. As such, evidence considering physical activity alone might conclude that caregiving has positive effects on behavioural health without investigating a more complete picture.

3.4.2.3 Caregiver wellbeing

This final section discusses the literature on the wellbeing implications of caregiving. There is less evidence connecting caregiving to wellbeing than that of health, and the relationship appears more consistent: caregiving is frequently shown to be linked to poorer wellbeing (Ekwall *et al.*, 2005; Dahlrup *et al.*, 2015; Sin *et al.*, 2016). However, there is also evidence to suggest that the positive aspects of caregiving, when researched in isolation, can have positive effects on wellbeing (Quinn *et al.*, 2019; Quinn and Toms, 2019).

Compared to the general population, caregivers exhibited significantly lower wellbeing scores (Sin *et al.*, 2016). Wellbeing was substantially lower among a sample of caregiving siblings (N=90, aged 16-58), than a comparable sample (N=2746, aged 16-54) of the general population from Health Survey for England (HSE) (*ibid*). However, once stratified by sex, caregiver wellbeing scores were significantly lower than the general population for females, but not males. Despite this, further analysis suggested that sociodemographic characteristics (including sex) were **not influential on** wellbeing scores among caregivers. This means male and female wellbeing was not significantly different within caregivers, but sex differences were apparent, compared to the general population.

Qualitative evidence, collected from caregivers of individuals with advanced cancer indicated that caregiver QoL was indistinguishable from care recipients' QoL (McDonald *et al.*, 2018). A key theme that emerged from the study was that caregivers were "living in the patient's world" (*ibid*, p.71), caregiving burden and that of the cancer diagnosis influenced the caregivers emotionally, physically, socially and financially, thus having a large impact on their QoL. However, this study

was conducted with caregivers of patients receiving, or eligible for palliative care, therefore it could be considered that caregivers to recipients without a terminal condition (e.g. caregivers to older adults at earlier stages of health conditions) may experience less burden and thus less consequence on their QoL.

Additionally, among Swedish caregivers (N=369) and non-caregivers (N=2,233) caregiver burden (high- and low-strain) significantly impacted wellbeing, but the impact of caregiving itself was not significant (Dahlrup *et al.*, 2015). To illustrate, high-strain caregivers demonstrated significantly lower life satisfaction scores, compared to both non-caregivers and low-strain caregivers, whereas low-strain caregivers demonstrated higher life satisfaction than both non-caregivers and high-strain caregivers. Overall, the low-strain group could also be considered low-intensity, as they spent less time caregiving than high-strain caregivers. Therefore, the implications of the wellbeing research supplement the findings of Vlachantoni *et al.* (2016) and Lacey *et al.* (2018), suggesting that low-intensity caregiving may also be beneficial to caregiver wellbeing as well as health. Furthermore, in Switzerland, Tough *et al.* (2018) examined disabled (spinal injury) respondents (N=123) and their caregiving partners. Disabled respondents reported lower average loneliness and life satisfaction scores than their caregivers. Both loneliness and relationship quality with the care recipient were associated with caregiver life satisfaction scores. This suggests that disability, or perhaps health in general, is strongly associated with wellbeing. However, the results also imply that aspects of social networks (e.g. relationship quality), often measured alongside loneliness, appear more relevant in caregiving populations. As discussed in section 3.2.2.2 relationship quality is a key **determinant** of loneliness among caregivers, but this additional evidence suggests it may also be linked to caregiver wellbeing.

Alternatively, positive aspects of caregiving (PAC) are under-reported in comparison to negative aspects (de Labra *et al.*, 2015; García-Mochón *et al.*, 2019). Moreover, PAC may have beneficial effects on caregiver wellbeing. Quinn and Toms (2019) produced a systematic review (N=59 publications) exploring the impact of PAC on wellbeing among dementia caregivers. PAC were linked to higher QoL, increased life satisfaction, greater self-efficacy, and reduced burden. However, PAC were determined using a range of twenty different scales, therefore comparability between the studies may be limited. Additional evidence among dementia caregivers supported the link between PAC, QoL, and life satisfaction (Quinn *et al.*, 2019). Furthermore, in some European countries it has been highlighted that state provision of long-term care may influence caregiver wellbeing: evidence using SHARE data (Sweden and Denmark) over multiple time-points demonstrates that caregiving was negatively associated with QoL among all caregivers, compared to non-caregivers, with negligible difference in QoL between those caregiving at higher-intensities (daily/every week) and those providing care less often (van den Broek and Grundy, 2020). This suggests that caregiving intensity was not linked to caregiver wellbeing. However, the study suggested that as state provision changed between the waves, the effect of care on caregivers' QoL was weaker when state provision was more readily available. The authors suggest this could be linked to obligation to care, as in

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countries with generous long-term care provision, informal care is likely provided through choice, not necessity. As suggested by Li and Lee (2020) increased choice around caregiving is linked to fewer psychological symptoms among caregivers.

Overall, the evidence suggests a strong link between caregiving and wellbeing, but the concept of wellbeing is poorly measured within caregiving research. In the systematic review by Quinn and Toms (2019), burden was considered a wellbeing outcome, whereas Dahlrup *et al.* (2015) employed burden as a predictor of QoL. Some studies considered health and mental health as wellbeing outcomes, but, as discussed in section 1.2.3, although linked, health and wellbeing are separate constructs. Typically, it is understood that positive aspects of caregiving have beneficial effects on wellbeing, and negative aspects of caregiving, such as stress or burden, can have negative wellbeing consequences.

3.5 Chapter summary

This chapter identified and critically discussed relevant literature to this thesis, including: determinants of loneliness, key sociodemographic and socioeconomic characteristics of caregivers, the caregiving relationship, factors related to the caregiving role, and loneliness, health and wellbeing in the general population and among caregivers. Research into determinants of loneliness suggests that sex, marital status, and social networks are significant predictors of loneliness. However, the impact of sex appears, in some cases, to be conditional upon mediating factors such as age, and the association can easily be influenced by the measurement tools used to determine loneliness. Moreover, marriage appears largely protective against loneliness, but evidence on social networks suggest that all aspects contribute significantly to a loneliness outcome, including network size, relationship quality and satisfaction. Therefore, this would imply that the existence of a marriage alone does not necessarily protect against loneliness, and that quality or satisfaction within the marriage could be an important factor. This evidence could be an indication why prevalence of loneliness is higher among caregivers, and for potential discrepancies between the determinants of loneliness. To illustrate, large percentages of caregivers are female, and caregiving is shown to impact relationship quality and social networks. This would therefore suggest that caregiving may amplify these determinants of loneliness. Moreover, the literature suggests that caregiver characteristics, the caregiving relationship and the caregiving role are interlinked. For example, significant associations were reported between the age of a caregiver and the intensity of care provided, and in particular, spousal caregivers broadly differ from other caregiving subgroups, in relation to both characteristics and role.

Loneliness has proven detrimental to multiple aspects of health and wellbeing, while health has also been linked to loneliness outcomes, suggesting a high level of simultaneity between the concepts. The measures of health and wellbeing vary considerably within the literature, but typically focus on similar aspects, such as mental health and depression, general self-rated health, or areas such as life

satisfaction. Arguably, there is less detailed evidence on health outcomes, for example, the impact on specific health conditions. Finally, research within the caregiving population examines the link between caregiving, loneliness, health, and wellbeing predominantly as distinct relationships. Negative aspects of caregiving (e.g. burden) have been linked to poorer health and wellbeing consequences. However, although less researched, positive aspects have demonstrated promise in areas of health and wellbeing. For example, highly satisfied caregivers are typically those who provide lower-intensity care, which has been reported to have positive health effects.

3.5.1 What are the research gaps?

Fundamentally, there is a substantial lack of cross-sectional, and longitudinal research carried out in caregiving populations. Where caregiving populations are investigated, this is often limited to one recipient health condition (e.g. dementia), or one type of caregiver (e.g. spousal). Therefore, diversity within the caregiving population is largely under-researched and subsequently, under-represented in the literature.

More specifically, there is a lack of evidence on the determinants of loneliness among caregivers. Thus, despite caregivers being frequently reported as vulnerable to loneliness, there is little robust evidence examining whether typical determinants of loneliness within the general population are also applicable to caregivers. As concluded in section 3.2.5, the body of literature is limited, but the available evidence suggests that many of the determinants of loneliness in the general population may not be applicable to caregivers. This means that caregiving support services cannot work to effectively prevent loneliness, because risk factors and indicators are not clearly understood within this subgroup of the population. Loneliness prevention would, arguably, be more beneficial than supporting caregivers to overcome loneliness, because the likelihood of negative consequences on health and wellbeing would be significantly less.

Moreover, greater clarity is needed around the division of short- and long-term caregivers or low- and high-intensity caregivers. The latter, considerably more researched than the former, has proven to be largely influential on caregiver loneliness, health, and wellbeing. However, within the literature, what constitutes high-intensity ranges from ≥ 10 hpw to ≥ 20 hpw, which is misleading when comparing the implications. Finally, there is considerable research on the health implications of caregiving, and lesser, but expanding bodies of evidence on loneliness and wellbeing among caregivers. However, little research has been conducted on the concepts simultaneously. Despite evidence from the general population suggesting strong links between loneliness and health, loneliness and wellbeing, and health and wellbeing, few studies have explored whether the health and wellbeing implications of loneliness differ for caregivers. As caregiving is known to impact loneliness, health, and wellbeing, it could be expected that the combined effect of caregiving and loneliness would have greater impacts on health and wellbeing than caregiving or loneliness individually, which highlights a substantial research gap.

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Moreover, there are a vast range of health and wellbeing measures applied within the literature. Often these are general health measures (e.g. self-reported general health) or omnipresent factors such as depression and other mental health outcomes. Further evidence is needed on more specific and scarcer health measures, such as provided by the SET pathways. Additional research on the impact of caregiving and loneliness on specific areas of health, such as physiological health conditions, health behaviours and perceptions about future health can expand the understanding of the link between loneliness and health and provide greater scope for support services and policy recommendations for areas of health to monitor.

3.5.1.1 *Original contribution*

This thesis seeks to address the aforementioned research gaps by including a diverse range of caregivers, including spousal, parental, filial, and other, without restricting the analyses to caregivers of people with a particular health condition or disease. Moreover, comparing determinants of loneliness in caregiving and non-caregiving subgroups seeks to clarify which factors **are associated with** loneliness among caregivers, and whether these differ from the general population. Reported prevalence of loneliness can differ, depending on the loneliness measure used, which has largely been evidenced by comparing males and females. It could be hypothesised that a similar division would be observed among caregivers, whereby the stereotype around caregiving and loneliness (e.g. that caregivers should not be lonely because they spend time with the care recipient) could act as a barrier for caregivers directly reporting loneliness; alternatively, because caregivers are predominantly female until older ages, direct loneliness measures may show little contrast to indirect scale measures within this subgroup. This thesis aims to investigate whether discrepancies between loneliness measures are also relevant among caregivers. Finally, by way of uncovering and clarifying relationships between loneliness, health, and wellbeing among caregivers, the concepts will be examined simultaneously, and in various combinations, to contribute towards the knowledge gaps. Moreover, health theories (SET) are applied to gain a more structured insight into specific health outcomes. This aids the disentanglement of the relationships and provides a clearer framework for the development of policy and practice recommendations. As such, identifying significant impacts on behavioural health may lead to more targeted recommendations than those from self-rated general health measures. The next chapter outlines the methodology applied to address these research gaps.

Chapter 4 Methodology

4.1 Chapter outline

This research adopts a quantitative approach, using secondary data analysis (SDA) to analyse the ELSA dataset cross-sectionally and through follow-up analysis. Chapter four explains the methodological decisions, justifying the methods and materials using published literature. The selected research strategies are outlined and research materials discussed in relation to comparable datasets (section 4.2). Moreover, key variables are identified (section 4.3), including those computed for the analysis, and weights. Subsequently (section 4.4), the quantitative methods for both the cross-sectional and follow-up analyses are presented.

4.2 Research strategy

The quantitative methods of this thesis are deductive, primarily following a positivist epistemology (Bryman, 2016). As the main aims of this thesis are to examine associations and identify determinants, this is most effectively achieved in larger samples using numerical data; therefore, a quantitative approach is the most appropriate. Quantitative research can be used to test pre-determined hypotheses, whereas qualitative methods often seek to develop deeper understanding, such as understanding why something occurs (McCusker and Gunaydin, 2015). Section 4.2.1 discusses the advantages and disadvantages of secondary analysis, cross-sectional and follow-up methods. Moreover, section 4.2.2 introduces the data, and the study population examined within this thesis.

4.2.1 Research design

Secondary analyses are conducted on multiple waves of ELSA (section 4.2.2) through two research designs: cross-sectional and follow-up. These designs are complimentary, while the first can be used to identify associations between variables and prevalence of a phenomenon (e.g. loneliness among caregivers), the latter can further investigate the time-order of associated variables (e.g. is caregiving in an earlier wave, indicative of reporting loneliness in a later wave?).

4.2.1.1 *Secondary analysis*

The main advantages of SDA include high-quality data, reduced burden on potential participants, cost and time effectiveness, and the opportunity for new interpretations (Bryman, 2016). Many of the existing SDA datasets are high-quality (ESRC, 2019) with rigorous sampling procedures; this means that the study sample is often representative of the general population, thus conclusions are frequently more generalisable than results from smaller studies using less diverse primary data. To

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clarify, time and cost associated with collecting a large representative sample often means that primary data collection is limited to desired characteristics. Smaller studies may focus less on matching demographic characteristics to the general population (e.g. proportions of age categories), and collect participants with a specific attribute (e.g. caregivers for individuals with certain health conditions). This would restrict the generalisability of the results to the specific characteristic, or context, within the study.

For data collected with the intention of SDA, informed consent is obtained from the respondents for the re-use of their data. The respondents can withdraw their data at any time, but obtaining initial consent for re-use is essential; otherwise, respondents would need to be contacted each time a researcher analysed the dataset. This is likely to be infeasible and result in excessive burden on the respondents, potentially reducing the likelihood of future participation. However, the re-use of collected data, such as that in ELSA, can reduce this burden on potential participants; individuals are aware that data are collected on a biennial basis, and therefore do not have to go through the recruitment process at each wave. Furthermore, existing SDA datasets often have a larger number of participants than would be available to individual researchers collecting primary data (Windle, 2010); this reduces the costs associated with data collection and is substantially less time-consuming, thus more efficient. Finally, Bryman (2016) suggests that social research is often under-analysed, meaning that the full potential of data resources are yet to be explored. New interpretations could occur through using a more exhaustive range of the available variables, analysing different combinations of variables, or exploring different subgroups. Particular advantages that are pertinent to the research in this thesis, that is SDA of the ELSA dataset, are the opportunities for follow-up and subgroup analysis. The availability of large quantities of longitudinal data means that time-order can be investigated, which may lead to conclusions that can suggest causality. Large samples also permit subgroups to be explored (e.g. by age, or other characteristics); in the case of this research, caregivers are contrasted with non-caregivers.

Nevertheless, SDA is not without limitations. Bibb (2007) highlights three key limitations: locating data, compatibility, and data quality. Locating data is not too critical a limitation for this thesis, as the UK Data Archive holds a large range of high-quality, impactful data available for secondary analysis, including ELSA, and is updated regularly. Compatibility refers to the extent to which available data fits the proposed research questions, which can be addressed by altering the research approach (Bibb, 2007). Designing research questions to fit an existing dataset increases the likelihood of securing compatible data; alternatively, existing data can be found to fit the research questions. However, the latter approach is often more difficult and, depending on the available data, may require multiple adaptations to the original research questions. Arguably, research questions should be modelled from a research gap rather than from available data; for this thesis, the research questions were designed around previous literature and the most suitable dataset was identified to answer those research questions. Finally, data quality is highlighted as a limitation of SDA by several authors (Bibb, 2007; Windle, 2010; Bryman, 2016). Data quality may be compromised, due to incomplete

or inaccurate records (Windle, 2010), or a lack of key variables between waves of data (Bryman, 2016). For example, in ELSA, loneliness expectations questions were asked in waves two, seven and eight, but were missing in waves three through six, which restricted availability to analyse changes over all of the waves. Nonetheless, adaptations were made to analyse changes over the available waves (section 4.3.8.2). To assess data quality, data familiarisation is essential, and, as with primary analysis, data organisation and cleaning (Bibb, 2007); this allows the researcher to identify and resolve issues with missing data. During the familiarisation period for this thesis, several variables were recoded (section 4.3).

4.2.1.2 Cross-sectional research design

This thesis uses cross-sectional analysis to identify associations between caregiving, loneliness, health, and wellbeing in wave eight of ELSA. Cross-sectional research occurs at a single time-point (Sedgwick, 2014); characteristically this involves a large number of cases and variables (Bryman, 2016). Cross-sectional studies are particularly suited for exploring prevalence within a specific population (Sedgwick, 2014); in this thesis, the prevalence of loneliness is examined among caregivers and non-caregivers. Additionally, cross-sectional studies often provide the foundations for further analysis (*ibid*). In this thesis, some of the associations uncovered through cross-sectional analysis are investigated further within the follow-up analysis. As such, cross-sectionally, caregiving was significantly associated with loneliness, this was further investigated in the follow-up analyses to identify longer-term associations between caregiving and loneliness.

Typically, internal validity in cross-sectional research is weak, as causality cannot be established (Levin, 2006; Bryman, 2016); however, external validity can be strong, when the sample is collected randomly, as the results can often be generalised to wider populations. Cross-sectional research is widely used, as associations can be uncovered with minimal time commitment, in comparison to longitudinal or repeated methods, and there is relatively little expense (Levin, 2006). However, particularly within health research, cross-sectional methods are subject to prevalence-incidence bias, where risk factors associated with mortality may be under-represented within the respondents with the condition (*ibid*). To illustrate, when investigating health conditions that have high risk of mortality (e.g. strokes (Donkor, 2018)), the sample will predominantly include those who experienced mild to moderate strokes, as it is likely that the most severe strokes resulted in fatality. Therefore, severe, or advanced stages of conditions are often under-represented within research. As loneliness has been linked to increased physical and psychological morbidity, and is reported as a risk factor for mortality (Friedler *et al.*, 2015; Ong *et al.*, 2016), there is potential for under-representation within the sample. The response rate at wave eight across all cohorts is reported at 82%, with significant differences between responders and non-responders including, age by sex, and education (Banks *et al.*, 2018).

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In this thesis, cross-sectional design was applied to investigate associations between caregiving and different loneliness measures (RQ1a), to identify the determinants of loneliness (RQ1b), and to examine associations between caregiving, loneliness, health, and wellbeing (RQ1c). Furthermore, in RQ2, cross-sectional analysis was conducted to determine the associations between different caregiving factors and loneliness (RQ2a), health (RQ2b), and wellbeing (RQ2c). All of the variables analysed using cross-sectional research design were collected at a single time-point (wave eight).

4.2.1.3 *Follow-up research design*

This thesis uses follow-up analysis to identify associations between caregiving (wave two) and loneliness twelve-years later (wave eight). Follow-up studies are a branch of longitudinal research, which is characterised as an extension of cross-sectional research; data are collected over two or more time-periods (waves), using the same variables and respondents (Bryman, 2016). In contrast to cross-sectional research, longitudinal designs offer understanding into the time-order and potential causality between variables, as the variables arising first can be identified. Cohort and panel studies are the two main types of data for longitudinal research (*ibid*). Cohort studies are carried out on samples of people with shared characteristics or experiences that differentiate them from other cohorts (e.g. born at similar times) (Mason and Wolfinger, 2001). Whereas panel studies are initiated with a single cross-sectional study, followed by repeated data collections with the same individuals, although unlike cohort studies these individuals do not need a shared characteristic (*ibid*). Panel studies can identify ageing and cohort effects, whereas cohort studies are limited to ageing effects only, as the entire sample is from the same cohort (Bryman, 2016). ELSA is a panel study including representative cohorts of individuals aged ≥ 50 in England (Steptoe *et al.*, 2013a). Panel studies can result in skewed age distributions if new (younger) respondents are not introduced (Mason and Wolfinger, 2001); however, this is not the case with ELSA, as refreshment samples are included in multiple waves (section 4.2.2.1).

The main limitation of longitudinal data is attrition (Bryman, 2016; Kelfve *et al.*, 2017), which can be due to mortality, withdrawal, or selective attrition. In ELSA, 55% of the respondents from cohort one also responded in wave eight (Banks *et al.*, 2018), indicating an attrition rate of 45%. Approximately one-third of eligible cohort one responders in wave eight were listed as non-response due to 'other reasons'; it is reported that 'other reasons' including poor health or hospitalisation were most common among this cohort due to age-related circumstances (*ibid*). Additionally, among older samples, alongside higher mortality rates, respondents may have been unable to participate due to cognitive impairment (Kelfve *et al.*, 2017). However, if the respondents lost to follow-up differ significantly from the remaining respondents, this would introduce bias into the sample (*ibid*). To clarify, if a certain characteristic is highly prevalent among the dropouts (e.g. **non-employment**), this reduces the proportion of **non-employment** within the remaining sample, introducing potential bias towards employed respondents. This can reduce how representative the remaining sample is of the target population, and is particularly detrimental if the characteristics are key measures (Lynn, 2011).

Moreover, attrition due to mortality also introduces bias (Kelfve *et al.*, 2017). As the waves of the study progress, the sample ages, and mortality naturally reduces sample size. Within ELSA, to maintain a representative sample of those aged ≥ 50 , continuous recruitment of younger participants (aged 50/51) is essential to counteract the ageing sample (NatCen, 2018b).

However, this can lead to higher proportions of characteristics associated with higher life expectancy within the sample (e.g. females, and higher SES). Kelfve *et al.* (2017) term this as cohort inversion, where the sample gradually becomes healthier, as mortality reduces the groups with disadvantaged characteristics (healthy survivor effect). Within the data, it would appear that disadvantages such as lower SES reduce over time or with age, but this is not the case; reduced life expectancy among these characteristics skews the sample. The use of proxy responses, for example, for those unable to respond due to poor health, or incentives for participation, can combat attrition within longitudinal research (Lynn, 2011), and frequent refreshment samples ensure that the youngest ages are not under-represented (NatCen, 2018b). In accordance with this approach, the sample size and characteristics of the ELSA sample have remained relatively stable across the waves.

The follow-up research design is applied in RQ3 of this thesis. Initially, caregiving and relevant control variables from wave two were analysed in relation to loneliness in wave eight (RQ3a), which identified whether previous caregiving was linked to longer-term loneliness outcomes. Additionally, variables across multiple waves (2-8) were combined, to determine if caregiving, at any point within the 12-year period, was linked to loneliness within the same 12-year period (RQ3b). Finally, changes to caregiving variables across the waves were analysed in relation to loneliness (RQ3c), which examined how changes over the duration of the caregiving role impacted caregivers' loneliness.

4.2.1.4 Design summary

A combination of both cross-sectional and longitudinal research designs were employed in this thesis. By utilising both approaches, this combats the main disadvantages of cross-sectional research, whereby causal inference cannot be made and the order of events are unknown. Cross-sectional analyses were conducted on wave eight of ELSA to identify associations between variables, and follow-up analysis between waves two and eight, to suggest the time-order of variables and indicate potential causality. For further discussion on the statistical methods, see section 4.4, and corresponding results can be found in chapters five and six, respectively.

4.2.2 English Longitudinal Study of Ageing (ELSA)

Recruitment for ELSA began in 1998, based on characteristics to build a representative sample of individuals aged ≥ 50 in England; respondents from the 1998, 1999 and 2001 waves of HSE were selected (NatCen, 2018b). The study was designed as a companion study to the US-based Health and Retirement Study (HRS), and included data relevant to policies about ageing (Steptoe *et al.*, 2013a). Waves of data are collected biennially using interviews and questionnaires, with nurse visits for

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selected respondents every alternate wave, to collect biological samples and conduct physical examinations (NatCen, 2018b). A primary focus of the study is to evaluate policy-relevant data on ageing (Steptoe *et al.*, 2013a); therefore, a vast range of data are collected, including but not limited to, health, social participation, work and pensions, and housing (NatCen, 2018b).

ELSA is therefore the most appropriate dataset, in a UK context, to conduct analysis on loneliness, health, and wellbeing among caregivers. UKHLS is a comparable population-based survey; however, the availability of longitudinal analysis of loneliness was not possible. Throughout UKHLS, objective measures for social isolation are available (e.g. proximity of social networks), but the inclusion of a subjective measure for loneliness (3-item UCLA-LS) was not included until wave nine (data collected 2017-2019) (Understanding Society, 2019). When data analysis for this thesis began, wave nine was the most recent wave of UKHLS, and therefore no longitudinal analysis could be conducted on loneliness among caregivers. ELSA is also the most appropriate dataset due to the age range of respondents. In comparison to ELSA respondents, who are aged ≥ 50 , UKHLS interview respondents aged ≥ 16 , with an additional youth questionnaire for children aged as young as 10 (*ibid*). As discussed in section 3.3.1.1, the peak age for caregiving occurs around 50-years old (Vasileiou *et al.*, 2017). Moreover, evidence suggests that caregiving more commonly occurs in mid- to later-life (Dahlberg *et al.*, 2007; Nomis, 2018a, 2018b), therefore it could be argued that younger adult caregivers should be analysed separately, and not in combination with older caregivers. Additionally, research and policy for caregivers typically considers young caregivers (aged < 18) differently to adult caregivers (Powell *et al.*, 2020). Thus caregivers < 18 may not be comparable with adult caregivers, and the inclusion of child caregivers would be beyond the scope of this thesis.

4.2.2.1 Study population of ELSA

For the purpose of this thesis, waves two and eight of ELSA were analysed, however some data were obtained from the between waves to compute covariates; further discussion on key variables can be found in section 4.3. At the time of conducting the analysis, wave eight was the most recent wave of ELSA data and contained all the relevant variables to analyse caregiving and loneliness. Wave eight was therefore selected for the cross-sectional analysis, and also as the second time-point in the follow-up analysis. Using the most recent wave in the follow-up, this allowed for the longest-term analysis to be conducted using the available data. Wave one was excluded from the analyses because several key variables were not present, most importantly, UCLA-LS. Therefore, wave two was selected as the earliest time-point for the follow-up analyses. Wave two was chosen over the other waves for a number of reasons; firstly, variables examining expectations for future health and loneliness were only included in waves two, seven and eight. Previous evidence using ELSA indicated that **negative expectations for future loneliness were positively associated with experiencing** loneliness 2-8 years later (Pikhartova *et al.*, 2016). Therefore, comparing waves two and eight meant longer-term effects (12-years) were examined. Secondly, there is little research on the long-term effect of caregiving; while caregiving has been linked to loneliness, the evidence is

largely cross-sectional (section 3.4.2.1). Thus, investigating the long-term effects of caregiving in a 12-year follow-up identified whether loneliness is enduring among caregivers.

Table 1 shows sample sizes for each ELSA wave. In addition to core members, total respondents include partners of core members, some of which aged <50. However, younger partners are not age-eligible sample members and are not intended for analysis as respondents (Taylor *et al.*, 2007). In waves where the number of core member respondents increased (waves three, four, six and seven), a refreshment sample was added (NatCen, 2018b).

Table 1: The number of core and total respondents at each wave in ELSA waves 1-8

	Wave 1 2002 /03	Wave 2 2004 /05	Wave 3 2006 /07	Wave 4 2008 /09	Wave 5 2010 /11	Wave 6 2012 /13	Wave 7 2014 /15	Wave 8 2016 /17
Core member respondents	11,391	8,780	8,810	9,886	9,090	9,169	8,249	7,223
Total respondents (including partners)	12,099	9,432	9,771	11,050	10,274	10,601	9,666	8,445

Source: author's adaptation from NatCen (2018b: p16)

Interviews with younger partners enabled more complete data collection for core members and provided a representative sample of mixed-age couples (aged >50 and <50) (Institute of Fiscal Studies, no date). Partner responses are not weighted, and it is suggested that where weighted analyses are conducted, non-sample (e.g. partners) are removed from the baseline, as partner data is supplementary to core member data (*ibid*). Furthermore, proxy responses are also excluded from this thesis, due to the subjective nature of the questions on loneliness and other variables (e.g. health expectations), it cannot be guaranteed that proxy responses accurately reflect perceptions of core respondents.

4.2.2.2 Ethical considerations and consent

Ethical approval for all waves was obtained by the ELSA research team through the Research and Ethics Service, which is regulated by the National Health Service (NHS) (NatCen, 2018b). Respondents are advised that their data will be utilised by multiple researchers, but solely for research purposes; they are also assured that all data are anonymised with no possibility of identification (ELSA, 2019a). To uphold confidentiality, certain variables are collapsed, which eliminates the possibility that any respondents are identifiable within the data. As such, the age variable is collapsed at 90-years, with a collective age category for respondents aged ≥ 90 . Respondents of ELSA are educated on the longitudinal intent of the research, and therefore no time limit is placed upon the retention of their data, however, participants are informed of their right to withdraw (*ibid*). Specific to this thesis, ethical approval for SDA was obtained on 2nd November 2017 (Appendix A), through the University of Southampton Ethics and Research Governance Online (Submission ID: 30736). All data were stored and handled in line with General Data Protection Regulation and the Data Protection Act.

4.3 Key variables in ELSA

This section discusses the key variables analysed within this thesis, drawing on the instruments used by the ELSA researchers. Primarily, the variables can be divided into three main categories: explanatory, dependent, and covariates. Caregiving (section 4.3.1) was the main explanatory variable, manipulated to determine the effects on loneliness, health, and wellbeing, for example, caregivers *versus* non-caregivers, although caregiving-specific factors (characteristics, relationship, and role) were also used as explanatory variables (e.g. comparing caregivers by intensity). Variables which were used as dependent variables (DVs) included: loneliness (section 4.3.2), health (section 4.3.3) and wellbeing (section 4.3.4). The DV was contingent on the research question. To illustrate, in the follow-up portion of this thesis, the loneliness variable differed. In some regressions, loneliness at wave eight was the DV, whereas in others, a computed variable measuring loneliness across all waves was used (section 4.3.8). The covariates included sociodemographic (section 4.3.5), socioeconomic (section 4.3.6), and social network variables (section 4.3.7).

4.3.1 Caregiving variables

Within the ELSA survey (Clemens *et al.*, 2019), respondents were asked about activities they had engaged in within the past month, an option of which was ‘cared for someone’. Across waves 2-5, only respondents who mentioned providing care within the past month were eligible to answer a question about caregiving within the past week. However, in waves 6-8, the monthly activities question was no longer a prerequisite, and all respondents (excluding those residing in an institutionalised setting) were asked if they had looked after anyone in the past week (NatCen, 2014). In waves 6-8, a higher number of respondents identified as providing care within the past week, compared to the past month (Table 2), which is likely due to the aforementioned changes in the survey.

Table 2: Percentage of respondents providing care within the past week/month in ELSA waves 2-8

	Care provision: past week N (%)	Care provision: past month N (%)
Wave 2	1036 (11.0)	1344 (14.3)
Wave 3	1000 (10.2)	1270 (13.0)
Wave 4	999 (9.0)	1369 (12.4)
Wave 5	1006 (9.8)	1365 (13.4)
Wave 6	1962 (18.5)	1325 (12.5)
Wave 7	1647 (17.0)	1239 (12.9)
Wave 8	1480 (17.5)	1120 (13.3)

Notes: % percentage of the total sample at each wave, source: author’s analysis of ELSA waves 2-8

Within the monthly activities question, alongside caregiving, another option was ‘looked after home or family’. It is plausible that some respondents, particularly those whose care recipients were family members, may have selected this option over ‘cared for someone’. This links to the phase of CIT that the individual identifies with. As such, if they identified more as a family member than as a caregiver,

they may have considered ‘looked after’ as more appropriate than ‘cared for’ to describe their role. In waves 2-5, those for whom ‘looked after’ resonated more than ‘cared for’ would have been ineligible for the weekly care provision question. However, in waves 6-8, this is irrelevant, as all respondents were eligible to answer the weekly care provision question. Additionally, the weekly care provision question is worded as “Did you look after anyone in the past week (including your partner or other people in your household)?” supplemented by the interviewer explaining “By ‘look after’ we mean the active provision of care.” (NatCen, 2018a, p.413). Therefore, it is possible that, due to the use of ‘looked after’ in the weekly caregiving question, those who responded with ‘looked after home or family’ in the monthly activity question may have identified as caregivers. Moreover, responses to the monthly activities remains relatively stable throughout the waves. This suggests that it is not a change in the interpretation of the questions that contributed towards the increased weekly caregiving in later waves. Rather, placing less restriction on who was eligible for the question allowed those who did provide care, but did not necessarily identify as a caregiver in the monthly activities question, the opportunity to be included within the caregiving sample.

Although data suggest that there may be missing information in waves 2-5 from those who failed to mention caregiving activities within the past month, the responses to the weekly caregiving variable were used to determine the caregiving sample. This decision was made based on additional caregiving variables, such as caregiving intensity, which were weekly measurements (hpw), therefore, the weekly caregiving variable was deemed most appropriate to correspond with these.

Evidence suggests a continuous increase of the population in the UK who provide care. Data from the most recent (2011) Census identified around 6.5 million caregivers across the UK, (DCMS, 2018; Parliamentary Office of Science and Technology, 2018). In contrast, more recent surveys using Understanding Society data indicated that there were around 7.6 million caregivers (Petrie and Kirkup, 2018). Whereas, data collected in May 2020 suggest that as many as 13.6 million people in the UK could be providing unpaid care (Carers Week, 2020). However, it is important to consider that the age ranges for these sources differ from the ELSA sample. Census and Government data includes individuals aged ≥ 5 (ONS, 2013; Parliamentary Office for Science and Technology, 2018), whereas the 2020 polling involved respondents aged ≥ 18 (Carers Week, 2020). A further limitation was identified by Rutherford and Bu (2018), suggesting that measures used in surveys may be underestimating the scale of care provision. It is highlighted that due to discrepancies in question wording (as discussed above), and inconsistencies with recognition of caregiving activities (as identified by CIT), the rate of reporting caregiving roles is likely to be reduced. Table 2 previously identified that the percentage of caregivers (provision of care in the past week) ranged from 9-18.5% across the waves, although being a larger range, this is not inconsistent with alternative sources, which suggests that the proportion of caregivers in ELSA is representative of the general population of England.

Changes to caregiver identity cannot be directly examined within this thesis. There are no ELSA variables on identity; this therefore limits the exploration of caregiver identity in line with how CIT suggests. However, as proposed in section 2.2, higher-intensity care roles are likely to represent the later stages of CIT and lower-intensity roles the earlier stages. Whereby caregivers providing higher-intensity care are more likely to relate to their caregiver-recipient relationship rather than their pre-caregiving relationship. Therefore, caregiving intensity (see section 4.3.1.1) will be examined both in respect of the caregiving role, but also discussed as a proxy of caregiver identity. To examine identity in more depth, questions about how the caregiver feels about their role, specifically with regard to relationship changes, would be required in the data.

4.3.1.1 Caregiving-specific variables

In RQ2, caregiver characteristics include age, sex, marital status, employment status, health, and wealth. However, these variables represent sociodemographic, socioeconomic, and health characteristics in RQ1. These are outlined in subsequent sections (sections 4.3.5 to 4.3.7).

In the ELSA questionnaire, the subsequent question from looking after anyone in the past week, asked the respondent what relation this person was to them. The options were coded as spouse or partner, child, grandchild, parent, parent-in-law, other relative, friend or neighbour, and other; a maximum of eight responses were coded per respondent. Due to relatively small samples (relative to other categories) of respondents providing care to a parent-in-law (N=87) and other relatives (N=51), for this thesis, they were collapsed and merged with parent, and friend or neighbour, respectively. The variables for care recipients are displayed in Table 3. Provision of care to grandchildren is not typically recognised as informal care, therefore individuals who reported providing care to a grandchild were excluded from these analyses.

Table 3: Variables relating to the caregivers' relationship to the care recipient

Variable name	Variable label
Care_spouse	Provides care to partner/spouse
Care_child	Provides care to adult-children
Care_parents	Provides care to parent/parent-in-law
Care_others	Provides care to friends, neighbours or other relatives

Notes: value labels 0 = No, 1 = Yes, source: author's own

To determine the location of care, co-resident caregivers were compared with non-residential caregivers. The original question was phrased as "Does the person, or do any of the people you care for, live with you?" (NatCen, 2018a, p.414) with responses of 'yes' and 'no'. This variable remained unchanged, other than reordering the responses to use non-residential caregivers as the control group.

The caregiving intensity variable was computed from data on the number of hours the respondent had reported providing care during the past week. A specific hourly value (e.g. 12hpw) was reported, or if caregiving had occurred 'all of the time', this was coded as the maximum value (168hpw). In accordance with published literature and the earlier discussion (section 3.3.3.3), intensity was

grouped into 1-19 hours, ≥ 20 -hours, and a separate category for 168-hours (round-the-clock care). Similarly to caregiving intensity, the number of care recipients was collected as a continuous variable in ELSA; respondents provided a numerical value (range 1-20) for the number of recipients they provide care to. Of the caregivers in wave eight, the most common response was providing care to one person (86%). Respondents providing care to two or more people were grouped into 'Multiple care recipients' due to the increasingly small sample sizes for the higher care recipient values. To illustrate, 93 respondents indicated providing care to two people, and only a further 42 respondents provided care to three or more recipients. Thus, in the analyses for this thesis, caregivers to single recipients are compared with caregivers who provide care to two or more recipients.

As discussed in section 4.3.8.1 ahead, for the follow-up analyses, duration of care is calculated using the 'care provision within the past week' variable from each wave. This identifies caregivers who have provided care for a single wave (short-term) or for two or more waves (long-term and intermittent). This therefore cannot be accurately computed cross-sectionally, and the duration of care cannot be measured in the cross-sectional analyses. As a caregiving-specific factor, which conceptually should be strongly associated with loneliness among caregivers, this has potential implications and limitations for the caregiver-only cross-sectional analyses (RQ2) whereby it must be acknowledged that certain important factors related to the caregiving role cannot be accounted for.

As part of the caregiving questions, ELSA respondents were asked how strongly they agreed with the following statements: "Considering all the efforts that I have put into caring for someone, I am fully satisfied with what I have achieved so far" and "I have always received adequate appreciation from others" (NatCen, 2018a, pp.419-420). There are no direct questions on burden or satisfaction, but these could be used as proxy measures. As such, a lack of appreciation would contribute to increased stress and potential burden for the caregiver. However, as several established measures of burden already exist (e.g. Zarit Burden Interview), the use of these proxy measures would restrict any comparability with previous studies, and there would be limitations around how representative of burden and satisfaction the responses were. As such, while some caregivers may not receive appreciation from others, this does not automatically equate to experiences of burden. To accurately determine burden among caregivers, specific burden measures could be added to future waves of ELSA.

4.3.2 Loneliness variables

For the purpose of this thesis, three distinct measures were identified to determine loneliness: a multiple-item loneliness scale, a single-item direct question and loneliness expectations. As discussed in section 1.2.2.2, the UCLA-LS is commonly used to measure loneliness. For the purpose of this thesis, the 3-item UCLA-LS is the main variable used to measure loneliness. This version is suitable for use with older adults and relevant for a UK context (Campaign to End Loneliness, no

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date), which, as the 20-item version was developed using US students, arguably makes the shorter version more appropriate for the ELSA sample. The wording and scoring of the 3-item UCLA-LS was as follows: how often do you feel that you lack companionship, how often do you feel left out, and how often do you feel isolated from others? The responses to which are ‘hardly ever or never’, ‘some of the time’, or ‘often’ scored 1-3 respectively.

To determine overall score for UCLA-LS, the three items are summed (Hughes *et al.*, 2004; Steptoe *et al.*, 2013b): scores of 6-9 would suggest the presence of loneliness. While the scoring system allocates numerical categories, it does quantify loneliness (Campaign to End Loneliness, no date), as such classifying the UCLA-LS as ordinal, not interval. Therefore, when utilising this scale, calculating averages (e.g. mean scores) would be unreliable. To clarify, the difference between scoring six or seven does not necessarily indicate a standardised increase in loneliness. Both scores would suggest the presence of loneliness, but, the degree to which loneliness changes between scores is ultimately unknown. Numerical scores are assigned to subjective categories, the interpretation of which likely differs for each respondent. Moreover, the difference between ‘hardly ever or never’ and ‘some of the time’ may not equate to the difference between ‘some of the time’ and ‘often’, despite the assigned numerical differences being the same (+/-1). Therefore, mean scores are not a reliable interpretation of UCLA-LS.

4.3.2.1 *Alternative loneliness measures*

In addition to UCLA-LS, there are single-item direct questions for loneliness in ELSA. The first question asks whether the respondent has felt lonely much of the time during the past week. This is a dichotomous variable, asked during the face-to-face interview, with responses of yes or no. The second asks how often the individual feels lonely, without a defined timescale, and is scored on a 3-point scale: ‘hardly ever or never’, ‘some of the time’, or ‘often’. Restricting the experience of loneliness to the past week could exclude individuals who may typically feel lonely but have been feeling less so this week. However, answering questions about a specific timeframe (e.g. past week), and a more typical period (e.g. typical week), are both exposed to certain levels of bias (Chang and Krosnick, 2003). Typical week responses are often overestimated, whereas past week responses are often under-reported (*ibid*). Alternatively, Angrisani *et al.*, (2015) and Araujo *et al.*, (2017) indicate that past week questions are less predisposed to recall error and reduce cognitive load on respondents. This could imply that a respondent’s report of loneliness in the past week may be more accurate than questions with vague or no timescales. For example, the direct question without a timeframe may require the respondent to consider loneliness over a longer period of time and calculate an average, whereas loneliness in the past week is a simpler recall task.

Table 4: Crosstabulation of responses to the UCLA-LS and direct loneliness questions

Direct questions		UCLA-LS	
		Not Lonely N (%)	Lonely N (%)
Loneliness (no timescale)	Hardly ever or never	3878 (83.4)	151 (12.9)
	Some of the time	741 (15.9)	650 (55.7)
	Often	31 (0.7)	367 (31.4)
Loneliness (past week)	Not Lonely	4472 (96.3)	681 (58.3)
	Lonely	172 (3.7)	487 (41.7)

Notes: % of UCLA-LS, source: author's analysis of ELSA wave 8

Crosstabulation between the two direct measures and UCLA-LS (Table 4) indicate that there is substantial affinity between responses to direct loneliness (no timescale) and UCLA-LS, whereby around 87% of respondents who score as lonely (UCLA-LS) indicate they feel lonely some of the time or often. In contrast, only 42% of respondents who score as lonely (UCLA-LS) indicate feeling lonely much of the time during the past week. The direct question about loneliness in the past week is asked during the face-to-face interview, whereas the direct question without a timeframe is included as part of the self-completion questionnaire, preceded immediately by 3-item UCLA-LS. Therefore, it is reasonable to expect higher levels of similarity between this direct loneliness question and UCLA-LS. This is supported by findings from ONS (2018c), whereby an analysis was conducted of the loneliness questions in ELSA and found strong significant correlations between the direct loneliness (no timeframe) question and the 3-item UCLA-LS. Consequently, this collinearity may influence the analysis if this direct measure, and UCLA-LS, were included. Due to the identified differences in loneliness responses and the different contexts (face-to-face interview *versus* self-completion questionnaire), direct loneliness in the past week is the most appropriate direct question to contrast with UCLA-LS. Although both measure loneliness, it is indicative that different aspects of loneliness are measured, or that there are evident differences between directly reporting loneliness and using a measurement scale.

The previous crosstabulation of direct loneliness and UCLA-LS (Table 4) indicated the majority of respondents were 'not lonely' across both measures. However, there were a number of instances where the measures did not correspond: 4% of respondents who directly-reported loneliness were not lonely on the UCLA-LS, and 59% of UCLA-LS lonely respondents did not directly report loneliness. By comparing both measures of loneliness, the aim was to include as many individuals as possible, who may be experiencing loneliness. Additionally, due to the limitations of direct questioning, whereby the negative stigma surrounding loneliness is linked to under-reporting (Campaign to End Loneliness, no date), it is important to include alternative measures of loneliness, such as UCLA-LS. The larger percentage of respondents not directly reporting loneliness, but being categorised as lonely on the UCLA-LS suggests that there is an element of under-reporting present when directly asked, which may be related to the different contexts (self-report compared to face-to-face interview).

Waves two, seven and eight included questions on expectations for loneliness. Each of the waves contained similarly-worded questions; as such, in wave eight, respondents were asked both whether

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they expected to get lonelier as they got older and, if they considered old age to be a time of loneliness. Responses to which were: agree strongly, agree slightly, neither agree nor disagree, disagree slightly, and disagree strongly. The main reason for including this variable was to determine if negative expectations for loneliness were linked to increased likelihood of loneliness. For this reason, it was deemed unnecessary to differentiate between slight and strong positive or negative perceptions, as such, slightly agreeing and strongly agreeing both implied negative expectations for loneliness. Therefore, the strongly and slightly categories were collapsed to form a single ‘agree’ or ‘disagree’ response. This meant that positive, negative, and neutral expectations could be compared.

It was hypothesised that respondents ‘agreeing’ that they expect to get lonelier with age would also think old age was a time of loneliness, but this was not necessarily the case (Table 5). As shown, only 58% of respondents who agreed they expect to get lonelier as they age also agreed that old age was a time of loneliness.

Table 5: Crosstabulation of responses to two loneliness expectation questions

Old age is a time of loneliness	As I get older, I expect to become more lonely		
	Agree N (%)	Neither agree nor disagree N (%)	Disagree N (%)
Agree	1397 (57.9)	280 (16.3)	146 (8.7)
Neither agree nor disagree	686 (28.4)	896 (52.0)	228 (13.6)
Disagree	330 (13.7)	546 (31.7)	1304 (77.7)

Notes: % of ‘as I get older, I expect to become more lonely’, source: author’s analysis of ELSA wave 8

As there were evident discrepancies in the respondents’ interpretation of the questions, issues arose for the author when selecting variables. Further considerations were made around question wording to ensure the most appropriate variable was selected to represent loneliness expectations. It was considered that expecting to become lonelier as they age as opposed to believing old age was a time of loneliness was more personal and thus demonstrates that the stereotype was internalised, which aligns with the SET framework.

To measure loneliness, the predominant variable throughout this thesis is the UCLA-LS, however in RQ1a (section 5.2.2) three loneliness measures are compared to identify differences between the measurement tools. Additionally, in the follow-up analyses, loneliness expectations in earlier waves are examined in relation to UCLA-LS loneliness in wave eight and across all waves.

While ELSA includes a range of loneliness measures, such as the aforementioned UCLA-LS, two direct loneliness questions, and loneliness expectations, another common loneliness scale is the DJGLS (section 1.2.2.2). The main advantage of the DJGLS is the ability to examine the social and emotional subscales of loneliness, which is not possible with UCLA-LS. Therefore analysis of loneliness using ELSA data cannot separate the different loneliness types. Nevertheless, as demonstrated in this thesis (section 5.2.2) there is scope for comparing different methods of measuring loneliness, i.e. direct single-item, and indirect scale measures (UCLA-LS).

4.3.3 Health variables

Health is multi-dimensional. Within published literature, the measurement of health ranges, including: self-rated general health, self-reported health conditions, scales for mental health and the use of medical professionals' diagnoses. Within this thesis, a number of health measures are used, including variables that align with SET, mental health scales, and self-reported limiting illnesses.

Self-rated general health is a widely used health measure (Garbarski, 2016), which is reportedly related to health outcomes and mortality (Bailis *et al.*, 2003; Feenstra *et al.*, 2020). However, self-rated health was excluded from these analyses because of its generic nature; as such, the included health measures focus on specific areas of health, whereas self-rated health asks broadly about overall health. Moreover, an individual could also perceive their health as 'good', in relation to someone they know with poorer health than themselves, but they still may have chronic conditions, or poor behavioural health. Therefore this 'good' response would not necessarily reflect good health.

Garbarski (2016) indicates that often the purpose of self-rated health measures are to act as proxies for more objective measures, such as self-reported conditions. Arguably, therefore, self-rated general health is redundant since ELSA data includes more objective measures. Additionally, when identifying policy implications from the results of this thesis, the recommendations can be tailored more specifically to certain areas of health, if more objective measures are used. The following sections discuss the health measures used within this thesis: ones that align with SET and additional health measures.

4.3.3.1 *Stereotype embodiment theory: health-related measures*

As identified in section 2.1.2, SET outlines three distinct health pathways: physiological, behavioural, and psychological. For each of these pathways, the most appropriate variables were sourced within ELSA. This section will discuss the selection of each of these variables.

Physiological health considers the impact of internalised age-stereotypes on CV activity, and the stress response (Meisner and Levy, 2016). To measure physiological health, diagnoses of specific CV conditions are used. SET typically refers to particular outcomes, including CV responses such as heart rate and blood pressure measurements (Levy *et al.*, 2000), or specific CV events including angina, heart failure, heart attacks, and strokes (Levy *et al.*, 2009). However, Levy (2009) indicated that the heightened CV responses can also increase susceptibility to further CV problems and have negative consequences on recovery from CV events (Levy *et al.*, 2006). Within ELSA, there are data available on a large range of chronic CV conditions, including the aforementioned SET CV responses and events, but also additional data on arrhythmias and other diseases. In this thesis, a binary variable is created to identify individuals with a relevant health condition; which included the presence of one of the following: hypertension, angina, congestive heart failure, heart murmurs, heart attacks, strokes, arrhythmias, other heart diseases and dementia. Most of these conditions were selected because they

were specifically named in previous SET literature, as above. However, due to the highlighted susceptibility to other CV conditions it was deemed relevant to include all available CV conditions from the ELSA data.

Alternatively, dementia could be considered less appropriate for inclusion in the physiological pathway. However, dementia, specifically vascular dementia, which is the second most common form, is caused by reduced blood flow to the brain (NHS, 2017; British Heart Foundation, 2019) and is often medicated using drugs for hypertension (British Heart Foundation, 2019), so could theoretically be grouped with other CV conditions. Additionally, de Roos *et al.* (2017) advocate that dementia is CV-driven, primarily, problems with the proximal aorta are an indication of not only CV health, but also cerebrovascular damage, including memory loss, cognitive decline and dementia. Evidence also suggests that with progressing CV symptoms, ranging from risk factors to CV disease, the risk of developing cognitive impairment and consequently dementias increases (Abete *et al.*, 2014). Literature also suggests a prominent association between dementia and loneliness in both directions; for instance loneliness is associated with increased risk of cognitive decline and dementia (Holwerda *et al.*, 2014; Mushtaq *et al.*, 2014) and individuals with dementia are likely to report loneliness (Holmen *et al.*, 2000; Moyle *et al.*, 2011). Therefore, it was considered an important and highly relevant condition to include.

Conditions that the respondent 'still has' from previous waves, and any new diagnoses in the current wave were combined. A wide range of CV conditions were included in the physiological health variable, because research suggests that validity is higher among self-reported measures when a broader definition is adopted (Valtorta *et al.*, 2018). Arguably, several of the CV conditions listed in ELSA represent CVD risk factors (e.g. diabetes or high cholesterol). Individuals with diabetes are at higher risk of CVD (Diabetes UK, no date). Moreover, recent statistics from the American Heart Association categorise diabetes and high cholesterol as CVD risk factors (Benjamin *et al.*, 2019). The International Classification for Disease also states that metabolic conditions (i.e. diabetes), are excluded from the circulatory disease category (a component of CVD) (WHO, 2006). Although hypertension is also considered to be a risk factor (Benjamin *et al.*, 2019), simultaneously there are multiple hypertensive diseases that are categorised as CVD (WHO, 2006, Benjamin *et al.*, 2019). For these reasons, diagnoses of diabetes and/or high cholesterol are excluded. Furthermore, due to a high prevalence of hypertensive diseases (*ibid*), and the accepted classification of hypertensive diseases as CVD, hypertension was included in the physiological health variable.

Behavioural health refers to healthy practices, or preventative health behaviours. Examples of behavioural health variables in ELSA include alcohol consumption, smoking, and physical activity.

The questions on alcohol consumption in ELSA relate to the frequency, as opposed to the volume. This contrasts with published guidelines, which recommend weekly unit limits (NHS, 2018; Drink Aware, 2020). The aforementioned guidelines suggest that those regularly consuming 14 units per week should spread this over three days rather than frequently consuming excessive volumes of

alcohol, and that individuals should have several alcohol-free days each week (*ibid*). ELSA variables measure frequency of consumption over the past twelve months, and past seven days. Data over the past year gives a better impression of typical drinking patterns in comparison to the past week; for example, an individual may report that they have not had an alcoholic drink this week, but this may not be indicative of their usual drinking behaviours. Moreover, data for a larger proportion of the sample were collected for the past twelve months compared to the past week (N=7,134 and N=4,470 respectively in wave eight), as individuals who consumed alcohol on a less-than-weekly basis were ineligible for the question about the past week.

Furthermore, in ELSA, data were collected to identify respondents who had ‘ever smoked’ (i.e. previous smokers) and those who ‘smoked at all nowadays’ (i.e. current smokers). However, the ambiguity surrounding the ‘ever smoked’ variable made it difficult to quantify behavioural health. Theoretically, this would include individuals who had smoked only once, individuals who smoked briefly at a younger age but had not smoked for a substantial period of their life, and those who continuously smoked throughout their life but had recently quit, with no indication of which category the respondent might fall under. Moreover, there were a substantial amount of missing data, whereby a large proportion of the respondents were not asked about having ever smoked, with a sizeable majority of respondents marked as not applicable across the waves. The data were more populated for current smokers, the majority of respondents had provided a response. However, again, there were limitations, in that quantity or frequency of smoking behaviours could not be identified. Individuals who occasionally smoked, for example, socially with friends, would be categorised with individuals who smoked full packets of cigarettes daily.

With regard to physical activity, ELSA variables measure the frequency of mild, moderate and vigorous sports or activities; the responses to which are ‘more than once per week’, ‘once per week’, ‘one to three times per month’ and ‘hardly ever or never’ (Clemens *et al.*, 2019). Aligning with exercise guidelines, which recommend that 150 minutes of moderate aerobic activity, 75 minutes of vigorous aerobic activity, or an equivalent combination of both, are completed each week alongside strength training exercises on at least two days per week (NHS, 2019) the variables for moderate and vigorous activity were used to compute a new variable, which identifies all respondents participating in either moderate or vigorous activity more than once per week.

Initially, a behavioural health variable was constructed similar to the physiological health variable above, in that a binary variable identified respondents who presented with one or more measure of poor behavioural health (smoker, frequent alcohol consumption, or limited physical activity). Preliminary results returned non-significant results, and upon review it was deemed that aggregating the behavioural health variables was ineffective due to loss of information. Additionally, over 90% of the overall sample exhibited at least one negative health behaviour, skewing the sample towards poor behavioural health. In relation to loneliness, smoking, alcohol consumption and physical activity were likely to have substantially different relationships so further analyses were conducted

including all three behavioural health variables as controls. However, changes to confidence intervals and fit statistics suggested that overfitting may become a concern, particularly due to large numbers of health-related controls in some models. Therefore, for these analyses, a single example of behavioural health was selected.

The example of behavioural health utilised in these analyses was frequency of alcohol consumption. This was selected due to firstly, a stronger conceptual link with both caregiving and loneliness, known as a common coping mechanism. But also previous analysis suggested stronger links between alcohol and loneliness in comparison to the other two behavioural health variables when included in the models individually. A new variable was computed to reflect the guidelines of spreading consumption over a few days and having several alcohol free-days (Table 6). Although these groups do not reflect the volume of alcohol consumed, individuals consuming alcohol more than three to four days per week are not having several alcohol-free days, thus suggestive of high-risk drinking.

Table 6: Recoding of the behavioural health variable, frequency of alcohol consumption

How often the respondent had an alcoholic drink in the last 12 months	Over the past year, did the respondent regularly consume alcohol ≥ 3 days per week?
Almost every day	Yes
5-6 days per week	
3-4 days per week	
1-2 days per week	No
Once or twice per month	
Once every couple of months	
Once or twice per year	
Not at all in the last 12 months	

Source: author's analysis of ELSA wave 8

While psychological health may often be used interchangeably with mental health, in this thesis psychological health refers to health expectations and stereotypes within the SET pathway. Mental health is determined using depressive symptomatology (section 4.3.3.2). Similarly to the expectations for loneliness, corresponding questions were asked about health. In wave eight, respondents were asked both whether they worry about their health getting worse as they get older, and if they consider old age to be a time of ill health, responses to which were: agree strongly, agree slightly, neither agree nor disagree, disagree slightly, and disagree strongly (ELSA, no date [b], question 36). Corresponding with the loneliness expectations variable, the strongly and slightly categories were collapsed to form a single 'agree' or 'disagree' response, regrouping to form single positive, negative, and neutral categories. Table 7 shows the crosstabulation of responses to both questions: 61% of respondents who agreed that they expected health to get worse as they age, also agreed that old age was a time of ill health. The more personal question 'I worry that my health...' was selected as the measure for psychological health, as this reflected an internalised stereotype, in comparison with 'old age is...' which is arguably more generic.

Table 7: Crosstabulation of responses to two health expectation questions

Old age is a time of ill health	I worry that my health will get worse as I grow older		
	Agree N (%)	Neither agree nor disagree N (%)	Disagree N (%)
Agree	2482 (60.7)	262 (25.7)	163 (22.3)
Neither agree nor disagree	955 (23.4)	412 (40.4)	175 (23.9)
Disagree	651 (15.9)	345 (33.9)	393 (53.8)

Notes: % of 'I worry that my health will get worse as I grow older', source: author's analysis of ELSA wave 8

4.3.3.2 Other health measures

In addition to SET health pathways, self-rated LLTI is used as an overall health measure. This variable is applied as part of the caregiver characteristics, a determinant of loneliness and a health control variable in different research questions within the thesis. Long-term illnesses, particularly limiting ones, could be seen as restrictive. LLTI is also suggestive of disability, and may be indicative that the respondent requires assistance or receives care. This may influence the caregiving role, if an individual is receiving care, it is unlikely they will have capacity to provide care for others. Additionally, LLTIs may reduce physical and social activities outside of the caregiving role, which, in turn, may lead to loneliness.

The Centre for Epidemiological Studies Depression Scale (CES-D) measures depressive symptomatology. This scale is used to assess mental health amongst the respondents. CES-D is a valid and reliable measure amongst the general population and older adults, and is used commonly in large population-based studies such as ELSA and HRS (Karim *et al.*, 2015). The full version of CES-D is administered as a 20-item scale; however, an 8-item version is often favoured by researchers as the validity and reliability are comparable to the original version (*ibid*). Typically, CES-D is scored on a 4-point Likert scale. However, in ELSA, CES-D questions are binary, scored as yes/no. Therefore, instead of scores ranging from 4-32, scores ranged from 0-8, but higher scores remained suggestive of depression. This method of scoring is common in other population surveys, as CES-D results in ELSA are comparable with HRS (Kapteyn, 2008; Crimmins *et al.*, 2010), which also utilises dichotomous scoring (Steffick, 2000). Moreover, recent publications from Kobayashi and Steptoe (2018) and White *et al.* (2018) analyse CES-D in ELSA, and advocate a score of ≥ 3 is suggestive of depressive symptomatology. One of the questions within CES-D asks whether the respondent has felt lonely much of the time during the past week, which is utilised as the direct loneliness question. To avoid overlap, and potential multicollinearity, this question was excluded when calculating depressive symptomatology score; this exclusion was also applied in other literature analysing both loneliness and CES-D (Kobayashi and Steptoe, 2018).

4.3.4 Wellbeing variables

The CASP19 scale is a common measure of QoL among older adults (Wiggins *et al.*, 2008; Sim *et al.*, 2011; Howel, 2012). CASP refers to four life domains (Control, Autonomy, Self-realisation, and Pleasure), and 19 indicates the number of items. CASP19 includes a combination of negatively and

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positively worded items, and is typically scored from 0-57, with higher scores indicating greater QoL (Wiggins *et al.*, 2008; Sim *et al.*, 2011; Howel, 2012). In ELSA, the responses, 'often', 'sometimes', 'not often' and 'never', are all coded 1-4 respectively. Therefore, to reflect the 0-57 scoring system and to ensure that higher scores reflect greater QoL, recoding was required. The negatively worded questions were reverse coded (0-3 often to never), and the remaining positively worded questions were recoded from 3-0, often to never. For these analyses, the sum of all CASP19 variables was calculated to reflect the total score.

Finally, within literature, the Satisfaction with Life Scale (SWLS) is typically scored from 5-35 so that higher scores are indicative of greater life satisfaction. To reflect this, the seven-point Likert scale ranges from strongly disagree (1) to strongly agree (7) (Diener *et al.*, 1985). In the original ELSA data, these responses are reverse coded (strongly disagree=7, strongly agree=1), therefore recoding was necessary. Similarly to the CASP19, a variable was computed to determine total score. The score should remain continuous (*ibid*), thus SWLS reflects the sum of the seven variables.

4.3.5 Sociodemographic variables

Largely, sociodemographic characteristics act as control variables within the analyses. The inclusion of control variables allows insight into the effect of each variable after accounting for all of the other variables. Moreover, when characteristics such as sex are included in regression analyses, the results indicate effects for males *versus* females in isolation of all the other variables, in addition to the overall model. The sociodemographic characteristics included within this analysis are: age, sex, and cohabitation.

To reduce the likelihood of respondents being identified, age is collapsed at 90-years; therefore, the range within the analytical sample is 50-90 years. To analyse differences between age groups, this was split into 50-59, 60-69 and ≥ 70 . The decision was made not to separate 70-79 from ≥ 80 because only a small minority of caregivers were aged ≥ 80 -years (N=91, 10%), thus, in an attempt to minimise small cell counts throughout the regression analyses, this variable was collapsed further. The sex of respondents was determined using a dichotomous variable, permitting responses of either male or female. Within this thesis, this is termed as sex, not gender, due the lack of diversity in the response options. To clarify, the distinction between sex and gender is that sex refers to biological difference, whereas gender reflects a social identity of the individual (Mitchell, 2004). Therefore, to constitute gender, it additional responses should be available (e.g. non-binary or transgender); it is proposed that ELSA should include additional gender options in future waves.

Marital status is readdressed for all respondents at each wave. Therefore, changes such as widowhood or divorce can be observed longitudinally. The responses for marital status include: (i) single never married, (ii) first marriage, (iii) second or later marriages, (iv) legally separated, (v) divorced, and (vi) widowed. For the purpose of this thesis, legally separated and divorced were merged into a single

category, as representation of the legally separated variable was limited and conceptually, this was deemed most similar to divorced. Gov.UK (no date) suggest that legal separation is considered an alternative to divorce for individuals with religious beliefs that prohibit divorce. Furthermore, it is common within loneliness literature to merge non-married categories (e.g. separated and divorced), as they are reported to have similar psychological, social, or economic outcomes (Ben-Zur, 2012). In this thesis, widowhood remained separated from legally separated and divorced, because evidence suggests significant differences in loneliness between divorced, widowed, and married individuals (Dahlberg *et al.*, 2018a). In addition to marital status, cohabitation was measured by determining if respondents lived with a partner or spouse. Evidence suggests that research on cohabitation and loneliness is limited, compared to that on marital status (Buecker *et al.*, 2020), thus identifying a need for research that considers cohabitation. Arguably, the presence of a close relationship (cohabiting partner, married or unmarried) would have a more substantial effect on loneliness, than the legal status of the relationship. Research from Perelli-Harris and Styrac (2017) compared married and cohabiting individuals in relation to mental wellbeing, and suggested that relationship type had little effect. Furthermore, particularly throughout Europe, cohabitation is often considered an alternative to, or precursor to, marriage (Sassler and Lichter, 2020). As such, single, cohabiting individuals should experience similar benefits of a significant emotional attachment as for married cohabiting individuals. Von Soest *et al.* (2018) highlight that relationship quality is considered integral to loneliness, and therefore further emphasis should be placed on close relationships or spousal/cohabiting partners, in relation to loneliness. Within their study, cohabitation and marriage was combined suggesting the two are comparable.

A limitation of the ELSA dataset is the lack of ethnic diversity, with >95% of the total sample at each wave identifying as White. Moreover, the remaining ethnic categories are consolidated into a single category to create a dichotomous variable: White *versus* Non-White. Alongside the small sample of Non-White respondents, a further limitation is that the diversity of the Non-White ethnicities is lost by aggregating these respondents. To clarify, this category contains all Asian, Black, and other ethnic groups. Due to lack of a representative sample of ethnic minorities, ethnicity was excluded from the analyses; the omission of the ethnicity variable is common among studies using the ELSA dataset (Torres *et al.*, 2016; Wade *et al.*, 2017; Valtorta *et al.*, 2018).

4.3.6 Socioeconomic variables

There are several variables in ELSA which can be used to determine SES, such as education, employment status, and wealth. ELSA is known for having high-quality wealth variables (Banks *et al.*, 2011). Torres *et al.* (2016) indicate that wealth is the strongest indicator of SES in ELSA, and amongst older adults, as the association between wealth and mortality is greater than other SES indicators. To determine wealth, ‘total non-pension net wealth’, is commonly used (Demakakos *et al.*, 2016; Torres *et al.*, 2016); this reflects financial and physical wealth and wealth from business and property assets, minus any debt. **The wealth variable refers to the benefit unit, or household and**

provides an aggregate value of wealth (Oldfield, 2018). The ELSA researchers indicate in the financial variables user guide that the wealth variables are not equivalised because, there is no universally accepted method to adjust wealth in accordance with household size (ELSA, no date [a], p.8). This therefore could place single-person households at a disadvantage when measuring wealth, but arguably wealth is still more appropriate as a measure of SES than income, which is less relevant for older adults due to high prevalence of retirement. Moreover, Demakakos *et al.* (2016) highlight that this wealth variable is the most appropriate for use within an older adult population, derived from 22 wealth components, as well as reflecting assets accumulated over the lifecourse. Other SES variables, such as education, employment, or income do not consider assets accumulated over the lifecourse. Moreover, as a minority of older adults tend to be in paid employment, as opposed to retired, wealth is arguably more relevant to determine current SES. Within this thesis, quartiles of total non-pension net wealth were calculated.

Furthermore, in ELSA, employment status is determined by asking if the respondent was in paid employment during the last week, including temporary leaves of absence from their regular job. Arguably employment is not as relevant among older adults, due to the high prevalence of retirement; therefore, the number of non-employed respondents in the sample is likely to be considerably higher than those in employment. However, although not as strong an indicator of SES as wealth, employment status was deemed an important socioeconomic variable to include in these analyses. Firstly, as of 2017 (ELSA wave eight data were collected in 2016/17), the state pension age in the UK was 65-years (Age UK, 2017), thus there is a considerable portion of the ELSA sample still below statutory retirement age in England, i.e. those aged 50-64 years. This is also set to increase over the coming years, so employment will become increasingly more relevant for older samples. Additionally, evidence suggests non-employed caregivers experience higher levels of depression, mortality and functional limitations (Caputo *et al.*, 2016). Moreover, high-intensity caregiving has been shown to be negatively correlated with employment (Ciccarelli and van Soest, 2018). Thus employment was considered highly relevant when examining the impact of caregiving, even among older adults.

4.3.7 Social network variables

Stephens *et al.* (2011) suggest that both the size of social networks, and the members that constitute the network, impact perceived social support and loneliness. Moreover, many of the loneliness definitions emphasise the importance of both quality of relationships, alongside quantity (section 1.2.2). Therefore, to gain a more detailed insight into the social networks of respondents, it was necessary to acknowledge the number of people in an individual's network, but also consider the quality of these relationships.

In the self-completion questionnaires (ELSA, 2019b), respondents were asked about relationships with their children, immediate family, and friends. To determine average frequency of contact the

questions included several forms of communications (e.g. face-to-face, phone calls, and written communications). Although increased frequency of contact might suggest greater relationship quality, the multiple modes of contact could be construed differently. As such, an individual who lives within close geographical proximity of their family may have more face-to-face contact. Whereas an individual with family members in different locations may maintain regular contact via phone, but have limited availability to meet in-person. Thus, the mode of contact is not necessarily reflective of relationship quality without additional context. Alternatively, there were questions which asked how many of their children, family members, and friends, the respondent considered themselves to hold a close relationship with. These responses provide insight into the number of higher-quality relationships that an individual perceives themselves to have. For these analyses, the children and family members variables were merged, as both were considered reflective of immediate family, which also reduced the likelihood of respondents with no children being excluded from the analyses. However, it should be acknowledged, that while this variable allows the quantification of reported close relationships, it does not provide much detail about the quality of each. For example, those that listed being close with multiple friends and family members, it is unlikely that all these relationships were of the same quality. Therefore, the level of detail within this variable is focussed more on the size of someone's network than the quality. Additionally, while close family relationships can be separated from friendships, there is no supplementary information on who that person is, i.e. sibling or parent. This reflects both a limitation of the ELSA dataset, whereby specific questions about relationships were not included in the questionnaires or interviews in order to examine social networks in more detail, but this also limits the interpretation of the variable. To illustrate, using this variable, very little inference can be drawn on the link between loneliness and relationship quality or the members that constitute the network other than comparing family with friends.

Household demographics have also been linked to loneliness, such as whether a respondent has a spouse/partner (Kemperman *et al.*, 2019). As this information can be determined from marital status or cohabitation, additional household demographics were obtained using household size, that is, the number of people living in the household. Hill and Dunbar (2003) indicate that household members are fundamental to an individual's social network. In ELSA, household size was determined using a continuous variable, whereby in wave eight, the valid responses ranged from 1-11. The modal value was two, indicating that dual-person households were the most common. Due to small cell counts for the larger households, particularly for >5 people, the variable was collapsed into three categories: single person household, dual-person household, and large household (≥ 3 people).

4.3.8 Variables computed for the follow-up analysis

In RQ3 analyses were conducted using wave two as the first time-point, and wave eight as the second time-point. Using waves 3-7, variables were computed to control for changes that may have occurred

over the 12-year period between waves two and eight. The key areas of change were caregiving, loneliness, and mental health.

4.3.8.1 Defining the caregiving relationship and role across the waves

To analyse the long-term associations between caregiving and loneliness, it was important first to quantify caregiving over the 12-year period. Using the caregiving variable from each wave (2-8), 1,445 respondents had reported providing care in at least one wave. It was of interest to test whether caregiving for longer periods of time, rather than for shorter periods, was more likely to be associated with loneliness. Of the caregivers, most (N=633, 44%) provided care in only one wave, which were categorised 'short-term'. Only 14 caregivers (<1%) reported providing care in all waves. Thus, due to this small sample, it was not possible to statistically examine consistent caregivers (waves 2-8) as a distinct group. Moreover, there is limited definitive criteria surrounding what constitutes 'long-term' caregiving. US data suggests that the average length of a caregiving role is four-years, with 24% of caregivers providing care for ≥ 5 -years (National Alliance for Caregiving and AARP, 2015; Barnhart *et al.*, 2020). A Canadian study investigating the impacts of the caregiving role defined short- and long-term as less than, or more than two-years respectively (Williams *et al.*, 2014). Whereas Lacey *et al.* (2019) divided their UKHLS sample at ≥ 3 -years for long-term care. As ELSA data are collected every two-years, it is not possible to know what occurs between the data collection points, that is, whether caregivers continued to provide care consistently, or not. However, for the purpose of this analysis, long-term caregivers are defined as providing care for two or more consecutive waves (N=594, 41%). Some caregivers did not align with either the short-term or long-term classification; 15% (N=218) of caregivers reported providing care in more than one wave, but not consecutively (e.g. care provision in waves two and six). In this thesis, these individuals were categorised as 'intermittent caregivers'. However, caregivers providing multiple episodes of care have been labelled differently within the literature, Larkin (2009) initially developed the term 'serial caregiver', also adopted by Corey and McCurry (2018); whereas Lacey *et al.* (2019) refer to them as intermittent caregivers.

Dummy variables were used to identify whether caregivers had (i) ever provided care to any of the recipient groups (see below), (ii) ever provided co-residential care, (iii) ever provided high-intensity care, (iv) ever provided round-the-clock care, and (v) ever provided care to multiple recipients. These variables were created because, short-term caregivers were included in the analyses for RQ3b and RQ3c, therefore, as care provision occurred in only one wave for many of the sample, changes between waves could not be observed. To identify the care recipient, variables were created from reported relationships across all waves, and grouped into those who had 'ever cared for adult-child', 'ever cared for parent/parent-in-law' and 'ever cared for others', with spousal caregivers as the reference category. Due to individuals providing care to multiple recipients, which may be from the same, or different recipient groups (e.g. two parents, or a spouse and a neighbour), and missing data, it was not possible to accurately compute a variable to track care recipient changes between

caregiving episodes. Additionally, changes between care recipients within the same category would not be identified. For example, if a respondent was providing care to their mother-in-law in wave two, then to their own mother in wave six, both recipients would be classified as ‘parent/parent-in-law’.

4.3.8.2 *Loneliness and changes to loneliness expectations*

In RQ3b and RQ3c of the follow-up regressions, the DV represents loneliness occurring after the start of care provision. This was computed by identifying which waves caregiving and loneliness were first reported. Those who indicated providing care prior to reporting loneliness were compared with those never reporting loneliness. For example, for caregivers who started providing care in wave two, their loneliness was reported at wave three or later. An implication of this variable was therefore that all caregivers reporting loneliness at wave two were excluded, because it was not possible to identify if they provided care prior to reporting loneliness, as wave two was the first wave whereby all relevant variables for these analyses were included. Furthermore, caregivers from wave eight were excluded, because at the time of conducting the analyses, ELSA wave nine data were not available, so future loneliness could not be determined. Table 8 demonstrates the waves in which caregiving and loneliness could be reported for each respondent.

Table 8: Computing the loneliness occurring after the start of care provision variable

Wave in which caregiving was first reported	Wave in which loneliness was first reported
Wave 2	Waves 3-8
Wave 3	Waves 4-8
Wave 4	Waves 5-8
Wave 5	Waves 6-8
Wave 6	Waves 7-8
Wave 7	Wave 8

Source: author’s own

Loneliness expectations were only asked at waves two, seven, and eight. To control for loneliness expectations in the follow-up analyses, comparison was drawn between these time-points and individuals were grouped into six categories: (i) stable– always agree, (ii) stable– always neither, (iii) stable– always disagree, (iv) negative (disagree to agree/neither, or neither to agree), (v) positive (agree to neither/disagree, or neither to disagree) and (vi) fluctuating. It was deemed important to distinguish between the stable categories because individuals who persistently agreed (expected to get lonelier with age), in line with the theory of self-fulfilling prophecies in SET, should have different loneliness outcomes to those who persistently disagreed (did not expect to get lonelier with age). Moreover, it is unclear how individuals who responded with neither perceive their future loneliness, therefore there was a lack of evidence available to collapse this into another category.

4.3.8.3 *Changes to mental health: depressive symptomatology*

Research on obesity transitions, over an 8-year period in ELSA, computed a variable to account for changes to weight between the time-periods (Hamer *et al.*, 2015). To compute this variable, data were compared at baseline (wave two), a mid-point (wave four), and at follow-up (wave six). This method was applied when computing the mental health change variable for RQ3c (how are the caregiving relationship, and role, associated with loneliness for short-term *versus* long-term, or intermittent caregivers?). CES-D variables were compared at wave two, wave five, and wave eight, to identify how caregivers' mental health changed over the 12-year period. The respondents were classified according to whether their CES-D score was indicative of depressive symptomatology at each wave: (i) stable– no depressive symptoms, (ii) decrease in depressive symptoms, (ii) increase, or stable depressive symptoms, (iii) fluctuating. Due to a small number of respondents who had depressive symptoms at all data collection points (N=49, 1.7%), these were collapsed with the 'increase' group. It was deemed most appropriate to include those with persistent depressive symptoms with those who had developed depressive symptoms, as all other groups involved either absence or reduction in depressive symptoms at some point between waves two, five, and eight. Full descriptive information is included in section 6.2.1.2.

4.3.8.4 *Control variables in the follow-up analyses*

After reviewing published research using ELSA data, and similar follow-up methods over a range of different time-periods, the most common means of including control variables was to adjust for baseline measurements (Shankar *et al.*, 2013; Fancourt and Steptoe, 2018). As such, for this thesis, aside from the computed change variables for loneliness expectations (section 4.3.8.2) and mental health (section 4.3.8.3), the control variables included sociodemographic, SES, social network, health, and wellbeing variables from wave two (sections 6.2.2 and 6.2.3). This method of including only baseline controls, and treating them as time-invariant, was selected to avoid complex regression models whereby the interpretations would be difficult. However, changes to loneliness expectations and mental health were included to better understand the effect of these conceptually important variables on loneliness. For discussion on the limitations of this approach, see section 7.5.3.

There was conflicting evidence (using ELSA data) about whether controlling for the outcome variable at baseline was appropriate. For example, Jackson *et al.* (2019) examined the prospective association between age discrimination at wave five, and health outcomes at wave eight, and in their analyses, the outcome variable was excluded at baseline. Alternatively, Shankar *et al.* (2013) investigated the relationship between loneliness and isolation at wave two with cognitive function at wave four. These regressions were conducted with a control for baseline cognitive function. For the purpose of this thesis, both methods were adopted and contrasted. In RQ3a separate regressions were conducted (i) when lonely individuals at baseline were excluded, and (ii) controlling for baseline loneliness.

4.3.9 Weighting

Cross-sectional weighting was calculated by the ELSA research team for core sample members across all waves of the study. Weighted respondents include proxy and partial interviews, but do not include individuals living in institutionalised settings, those who live outside of England, and partners of core members (NatCen, 2018b). However, within this thesis, proxy responses were also excluded, alongside the non-weighted individuals. Cross-sectional weights were calculated separately for each cohort using ONS household data, and account for refreshment samples, and non-responders who may have responded in some waves, but not all. This ensures that all cohorts are represented in the same proportions. Weighting was also introduced for the self-completion questionnaire between waves 4-7, and individuals who returned the survey without answering the majority of the questions were allocated a weight of ‘system missing’ to be excluded from analyses (*ibid*).

To be eligible for longitudinal weighting, a core member must have responded to all of the waves of ELSA, to date. As such, longitudinally-weighted respondents in wave four were core members who had responded in waves 1-4 of the survey. Moreover, in wave eight, those with longitudinal weights had provided responses in waves 1-8. Unlike the cross-sectional weights, non-responders were not eligible for longitudinal weighting (NatCen, 2018b). The longitudinal weight was calculated for 3,470 core members who responded to all waves and continued living in private households, excluding individuals who reside in institutionalised settings.

The ELSA research team advocates the use of cross-sectional and longitudinal weights when analysing the data to minimise the bias of non-response (NatCen, 2018b). The cross-sectional weight applied to wave eight was ‘*w8xwgt*’, and the longitudinal weight, which was used to compare respondents between waves two and eight, was ‘*w8w1lwgt*’.

4.4 Quantitative methods

Within this thesis, several statistical techniques were used: initial linear regressions to obtain collinearity statistics and to rule out multicollinearity, descriptive analyses such as crosstabulations, and bivariate tests including Chi-squared statistics and Spearman’s Rho (r). For the multivariate analyses, the primary methods were binary and multinomial logistic regressions and linear regressions. The following sections will address the assumptions and provide an overview of each of the tests.

4.4.1 Bivariate analysis

Bivariate analyses were conducted to determine if any associations existed individually between any of the independent variables (IVs) and the two DVs. Chi-squared tests were used for categorical variables and Spearman’s r for continuous variables.

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A Pearson's Chi-squared test is used to determine whether two categorical variables are associated; the statistic is calculated by comparing observed with expected frequencies (Stockemer, 2019). The main assumption for a Chi-squared test is that both variables are categorical, and each variable has a minimum of two categories (e.g. caregiver and non-caregiver) (Field, 2013). A greater number of categories increases the degrees of freedom (df) for the test statistic, which equates to a larger critical value, Chi-squared statistics above the critical value are considered significant. Another assumption is that the observations are independent (McHugh, 2013); a Chi-squared test can be used to determine an association between caregiving and age, but should not be used to compare pre- and post-observations, such as self-rated health before and after caregiving, as these variables would be paired. One of the main limitations of the Chi-squared test is the sensitivity to sample size and cell counts; a larger sample size is advantageous and will yield results with greater statistical power. However expected cell counts must be greater than five for the majority of the cells (typically accepted that $\geq 80\%$ of cells should have an expected cell count > 5). In all reported Chi-squared analyses, these checks were carried out and, in all tables, less than 20% of cell counts were < 5 . A further limitation is that the Chi-squared test only indicates whether variables are independent. If an association is present, the nature and direction must be tested using alternate methods.

However, as the Chi-squared test is only appropriate for categorical variables, Spearman's r is used to determine bivariate correlations among continuous variables. A Pearson's correlation would not be an appropriate method, as an assumption of this test is that both variables are continuous. Unlike the Chi-square test, Spearman's r measures both the magnitude and the direction of a relationship between two variables. Spearman's r ranks the X and Y values independently of one another, then performs the correlation based on the ranks (Wilcox, 2016) and can be used with non-parametric data (Field, 2013).

4.4.2 Multivariate analysis

Logistic regressions are used to predict a categorical outcome, using a combination of categorical or continuous predictor variables. In this thesis, the main DV, UCLA-LS, alongside other loneliness and health variables (section 4.3) was categorical, therefore logistic regressions were the most appropriate method. Furthermore, binary logistic regressions were used when the outcome has two categories, or multinomial logistic regressions when the outcome has more than two categories. Although regressions are considered to be linear models, this assumption cannot be met with categorical variables; therefore, a link function of the outcome is given. For logistic regression, this

is typically the logit, or log-odds calculated as:
$$P(Y) = \frac{1}{1 + e^{-(b_0 + b_1 X_{1i})}}$$
 where P(Y) represents the probability of the outcome (e.g. being lonely, $Y=1$), e represents the natural logarithm base, b_0 the Y intercept, b_1 the predictor-outcome relationship, and X_{1i} the predictor variables' value (Field, 2013). In logistic regression output tables, B is given in log-odd units, thus it is assumed that the logit is

linearly related to the explanatory variables. However, odds ratios ($\text{Exp}(B)$) are more intelligible and are frequently used within research to interpret logistic regressions.

When using SPSS software, as standard, the logistic regression output reports the Nagelkerke R square. This statistic explains the proportion of variance in the outcome variable, which can be explained by the predictors in the model. Aurora and Elena (2019) suggest that Nagelkerke is favoured over Cox and Snell due to its ease of interpretation; the Nagelkerke scale ranges from 0-1 providing a percentage of variance, whereas this is not the case for Cox and Snell. In addition to Nagelkerke, the Hosmer-Lemeshow statistic is an additional measure of model fit. The Hosmer-Lemeshow test sorts observations into ten groups based on the regression model predictions. The observed and estimated frequencies are then compared in a contingency table, and a Chi-squared statistic is used to determine goodness of fit (Fagerland and Hosmer, 2017). If the significance level of the Chi-squared statistic is above 0.05, then the model is deemed a good fit, whereas a significant Chi-squared ($p < .05$) indicates a poor model fit.

Alternatively, linear regressions are applied when the outcome variable is continuous. A typical linear regression equation is denoted as: $Y_i = \beta_0 + \beta_1 X_i + \varepsilon_i$ whereby: Y_i represents the outcome variable, β_0 the intercept, X_i the predictor and β_1 corresponding coefficient, and ε_i is the error associated with the model (Field, 2013). One of the main assumptions of a linear model is that the DV is continuous, and the IVs are continuous or binary (Tranmer *et al.*, 2020). To accommodate this assumption, categorical variables in the analysis were recoded into dummy variables. The SPSS output from a linear regression provides an R^2 value. The R^2 value indicates the variance explained by the model (Field, 2013), similar to the Nagelkerke R^2 , discussed previously. Another main assumption of both regressions is limited multicollinearity, which is discussed in the subsequent section.

4.4.3 Missing data

A complete case analysis (CCA) approach was applied throughout this thesis, therefore all analyses were restricted to respondents with complete data for all included variables. The main limitation to this approach is that the sample size is often substantially affected, which can lead to a loss in statistical power (Lodder, 2013). However, CCA was deemed more appropriate than other methods of dealing with missing data, such as imputation. Largely, imputation methods require the missing data to be missing at random (dependent only on observed data but not unobserved data), or missing completely at random (unrelated to observed or unobserved data) (Hughes *et al.*, 2019; Griswold *et al.*, 2021). Whereas CCA can return unbiased results under most circumstances, for example, even where data are missing not at random (Bartlett *et al.*, 2014; Hughes *et al.*, 2019).

Imputation models should contain all the variables in the regression model, the outcome variable, variables that explain why the data are missing, and variables that predict the values of the incomplete

variables (Hughes *et al.*, 2019). As it was not possible to determine whether the missing data in ELSA was missing at random, or not at random, it would be difficult to be certain about what variables explained the missing data. While methods such as regression imputation can predict the missing values from other non-missing variables and maintain the distribution of the sample, they are still linked to biased estimates if the data are not missing completely at random (Lodder, 2013).

Within the full cross-sectional sample in this thesis, 16% are caregivers, 84% non-caregivers, these proportions were almost mirrored in the sample with missing data, whereby 17% were caregivers and 83% non-caregivers. Additionally, the sociodemographic characteristics of the missing data were similar to that of the full sample, suggesting limited bias was introduced into the remaining sample. Larger percentages of missing data were seen for regressions conducted for RQ1a and RQ1b, ranging from 45-48% of the full sample (N=5937) excluded due to incomplete data. The variable which was most likely to be missing from these cases was the number of close relationships with family, in comparison to key variables, the response rate for which was around 65% for those providing UCLA-LS scores, and 66% for those providing a response to the caregiving question. Furthermore, in all of the regressions conducted for RQ2, between 43-48% of the caregiving-only sample (N=962) were excluded due to incomplete data, this was likely due to the same low response rates to the number of close family relationships. Among the caregivers, 65% provided family relationship data. Finally, for the longitudinal caregivers with missing data, most were short-term caregivers (38%) or long-term caregivers (38%) which was similar to the proportions of caregiving durations within the full longitudinal caregiving sample (44% and 41% respectively). Similarly, the baseline sociodemographic characteristics of the missing respondents were similar to that of the full sample, for example, most were aged 50-59 (43%) as in the overall sample (46%). In RQ3c around 44% of the longitudinal caregiving sample (non-lonely caregivers, or caregivers experiencing loneliness after the start of care provision, N=938) were excluded due to incomplete data. The lowest response rate within this sample was for the computed changes to loneliness expectations variable, around 58% of caregivers provided this data over the three waves it was measured (waves two, seven and eight).

4.4.4 Multicollinearity

An assumption of regression models is that no strong linear relationships should exist between the predictor variables (Field, 2013), which is known as multicollinearity. Multicollinearity is problematic in regression analyses, causing large sampling variability among the coefficients reducing the accuracy of the results (Alin, 2010). Multicollinearity is measured using the variance inflation factor (VIF) and tolerance statistic, which can be obtained by running a linear regression. A larger VIF demonstrates higher sampling variability and suggests the presence of strong linear relationships, and tolerance represents the reciprocal of this value. The highest VIF value should not exceed 10 (Alin, 2010; Field, 2013), and the average should not be substantially greater than 1. Alternatively, Daoud (2017) indicates that VIF values of >5 suggest highly correlated variables, values from 1-5 suggest moderate correlation, and VIF equal to one shows no correlation. For

tolerance, it is typically agreed that values <0.1 indicate collinearity (Field, 2013; Daoud, 2017). Prior to conducting the regression analyses, multicollinearity was tested, and all values for VIF and tolerance were within accepted parameters.

4.5 Chapter summary

Chapter four has introduced the methods and materials used within this thesis. Justification was made for variable selection, and the bivariate and multivariate methods were outlined. This thesis used bivariate analyses when discussing the descriptive statistics, and multivariate methods, namely binary logistic and linear regressions, for the main analyses. A combination of both cross-sectional (chapter five) and follow-up methods (chapter six) were employed to disentangle the relationships between caregiving, loneliness, health, and wellbeing using ELSA data. The following chapters present the results from the analyses and build a narrative of how the key concepts are interrelated.

Chapter 5 Cross-sectional results

5.1 Chapter outline

Chapter five presents the cross-sectional results. In section 5.2 the first research question was addressed: how does loneliness differ for caregivers and non-caregivers? Descriptive and bivariate analyses were conducted for the wave eight sample in relation to both UCLA-LS and the direct loneliness question (section 5.2.1). Sections 5.2.2 to 5.2.4 display the results from the regression analyses, comparing loneliness, the determinants of loneliness, and the impact of loneliness on health and wellbeing, respectively, among caregivers and non-caregivers.

Additionally, section 5.3 focuses on the caregiving subsample only, answering research question two: how does caregiving affect loneliness, health, and wellbeing? The questions compare the caregiving sample through the caregiving characteristics, the caregiving relationship, and the caregiving role. Descriptive and bivariate analyses are presented in relation to UCLA-LS loneliness (section 5.3.1) and the subsequent sections (5.3.2 to 5.3.4) present the regression results for the loneliness, health, and wellbeing outcomes.

5.2 RQ1: how does loneliness differ for caregivers and non-caregivers?

5.2.1 Descriptive statistics for caregivers and non-caregivers

Once proxy responses were removed and the cross-sectional weight (*w8xwgt*) applied, the total sample was 5,937. The descriptive characteristics for wave eight include crosstabulations between caregiving and the key variables within the analysis, including sociodemographic characteristics, SES, social networks, health, and wellbeing.

No multicollinearity was observed within the included variables, and the VIF and tolerance values were well within the guidelines (VIF <10 and Tolerance >0.1, (Field, 2013)). VIF ranged from 1-3, suggestive of some moderate correlations. A correlation matrix revealed that the strongest correlations existed between cohabitation and household size ($r=-0.62$), CASP19 and SWLS ($r=-0.61$), and age and employment ($r=0.50$), and all other correlations were considerably weaker. The correlation between cohabitation and household size was expected as individuals cohabiting would have larger households than non-cohabiting (e.g. single households) but it was deemed important for household size to remain in the analyses to determine if differences existed for the larger households (≥ 3 people) as this would suggest that relationships outside of a spousal relationship were also important for loneliness. The wellbeing variables were correlated, however, previous literature identified an overlap but confirms QoL and life satisfaction are separate measures of wellbeing. For

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instance, Dodge *et al.* (2012) indicate that QoL cannot completely define wellbeing because it is a dimension, and similarly, life satisfaction plays a pivotal role in determining subjective wellbeing. This emphasises that the two are distinct, measuring separate, but linked, aspects of wellbeing. Finally, the association observed between age and employment is likely indicative of retirement, whereby under retirement age, employment rates are would be higher, and above retirement age, are expected to be lower. The caregiving role (e.g. caregiving intensity) is often influenced by the caregivers' employment status (Wang *et al.*, 2020b); moreover, caregivers often cease paid employment due to caregiving commitments (Carr *et al.*, 2018). Thus, employment was considered a key variable, not only for SES, but also in relation to the experience of caregivers.

Table 9 compares key variables for sociodemographic characteristics, SES, social networks, loneliness, health, and wellbeing between caregivers and non-caregivers. Respondents who identified as caregivers, having provided care within the past week, represented 16% of the sample (N=962).

In addition, bivariate analyses were conducted; each of the variables were tested for associations with directly-reported and UCLA-LS loneliness (Appendix B).

Table 9: Descriptive statistics for caregivers and non-caregivers in ELSA wave eight

		Non-caregivers N (%)	Caregivers N (%)
Caregiving status		4975 (83.7)	962 (16.2)
Age (years)	50-59	1469 (29.5)	352 (36.6)
	60-69	1656 (33.3)	311 (32.3)
	≥70	1849 (37.2)	299 (31.1)
Sex	Male	2489 (50.0)	381 (39.6)
	Female	2487 (50.0)	582 (60.4)
Marital status	Married/civil partnership	2672 (53.7)	590 (61.4)
	Single, never married	415 (8.3)	54 (5.7)
	Remarried	495 (10.0)	121 (12.6)
	Divorced/legally separated	725 (14.6)	146 (15.1)
	Widowed	666 (13.4)	51 (5.3)
Cohabitation (spouse/partner)	No	1509 (30.5)	189 (19.6)
	Yes	3436 (69.5)	774 (80.4)
In paid employment	No	3082 (62.4)	630 (65.6)
	Yes	1859 (37.6)	330 (34.4)
Wealth	Quartile 1 (poorest)	1210 (24.6)	257 (26.9)
	Quartile 2	1231 (25.1)	237 (24.8)
	Quartile 3	1247 (25.4)	219 (22.9)
	Quartile 4 (wealthiest)	1221 (24.9)	242 (25.3)
Household size	Single person household	1245 (25.0)	92 (9.6)
	Dual-person household	2706 (54.4)	614 (63.8)
	Large household (≥3)	1025 (20.6)	256 (26.6)
Close relationships	with family, mean (SD)	4.6 (2.9)	4.9 (3.0)
	with friends, mean (SD)	3.5 (3.1)	3.7 (2.7)
Direct loneliness question	Not lonely	4405 (88.6)	856 (89.2)
	Lonely	565 (11.4)	104 (10.8)
UCLA-LS	Not lonely	3905 (80.0)	746 (79.6)
	Lonely	977 (20.0)	191 (20.4)
Loneliness expectations	Agree	2041 (41.7)	392 (41.1)
	Neither agree nor disagree	1450 (29.6)	277 (29.2)
	Disagree	1406 (28.7)	279 (29.4)
LLTI	No	3384 (68.0)	635 (66.0)
	Yes	1592 (32.0)	327 (34.0)
Physiological	No chronic CV conditions	2702 (54.3)	582 (60.5)
	≥1 chronic CV condition	2273 (45.7)	380 (39.5)
Health expectations	Agree	3434 (70.0)	669 (70.2)
	Neither agree nor disagree	861 (17.6)	161 (16.9)
	Disagree	608 (12.4)	123 (12.9)
Alcohol consumption	<3 days per week	3279 (66.7)	680 (71.4)
	≥3 days per week	1634 (33.3)	272 (28.6)
CES-D	No depressive symptomatology	4128 (83.5)	725 (76.0)
	Depressive symptomatology	814 (16.5)	229 (24.0)
Wellbeing	CASP19, mean (SD)	41.7 (9.0)	39.9 (10.1)
	SWLS, mean (SD)	25.4 (6.4)	24.9 (7.1)

Notes: standard deviation (SD), source: author's analysis of ELSA wave 8

5.2.1.1 Sociodemographic characteristics and socioeconomic status

Typically, caregivers were younger than non-caregivers, as higher percentages of caregivers (37%) were aged 50-59 compared to non-caregivers (30%). Moreover, caregivers were predominantly female (60%), whereas the male and female split was exactly 50% among non-caregivers. This female majority could have been expected, as literature and previous evidence suggests a higher prevalence of caregiving among females compared to males, except in the oldest age groups (Milligan and Morbey, 2016).

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Amongst caregivers and non-caregivers, respondents were most commonly married (61% and 54% respectively). However, small cell counts were observed for single, never married (N=54, 6%) and widowed caregivers (N=51, 5%) which resulted in large confidence intervals and empty cells in an initial regression analysis. Measures were taken to collapse these categories, as it was hypothesised that the presence or absence of a relationship would be a substantial factor related to loneliness and should be accounted for. It was assumed that single, never married would refer to individuals without a significant attachment (e.g. partner), however crosstabulation with the cohabitation variable (Table 10) indicated that a large percentage of the single caregivers (40%) reported cohabiting with a partner. Furthermore, 25% of divorced or legally separated and 14% of widowed caregivers also reported cohabitation. This raised complications with collapsing the categories; for instance, collapsing into ‘currently married’ (married and remarried) and ‘not currently married’ (single, divorced or separated and widowed) would mean a substantial proportion of the ‘not currently married’ were still cohabiting with a partner. Therefore, single-cohabiting individuals may experience similar emotional attachment benefits to married-cohabiting individuals, although in the ELSA data, this would not be accounted for by controlling for marital status alone. However, given that the majority of ‘currently married’ caregivers were cohabiting, the cohabitation variable would account for the aforementioned attachment. Moreover, the small cell counts of ‘currently married’ caregivers who were not cohabiting prevented the inclusion of both variables in the regressions. Due to the arguments presented above, it was deemed more conceptually appropriate to include cohabitation in the regression analyses, rather than marital status.

Table 10: Crosstabulation of caregivers’ responses to marital status and cohabitation variables

Marital status		Cohabitation	
		No N (%)	Yes N (%)
Currently married	Married, first and only marriage	2 (0.3)	588 (99.7)
	Remarried, second or later marriage	0 (0.0)	121 (100.0)
Not currently married	Single, never married	33 (60.0)	22 (40.0)
	Divorced or legally separated	109 (75.2)	36 (24.8)
	Widowed	44 (86.3)	7 (13.7)

Notes: % percentage of marital status, source: author’s analysis of ELSA wave 8

SES was determined through employment status and wealth. Levels of employment were comparable between the two groups: 38% of non-caregivers and 34% of caregivers were employed. Finally, the distribution of wealth was consistent across the quartiles for both caregivers and non-caregivers, although a slightly larger percentage of caregivers were in the lowest quartile (27%), compared to non-caregivers (25%).

5.2.1.2 Social networks

Caregivers and non-caregivers differed considerably in household size, whereby 25% of non-caregivers lived in single person households, compared to around 10% of caregivers. As the data indicated the majority of caregivers were cohabiting (80%), this suggests that a large percentage of caregivers may live with the care recipient. The descriptive analyses for RQ2 (section 5.3.1) confirmed this, indicating that over half (51%) of caregivers reside with their care recipient.

The number of close relationships with family and friends reported by caregivers and non-caregivers were similar. To illustrate, the mean number of close family relationships was 4.9 for caregivers and 4.6 for non-caregivers. Similarly, the mean number of close friendships was 3.7 and 3.5 for caregivers and non-caregivers respectively. This suggests that among both groups, respondents had larger family than friendship networks.

5.2.1.3 *Loneliness*

Three measures of loneliness were included in the analyses for RQ1a, the first of which was a direct question: whether the respondent felt lonely much of the time during the past week. Within the sample, 11% of both caregivers and non-caregivers directly-reported feeling lonely. Whereas, for the UCLA-LS, an indirect 3-item loneliness scale, the prevalence of loneliness appeared much higher. For both groups, 20% of respondents were lonely. As discussed in section 4.3.2.1, stigmas around loneliness may have influenced the likelihood of directly reporting, therefore this may explain why considerably fewer respondents were lonely when using this measure.

The final method determined the respondents' future loneliness expectations. These expectations were similar amongst caregivers and non-caregivers, as such 41% of caregivers and 42% of non-caregivers 'agreed' that they expected to become lonelier with age. Similar percentages (29%) were also observed for those who 'disagreed', in that they did not expect to become lonelier.

5.2.1.4 *Health and wellbeing*

Health status was not substantially different for caregivers and non-caregivers, the majority of both groups were healthy across all measures. Furthermore, all health measures were significantly associated with both loneliness measures. The prevalence of LLTIs was slightly higher among caregivers (34%) than non-caregivers (32%), and caregivers showed elevated levels of depressive symptoms (24%) compared to non-caregivers (17%). Among the SET health pathways, similar percentages (70%) of caregivers and non-caregivers 'agreed' that they expected their health to get worse with age. Moreover, for behavioural health, non-caregivers (33%) were more likely to consume alcohol frequently (≥ 3 days per week), than caregivers (29%). Additionally, non-caregivers reported a higher prevalence of chronic CV conditions (46%), compared to caregivers (40%). When considering only the SET health pathways, caregivers appeared healthier than non-caregivers.

Overall caregivers displayed poorer wellbeing than non-caregivers based on both QoL and life satisfaction. QoL among caregivers was on average 2.2 points lower than non-caregivers. Similarly, caregivers reported lower life satisfaction than non-caregivers.

5.2.2 **RQ1a: is caregiving associated with loneliness?**

Alongside investigating whether loneliness differed between caregivers and non-caregivers, analyses were conducted using different loneliness measures. Comparison between the results identified

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whether reporting of loneliness was consistent across different measurement tools. Binary and multinomial logistic regression analyses were conducted with the three loneliness measures (direct question, UCLA-LS, and loneliness expectations) to determine whether caregiving was associated with loneliness. Table 11 depicts the models applied for each of the regressions in RQ1a.

Table 11: Regression models for RQ1a: is caregiving associated with loneliness?

Model number	Variables included in the model
1	Caregiving status
2	Model 1 + sociodemographic characteristics and socioeconomic status
3	Model 2 + social networks
4	Model 3 + health and wellbeing

Source: author's own

The initial model (model one) tested whether caregiving individually, was significantly associated with the different loneliness measures, whereas in model two sociodemographic characteristics and SES were included as covariates alongside caregiving. Model two tested whether caregiving was associated with loneliness after controlling for characteristics such as age, sex, employment status and wealth. Some sociodemographic characteristics are considered to be both determinants of loneliness and typical caregiver characteristics. For example, evidence from literature suggests that females are more likely to be caregivers (section 3.3.1.2) and more likely to report loneliness (section 3.2.1). Therefore, by controlling for sex in the analyses, any improvements or attenuation to the relationship between caregiving and loneliness demonstrates whether any of the relationship can be accounted for by sex.

Model three included the addition of social network variables: household size, close family relationships and close friendships. The literature review highlighted that factors, such as social isolation and social networks, are closely linked to loneliness (section 3.2.3), therefore it was important to evaluate the impact of these variables. By adding these in model three, separately from sociodemographic variables and SES, the results would indicate whether social networks better account for the relationship between caregiving and loneliness, after having already controlled for the variables in model two. Health and wellbeing variables were added into model four (fully-adjusted model). Research suggests that poor health and wellbeing contribute to loneliness, thus any attenuation to previously significant relationships (e.g. caregiving and loneliness) would indicate that health and wellbeing were more strongly related to loneliness, after controlling for caregiving. Health and wellbeing were added separately to sociodemographic characteristics, SES, and social networks because, typically, research has shown that health and wellbeing have different effects on loneliness in comparison with the other characteristics.

5.2.2.1 Is caregiving associated with directly reporting loneliness?

The first binary logistic regression was conducted with direct loneliness as the DV; 45% (N=2701) of the sample were excluded from the analyses due to missing data. In this analysis, caregiving was

not significantly associated with directly reporting loneliness, even after controlling for differences in sociodemographic characteristics, SES, social networks, health, and wellbeing (Appendix C).

In the fully-adjusted model (Figure 3), for sociodemographic and socioeconomic variables, cohabitation was negatively associated with loneliness and wealth positively associated. Other factors negatively associated with loneliness were: household size, LLTIs, QoL, and life satisfaction, with depressive symptomatology demonstrating a positive association to loneliness. This suggests that health and wellbeing largely influenced directly-reported loneliness.

LLTIs were negatively associated with loneliness; odds of respondents with LLTIs reporting loneliness were 29% lower than those without LLTIs (odds ratio (OR)=0.71, 95% confidence interval (95CI)=0.51-0.99). Typically, within the literature, health has been shown to be negatively correlated with loneliness. A review conducted by Cohen-Mansfield *et al.* (2016) identified that poor health and functional limitations were linked to increased loneliness, although the loneliness measurement tool varied across these studies. Moreover, a link was established between long-term health conditions, determined through the receipt of disability pension, and directly reporting loneliness (von Soest *et al.*, 2020). Therefore, it was unexpected that the results of this thesis suggests LLTIs are indicative of lower odds of loneliness, as this contradicts published findings. One explanation for this could be that individuals with LLTIs may be more likely to receive help due to their illness, whether from professionals or family members; they may have people coming into their home or accompanying them to assist with tasks such as shopping. These visits may provide companionship and therefore the respondent may be less likely to feel lonely. Individuals without LLTIs are likely not to receive assistance and thus could feel lonelier, despite better health. Conversely, evidence suggests health is a determinant of loneliness, but, when using a direct measure, health was inferior to partner status (defined as having a spouse/cohabitant) in predicting loneliness (Nicolaisen and Thorsen, 2014b). The findings from this regression may support this conclusion, as cohabitation remained significant after the inclusion of health and wellbeing in the fully-adjusted model, which could indicate a strong relationship between cohabitation and directly-reported loneliness.

The Nagelkerke r^2 indicated that the fully-adjusted model accounted for 39% of variance in loneliness, which was a substantial increase from model three (20%). This indicates that health and wellbeing variables play a large role in the variance of loneliness. However, the Hosmer-Lemeshow statistic advocates that model three ($p=.844$) was a better fit than the fully-adjusted model ($p<.001$). Despite the significant results, the reduced model fit would suggest that the remaining relationships in the fully-adjusted model were contributing poorly to the model fit. As such, health and wellbeing may have such a substantial effect that it overshadows the other variables.



Figure 3: Odds ratio plot, factors associated with directly reporting loneliness

Source: author's analysis of ELSA wave 8

5.2.2.2 Is caregiving associated with loneliness on the UCLA loneliness scale?

Caregiving was significantly positively associated with UCLA-LS loneliness in the first three models, but the significance attenuated with the inclusion of health and wellbeing variables in the fully-adjusted model (Appendix D). The regression analysis included 54% of the full sample, 46% (N=2724) were excluded from the analyses due to missing data. In the initial model, with no additional controls, odds of caregiver loneliness (score of ≥ 3 on the UCLA-LS) were higher than non-caregivers (OR=1.35, 95CI=1.06-1.71). However, the Nagelkerke r^2 indicated that this initial model accounted for less than 1% of variance in loneliness and the Hosmer-Lemeshow statistic demonstrated that the model was a poor fit. With the inclusion of sociodemographic characteristics, SES, and social networks in model three, the odds of caregivers being lonely were almost 1.5 times higher than non-caregivers (OR=1.46, 95CI=1.13-1.89). The Nagelkerke r^2 indicated that model three accounted for more variance (15%) but overall the model fit did not substantially improve ($p=.004$). In the fully-adjusted model (Figure 4), caregiving was no longer significant, but the Hosmer-Lemeshow statistic suggests that this model better fits the data ($p=.675$).

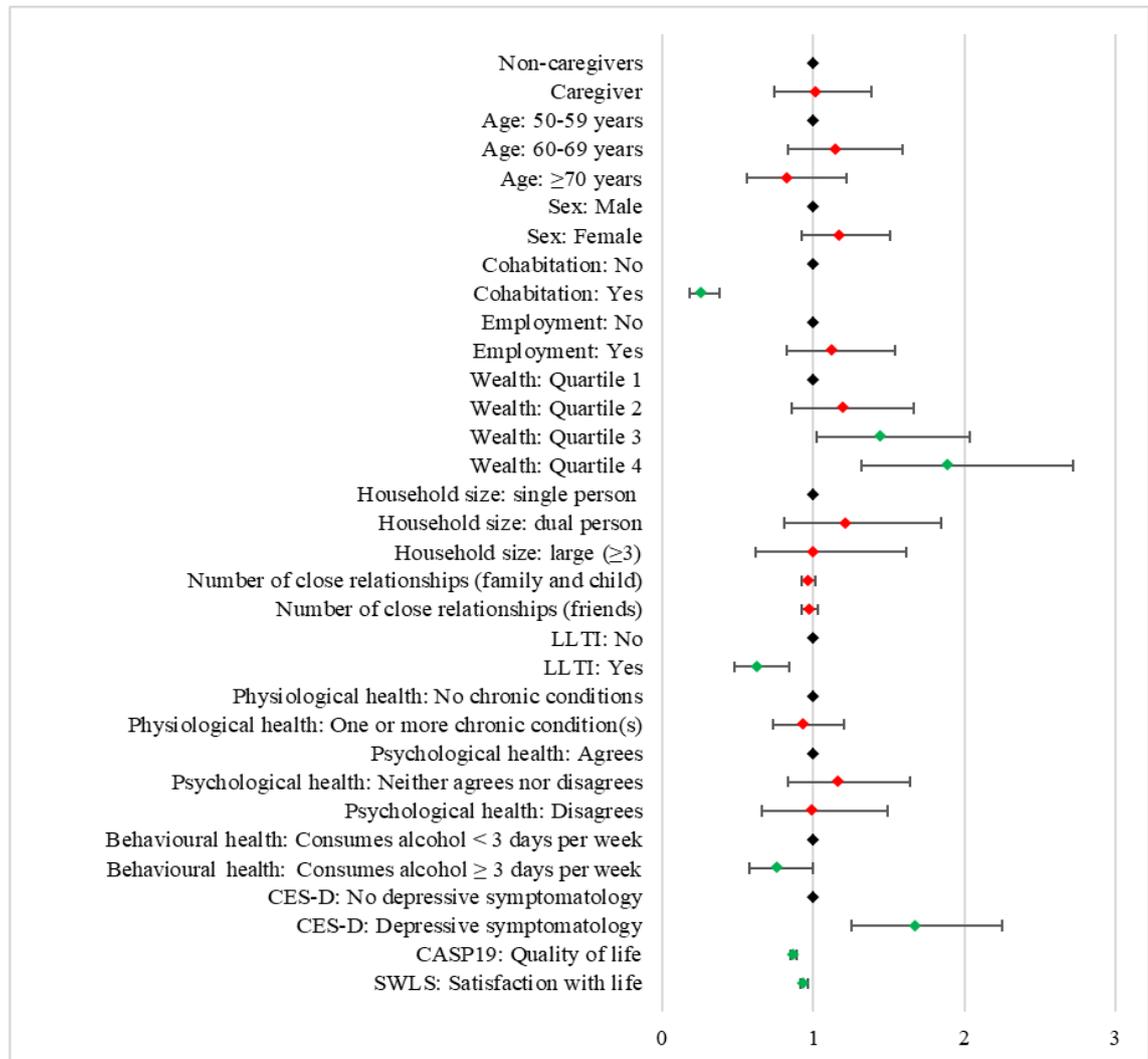


Figure 4: Odds ratio plot, factors associated with UCLA-LS loneliness

Source: author's analysis of ELSA wave 8

Similar to the direct loneliness regression (section 5.2.2.1), cohabitation, LLTIs, higher QoL and higher life satisfaction were negatively associated with UCLA-LS loneliness. Wealth and depressive symptomatology were significantly positively associated with loneliness. In contrast, household size was not statistically significant, and frequent alcohol consumption was negatively associated with UCLA-LS loneliness, but not significantly associated with directly-reported loneliness.

As with direct loneliness, after controlling for health and wellbeing in the fully-adjusted model, wealth was positively associated with loneliness. However, unlike direct loneliness, wealth was significant in previous models. Prior to the inclusion of health and wellbeing controls, wealth was negatively associated with loneliness. Wealthier people tend to have better access to healthcare, additionally, the negative association between health and loneliness is well-reported in literature (section 3.4.1). Therefore, prior to controlling for health, it could be predicted that those in higher wealth quartiles may have better health, and are therefore less likely to be lonely. Conversely, once controlled for health and wellbeing differences in the fully-adjusted model, wealth had contrasting effects. Higher wealth was indicative of higher odds of loneliness. This contrasts with previous

literature, as it is commonly reported that lower SES is linked to poorer social relations (Vonneilich *et al.*, 2012).

Respondents who consumed alcohol three or more days per week were found to have significantly lower odds of loneliness, compared to those who consumed alcohol less frequently (OR=0.76, 95CI=0.58-0.99). Canham *et al.* (2016) investigated the association between loneliness and alcohol, also finding that loneliness was negatively associated with frequent alcohol consumption. Descriptive analyses of their sample showed that among the respondents drinking ≥ 4 days per week, only 27% reported feeling lonely often, whereas respondents reporting drinking one day per week were lonelier (39% reported feeling lonely often). There is limited evidence reporting the effect of alcohol consumption on loneliness, however, Dunbar *et al.* (2017) suggest that moderate alcohol consumption can have social benefits. In particular, those who drink in their 'local' or community pubs had higher social engagement than that of non-drinkers. Nevertheless, due to the cross-sectional nature of this part of the analysis, it is not possible to determine the direction of the relationship, i.e. whether increased alcohol consumption reduced likelihood of loneliness, or whether lonelier people were less likely to frequently consume alcohol. Greenstone *et al.* (2019) examined the bi-directional effects between loneliness and alcohol and found no significant evidence of causality in either direction. However, it was suggested that stress played an indirect role in risky behaviours (*ibid*), therefore the relationship between alcohol and loneliness may be stronger among the caregiving sample, due to stress from the caregiving role. This is investigated further in section 5.2.4.2.

5.2.2.3 Does caregiving impact loneliness expectations?

The final regression for RQ1a was conducted with loneliness expectations as the DV, 45% (N=2678) of the sample were excluded due to missing data. Respondents either 'agreed', 'disagreed', or 'neither agreed nor disagreed' that loneliness would increase as they grew older. In these multinomial logistic regressions, caregiving was not significantly associated with loneliness expectations. Nagelkerke r^2 indicated that the fully-adjusted model accounted for 19% of variance in loneliness expectations, which suggests that there are additional factors, not included in the model, which may have a substantial impact on loneliness expectations.

Significant factors associated with loneliness expectations varied for 'neither agree nor disagree' ('neither') and 'disagree', in relation to 'agree' (Appendix E). An individual who 'disagrees' does not expect to become lonelier with age, whereas those who responded with 'neither' may be unsure about whether they expected increased loneliness as they age. In the fully-adjusted model for 'disagree' compared to 'agree', sex, wealth, and depressive symptomatology were negatively associated with 'disagreeing', whereas cohabitation, close relationships with family and friends, LLTIs, health expectations, and QoL were positively associated with 'disagreeing'. In contrast, for 'neither' compared to 'agree', sex, employment, wealth, and depressive symptomatology were

negatively associated, and physiological health, health expectations, and QoL positively associated with the 'neither' response.

Odds of disagreeing with loneliness expectations, compared to agree

In the fully-adjusted model (Figure 5), odds of 'disagreeing' were significantly lower for females than males (OR=0.80, 95CI=0.66-0.97), which suggests that females expected to become lonelier as they grow older. It is frequently reported that females are more inclined to report being lonely, compared to males (Pinquart and Sörensen, 2011). It is therefore possible that this stereotype (that females are lonelier) has been internalised, influencing their perception of loneliness. Moreover, cohabitation was positively associated with 'disagreeing' (OR=1.53, 95CI=1.02-2.29); individuals living with a spouse or partner were less likely to expect to get lonelier with age, than those not cohabiting. This could be attributed to the presence of a strong emotional attachment with their spouse. As shown in the previous two analyses, cohabitation was negatively associated with directly-reported and UCLA-LS loneliness. Therefore, those living with their spouse were less likely to be lonely, which in turn is likely to have a positive effect on their loneliness expectations. As such, individuals who are currently lonely may be more likely to expect to stay lonely, or become lonelier, whereas those who are not currently lonely may not expect to become lonely, as they have their spouse and/or other network members and may expect this to continue.

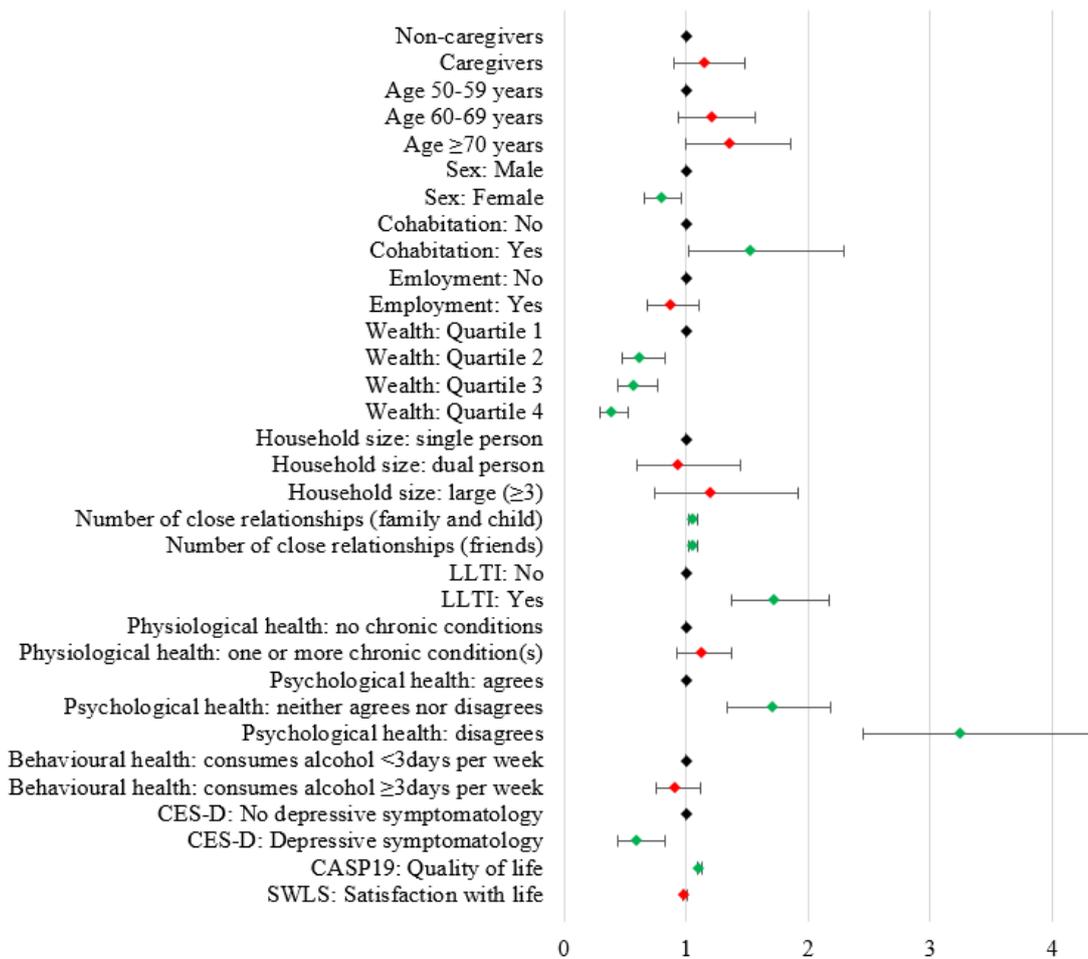


Figure 5: Odds ratio plot, factors associated with disagreeing with loneliness expectations
 Source: author's analysis of ELSA wave 8

Close relationships play a role in an individual's future loneliness expectations. The number of close family members (OR=1.06, 95CI=1.03-1.10) and close friendships (OR=1.06, 95CI=1.02-1.09) were positively associated with 'disagreeing' with loneliness expectations. This advocates that those with larger close social networks were more positive about future loneliness expectations, possibly because they expect to maintain their networks as they age. Those with smaller, or without close networks may expect to be lonelier with age, as they may already be experiencing loneliness. Alternatively, household size was not significantly associated with loneliness expectations. This indicates it is not the number of people an individual has around them, more so the quality (or closeness) of those relationships which impact perceptions of loneliness. Additionally, health expectations were positively associated with loneliness expectations. For example, respondents who did not expect their health to deteriorate with age, were also less likely to expect increased loneliness (OR=3.25, 95CI=2.45-4.33). This is suggestive of dispositional optimism, whereby individuals' personalities predispose them to more positive expectations (Rius-Ottenheim *et al.*, 2012). Furthermore, optimism is not limited to one area of life (e.g. health) and more likely to be generalised (e.g. health, loneliness, and other aspects).

The results suggest that depressive symptomatology was suggestive of a negative outlook on loneliness and age. The odds of 'disagreeing' with loneliness expectations were considerably lower

among respondents experiencing depressive symptoms than those without depressive symptomatology (OR=0.60, 95CI=0.44-0.82). Evidence suggests that depression is linked to negative self-evaluation, in that individuals are more likely to consider themselves worse off than others (McCarthy and Morina, 2020). Therefore, it is likely that individuals with depressive symptomatology may consider themselves lonelier than others, and thus demonstrate a negative outlook on future loneliness. It was expected that poor physical health (LLTI) would increase the likelihood of loneliness, but, as discussed previously (section 5.2.2.1), potential assistance received due to illness may act as a buffer between poor health and loneliness. In contrast, individuals with poor mental health may be less likely to receive help, as late-life depression is considerably underdiagnosed and undertreated (Mann *et al.*, 2020). These individuals may already experience loneliness and expect this to develop with age.

Odds of neither agreeing nor disagreeing with loneliness expectations, compared to agree

Females were less likely to be uncertain about future loneliness than males (OR=0.83, 95CI=0.70-0.99). As females were also less likely to ‘disagree’ (see previous section: disagree *versus* agree), this would indicate that males have a more positive outlook on future loneliness, compared to females. However, as discussed from previous results and published literature, females are more likely to report loneliness, therefore this stereotype could influence their perceptions.

In the fully-adjusted model (Figure 6), the odds of individuals with poor physiological health, determined by chronic CV conditions, reporting ‘neither’, were 1.2 times higher than those with good physiological health (OR=1.21, 95CI=1.01-1.46). Individuals with chronic CV conditions, (e.g. hypertension), may be unsure about the progression of their condition, and the forthcoming impact it may have. To illustrate, if their condition considerably worsened, this would limit their ability to go out and socialise, but if their condition remained stable, it may involve limited change to their lives, hence the increased likelihood of uncertainty. As discussed in the previous section (disagree *versus* agree), expectations for health and expectations for loneliness were related, although it is unknown whether this was due to a generalised outlook on life, or due to relationships between loneliness and health. For example, if an individual is unsure about future health it may be difficult to make an accurate judgement on how lonely they expect to be, as this will depend on other factors (such as health). Therefore, it was expected that a ‘neither’ response for health expectations was likely to be linked to higher odds of a ‘neither’ response for loneliness expectations, which was reflected in the results (OR=1.55, 95CI=1.22-1.96).

Similarly to ‘disagree’, odds of uncertainty about future loneliness were lower among respondents with depressive symptomatology than those without depressive symptoms (OR=0.52, 95CI=0.39-0.68). As discussed, depression is linked to negative self-evaluation (McCarthy and Morina, 2020), which implies, and as the results show, individuals with depressive symptoms are more likely to ‘agree’ with loneliness expectations than be uncertain. Finally, QoL was positively associated with

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the ‘neither’ response (OR=1.04, 95CI=1.02-1.05), but life satisfaction was non-significant. The SWLS asks whether individuals have important things in their life and, if they could relive their life, would they change much, whereas CASP19 includes several questions about the future. Therefore, in contrast, CASP19 is more likely to be related to future expectations than SWLS, which is more focused on current perceptions.

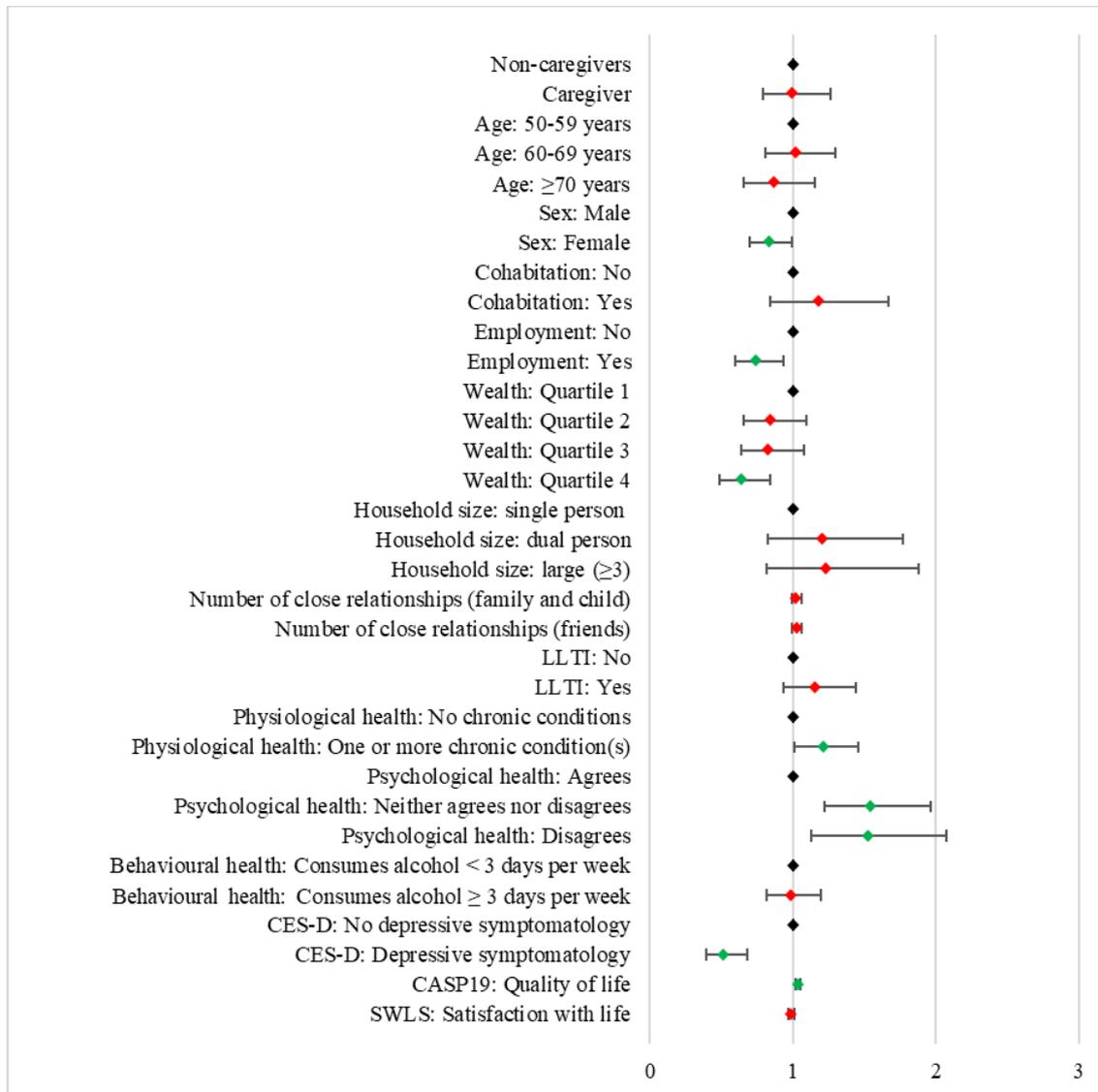


Figure 6: Odds ratio plot, factors associated with neither agreeing or disagreeing with loneliness expectations

Source: author's analysis of ELSA wave 8

5.2.2.4 Summary: is caregiving associated with loneliness

Caregiving was significantly positively associated with UCLA-LS loneliness across the first three models, prior to the inclusion of health and wellbeing controls. In contrast, caregiving was not significant in any model for direct loneliness or loneliness expectations. This highlights a substantial discrepancy between the loneliness measures, whereby caregivers were more likely to be categorised as lonely using an indirect, but not direct, measure. This may be due to assumptions that caregivers cannot be lonely, because they spend time caregiving for others. Aligning with the psychological SET pathway, if this assumption is internalised, caregivers may overlook feelings of loneliness, or

feel unable to report them because they believe that caregivers cannot be lonely. However, as discussed in the definitions (section 1.2.2) an individual can feel lonely without being alone. Using HRS data, Shiovitz-Ezra and Ayalon (2012) compared the same loneliness measures: the direct CES-D question and 3-item UCLA-LS. The authors reported an overlap between the direct question and UCLA-LS, but also several discrepancies between the measures. A direct measure was considered more appropriate in self-completion questionnaires compared to face-to-face (as it is asked in ELSA) or telephone interviews, due to stigmatisation of loneliness. The two scales captured different samples with distinct characteristics (*ibid*), and therefore comparison is important to determine which scale is the most appropriate in the given sample.

Table 12: Summary of significant results for RQ1a: is caregiving associated with loneliness?

Variables	Direct Question	UCLA-LS	Loneliness expectations	
			Neither agree nor disagree	Disagree
Caregiving	NS	NS	NS	NS
Age: 60-69	NS	NS	NS	NS
≥70	NS	NS	NS	NS
Sex	NS	NS	*	*
Cohabitation	***	***	NS	*
Paid employment	NS	NS	*	NS
Wealth: quartile 2	**	NS	NS	**
Quartile 3	**	*	NS	***
Quartile 4	*	**	**	***
Household: dual-person	**	NS	NS	NS
Household: large (≥3 people)	*	NS	NS	NS
Close family relationships	NS	NS	NS	**
Close friendships	NS	NS	NS	**
LLTI	*	**	NS	***
Physiological health	NS	NS	**	NS
Health expectations: neither agree nor disagree	NS	NS	***	***
Health expectations: disagree	NS	NS	**	***
Alcohol consumption	NS	*	NS	NS
CES-D: depressive symptomatology	***	**	***	**
CASP19	***	***	***	***
SWLS	**	***	NS	NS

Notes: NS non-significant, *p<.05, ** p<.01, *** p<.001, source: author's analysis of ELSA wave 8

In addition to this, the significance of covariates fluctuated between the loneliness measures (Table 12). This further emphasises differences between loneliness when measured directly or indirectly. Arguably, UCLA-LS is more reflective of feeling lonely, compared to directly reporting, because there may be barriers which inhibit direct responses, such as feeling guilty or unable to report loneliness due to circumstances. Moreover, evidence suggests that factorial surveys (such as the UCLA-LS) in comparison with direct single-item questions, can combat social desirability bias (Walzenbach, 2019). Additionally, the UCLA-LS enquires about both companionship and inclusion which incorporates different aspects of loneliness, which may not otherwise be considered when directly asked if feeling lonely.

Furthermore, the multinomial regression for loneliness expectations demonstrated that different factors were associated with the 'neither' and 'disagree' responses in relation to 'agree'. In the fully-adjusted model, close relationships with family and friends were significantly positively associated with higher odds of 'disagreeing' that loneliness would increase with age. However, none of the

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social network variables were significantly **associated with** the ‘neither’ response in relation to ‘agree’. One interpretation of ‘neither’ is that individuals were unsure whether loneliness will change with age, as respondents may recognise that loneliness is circumstantial and factors, other than age, have influence. Aspects related to social networks, such as close relationships with family, therefore, may be more likely to prompt a positive or negative response; those with close family networks may not expect loneliness, because they recognise that children and grandchildren will be there as they age. Furthermore, close family networks may be unlikely to elicit a neutral response because respondents can be more certain about most of their family network. To clarify, with age, individuals may expect spousal or friend bereavements, however the loss of children and grandchildren is less likely. Thus individuals with larger family networks may not expect to grow lonelier as they can rely on children and grandchildren within the family network.

Overall, it is important to pursue the comparison between caregivers’ and non-caregivers’ loneliness despite the contrasting results for RQ1a, in which only one of the three loneliness measures identified a significant difference. Firstly, further investigating what is contributing towards the difference in UCLA-LS loneliness for caregivers and non-caregivers, through both shared characteristics (RQ1b) and caregiving-specific factors (RQ2a), may aid understanding as to why no difference was observed for the direct measure. Thus, this contributes towards the body of evidence which discusses differences between direct and indirect approaches to measuring loneliness. Additionally, this research is meaningful because, as identified in the research gaps (section 3.5.1) from the literature review, there is a dearth of studies researching caregiving and loneliness longitudinally. RQ1a suggests that the **positive association** between caregiving and loneliness attenuates after controlling for health and wellbeing, however, one limitation of cross-sectional evidence is that data are collected at a single time-point, therefore the direction of relationships is unknown. Further analysis (RQ3) identifies whether the connection between caregiving and loneliness is long-term, and how this is impacted by changes to the caregiving role, and caregivers’ health.

5.2.3 RQ1b: are the determinants of loneliness different for caregivers and non-caregivers?

To assess whether determinants of loneliness differed for caregivers and non-caregivers, binary logistic regression analyses were conducted on caregivers and non-caregivers separately. The analyses were carried out using UCLA-LS loneliness as the DV. This decision was made on the basis that UCLA-LS loneliness significantly differed for caregivers and non-caregivers (prior to controlling for health and wellbeing), whereas direct loneliness did not. Therefore, it would be logical to assume that if the determinants of loneliness were different, this likely would be more evident for UCLA-LS where significant differences were already apparent. Furthermore, as identified in RQ1a the UCLA-LS is arguably a more effective measure of loneliness because the responses are not inhibited by a preconception of whether respondents feel able to say they are lonely. Additionally,

the three items cover different aspects of loneliness and, when collated, give a multifaceted indication of loneliness, in comparison to a singular direct question. Table 13 outlines the regression models applied for RQ1b.

Table 13: Regression models for RQ1b: are the determinants of loneliness different for caregivers and non-caregivers?

Model number	Variables included in the model
1	Age, sex, cohabitation, LLTI, loneliness expectations, public transport use.
2	Model 1 + socioeconomic status
3	Model 2 + social networks
4	Model 3 + health and wellbeing

Source: author's own

The initial model (model one) included determinants of loneliness: variables identified through reviewing literature and theory. The variables in these regressions differ from the regressions in RQ1a because, factors such as age, and sex were pivotal within both caregiving and loneliness literature, and were therefore discussed in depth within the literature review (section 3.2), whereas the use of public transport was identified as a determinant of loneliness (van den Berg *et al.*, 2016; Kemperman *et al.*, 2019), but was not a common theme raised within caregiving literature. Therefore the inclusion of this variable in this regression analysis can identify whether public transport use was linked to loneliness among caregivers, as well as the general population. The aim of RQ1a was to establish whether an overall association was present between caregiving and loneliness, when controlling for known covariates; whereas RQ1b seeks to determine whether the determinants of loneliness differ for caregivers and non-caregivers. For this reason, the inclusion of additional variables reported as determinants of loneliness were key in determining the relevance of these factors for both caregivers and non-caregivers. In model two SES variables were added as covariates alongside the determinants of loneliness. This second model differs from the second model in RQ1a because the inclusion of sociodemographic variables was not necessary, because age, sex and cohabitation were all previously used as determinants of loneliness. Model three determined the impact of social networks on the relationships between the aforementioned determinants and loneliness, for both caregivers and non-caregivers. Any attenuation to previously significant relationships would suggest that social networks better account for loneliness than SES or the proposed determinants. Finally, in model four, additional health and wellbeing variables were included as covariates. As health status was identified within the literature as a determinant of loneliness, presence of LLTIs was included from model one, but adding other health and wellbeing variables in the fully-adjusted model (model four), tested whether specific health (e.g. SET pathways) and wellbeing measures were more strongly associated with loneliness for either caregivers or non-caregivers.

5.2.3.1 Determinants of loneliness among caregivers

In the fully-adjusted model (Figure 7), which included the determinants of loneliness and all covariates, being female was positively associated with loneliness among caregivers, whereas

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'disagreeing' with loneliness expectations, being in paid employment, close relationships with friends, and higher QoL were indicative of lower odds of caregiver loneliness (Appendix F). Both the Nagelkerke r^2 and Hosmer-Lemeshow ($p=.517$) demonstrate that the fully-adjusted model was the best fit and accounted for the greatest variance in loneliness in comparison to previous models; accounting for 57% of variance in caregiver loneliness. The regression analysis was conducted on 52% of the caregiving sample, as 48% (N=459) were excluded from the analyses due to missing data.

Odds of female caregivers being lonely were three times higher than for male caregivers (OR=3.06, 95CI=1.49-6.30); however, this was not significant in previous models. The reason for this could be that, among caregivers, owing to the slight female majority in the sample, the relationship between sex and loneliness among caregivers is weaker. However, with the introduction of a stronger association (e.g. between health and/or wellbeing and loneliness), and, in turn, the sex differences that arise between the health and wellbeing variables and loneliness, this may explain the significant result.

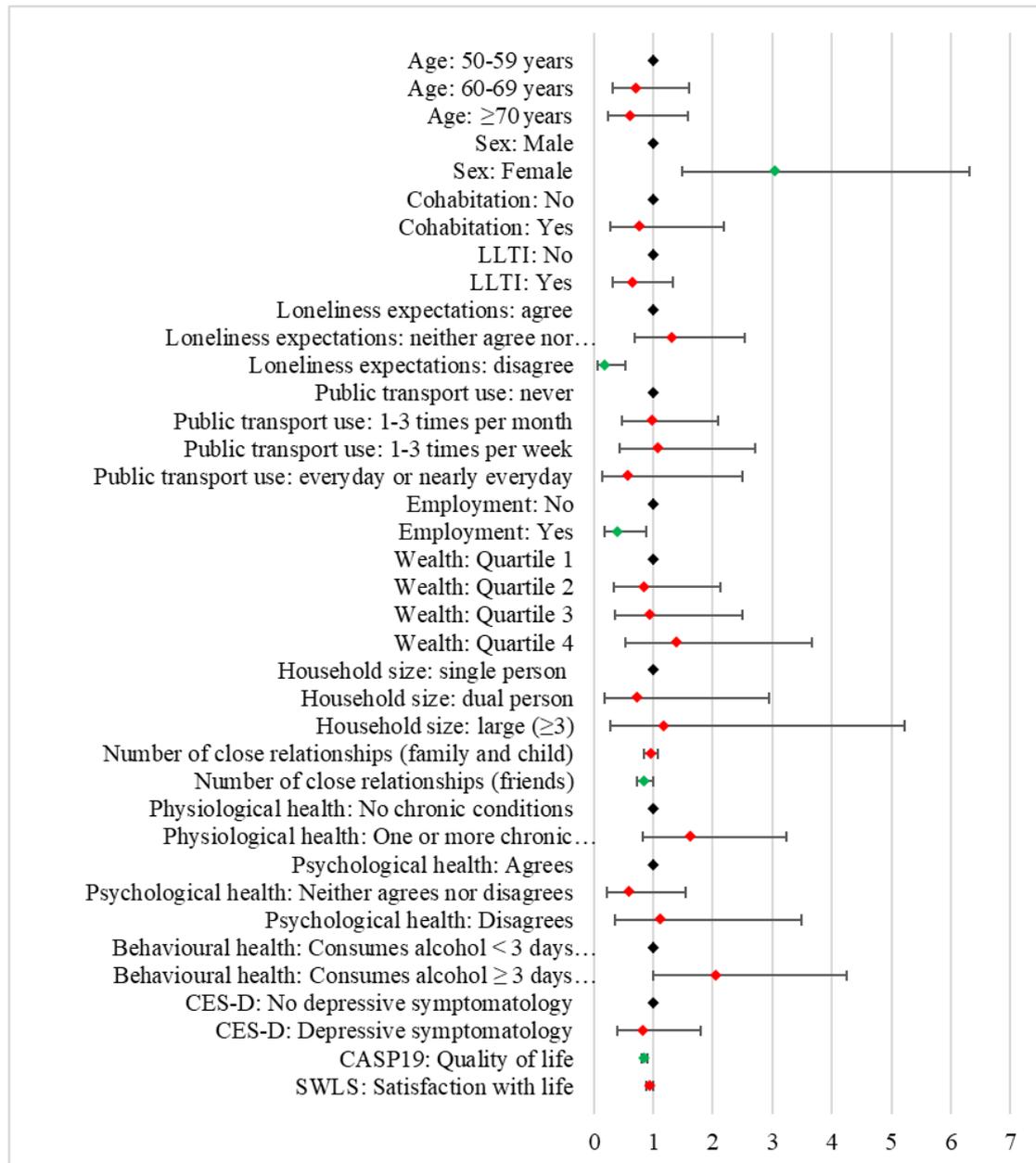


Figure 7: Odds ratio plot, determinants of caregivers' loneliness

Source: author's analysis of ELSA wave 8

'Disagreeing' with loneliness expectations (not expecting to get lonelier with age) was negatively associated with loneliness (OR=0.18, 95CI=0.06-0.54). In accordance with SET, evidence suggested that internalised beliefs can become self-fulfilling prophecies (Levy, 2009; Meisner and Levy, 2016), indicating that expecting to be lonely would result in higher likelihood of actually being lonely, which aligns with the findings in this thesis. Research also suggests that use of transport (e.g. buses) is related to lower loneliness (Kemperman *et al.*, 2019), giving access to social situations outside the local neighbourhood, and providing opportunities for interactions during the journey (van den Berg *et al.*, 2016). However, the results from this thesis suggest otherwise: the odds of loneliness among caregivers who never used public transport were not significantly different from those who used it frequently. Nevertheless, other factors may be influencing this relationship, such as SES. Caregiving roles are reported to negatively impact the financial situation of caregivers (Chiao *et al.*, 2015), thus

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public transport may be less accessible. Alternatively, those in higher wealth categories may be more likely to own a car, so measuring public transport use may be largely redundant.

Caregivers in paid employment alongside their caregiving role demonstrated lower odds of loneliness than caregivers without additional employment (OR=0.40, 95CI=0.18-0.89), which is likely due to increased opportunities to socialise outside of the caregiving role. Furthermore, a greater number of close relationships with friends was linked to lower loneliness odds (OR=0.84, 95CI=0.72-0.99). Conversely, close relationships with family members were not significantly associated with loneliness among caregivers. This suggests that caregivers in employment, with a larger friendship network outside of the family and caregiving role may experience greater levels of social support and are less likely to experience loneliness. Finally, QoL (OR=0.85, 95CI=0.81-0.90) was negatively associated with loneliness among caregivers, but none of the health measures were significant, which would suggest that wellbeing has a stronger association with loneliness among caregivers than health.

5.2.3.2 *Determinants of loneliness among non-caregivers*

The same models were applied within the non-caregiving sample; however, different determinants were associated with loneliness, highlighting inconsistency between determinants of loneliness for caregivers and non-caregivers. Similarly, around 46% (N=2274) of the non-caregiving sample were excluded from the regression analyses due to missing data. The Hosmer-Lemeshow statistic was non-significant ($p>.05$) across all models, indicating a good fit to the data. Moreover, the Nagelkerke r^2 increases with each model, with the fully-adjusted model accounting for the greatest variance in loneliness (49%).

For non-caregivers (Appendix G), in the fully-adjusted model (Figure 8), cohabitation with a partner was negatively associated with loneliness (OR=0.21, 95CI=0.14-0.33). Furthermore, LLTIs were also negatively associated with loneliness (OR=0.71, 95CI=0.51-0.99). Neither of these were determinants of caregiver loneliness. As discussed in RQ1a, those with LLTIs may receive help from family or friends and therefore may experience social contact due to this. In contrast, caregivers with LLTIs may receive less help for their own illness as, owing to the caregiving role, they may be perceived as more capable or able to look after themselves, therefore the additional social contact may not occur for caregivers. Amongst non-caregivers, both uncertainty about (OR=0.30, 95CI=0.22-0.41) and 'disagreeing' with (OR=0.21, 95CI=0.14-0.32) loneliness expectations were negatively associated with loneliness, compared to 'agreeing' that respondents would be lonelier as they aged. This suggests that, aligning with the SET hypothesis of self-fulfilling prophecies, expecting loneliness is linked to experiencing loneliness, as all other responses, compared to 'agree', were suggestive of lower odds of loneliness. However, as with the caregiving sample, use of public transport was non-significant in all models, suggesting no association with loneliness. As discussed previously (section 5.2.3.1), this contrasts with the literature; however, additional factors, such as

access to a car, may mediate the effect of public transport use. For example, those with a car may not use public transport often, but they would still be able to travel to social events.

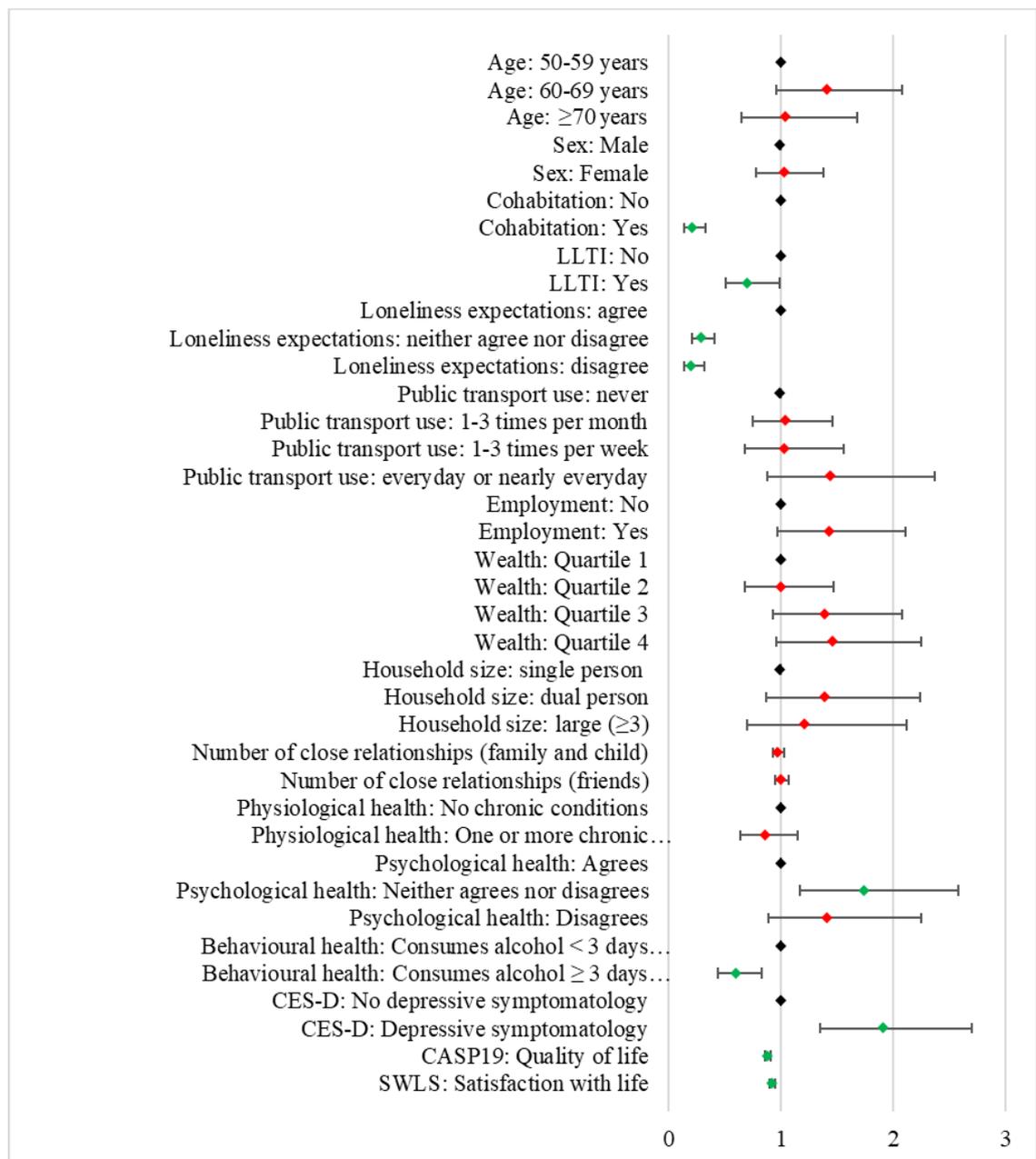


Figure 8: Odds ratio plot, determinants of non-caregivers' loneliness
Source: author's analysis of ELSA wave 8

Among the health and wellbeing variables, uncertainty about future health, in comparison with 'agreeing' health would get worse with age (OR=1.74, 95CI=1.17-2.58), and depressive symptomatology, compared to no depressive symptoms (OR=1.91, 95CI=1.35-2.70), were indicative of higher odds of loneliness for non-caregivers. In contrast, frequent alcohol consumption (≥ 3 days per week), compared to less frequent consumption (OR=0.61, 95CI=0.44-0.83), QoL (OR=0.88, 95CI=0.86-0.91) and life satisfaction (OR=0.93, 95CI=0.90-0.95) were negatively associated with loneliness among non-caregivers. Although alcohol consumption may be a coping mechanism for loneliness, and has been shown to be used among adolescents to avoid feelings of loneliness (McKay *et al.*, 2017), the relationship between alcohol consumption and loneliness is largely inconclusive

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(Segrin *et al.*, 2018). It is plausible that under these circumstances the context of the alcohol consumption may be accounting for this significant association. To clarify, if the alcohol consumption is occurring in a pub or similar establishment, it is likely that socialising will occur (Dunbar *et al.*, 2017) and therefore the individual may not feel lonely. Alternatively, consuming alcohol frequently alone at home is likely to involve limited social interactions, and therefore the experience of loneliness may be more likely. However, it was not possible to investigate from this data where alcohol was consumed, but it is logical to consider that if an individual is consuming alcohol frequently outside the home, that it may be occurring with friends or family. The health and wellbeing determinants vary substantially from the findings for caregivers, **only QoL was significantly negatively associated with** caregiver loneliness. This difference between caregivers and non-caregivers indicate that factors related to caregiving (e.g. intensity) may be playing an important role in determining loneliness.

5.2.3.3 Summary: are the determinants of loneliness different for caregivers and non-caregivers?

The **variables associated with** loneliness differed substantially in the caregiver and non-caregiver analyses, indicating that the determinants of loneliness were different for each group. The only corresponding **determinants** of loneliness for both caregivers and non-caregivers were ‘disagreeing’ with loneliness expectations and lower QoL (Table 14).

Among caregivers, the odds of female caregivers being lonely were three times higher than male caregivers, however sex was not a significant determinant of loneliness among non-caregivers. Similarly, paid employment was **negatively associated** with loneliness among caregivers, but no significant loneliness differences were found between employed and **non-employed** non-caregivers. Finally, a larger close network of friends was indicative of lower odds of loneliness among caregivers, but not non-caregivers. In contrast, cohabitation, LLTI, health expectations, alcohol consumption, depressive symptomatology, and life satisfaction were all determinants of loneliness among non-caregivers, but not caregivers.

The considerable differences between caregivers and non-caregivers highlighted that the determinants of loneliness may differ, based on caregiving circumstances. Fewer of the included determinants and covariates were significant among caregivers than the non-caregivers, which could suggest that aspects of caregiving (e.g. relationship to care recipient) may be affecting the loneliness of caregivers. This was further investigated in section 5.3, where caregiving-specific variables were investigated in relation to loneliness, health, and wellbeing.

Table 14: Summary of significant results for RQ1b: are the determinants of loneliness different for caregivers and non-caregivers?

Variables	Caregivers	Non-caregivers
Age: 60-69	NS	NS
≥70	NS	NS
Sex	**	NS
Cohabitation	NS	***
LLTI	NS	*
Loneliness expectations: neither agree nor disagree	NS	***
Loneliness expectations: disagree	**	***
Public transport use: 1-3 times per month	NS	NS
1-3 times per week	NS	NS
Every day or nearly every day	NS	NS
Paid employment	*	NS
Wealth: quartile 2	NS	NS
Quartile 3	NS	NS
Quartile 4	NS	NS
Household: dual-person	NS	NS
Household: large (≥3 people)	NS	NS
Close family relationships	NS	NS
Close friendships	*	NS
Physiological health	NS	NS
Health expectations: neither agree nor disagree	NS	**
Health expectations: disagree	NS	NS
Alcohol consumption	NS	**
CES-D: depressive symptomatology	NS	***
CASP19	***	***
SWLS	NS	***

Notes: NS non-significant, *p<.05, ** p<.01, *** p<.001, source: author's analysis of ELSA wave 8

5.2.4 RQ1c: how does the interaction between caregiving and loneliness affect the relationships between loneliness and health and wellbeing?

To investigate how caregiving interacts with the relationship between loneliness and health, or loneliness and wellbeing, a caregiving-loneliness interaction term was created. The interaction was included because, as identified in RQ1a, caregiving was significantly **negatively associated with** UCLA-LS loneliness in the first three models prior to the inclusion of health and wellbeing, and in RQ1b fewer of the health and wellbeing variables were **associated with** loneliness among caregivers compared to non-caregivers. Therefore, it was hypothesised that the relationship between loneliness and health or loneliness and wellbeing should differ between caregivers and non-caregivers.

The interaction was included in model two to determine the combined effect of caregiving and loneliness, in contrast with the conditional main effects of each variable (model one). Using this interaction, binary logistic and multinomial logistic regression analyses were conducted with the health DVs, and linear regressions with the wellbeing DVs. The analyses were carried out using UCLA-LS loneliness and, similar to previous research questions, sociodemographic characteristics, SES, and health or wellbeing variables were included as blocks of covariates (Table 15).

Table 15: Regression models for RQ1c: how does the interaction between caregiving and loneliness affect the relationships between loneliness and health and wellbeing?

Model number	Variables included in the model
1	Caregiving status and UCLA-LS
2	Model 1 + caregiving-loneliness interaction
3	Model 2 + sociodemographic characteristics and socioeconomic status
4	Model 3 + health or wellbeing*

Notes: *To determine the effect of wellbeing on health, and health on wellbeing, in regressions with health DVs, wellbeing covariates were included and in regressions with wellbeing DVs, health covariates were included.

Multicollinearity was tested among all the variables, all tolerance and VIF statistics were within accepted parameters, but strong correlations were observed between the two wellbeing variables.

Source: author's own

The results for RQ1c are separated into seven specific health and wellbeing measures: physiological health (chronic CV conditions), behavioural health (alcohol consumption), health expectations, depressive symptomatology, LLTIs, QoL, and life satisfaction. The main objective of this research question was to further investigate which areas of health or wellbeing loneliness and caregiving were more strongly associated, in order to develop targeted policy recommendations. Self-rated general health was not included as a health measure due to its more generic and subjective nature, as such obtaining information about specific health conditions would not be possible, see section 4.3.3 for discussion on this variable.

5.2.4.1 **Caregiving, loneliness, and physiological health**

This regression included 89% of the sample, with 11% (N=662) excluded due to missing data.

Caregiving was significantly **negatively associated** with poor physiological health, measured by the presence of one or more chronic CV conditions (Appendix H). In contrast, loneliness was found to increase the odds of poor physiological health in models 1-3, but this **positive association** attenuated with the inclusion of wellbeing covariates. In the fully-adjusted model (Figure 9), odds of caregivers experiencing poor physiological health were lower than non-caregivers (OR=0.71, 95CI=0.59-0.85). This could suggest a positive effect of caregiving on physiological health, or, more likely, it may highlight the capacity to care. For example, individuals with severe CV conditions are unlikely to be healthy enough to provide substantial care to another individual with separate health needs (healthy caregiver effect). The follow-up analyses within this thesis (section 6.2) aids the interpretation of this, determining time-order of caregiving and loneliness, and considering changes to health to identify if a healthy caregiver effect may be occurring. The caregiving-loneliness interaction was not significant in any model, which indicates that the relationship between loneliness and physiological health did not differ, depending on caregiving status.

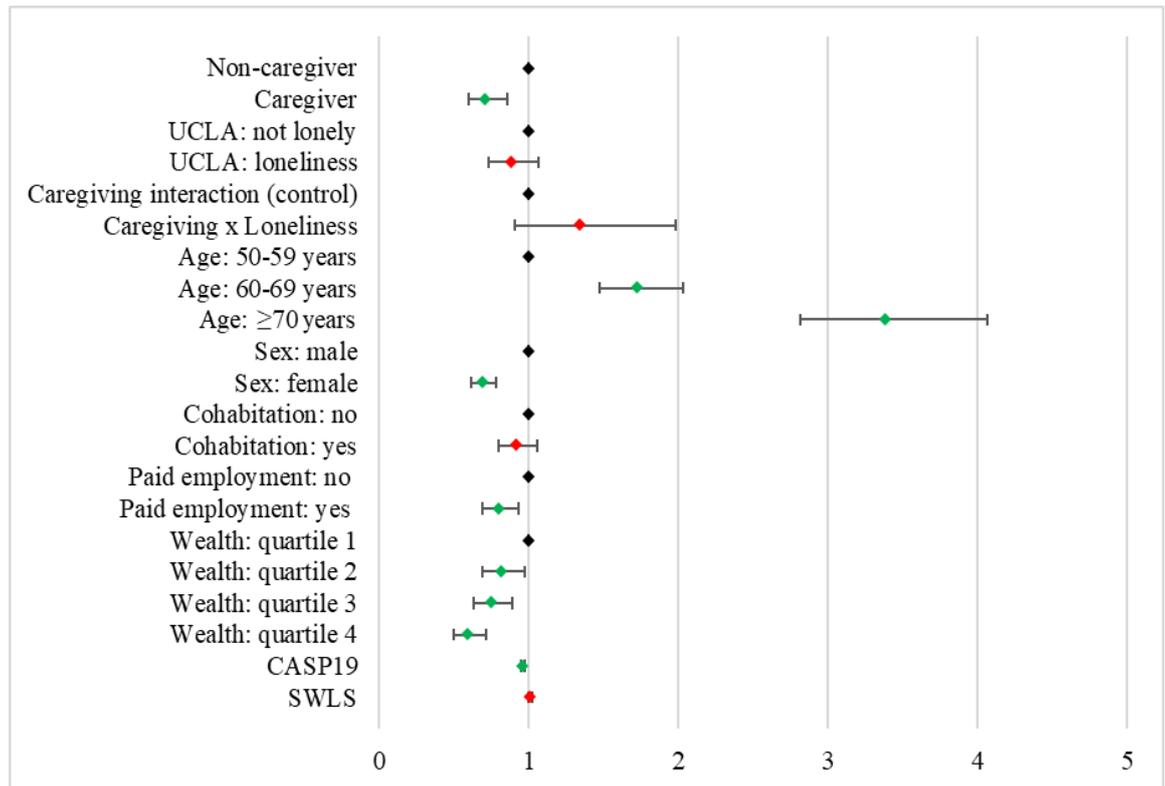


Figure 9: Odds ratio plot, factors associated physiological health

Source: author's analysis of ELSA wave 8

Similarly to the aforementioned healthy caregiver effect, a comparable association may be observed with employment (healthy worker effect). ORs suggest that those in employment were less likely to have chronic CV conditions, compared to those not in employment (OR=0.80, 95CI=0.69-0.93). The healthy worker effect would infer that those with poor physiological health were less able to work due to their condition, and therefore, those in employment were more physically able. Moreover, wealth was also negatively associated with physiological health. Respondents in the highest quartile were less likely to report CV conditions compared to the lowest quartile (OR=0.60, 95CI=0.50-0.71). This could be due to better access to healthcare and wealthier individuals sustaining a higher-quality of living, for example greater access to healthy nutrition and preventative medicine (Semyonov *et al.*, 2013) which would in turn reduce CVD risk.

The Nagelkerke r^2 indicates that the fully-adjusted model accounted for only 15% of variance in physiological health, implying that a considerable number of factors, influential to physiological health, were not included in the model. Moreover, although the Hosmer-Lemeshow ($p=.279$) indicates good model fit, because the interaction term was non-significant, and loneliness was not significantly associated with physiological health after controlling for wellbeing, the interaction between caregiving and loneliness had little or no impact on physiological health.

5.2.4.2 Caregiving, loneliness and behavioural health

In model one, including only caregiving and loneliness, loneliness was negatively associated with frequent alcohol consumption (OR=0.63, 95CI=0.54-0.74) as was caregiving (OR=0.79, 95CI=0.67-

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0.93) (Appendix I). The **negative association** between caregiving and alcohol consumption remained significant across all models after controlling for the caregiving-loneliness interaction and other covariates. However, the **negative association** between loneliness and alcohol consumption attenuated with the inclusion of wellbeing in the fully-adjusted model and was no longer statistically significant. **This regression included 88% of the sample, with 12% (N=698) excluded due to missing data.**

In the fully-adjusted model, caregivers were less likely to frequently consume alcohol compared to non-caregivers (OR=0.78, 95CI=0.65-0.94). Furthermore, the caregiving-loneliness interaction was positively associated with alcohol consumption; a combination of caregiving and loneliness was suggestive of a greater likelihood of frequent alcohol consumption. As shown in Figure 10, lonely caregivers, on average, consume alcohol more frequently than lonely non-caregivers. While, for lonely and non-lonely caregivers, mean alcohol consumption score was similar, for non-caregivers the difference between lonely and non-lonely individuals was much greater. Non-lonely, non-caregivers may have more time (no caregiving commitments) for social activities, and therefore may be more likely to spend time with friends (e.g. in a pub). This could explain why these individuals consumed alcohol more frequently, and were not lonely. Alternatively, the lonely non-caregivers may spend less time going out with friends, meaning that alcohol is consumed less frequently.

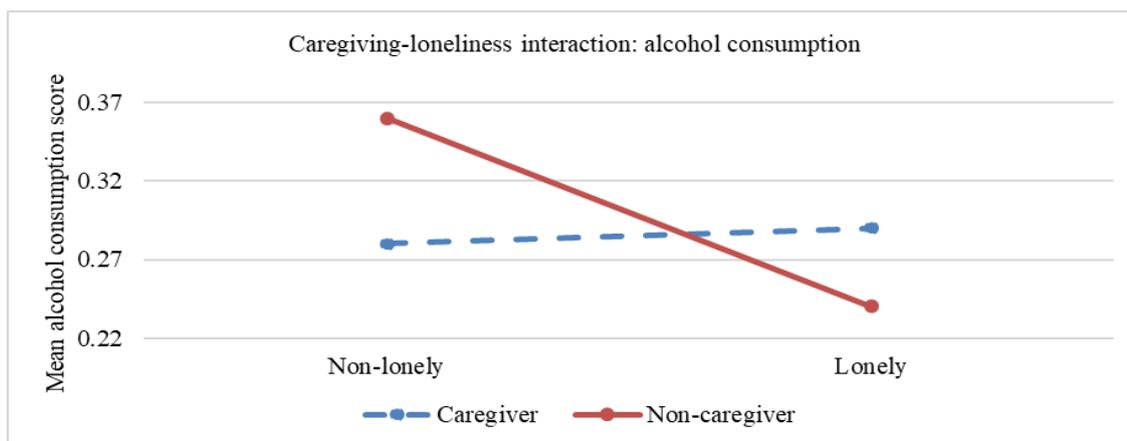


Figure 10: Interaction plot, alcohol consumption by loneliness and caregiving status
Source: author's analysis of ELSA wave 8

Sex was negatively associated with alcohol consumption in the fully-adjusted model (Figure 11), whereas wealth and QoL were positively associated. Females had lower odds of frequent alcohol consumption, compared to males (OR=0.51, 95CI=0.45-0.58), which is consistent with published literature, whereby males consistently were found to drink more frequently and in higher quantities compared to females (Kirchner *et al.*, 2007; Hughes *et al.*, 2016). Alternatively, wealth was **positively associated** with frequent alcohol consumption: odds of frequent consumption for respondents in the highest quartile were three times higher than those in the poorest quartile (OR=3.00, 95CI=2.48-3.62). This result was largely unsurprising, as wealthier individuals may be able to afford to buy alcohol more frequently, whereas poorer individuals may be more conscious about unnecessary spending and opt to consume alcohol less frequently. Moreover, Moos *et al.*

(2010) indicate a link between increased financial resources and higher likelihood of high-risk drinking behaviour among older adults.

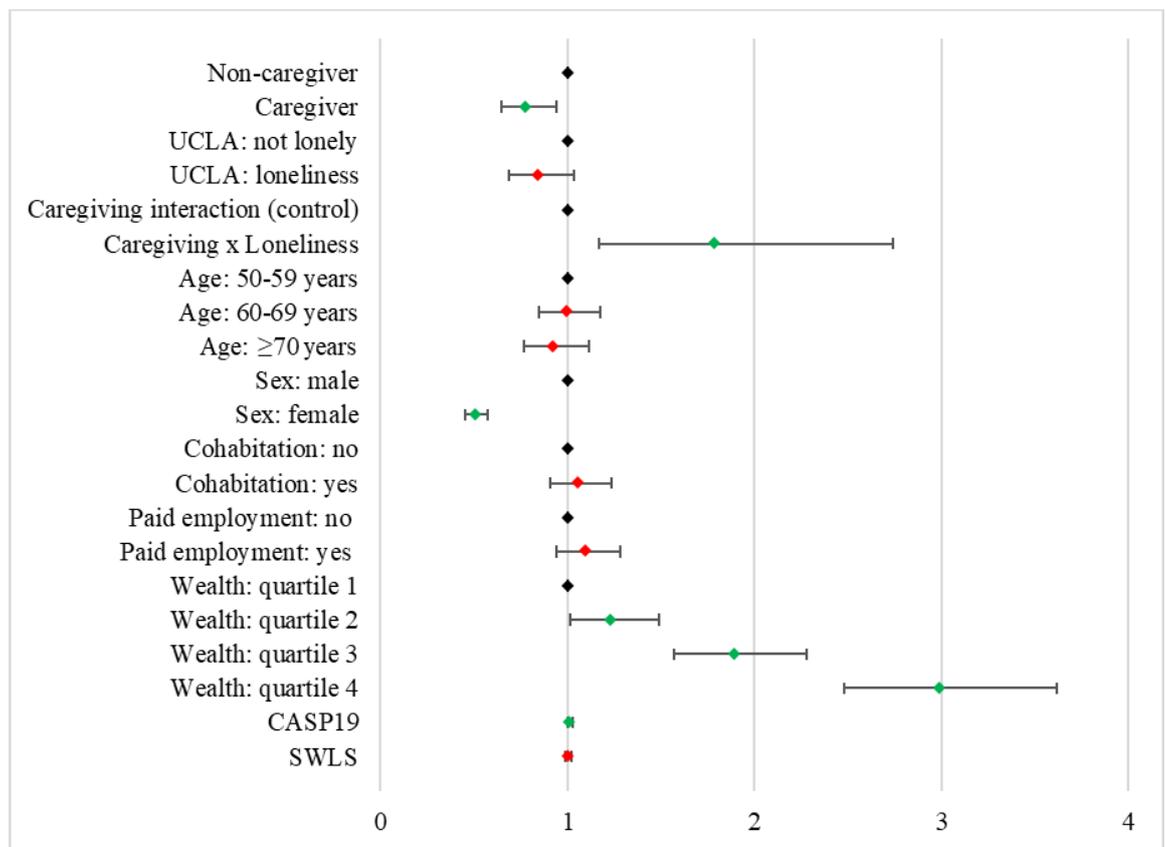


Figure 11: Odds ratio plot, factors associated with alcohol consumption

Source: author's analysis of ELSA wave 8

Overall, the caregiving-loneliness interaction suggests that the relationship between loneliness and alcohol consumption differs depending on caregiving status, but overall, the relationship is largely unexplained by these models. Although the Hosmer-Lemeshow statistic ($p=.298$) indicated a good model fit, the Nagelkerke r^2 statistic highlighted that the fully-adjusted model accounted for only 12% of variance in frequency of alcohol consumption, thus there are many additional factors influencing alcohol consumption among the respondents.

5.2.4.3 Caregiving, loneliness and health expectations

As outlined in section 4.3.3.1, the psychological health pathway involves future health expectations. The analysis was conducted in relation to the 'agree' response (expecting health to get worse with age), whereby comparison was drawn with the likelihood of a respondent 'disagreeing' (not expecting health to get worse with age) or responding with 'neither' (uncertainty about future health). In this regression included 11% (N=662) of the sample were excluded from the analysis due to missing data. Nagelkerke r^2 indicated that the fully-adjusted model explained only around 9% of variance in health expectations, which suggests that there are influential factors which have not been included. For example, current health is likely to have a substantial impact on health expectations. Controlling for current health status may have contributed to a greater explanation of variance, but also higher multicollinearity. Moreover, the focus of the research question was to determine the

impact of caregiving and loneliness on health expectations, not necessarily focus on the impact of health on health expectations. The following sections discuss the results from the multinomial logistic regression models (Appendix J).

Odds of disagreeing with health expectations, compared to agree

Health expectations were not significantly different for caregivers and non-caregivers. Furthermore, the caregiving-loneliness interaction was not statistically significant in any model. This suggests that caregiving, and the relationship between caregiving and loneliness, was not related to health expectations. Alternatively, lonely individuals were less likely to ‘disagree’, and more likely ‘agree’ than non-lonely individuals in models 1-3, although the significant association attenuated in the fully-adjusted model with the inclusion of wellbeing variables. This suggests that the association between wellbeing and health expectations may account for differences in loneliness. As loneliness is known, from previous literature, to be **negatively associated with health outcomes** (Mushtaq *et al.*, 2014; Friedler *et al.*, 2015; Ong *et al.*, 2016), it is likely that the lonely respondents may already be experiencing some negative health consequences, which may be contributing towards their health expectations.

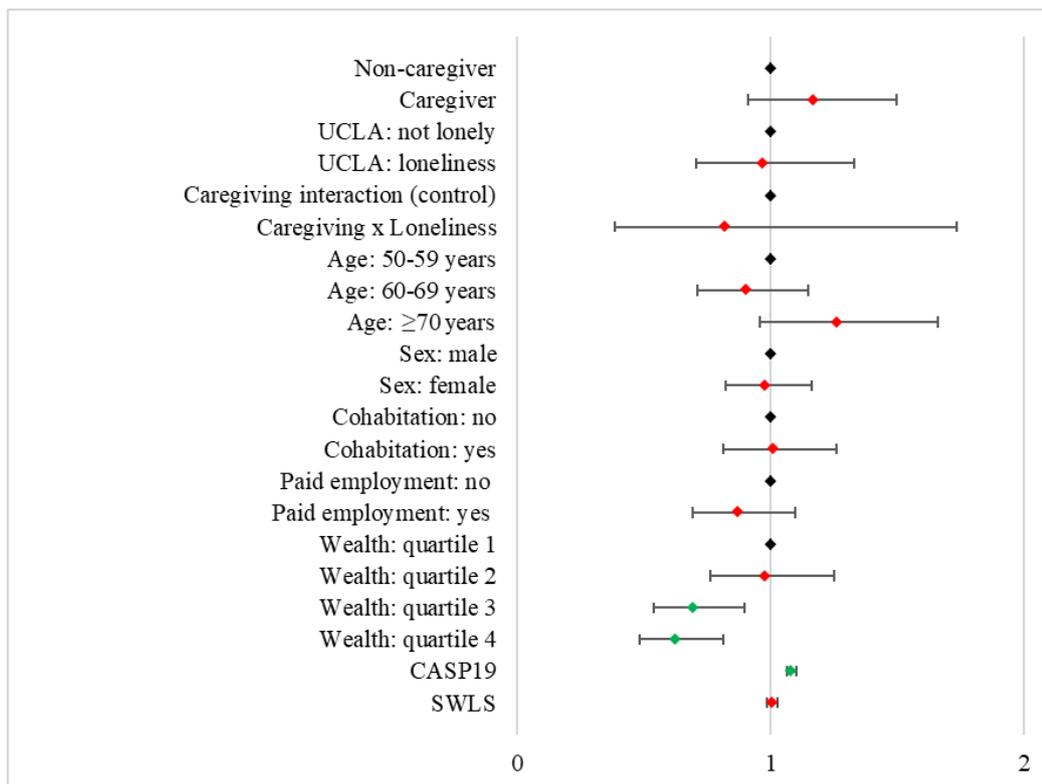


Figure 12: Odds ratio plot, factors associated with disagreeing with health expectations
 Source: author’s analysis of ELSA wave 8

In the fully-adjusted model (Figure 12) individuals with higher QoL scores demonstrated a more positive outlook on future health (OR=1.08, 95CI=1.07-1.10). Alternatively, the odds of respondents in the wealthiest quartile, reporting that they did not expect to be unhealthier when they were older, were lower than that of those in the poorest quartile (OR=0.63, 95CI=0.48-0.81). This suggests that wealthier individuals have fewer positive expectations for health, in comparison with poorer

individuals. In the physiological health analysis (section 5.2.4.1), wealthier individuals had lower odds of reporting CV conditions, and furthermore, in the LLTI analysis (section 5.2.4.5), wealthier individuals were less likely to report having LLTIs. This suggests that overall higher wealth quartiles had better health status, than lower quartiles. For this reason, wealthier individuals may be expected to have a more positive outlook on future health, but the results of this current analysis suggest otherwise. Findings among a sample of post-menopausal women also reported that lower SES was linked to more positive attitudes towards ageing (Kavirajan *et al.*, 2011), although this was not only limited to health expectations. Overall, literature is limited and inconclusive on the association between SES on health expectations. Amongst older adults with low SES, a link was found between ageing expectations and physical and mental health (Dogra *et al.*, 2015), whereas in other studies, no significant associations were reported between SES and expectations for ageing (Sarkisian *et al.*, 2002) or subjective quality adjusted life years (Rappange *et al.*, 2016).

Odds of neither agreeing nor disagreeing with health expectations compared to agree

As with the previous section (disagree *versus* agree), caregivers' and non-caregivers' health expectations were not significantly different, nor was the caregiving-loneliness interaction significant in any model. This further clarifies that caregiving and the relationship between caregiving and loneliness were not related to health expectations within this sample. Similar to the 'disagree' response, loneliness was significantly negatively associated with uncertainty about health expectations across models 1-3, lonely respondents were more likely to 'agree' that they expect health to get worse as they age. However, this significance, again, attenuated with the inclusion of wellbeing in the fully-adjusted model (Figure 13).

Older (aged ≥ 70) respondents were more likely to be uncertain about their future health, than younger (aged 50-59) respondents (OR=1.49, 95CI=1.17-1.89), but no significant difference was observed between ages 50-59 and 60-69. WHO (2018) suggests that although not exclusively a linear association, ageing is positively associated with increased risk of disease and decline in physical and mental capacity, therefore it could be, amongst the oldest group, that many already experience several health conditions. Therefore, older individuals may have adapted to the presence of health conditions, and if their health has remained relatively stable, they may not consider it likely to get worse. However, the age difference was not significant for the 'disagree' response, thus suggesting that the older individuals are more uncertain about health, than expecting it to decline.

In contrast to the 'disagree' results, significant differences were only observed between quartile two and the poorest wealth quartile (OR=1.49, 95CI=1.17-1.89). However, similar to the previous section (disagree *versus* agree), QoL was also positively associated with likelihood of reporting 'neither' over 'agree' (OR=1.07, 95CI=1.05-1.08). This supports the interpretation that individuals with lower QoL were more likely to have a more negative perception on future health.

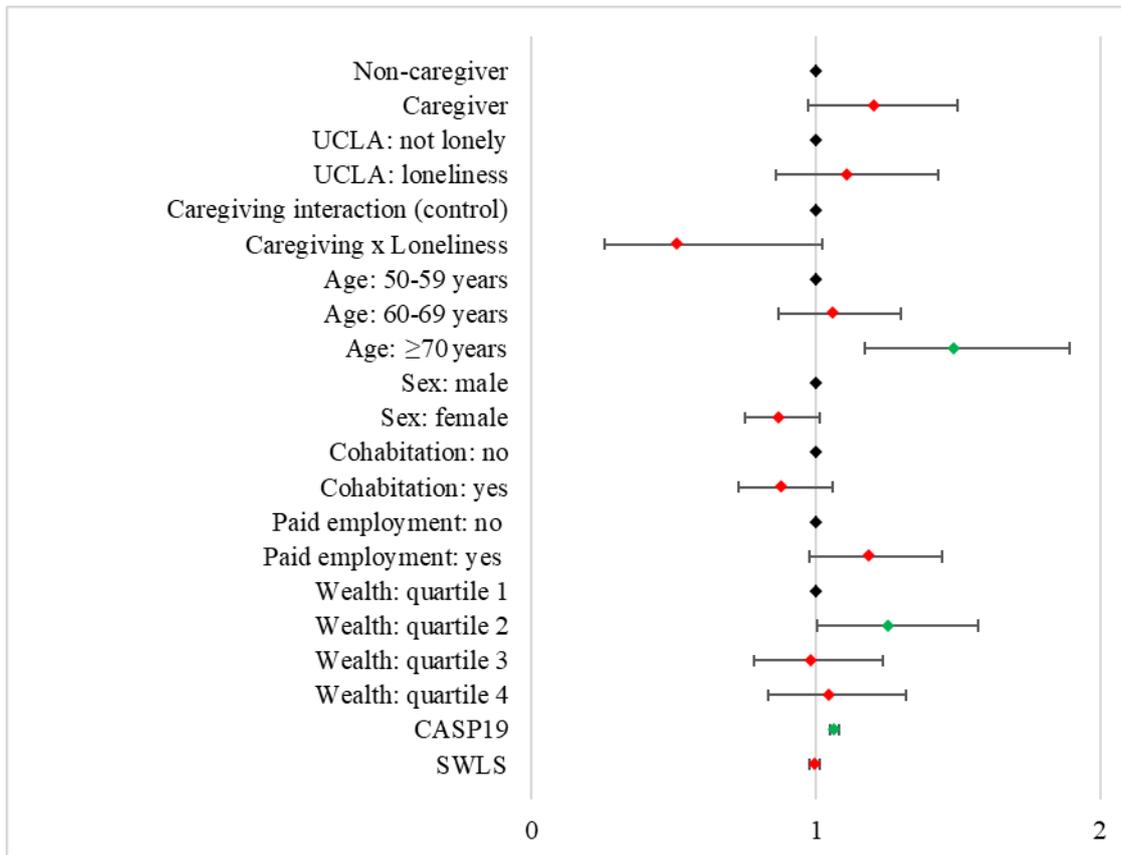


Figure 13: Odds ratio plot, factors associated with neither agreeing nor disagreeing with health expectations

Source: author's analysis of ELSA wave 8

5.2.4.4 Caregiving, loneliness, and depressive symptomatology

Despite the Nagelkerke r^2 indicating that the fully-adjusted model accounted for the greatest amount of variance explained in depressive symptomatology ($r^2=0.38$), compared to other health conditions (e.g. physiological health $r^2=0.15$), the Hosmer-Lemeshow suggests that the fully-adjusted model was not a good fit ($p=.002$). Model three accounted for less variance (23%), but was a better fit ($p=.358$), so although adding wellbeing explained greater variance in depressive symptomatology, it did not improve model fit. There is evidence to suggest that increased numbers of predictors negatively influences the power of Hosmer-Lemeshow tests (Blanchard, 2016), but this was not an issue in previous analyses, containing the same number of variables, so the reduction in model fit is unlikely due to the additional predictors. Due to missing data, 12% ($N=692$) of the sample were excluded from the analysis.

Caregiving, and loneliness, were positively associated with depressive symptoms, and the caregiving-loneliness interaction was also significant indicating that the impact of loneliness on depressive symptoms differed for caregivers and non-caregivers. However, the conditional main effect of loneliness on depressive symptomatology was smaller in the fully-adjusted model after controlling for wellbeing (Appendix K). Odds of lonely individuals reporting depressive symptomatology were 1.8 times higher ($OR=1.77$, $95CI=1.41-2.23$) than non-lonely individuals in the fully-adjusted model, compared to odds 5.4 times higher in model 3 ($OR=5.43$, $95CI=4.47-6.58$).

This suggests that wellbeing may account for some of the relationship between loneliness and depressive symptomatology. In the fully-adjusted model, odds of caregivers reporting depressive symptoms were almost twice that of non-caregivers (OR=1.79, 95CI=1.34-2.31). The caregiving-loneliness interaction was negatively associated with depressive symptomatology, as depicted below (Figure 14), the combined impact of caregiving and loneliness was indicative of greater depressive symptoms.

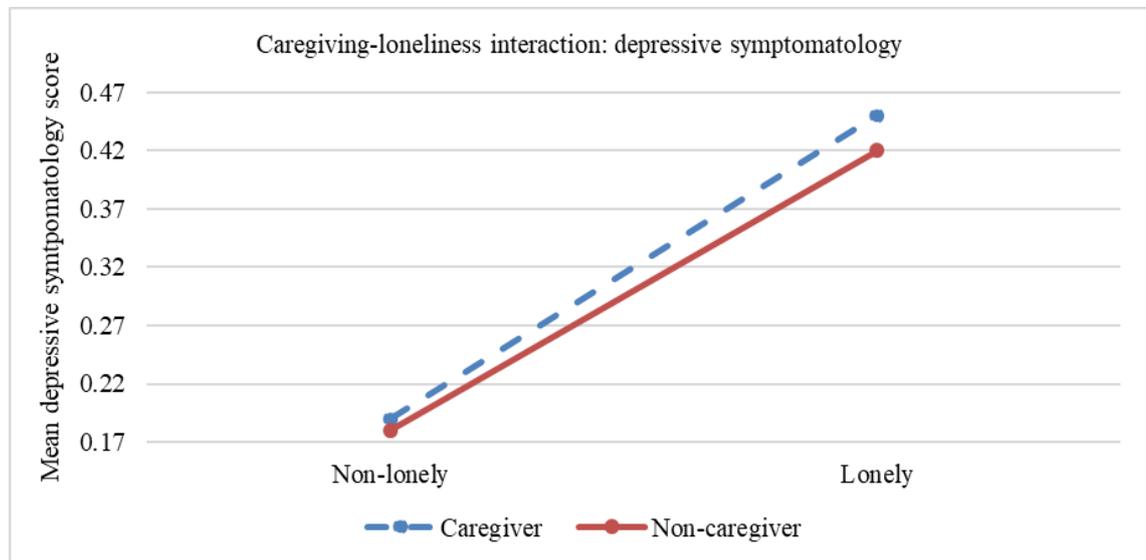


Figure 14: Interaction plot, depressive symptomatology by loneliness and caregiving status
 Source: author's analysis of ELSA wave 8

All covariates in the fully-adjusted model, except cohabitation, were associated with depressive symptomatology (Figure 15). For instance, the oldest respondent group (aged ≥ 70) were less likely to report depressive symptoms compared to the youngest group (aged 50-59) (OR=0.59, 95CI=0.45-0.77), however no significant difference was observed between ages 50-59 and 60-69. Evidence suggested that prevalence of depressive symptoms among older adults, although still substantial, are lower than both younger and middle-aged adults (Haigh *et al.*, 2018), therefore this finding aligns with previous literature.

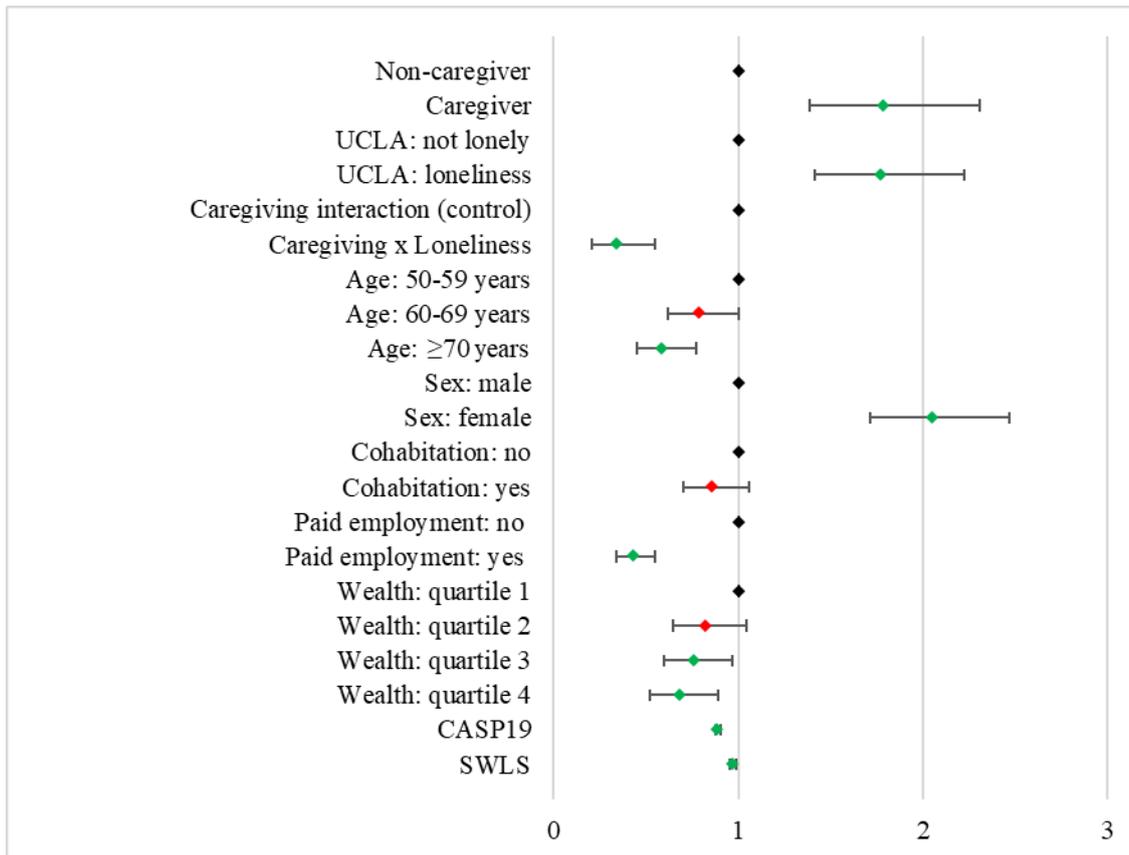


Figure 15: Odds ratio plot, factors associated with depressive symptomatology

Source: author's analysis of ELSA wave 8

Furthermore, both QoL and life satisfaction were negatively associated with depressive symptomatology (OR=0.89, 95CI=0.88-0.90 and OR=0.97, 95CI=0.96-0.99 respectively). Depression has previously been linked to negative self-evaluation (McCarthy and Morina, 2020). Furthermore, lower life satisfaction could be considered a negative evaluation, which may suggest why those with lower satisfaction and QoL were more likely to report depressive symptoms.

5.2.4.5 Caregiving, loneliness and limiting long-term illnesses

Initially (models 1-3), loneliness was positively associated with LLTIs: odds of lonely individuals reporting LLTIs were significantly higher than non-lonely. However, after controlling for wellbeing, this association was reversed (Appendix L). In the fully-adjusted model (Figure 16), which included 89% of the overall sample, odds of lonely individuals reporting LLTIs were lower than that of non-lonely, which is consistent with previous results (sections 5.2.2.2, and 5.2.3.2) whereby presence of LLTIs were linked to lower odds of loneliness. The fully-adjusted model accounted for around 28% of LLTI variance, which was an improvement from model three (17%).

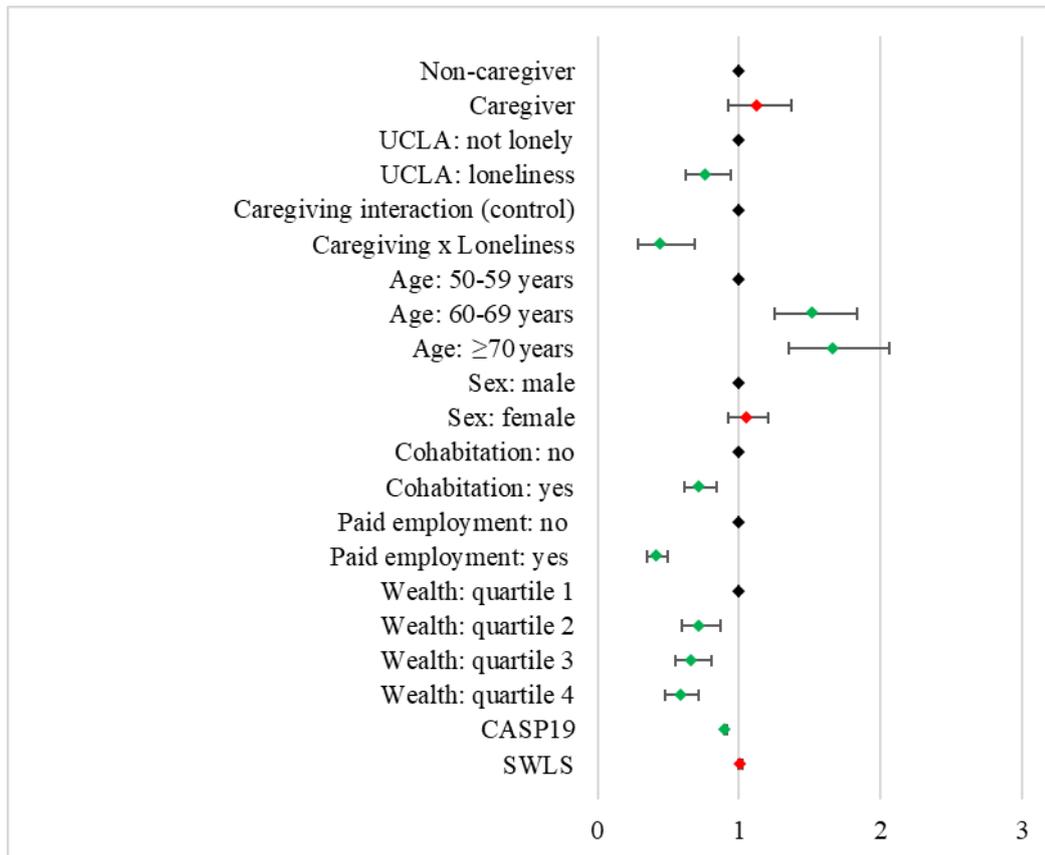


Figure 16: Odds ratio plot, factors associated with LLTI
 Source: author's analysis of ELSA wave 8

Lonely individuals demonstrated lower odds of reporting LLTIs compared with non-lonely (OR=0.77, 95CI=0.63-0.94). However, the significant interaction indicated that the combined effect of caregiving and loneliness impacts the relationship between loneliness and LLTIs. Non-lonely caregivers reported LLTIs more commonly than non-lonely non-caregivers (Figure 17), whereas lonely caregivers reported fewer LLTIs compared to lonely non-caregivers.

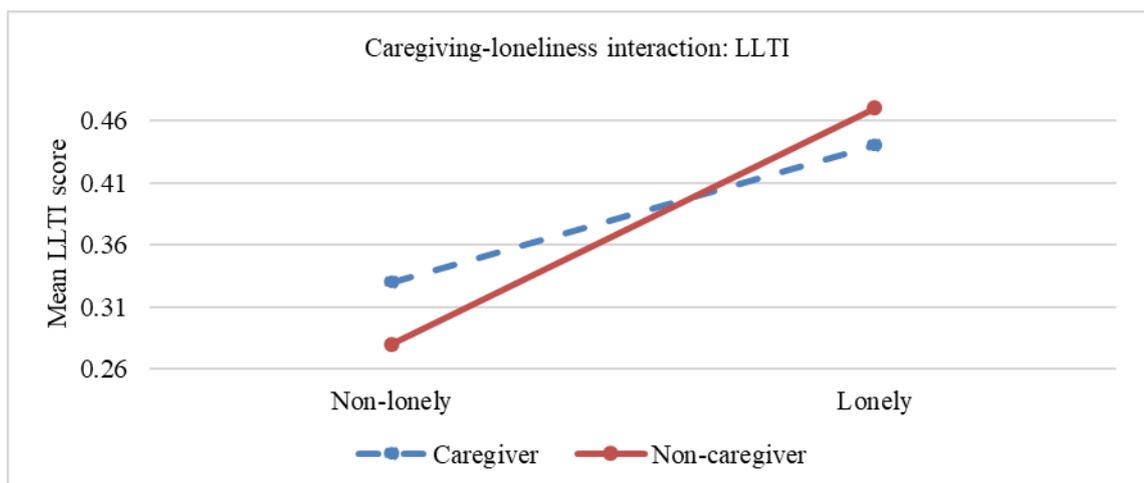


Figure 17: Interaction plot, LLTI by loneliness and caregiving status
 Source: author's analysis of ELSA wave 8

Cohabitation was linked to lower odds of reporting LLTIs (OR=0.72, 95CI=0.61-0.84). However, in all previous health measures, cohabitation was not significant. Individuals cohabiting with a spouse may be likely to receive assistance from their partner as part of their daily life and ongoing

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relationship, which may reduce the perception of the long-term illness. As such, the respondent may find it less limiting because they receive help, and are therefore less likely to report LLTIs than those living alone.

As discussed previously (section 5.2.4.1), healthy worker effects may also explain the negative association between employment and LLTI. Odds of employed respondents reporting LLTIs were considerably lower than **non-employed** (OR=0.42, 95CI=0.35-0.50). However, those with LLTIs may be less able to work due to illness, rather than a causal relationship existing between employment and health. Furthermore, wealthier individuals may have greater access to healthcare, and typically report being healthier than poorer individuals. Thus, it was expected that odds of reporting LLTIs would also decrease between the wealth quartiles. As predicted, the odds of the wealthiest quartile reporting LLTIs were substantially lower than quartile one (OR=0.59, 95CI=0.48-0.72).

Finally, QoL, but not life satisfaction, was **significantly negatively associated with LLTIs** (OR=0.90, 95CI=0.89-0.92). When considering the differences between the wellbeing measures, SWLS asks respondents whether they would change their life or if they have the things they want (Diener *et al.*, 1985), whereas the CASP19 (QoL) scale contains questions about feeling full of energy and their health preventing them doing things (Sim *et al.*, 2011). Therefore, it is reasonable that CASP19 was more closely related to health measures, as there are health-related items within the questionnaire.

5.2.4.6 Caregiving, loneliness and quality of life

QoL was quantified in this analysis using CASP19: higher scores were indicative of greater QoL. As a continuous variable, a linear regression was required, instead of logistic regressions used for categorical health variables. **Due to missing data, 10% (N=571) of the sample were excluded from the analysis.** The fully-adjusted model (Table 16) was significant ($F(17, 5348)=285.51, p<.001$) with an R^2 of 0.48. Full regression table can be seen in Appendix M.

Table 16: Fully-adjusted linear regression model examining how the interaction between caregiving and loneliness affects the relationships between caregiving, loneliness and quality of life

Variables	B (std. error)
Constant	41.26 (0.38)***
Caregiving	-0.82 (0.28)**
Loneliness	-7.51 (0.28)***
Caregiving-loneliness	-3.08 (0.63)***
Age	
60-69 years	1.47 (0.25)***
≥70 years	0.04 (0.15)
Sex: female	1.49 (0.19)***
Cohabitation	-0.13 (0.22)
In paid employment	0.43 (0.24)
Wealth	
Quartile 2	2.15 (0.27)***
Quartile 3	2.60 (0.27)***
Quartile 4	3.67 (0.28)***
LLTI	-3.85 (0.22)***
CES-D: depressive symptomatology	-6.22 (0.27)***
Physiological health: chronic CV condition(s)	-1.06 (0.20)***
Health expectations	
Neither agrees nor disagrees	2.38 (0.25)***
Disagrees	2.97 (0.28)***
Alcohol consumption ≥3days per week	0.86 (0.20)***

Notes: Linear regression, DV – CASP19; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Loneliness, caregiving, and the caregiving-loneliness interaction were negatively associated with QoL. Lonely individuals reported QoL scores, on average, 7.5 points lower than non-lonely, and QoL score was 0.8 lower for caregivers compared to non-caregivers. The combined effect of caregiving and loneliness, as identified through the significant caregiving-loneliness interaction (Figure 18), was suggestive of lower QoL. Although individually, both loneliness and caregiving were suggestive of poorer QoL, the difference in QoL scores was much greater between lonely caregivers and non-caregivers, than the non-lonely caregivers and non-caregivers.

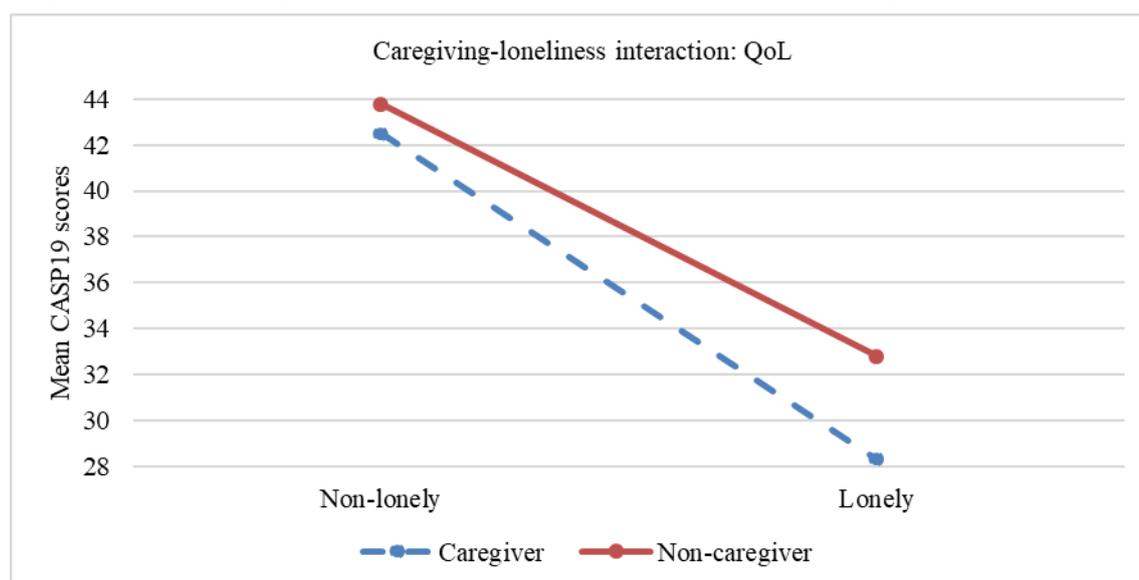


Figure 18: Interaction plot, quality of life by loneliness and caregiving status

Source: author's analysis of ELSA wave 8

All included variables, except cohabitation and employment, were significantly associated with QoL in the fully-adjusted model. Moreover, some noteworthy results arose surrounding the health

covariates. As expected, LLTI, depressive symptomatology, and poor physiological health were negatively associated with QoL. Additionally, respondents who expected their health to worsen with age ('agree') were more likely to have lower QoL scores than those who 'disagreed' or were uncertain. Conversely, alcohol consumption was positively related to QoL, as respondents who frequently consumed alcohol reported higher QoL, compared to less frequent drinkers. As discussed previously (section 5.2.3.2), the context in which alcohol consumption takes place may be impacting the result. If respondents are consuming alcohol in pubs with friends, this is likely to enhance their QoL score, particularly as some of the CASP19 items refer to the company of others and choosing to do things they want to do (Sim *et al.*, 2011).

5.2.4.7 Caregiving, loneliness and life satisfaction

Similarly to CASP19, higher SWLS scores indicate greater life satisfaction. In model one, both caregiving and loneliness were significantly negatively associated with life satisfaction. However, in subsequent models, with the introduction of the caregiving-loneliness interaction and other control variables, the association between caregiving and life satisfaction attenuated (Appendix N). The volume of missing data was much less in this regression, only 8% of the sample were excluded from the analysis. The fully-adjusted model (Table 17) was significant overall ($F(17, 5464)=175.39$, $p<.001$), with an R^2 of 0.35.

Table 17: Fully-adjusted linear regression model examining how the interaction between caregiving and loneliness affects the relationships between caregiving, loneliness and life satisfaction

Variables	B (std. error)
Constant	23.25 (0.30)***
Caregiving	-0.12 (0.22)
Loneliness	-4.91 (0.21)***
Caregiving-loneliness	-1.38 (0.48)**
Age	
60-69 years	1.03 (0.19)***
≥70 years	0.70 (0.11)***
Sex: female	0.92 (0.15)***
Cohabitation	2.16 (0.17)***
In paid employment	-0.18 (0.19)
Wealth	
Quartile 2	0.91 (0.21)***
Quartile 3	1.25 (0.21)***
Quartile 4	1.75 (0.22)***
LLTI	-1.35 (0.17)***
CES-D: depressive symptomatology	-3.54 (0.21)***
Physiological health: chronic CV condition(s)	-0.23 (0.15)
Health expectations	
Neither agrees nor disagrees	1.11 (0.19)***
Disagrees	1.45 (0.22)***
Alcohol consumption ≥3 days per week	0.46 (0.16)**

Notes: Linear regression, DV – SWLS; * $p<.05$, ** $p<.01$, *** $p<.001$; source: author's analysis of ELSA wave 8

Nevertheless, loneliness was negatively associated with life satisfaction: SWLS score was, on average, 4.9 points lower for lonely individuals, compared to non-lonely. Although the conditional main effect of caregiving was not significant once controlled for the interaction effect, sociodemographic characteristics, SES, and health, the caregiving-loneliness interaction was

statistically significant. Caregiving and loneliness combined was indicative of even lower life satisfaction than that of loneliness among non-caregivers (Figure 19).

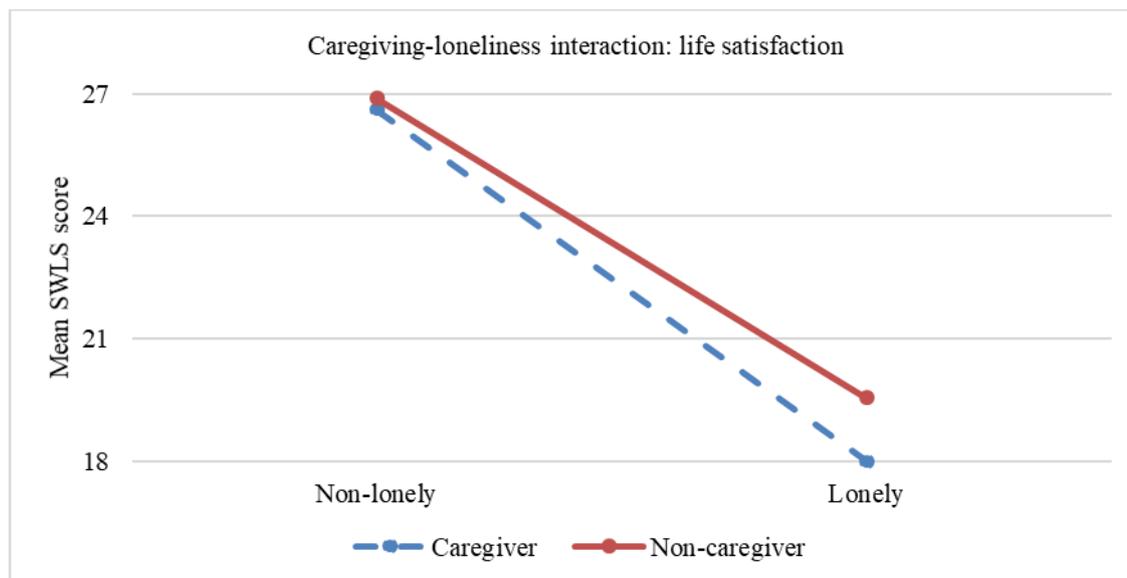


Figure 19: Interaction plot, life satisfaction by loneliness and caregiving status

Source: author's analysis of ELSA wave 8

In the fully-adjusted model, age, sex, cohabitation, wealth, health expectations, and alcohol consumption were positively associated with life satisfaction, whereas LLTI and depressive symptomatology were negatively associated with life satisfaction. Moreover, the consistent positive association between alcohol consumption and wellbeing (both QoL and life satisfaction), alongside the negative association with loneliness (lower odds of loneliness within the full sample, section 5.2.2.2 and among non-caregivers, section 5.2.3.2) supports the interpretation that the social aspect of alcohol consumption may be influencing these results. A more appropriate measure to determine the specific health and wellbeing effects of alcohol, may be volume of alcohol consumed, which would likely show more direct effects, in contrast to frequency, which appeared to be mediated by socialising occurring during the alcohol consumption. Furthermore, it is not evident whether respondents are consuming single or multiple drinks on each occurrence, which would also impact the relationship with health. Future research might consider this alternative, if using other data sources, but this information was largely unavailable for the sample within this thesis.

In contrast, physiological health was not significantly associated with life satisfaction. Although it could be reasoned that chronic CV conditions would reduce life satisfaction, it could also be argued that LLTIs would be more likely to influence life satisfaction than physiological health. For instance, respondents with a chronic CV condition may not be dissatisfied with their life, if the condition is managed sufficiently, as they may not find it as restrictive as they do an illness they have specifically identified as limiting (LLTI).

5.2.4.8 *Summary: how does the interaction between caregiving and loneliness affect the relationships between loneliness and health and wellbeing?*

The same models were applied for each of the health and wellbeing variables, with the exception of including wellbeing controls in health regressions and vice versa, which enabled comparison to be drawn. As highlighted in each section, model fit and variance ranged across all of the measures. This highlights key differences and indicates that different aspects of health are not all influenced by the same factors. Tables 18 and 19 summarise the results across all of the health and wellbeing measures.

Overall, it was evident that loneliness and caregiving have differing relationships with different aspects of health and wellbeing. The results suggest lonely individuals were less likely to report LLTIs, but more likely to experience symptoms of depression and reduced wellbeing. In addition, caregivers were less likely to report poor physiological health and frequently consume alcohol, but more likely to exhibit depressive symptoms and lower QoL, compared to non-caregivers. Furthermore, the caregiving-loneliness interaction was significantly associated with alcohol consumption, LLTI, depressive symptomatology, and both wellbeing measures, suggesting the effect of loneliness on these outcomes differed between caregivers and non-caregivers.

Table 18: Summary of significant results for RQ1c: how does the interaction between caregiving and loneliness affect the relationships between loneliness and health?

Variables	Physiological health	Alcohol consumption	Health expectations		CES-D	LLTI
			Neither agree nor disagree	Disagree		
Caregiving	***	**	NS	NS	***	NS
Loneliness	NS	NS	NS	NS	***	*
Caregiving-loneliness	NS	**	NS	NS	***	***
Age: 60-69	***	NS	NS	NS	NS	***
≥70	***	NS	**	NS	***	***
Sex	***	***	NS	NS	***	NS
Cohabitation	NS	NS	NS	NS	NS	***
Paid employment	**	NS	NS	NS	***	***
Wealth: quartile 2	*	*	*	NS	NS	**
Quartile 3	**	***	NS	**	*	***
Quartile 4	***	***	NS	***	**	***
CASP19	***	**	***	***	***	***
SWLS	NS	NS	NS	NS	**	NS

Notes: NS non-significant, *p<.05, ** p<.01, *** p<.001, source: author's analysis of ELSA wave 8

Table 19: Summary of significant results for RQ1c: how does the interaction between caregiving and loneliness affect the relationships between loneliness and wellbeing?

Variables	Quality of life	Life satisfaction
Caregiving	**	NS
Loneliness	***	***
Caregiving-loneliness	***	**
Age: 60-69	***	***
≥70	NS	***
Sex	***	***
Cohabitation	NS	***
Paid employment	NS	NS
Wealth: quartile 2	***	***
Quartile 3	***	***
Quartile 4	***	***
LLTI	***	***
CES-D: depressive symptomatology	***	***
Physiological health	***	NS
Health expectations: neither agree nor disagree	***	***
Health expectations: disagree	***	***
Alcohol consumption	***	**

Notes: NS non-significant, *p<.05, ** p<.01, *** p<.001, source: author's analysis of ELSA wave 8

5.2.5 Summary: how does loneliness differ for caregivers and non-caregivers?

Research question one addressed three key questions: (RQ1a) is caregiving associated with loneliness? (RQ1b) are the determinants of loneliness different for caregivers and non-caregivers? and (RQ1c) how does the interaction between caregiving and loneliness affect the relationships between loneliness, health, and wellbeing? Descriptive analyses indicated that there was little difference in the percentage of lonely caregivers, compared to lonely non-caregivers. Using the direct measure 11% of both caregivers and non-caregivers were lonely, whereas for the UCLA-LS, 20% of both groups were lonely. Similarly, 42% of non-caregivers and 41% caregivers 'agreed' that they expected to be lonelier as they age. Chi-squared analyses suggests that caregiving was independent from all of the loneliness measures, whereby no significant bivariate associations were found.

However, the results suggest that once controlled for theoretically important variables, caregiving was **positively associated with** loneliness, but only for the UCLA-LS, not the direct question or loneliness expectations, and this **positive association** attenuated with the inclusion of health and wellbeing controls. Additionally, the determinants of loneliness were found to significantly differ between caregivers and non-caregivers. For example, factors reported in literature, such as cohabitation or health-related predictors of loneliness were not significant in determining caregiver loneliness, which could indicate that factors associated with the caregiving role are more influential towards loneliness. Aspects of caregiving, including caregiver characteristics, the caregiving relationship and the caregiving role were analysed further in RQ2 (section 5.3).

Finally, the caregiving-loneliness interaction was significantly associated with three of the five health variables (depressive symptomatology, LLTI and alcohol consumption) and both wellbeing variables (QoL and life satisfaction). For the majority, the caregiving-loneliness interaction increased the likelihood of a negative outcome, i.e. more likely to frequently consume alcohol, report depressive symptoms, lower QoL, or lower life satisfaction. However, the caregiving-loneliness interaction

indicated that lonely caregivers were less likely to report LLTIs, compared to lonely non-caregivers. As discussed, this could be a healthy caregiver effect, but non-lonely caregivers were more likely to report LLTIs, than non-lonely non-caregivers. Therefore this is unlikely to be the full explanation. Further analysis into the time-order of caregiving, loneliness, and health (chapter six) sought to clarify this interpretation.

5.3 RQ2: how does caregiving affect loneliness, health, and wellbeing?

5.3.1 Descriptive statistics for the caregiving sample

This second research question analyses the caregiving sample (N=962). Subsequent to RQ1, in which differences were observed between caregivers and non-caregivers for the determinants of loneliness, and health and wellbeing outcomes, this section addresses differences within the caregiving group. Analysing caregiving-specific variables, such as factors relating to the caregiving relationship and role, may explain some of the differences observed between caregivers and non-caregivers, for example, identifying caregiving-specific determinants of loneliness. Descriptive statistics relating to characteristics, the caregiving relationship, role, and burden are presented below (Table 20). Further descriptive details, such as social networks, loneliness, health and wellbeing have been previously reported in Table 9 (section 5.2.1). The results from the bivariate analyses, including Chi-squared tests for categorical variables and Spearman's r for continuous variables are included in Appendix O.

Moreover, collinearity checks were all within accepted parameters: VIF typically ranged from 1-5, suggestive of some moderate correlations. However, VIF for spousal care was 6.9, suggesting stronger correlations, although this was still below the accepted parameters of 10. Correlations between all variables was checked using a correlation matrix. Correlations existed between the care recipient variables, which can be largely explained by care provision to multiple recipients (e.g. caregivers providing care to parents and others), whereby a stronger correlation would be expected. Additionally, as mentioned in section 5.2.1, correlations that existed between wellbeing variables were likely due to links between QoL and life satisfaction. However, evidence confirms that CASP19 and SWLS are distinct measures that measure separate aspects of wellbeing.

Table 20: Descriptive statistics for caregivers in ELSA wave eight

		Caregivers N (%)	
Caregiver characteristics	Age (years)	50-59	352 (36.6)
		60-69	311 (32.3)
		≥70	299 (31.1)
	Sex	Male	381 (39.6)
		Female	582 (60.4)
	Marital status	Married/civil partnership	590 (61.4)
		Single, never married	54 (5.7)
		Remarried	121 (12.6)
		Divorced/legally separated	146 (15.1)
	Cohabitation (spouse/partner)	Widowed	51 (5.3)
No		189 (19.6)	
Paid employment	Yes	774 (80.4)	
	No	630 (65.6)	
Wealth	Yes	330 (34.4)	
	Quartile 1 (poorest)	257 (26.9)	
	Quartile 2	237 (24.8)	
	Quartile 3	219 (22.9)	
Caregiving relationship	Care recipient	Quartile 4 (wealthiest)	242 (25.3)
		Spouse or partner	376 (39.1)
		Adult-child	112 (11.7)
		Parent or parent-in-law	272 (28.2)
	Co-residential care	Other relative, friend or neighbour	234 (24.4)
No		469 (48.7)	
Caregiving role	Caregiving intensity	Yes	493 (51.3)
		Low (≤19hpw)	566 (59.7)
		High (≥20hpw)	200 (21.1)
	Number of care recipients	Round-the-clock (168hpw)	181 (19.1)
Single recipient		828 (86.1)	
Caregiving appraisal	Feels adequately appreciated for their caregiving role	Multiple recipient	134 (13.9)
		Agree	882 (92.2)
	Feels satisfied with what they have gained from caregiving	Disagree	75 (7.8)
		Agree	931 (97.1)
		Disagree	28 (2.9)

Notes: total percentage for care recipients surpasses 100% due to caregivers providing care to multiple recipients, source: author's analysis of ELSA wave 8

5.3.1.1 Caregiver characteristics

The mean age of caregivers was 65.2, with the largest percentage of caregivers aged 50-59 (37%). As implied by previous literature and other caregiving data (Dahlberg *et al.*, 2007; van Campen *et al.*, 2013; Lacey *et al.*, 2018), the caregiving sample was predominantly female (60%). Milligan and Morbey (2016) highlight that this is not the case among older caregivers, whereby male caregivers are more prevalent than female among caregivers aged ≥65. However, as highlighted above, the age distribution of caregivers within ELSA data indicates a larger quantity of younger caregivers (aged 50-59), therefore a female majority was expected.

As previously identified (section 5.2.1.1), few caregivers identified as single, never married or widowed, this posed difficulties when running the analyses and contradictions arose with the cohabitation variable, whereby grouping into 'currently married' or 'not currently married' was not appropriate. Thus, the alternative measure relevant to relationship status was cohabitation (whether

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residing with a spouse or partner), and among caregivers, 80% were cohabiting. The remaining caregiver characteristics measure SES through employment status and wealth. Employment alongside the caregiving role was less common (34%), and distribution across wealth quartiles was relatively balanced.

5.3.1.2 Caregiving relationship

Spousal caregivers were most common (39%), followed by care to parents/parents-in-law (28%). This is consistent with UK data, whereby 34% of caregivers aged ≥ 50 provide spousal care, and 32% to parents (Colombo *et al.*, 2011). Spousal caregivers tend to be older (Broese van Groenou *et al.*, 2013), thus among this sample of caregivers (aged ≥ 50), a high number of spousal caregivers would be expected. Care recipient variables were coded as dummy variables to account for caregivers of multiple recipients, therefore Chi-squared tests were conducted for each of the care recipient groups.

In this ELSA sample, over half of the caregivers lived with their care recipient (51%). Due to the high percentage of spousal caregivers, a large percentage of co-resident caregivers was expected, as it is typical for married couples, and spousal caregivers, to cohabit (Broese van Groenou *et al.*, 2013). Further crosstabulation analysis confirmed that most spousal caregivers (97%) lived with their care recipient, and similarly, most caregivers to adult-children were co-resident (72%). For all other recipients, it was more common that the caregiver lived separately: 17% of caregivers to parents/parents-in-law and 10% of caregivers to others reported living with the recipient.

5.3.1.3 Caregiving role

Although most commonly (60%), caregivers provided low-intensity (≤ 19 hpw) care, there were a considerable number of caregivers providing high-intensity (≥ 20 hpw) care (21%), and almost as many (19%) were providing round-the-clock care (168hpw).

The majority of caregivers (86%) provided care to only one recipient. Further analysis indicated that for caregivers to multiple recipients, the most common recipient combinations were multiple parents/parents-in-law (32%), and multiple others (27%). This suggests that the relationship with the care recipient influences whether, and to whom, additional care is provided. As such, providing care to an adult-child is likely due to a long-term disability. Therefore care needs may be greater and more complex than, for example, for parents, who may just require help with shopping. Complex care needs for a single recipient would limit caregivers' capacity to provide care to wider network members, as recipients with higher care needs are more dependent on their caregiver (Cottagiri and Sykes, 2019). This is reflected in the data, as only 16% of caregivers to multiple recipients provided care to an adult-child, compared to 51% providing care to parents/parents-in-law.

5.3.1.4 *Caregiving burden*

Most of the caregiving sample did not appear to experience heightened levels of burden when considering role satisfaction and perceived appreciation as proxy measures. Over 92% of caregivers felt adequately appreciated, and over 97% were satisfied with what they had gained from caregiving. Satisfaction and appreciation variables were included in preliminary variations of the regression models. However, upon evaluation, the small percentages of caregivers not feeling adequately appreciated (N=75, 8%) or lacking satisfaction (N=28, 3%) contributed towards large CIs and the author considered that the findings from these variables could be invalidated by these small numbers. Thus, these variables were excluded from the regression analyses.

5.3.1.5 *Social networks and living arrangements*

Most caregivers lived in dual-person households (64%), with 27% living in households of three or more, and less than 10% living alone. Moreover, caregivers were inclined to have more close family relationships than friendships. The mean number of close family members was 4.9, compared to 3.7 for close friends.

5.3.1.6 *Loneliness, health, and wellbeing*

Loneliness (UCLA-LS) was present among 20% of caregivers (N=191). However, caregivers' expectations for loneliness differed considerably: most (41%) 'agreed' that they expected to get lonelier with age, whereas 29% 'disagreed', and did not expect to get lonelier with age. A further 29% 'neither agreed nor disagreed', which was interpreted as uncertainty about future loneliness.

Health was determined through several measures, including SET health pathways (physiological, behavioural, and psychological) and depressive symptomatology (mental health). In contrast to RQ1, LLTI was not included in a health measure. Firstly, LLTI was not significantly associated with caregiver loneliness (section 5.2.3.1), and the caregiving-loneliness interaction results indicated that loneliness among caregivers was suggestive of lower odds of LLTI, compared to loneliness among non-caregivers (section 5.2.4.5). Arguably, LLTI is somewhat generic, in that it can refer to any illnesses that limit the individual, whereas SET pathways and depressive symptomatology refer to very specific areas of health, thus fostering a more unambiguous discussion on caregivers' health. Across most of these measures, a larger percentage of caregivers demonstrated good health. For the SET physiological and behavioural pathways, 40% reported having chronic CV conditions, and 29% reported consuming alcohol frequently. Alternatively, for health expectations, a substantial majority 'agreed' that they expected their health to get worse as they age (70%). Additionally, a larger portion of caregivers were uncertain about future health (17%) than in disagreement (13%). Finally, CES-D scores suggest that 24% of the caregiving sample showed depressive symptomatology, overall implying that caregivers were in relatively good health.

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Higher CASP19 scores are indicative of greater QoL, and the highest possible score is 57. Average (mean) CASP19 score for caregivers was 39.9, indicating a relatively high QoL. The final wellbeing measure was SWLS. Scoring ranged from 5-35, whereby higher scores indicated greater satisfaction. Mean SWLS score among the caregiving sample was 24.9, suggesting high life satisfaction.

5.3.2 RQ2a: how does caregiving affect loneliness?

To examine the impact of caregiving on loneliness, caregiver characteristics, the caregiving relationship and the caregiving role were examined in relation to loneliness. A binary logistic regression, with the following models (Table 21) was conducted to determine whether caregiving-specific variables were associated with loneliness.

Table 21: Regression models for RQ2a: how does caregiving affect loneliness?

Model number	Variables included in the model
1	Characteristics: age, sex, cohabitation, employment, and wealth Relationship: care recipient, and co-residential care Role: caregiving intensity, and number of recipients
2	Model 1 + social networks
3	Model 2 + health and wellbeing

Source: author's own

Model one included the caregiving-specific variables outlined in section 4.3.1.1. This determined which aspects of caregiving were associated with loneliness. In model two, the addition of social networks highlighted the impact of close relationships with family members and friends on the relationship between caregiving and loneliness. Finally, model three included health and wellbeing controls, any changes observed to previously significant relationships after controlling for health and wellbeing would indicate that health and/or wellbeing were more strongly associated with loneliness, after controlling for caregiving-specific variables.

5.3.2.1 How does caregiving affect loneliness on the UCLA Loneliness Scale?

Of the 962 caregivers in the sample, 464 (48%) were excluded from this regression due to incomplete data. In the fully-adjusted model (Figure 20), being female, providing care to an adult-child, and frequent consumption of alcohol were positively associated with loneliness, whereas paid employment, larger numbers of close friendships and higher QoL scores were negatively associated.

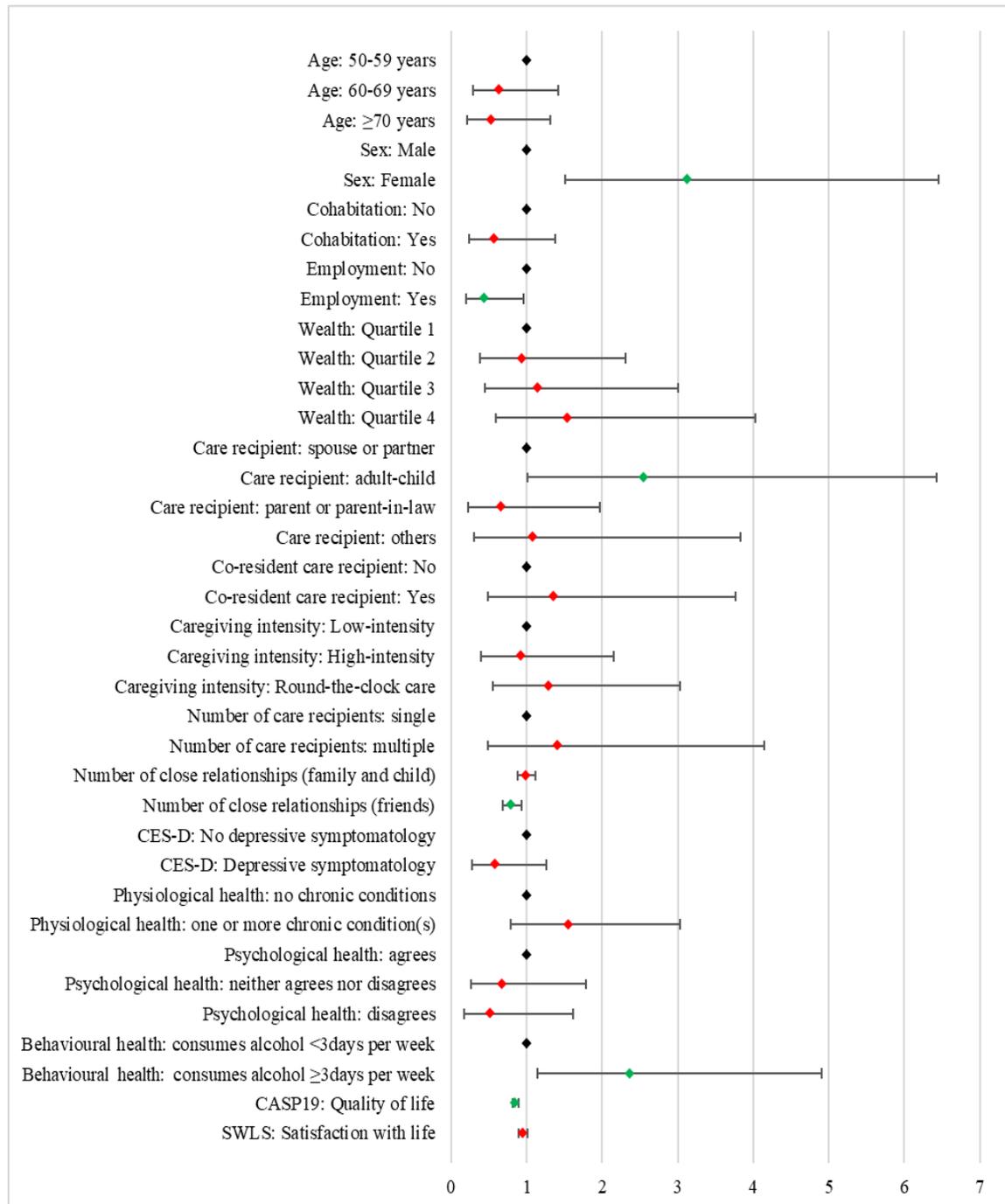


Figure 20: Odds ratio plot, caregiving-specific factors associated with caregivers' loneliness

Source: author's analysis of ELSA wave 8

Caregiver characteristics: in the first two models, age, employment and wealth were significantly **negatively associated** with loneliness (Appendix P). However, only employment remained significant after controlling for health and wellbeing. Employment was linked to 46% reduced odds of loneliness (OR=0.44, 95CI=0.20-0.96). As with the analysis of the full-sample, the opportunity to socialise in a work environment likely explains the reduction in loneliness. Moreover, in the fully-adjusted model, the odds of female caregivers experiencing loneliness were over three times higher than male caregivers (OR=3.13, 95CI=1.52-6.45). This is consistent with the results from RQ1b, where sex was a significant determinant of caregiver loneliness. Similarly, this result was only significant after controlling for health and wellbeing. It was considered that additional sex differences

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that arose with the inclusion of health and wellbeing likely enhanced the relationship between sex and loneliness.

Caregiving relationship: co-residential care was positively associated with loneliness in model one, whereby living with the care recipient was indicative of a higher likelihood of loneliness. However, this relationship attenuated in model two with the inclusion of social networks. Furthermore, significant loneliness differences were observed between caregivers providing care to an adult-child, and spousal caregivers in models two and three, after controlling for social networks and health and wellbeing. In the fully-adjusted model, odds of loneliness for caregivers to an adult-child were over 2.5 times higher than for spousal caregivers (OR=2.55, 95CI=1.01-6.43). However, no significant differences were observed for caregivers to parents, or others, in comparison to spousal caregivers. One interpretation of these findings was that providing care to an adult-child is a long-term commitment, and frequently higher-intensity than other caregiving roles (Barnhart *et al.*, 2020). Care provision is most likely due to disability throughout their childhood and adulthood, which would limit the caregivers' availability to seek employment or socialise outside of the household. The caregivers to adult-children may have experienced lower numbers of friendships, which could also contribute towards loneliness.

Caregiving role: neither caregiving intensity nor the number of care recipients were significantly associated with loneliness.

Moreover, frequency of alcohol consumption was positively associated with loneliness (OR=2.37, 95CI=1.15-4.90). It is plausible to consider that frequent alcohol consumption may be a coping mechanism for loneliness and/or caregiving. As such, a US sample of persons aged ≥ 45 found that lonely respondents tended to drink alcohol as a coping mechanism for loneliness. Consuming alcohol when lonely was more common among lonely respondents than non-lonely (Wilson and Moulton, 2010). Moreover, caregivers experiencing social or emotional burden are more likely to exhibit problematic drinking behaviours (Rospenda *et al.*, 2010). In contrast, in RQ1a, frequent alcohol consumption reduced the odds of loneliness within the full sample. However, as discussed, it was assumed that alcohol consumption may occur in social situations, particularly amongst non-caregivers. Therefore, in comparison to caregivers, who are more likely to consume alcohol as a coping mechanism, contrasting effects on loneliness were expected.

Improvement in model fit was observed across all three models, but overall, the fully-adjusted model was the best fit for the data, with a large Hosmer-Lemeshow p-value ($p=.883$), and accounting for 56% variance in loneliness. This suggests that health and wellbeing variables play a substantial part in explaining loneliness among caregivers. However, the results from RQ1b (section 5.2.3.1) would suggest that wellbeing may be more influential than health, as none of the health variables were previously significantly associated with caregiver loneliness.

5.3.2.2 Summary: how does caregiving affect loneliness?

In the fully-adjusted model (Table 22), for caregiver characteristics, sex (female) was positively associated with loneliness and employment negatively associated with loneliness. Additionally, for the caregiving relationship, only providing care to an adult-child showed a significant positive association with loneliness in comparison with spousal care. Moreover, contrary to expectation, none of the caregiving role variables were significantly associated with caregiver loneliness. It is important to consider the larger confidence intervals observed for variables, such as sex, and caring for an adult-child. A common explanation for large confidence intervals is often smaller sample sizes (Foster *et al.*, 2015). However, considerable efforts were made to minimise small cell counts, particularly among variables whereby category cell counts were <100. Therefore, this is likely not the case for sex, nor caring for an adult-child. An alternative explanation for the larger confidence intervals is variability. There are a large number of female caregivers, but the result demonstrates that loneliness varied, in that not all female caregivers were lonely.

Table 22: Summary of significant results for RQ2a: how does caregiving affect loneliness?

Variables	Loneliness
Age: 60-69	NS
≥70	NS
Sex	**
Cohabitation	NS
Paid employment	*
Wealth: quartile 2	NS
Quartile 3	NS
Quartile 4	NS
Care recipient: adult-child	*
Parent or parent-in-law	NS
Other relative, friend or neighbour	NS
Lives with care recipient	NS
Caregiving intensity: high-intensity (≥20hpw)	NS
Round-the-clock care (168hpw)	NS
Multiple care recipients	NS
Close family relationships	NS
Close friendships	**
CES-D: depressive symptomatology	NS
Physiological health	NS
Health expectations: neither agree nor disagree	NS
Health expectations: disagree	NS
Alcohol consumption	*
CASP19	***
SWLS	NS

Notes: NS non-significant, *p<.05, **p<.01, ***p<.001, source: author's analysis of ELSA wave 8

5.3.3 RQ2b: how does caregiving affect health?

To determine the impact of caregiving-specific variables on health, binary and multinomial logistic regressions were carried out with the SET health pathways (physiological, behavioural, and psychological) as DVs. The models for RQ2b were largely similar to those in RQ2a. However, model three included loneliness as a control in place of health measures (Table 23). These omissions were made because including health controls would influence the outcome when health variables were the DVs. It would be assumed that, even though CES-D measures different aspects of health than SET

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health pathways, a relationship may be present because the variables were all health-related. As such, when examining the impact of caregiving on health, controlling for health was considered counterproductive.

Table 23: Regression models for RQ2b: how does caregiving affect health?

Model number	Variables included in the model
1	Characteristics: age, sex, cohabitation, employment, and wealth Relationship: care recipient, and co-residential care Role: caregiving intensity, and number of recipients
2	Model 1 + social networks
3	Model 2 + loneliness and wellbeing

Source: author's own

In this research question, only the three SET health pathways are examined as outcomes. As health status was considered to be determinant of loneliness, the impact of LLTIs on loneliness was analysed, but LLTI was not significantly associated with caregiver loneliness (section 5.2.3.1). However, it was considered that this might be due to the more generic nature of the variable, in that LLTI can represent any condition the respondent perceives to be limiting. Thus, it was decided that the health measures in this caregiver-only analysis should look more specifically at distinct areas of health as opposed to a broad range of health outcomes. For example, physiological health in this study focuses on CV conditions only. Furthermore, the association between caregiving and mental health is robust and well-researched (Schulz *et al.*, 1997), and connections between caregiving and mental health have been consistently reported over several decades. Therefore, by restricting the analyses to the SET pathways, a more thorough discussion can occur around the impact of caregiving on physiological, behavioural and health expectations. This can potentially foster new understanding, clearer implications, and detailed areas for support for caregivers.

5.3.3.1 How does caregiving affect physiological health?

Some caregiver characteristics were significantly associated with physiological health, but factors relating to the relationship or role were not (Appendix Q). Caregiving characteristics **negatively associated** with poor physiological health were sex and employment (Figure 21). Moreover, being female compared to male (OR=0.43, 95CI=0.28-0.66), and employed compared to **non-employed** (OR=0.52, 95CI=0.32-0.87) were indicative of lower odds of poor physiological health. **Whereas age was positively associated with poor physiological health**; odds of caregivers aged 60-69 (OR=3.37, 95CI=1.92-5.93) or ≥ 70 (OR=3.37, 95CI=1.79-6.38) experiencing physiological health conditions were over three times greater than age 50-59. The results are consistent with previous research, whereby female caregivers were more likely than males to experience serious medical illnesses and report poorer health (Navaie-Waliser *et al.*, 2002). This also aligns with previous findings (section 5.2.4.1) amongst the full sample; both females and employed individuals were less likely, whereas older ages were more likely, to report poor physiological health. This implies that the impact of sociodemographic characteristics and SES on physiological health does differ for caregivers and non-caregivers. Formerly, caregivers showed significantly lower odds of poor

physiological health compared to non-caregivers. From this, it may have been anticipated that significant associations between other caregiving-specific variables (e.g. relationship or role) may have explained this relationship. Yet none of the factors related to the caregiving relationship or role were significantly associated with the physiological health of caregivers. This therefore strengthens the argument for a healthy caregiver effect, in that none of the factors related to caregiving appeared to be protective of health, but caregivers' physiological health was generally better.

The fully-adjusted model explained around 32% of variance in physiological health, but the Hosmer-Lemeshow statistic was significant ($p=.024$), which would suggest poor model fit. In this analysis, 53% of caregivers were included, with 48% ($n=457$) removed due to missing data. This indicates that caregiving-specific variables, and therefore caregiving overall, when considered alongside social networks, loneliness and wellbeing, have limited influence in the explanation of caregivers' physiological health.

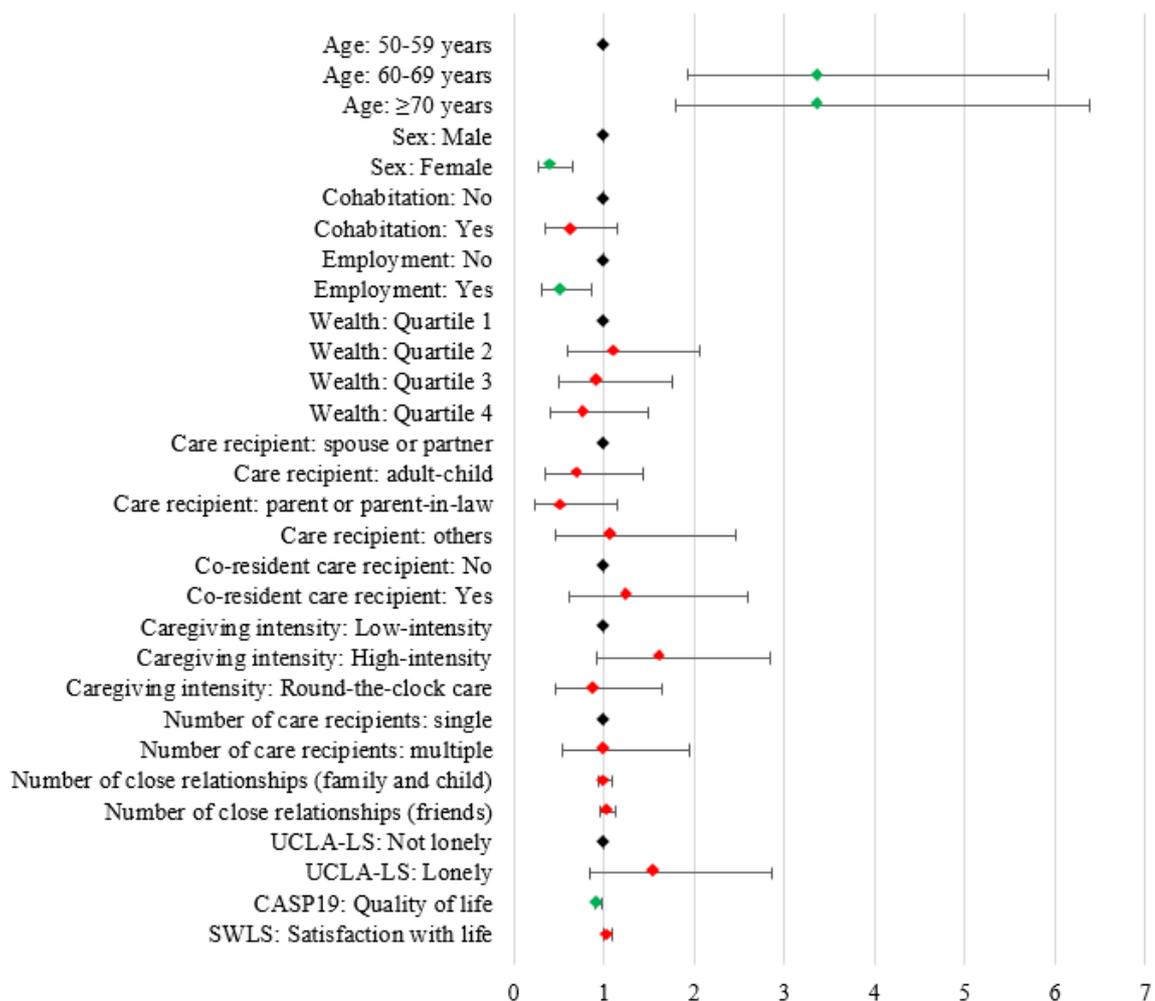


Figure 21: Odds ratio plot, caregiving-specific factors associated with caregivers' physiological health

Source: author's analysis of ELSA wave 8

5.3.3.2 *How does caregiving affect behavioural health?*

Poor behavioural health was quantified by frequent alcohol consumption (≥ 3 days per week). In the fully-adjusted model (Figure 22), which, due to incomplete data, included 52% of the caregiving sample, the factors significantly negatively associated with alcohol consumption were sex, and provision of care to adult-children. Alternatively, wealth was positively associated with frequent alcohol consumption.

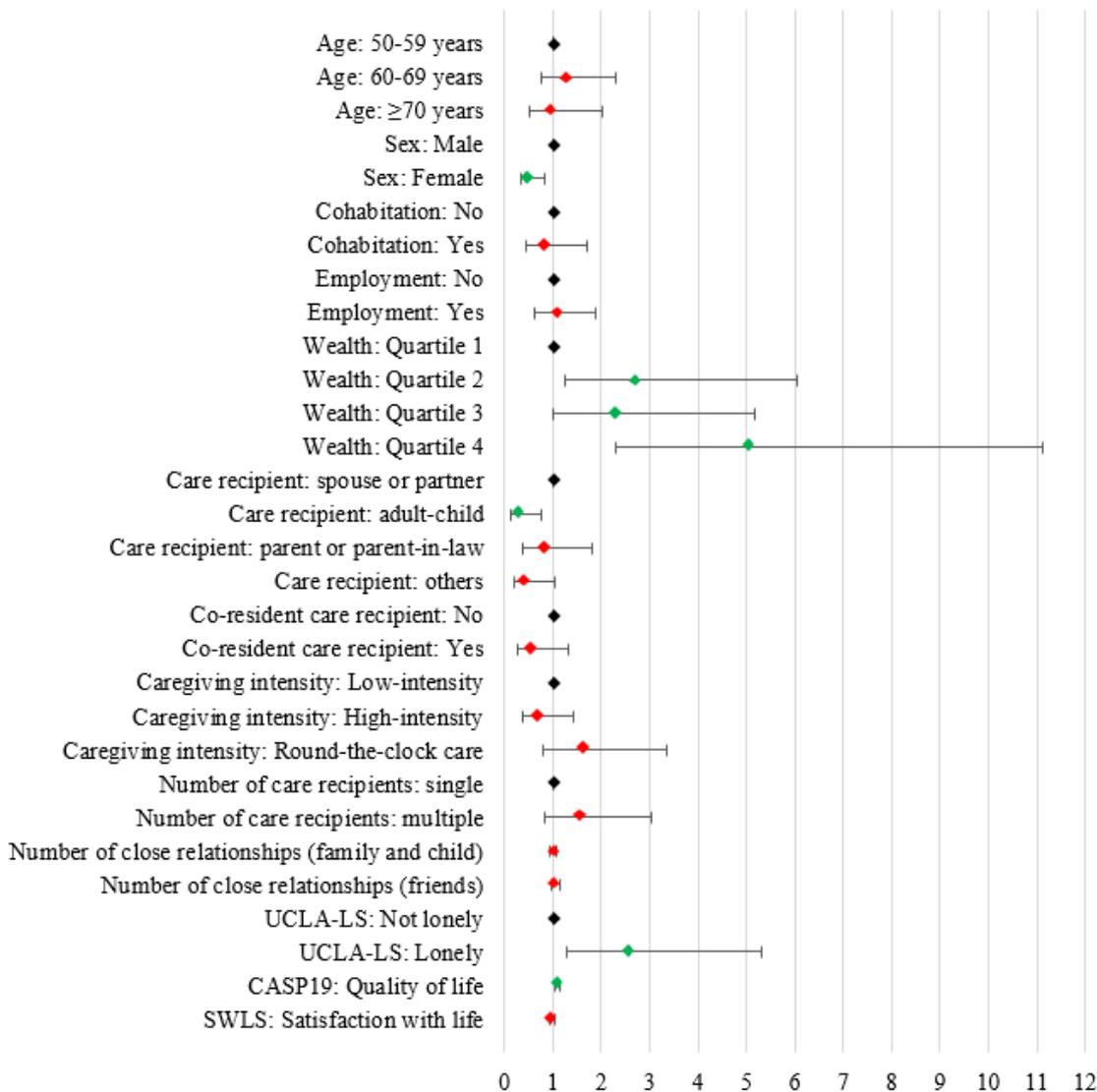


Figure 22: Odds ratio plot, caregiver-specific factors associated with caregivers' alcohol consumption
Source: author's analysis of ELSA wave 8

Female caregivers demonstrated lower odds of frequent alcohol consumption, compared to male caregivers (OR=0.53, 95CI=0.33-0.84), which is consistent with non-caregiver research. It is well-reported that, globally, males drink more frequently, and in higher quantities, than females (Hughes *et al.*, 2016). Caregivers in all wealth quartiles were much more likely to drink alcohol frequently than those in the lowest quartile. As in previous discussions (section 5.2.4.2), increased wealth is likely reflective of higher discretionary income. Moreover, evidence on alcohol consumption among caregivers suggests that drinkers reported having higher household income (i.e. higher SES)

(Rospenda *et al.*, 2010). Compared to spousal caregivers, caregivers providing care to adult-children displayed lower odds of frequent alcohol consumption (OR=0.31, 95CI=0.12-0.77).

Alternatively, care provision to multiple recipients was **positively associated with** frequent alcohol consumption in models one and two (Appendix R) but was not significant in the fully-adjusted model. This suggests that caregivers to multiple recipients may consume alcohol as a coping mechanism, for perhaps loneliness experienced due to their caregiving commitments. Hence, once controlled for loneliness differences, this association was no longer significant.

Additionally, caregiver loneliness (OR=2.59, 95CI=1.27-5.30), and QoL (OR=1.09, 95CI=1.04-1.14), **were positively associated with** frequency of alcohol consumption. This suggests loneliness and wellbeing were associated with alcohol consumption, after accounting for caregiving-specific variables and social networks. However, the inclusion of loneliness and QoL variables in the fully-adjusted model attenuated the previously significant relationship between number of care recipients and alcohol consumption. Thus, associations between loneliness, QoL and alcohol consumption may have reduced the strength of relationships between caregiving-specific variables and alcohol consumption. This would explain the reduction in model fit observed between models two and three (Hosmer-Lemeshow: $p=.839$ and $p=.022$ respectively). Moreover, the greater explanation of variance in the fully-adjusted model (Nagelkerke $r^2=0.24$) may suggest that the impact of loneliness and wellbeing on alcohol was greater than the impact of caregiving.

It could be considered contradictory that higher QoL would be indicative of more frequent alcohol consumption among caregivers. Previously it was interpreted that lonely individuals may seek to cope with loneliness by consuming alcohol, (e.g. by going out for a drink with friends), which increased socialisation and subsequently contributed towards higher QoL. However, this may not be possible for some caregivers, i.e. those providing care to an adult-child, as the complexity and duration of care is likely to be higher, leaving limited time for social activities. This could explain why the only significant difference in alcohol consumption was observed for caregivers to adult-children, as all other caregiving groups may have more free time to socialise. This might also elucidate why caregiving intensity was not significant, for example, the link between care recipient and intensity may account for any differences between intensity and alcohol consumption.

5.3.3.3 How does caregiving affect health expectations?

A multinomial logistic regression was used to compare caregivers' health expectations (Appendix S). **The analytic sample represented 56% of the full caregiving sample, due to 44% (N=424) with incomplete data.** The reference group ('agree') included individuals who expected their health to deteriorate with age. In comparison, 'disagree' indicated that caregivers did not expect their health to get worse and 'neither' was interpreted that the caregiver was unsure. As indicated in the descriptive statistics, the majority of caregivers expected health decline (70%) compared to 13% who did not, and 17% who were uncertain. Overall the fully-adjusted model did not explain a substantial

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amount of variance in health expectations (Nagelkerke $r^2=0.23$), but the likelihood ratio (Chi-squared=106.6, $p<.001$) suggests that the fully-adjusted model fit the data significantly better than an empty model.

Odds of caregivers disagreeing with health expectations, compared to agree

In the fully-adjusted model (Figure 23), only provision of round-the-clock care was significant. The odds of respondents providing round-the-clock care ‘disagreeing’ were over twice that of respondents providing low-intensity care (OR=2.60, 95CI=1.07-6.31). However, caregivers with the capacity to provide round-the-clock care, are unlikely to be currently experiencing any major health concerns, which is likely to impact their perception of future health. Additionally, as their recipient is dependent upon them 24/7, they may not consider, or want to consider, the possibility of their own health deteriorating, as this may compromise their caregiving situation. Moreover, in contrast to findings from RQ1c, which indicated increased wealth was **negatively associated with the** ‘disagree’ response in the whole sample (section 5.2.4.3), there were no significant wealth differences in caregivers’ health expectations. Therefore, it appears that the impact of wealth is less relevant to health expectations among caregivers, implying that when caregivers evaluate their future, they place less emphasis on SES.

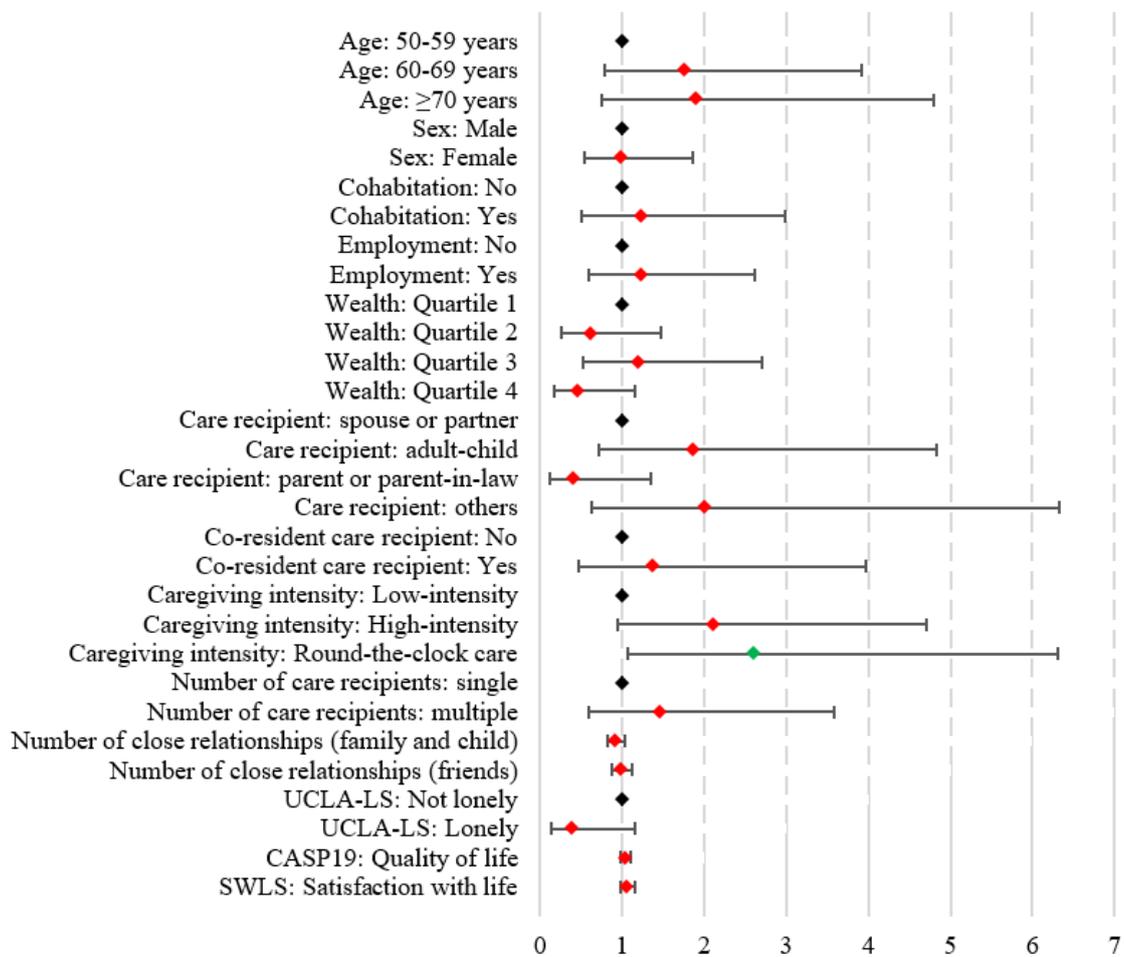


Figure 23: Odds ratio plot, careiving-specific factors associated with caregivers disagreeing with health expectations

Source: author's analysis of ELSA wave 8

Odds of caregivers neither agreeing nor disagreeing with health expectations compared to agree

Alternatively, employment, and QoL were positively associated, and relationship with the care recipient was negatively associated with the 'neither' response (Figure 24). Employed caregivers were less certain about future health, demonstrating higher odds of responding with 'neither', than non-employed caregivers (OR=2.02, 95CI=1.08-3.78). One interpretation could be that non-employed caregivers may be unable to work, due to the increased needs of their recipient. This may be negatively impacting caregivers' health, as high-intensity care has been shown to do (Lacey *et al.*, 2018). Therefore, non-employed caregivers may already experience health limitations, and thus be more likely to expect their health to deteriorate, compared to those who have the availability and capacity to work alongside their caregiving role. Moreover, research into health stereotypes in the general population (US-based) found no significant differences between employment groups (e.g. employed *versus* retired), suggesting that employment status, particularly retirement, had little influence on health stereotypes or expectations. This would advocate that factors outside of employment (i.e. careiving-specific) might contribute towards caregivers' perceptions on future health.

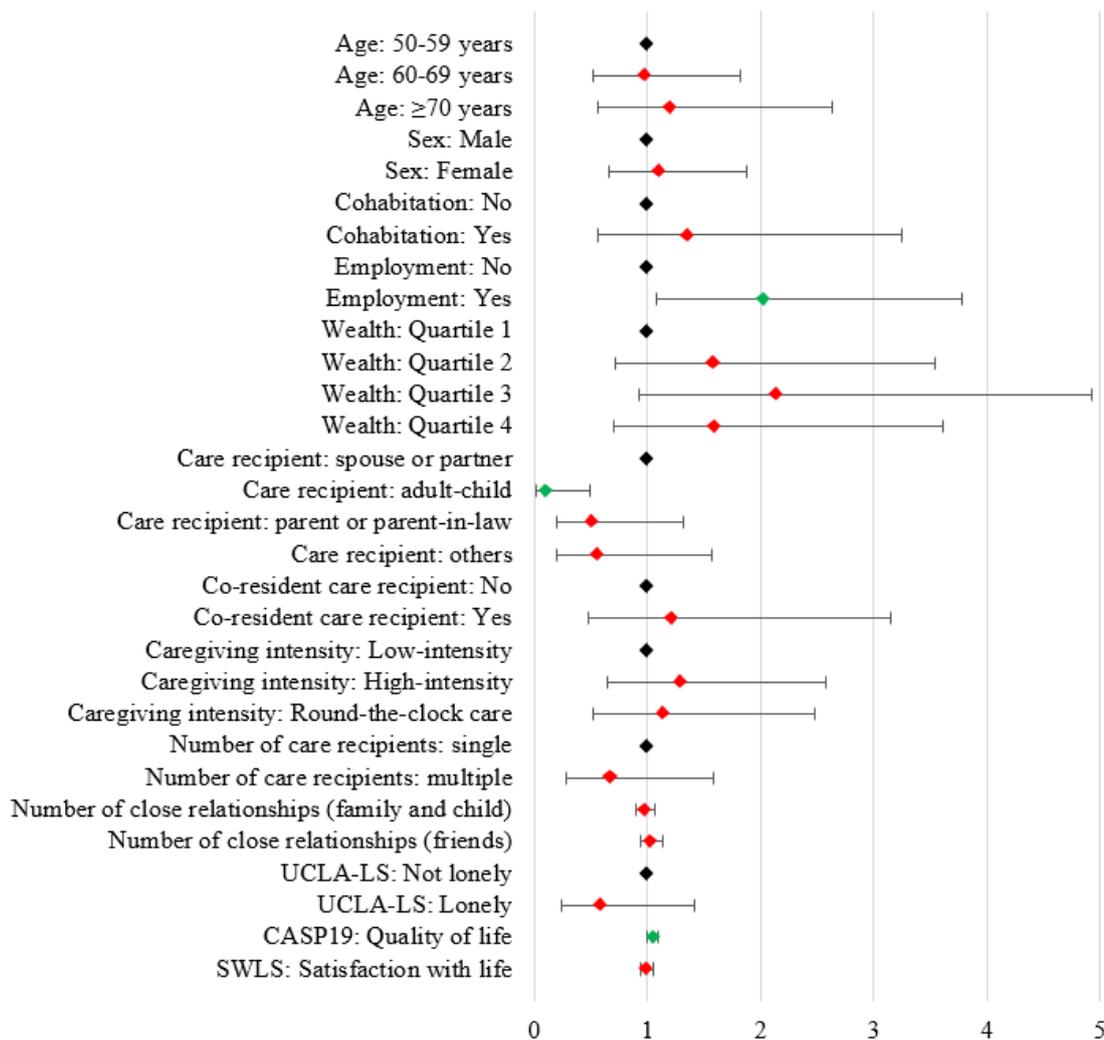


Figure 24: Odds ratio plot, caregiving-specific factors associated with caregivers neither agreeing nor disagreeing with health expectations

Source: author's analysis of ELSA wave 8

As discussed throughout the thesis, providing care to adult-children has, most likely, been a long-term commitment throughout the recipient's life, and may involve complex care needs due to disabilities. Caregivers to adult-children demonstrated significantly lower odds of responding with 'neither', compared to spousal caregivers (OR=0.10, 95CI=0.02-0.49). This suggests that this subgroup of caregivers was more likely to expect that their health would get worse with age. This could be for a number of reasons. For example, caregivers may already be experiencing health concerns. Lee *et al.* (2017b) found that caregivers of children with disabilities experienced greater odds of several chronic health conditions, compared to caregivers of children without disability. Alternatively, caregivers may recognise that over the course of providing care their health has deteriorated and they expect this to continue in line with their own ageing process.

Finally, higher QoL was positively associated with the 'neither' response, (OR=1.05, 95CI=1.00-1.10). Similarly to the analysis with the full sample (section 5.2.4.3), caregivers with greater wellbeing are likely to have a more positive outlook on health, or life in general. However, in contrast with the previous results, caregivers' QoL was only positively associated with the 'neither' response, not 'disagree', although this could still be considered a more positive outlook than 'agreeing'.

Therefore, the lack of **positive** association between QoL and ‘disagreeing’ may be attributed to the experience of caregiving, increasing uncertainty in caregivers with regard to their health.

5.3.3.4 Summary: how does caregiving affect health?

The **factors associated with** health were not consistent across the different health measures (Table 24). This indicates that differences between caregivers, or within the caregiving relationship and role, impact different aspects of health. Caregiver characteristics appear to have the greatest effect on health overall, as significant associations were observed across all three pathways. The strongest connection was observed for physiological health, whereby age was **positively associated** with, and sex and employment were **negatively associated** with poor physiological health. Moreover, providing care to an adult-child was **negatively associated** with both frequent alcohol consumption and neutral health expectations, whereas residing with the care recipient was not significantly associated with any of the health pathways. It was discussed that the reduced frequency of alcohol consumption and negative health expectations were likely linked to the high care needs of the recipient. For example, more intense and longer durations of care are linked to providing care to a dependent adult-child (Barnhart *et al.*, 2020), which is likely to increase potential burden, alongside limiting availability to socialise, (e.g. going out with friends to consume alcohol). Alternatively, providing care to single, or multiple, recipients did not significantly impact SET health pathways among caregivers. Finally, caregiving intensity was only significantly **positively associated with** caregivers’ health expectations, not behavioural or physiological health. Round-the-clock caregivers were more positive about future health expectations than low-intensity caregivers, which was interpreted as, perhaps, avoidance because they had 24/7 dependents, they may not want to consider the possibility of their own health deteriorating for the sake of the recipient.

The findings from RQ2b highlight that, of the SET health pathways, loneliness was only significantly **positively** associated with frequent alcohol consumption among caregivers. This corresponds with RQ1c, as the caregiving-loneliness interaction was only significant for behavioural health, not physiological or psychological. This new result (RQ2b) therefore emphasises that with the combined impact of caregiving, loneliness was associated with increased alcohol consumption, which, in turn, could contribute to further health concerns.

Table 24: Summary of significant results for RQ2b: how does caregiving affect health?

Variables	Physiological health	Alcohol consumption	Health expectations	
			Neither agree nor disagree	Disagree
Age: 60-69	***	NS	NS	NS
≥70	***	NS	NS	NS
Sex	***	**	NS	NS
Cohabitation	NS	NS	NS	NS
Paid employment	*	NS	*	NS
Wealth: quartile 2	NS	*	NS	NS
Quartile 3	NS	*	NS	NS
Quartile 4	NS	***	NS	NS
Care recipient: adult-child	NS	*	**	NS
Parent or parent-in-law	NS	NS	NS	NS
Other relative, friend or neighbour	NS	NS	NS	NS
Lives with care recipient	NS	NS	NS	NS
Caregiving intensity:				
High-intensity (≥20hpw)	NS	NS	NS	NS
Round-the-clock care (168hpw)	NS	NS	NS	*
Multiple care recipients	NS	NS	NS	NS
Close family relationships	NS	NS	NS	NS
Close friendships	NS	NS	NS	NS
Loneliness	NS	**	NS	NS
CASP19	**	***	*	NS
SWLS	NS	NS	NS	NS

Notes: NS non-significant, *p<.05, **p<.01, ***p<.001, source: author's analysis of ELSA wave 8

5.3.4 RQ2c: how does caregiving affect wellbeing?

Linear regressions were carried out to investigate the impact of caregiving-specific variables on wellbeing (QoL and life satisfaction). The models below (Table 25) are comparable with the previous two research questions (RQ2a/b): models one and two remained consistent, but the controls in model three were loneliness and health, instead of wellbeing. This change was made because the wellbeing measures were used as DVs, and therefore were not used as control variables.

Table 25: Regression models for RQ2c: how does caregiving affect wellbeing?

Model number	Variables included in the model
1	Characteristics: age, sex, cohabitation, employment, and wealth Relationship: care recipient, and co-residential care Role: caregiving intensity, and number of recipients
2	Model 1 + social networks
3	Model 2 + loneliness and health

Source: author's own

5.3.4.1 Caregivers' quality of life

Of the caregiving sample (N=962), 540 provided complete data and were included in this regression analysis; however, 442 (44%) were excluded due to missing data. The fully-adjusted model (Table 26) was significant ($F(23, 516)=28.54, p<.001$), with an R^2 of 0.56. This indicates that caregiving-specific variables, social networks, health, and loneliness explain 56% of variance in QoL among caregivers.

Table 26: Fully-adjusted linear regression model examining how caregiving-specific variables affect caregivers' quality of life

Variables	B (std. error)
Constant	36.01 (1.76)***
Age	
60-69 years	1.50 (0.77)
≥70 years	0.46 (0.46)
Sex: female	1.43 (0.65)*
Cohabitation	0.28 (0.88)
In paid employment	0.88 (0.75)
Wealth	
Quartile 2	3.60 (0.91)***
Quartile 3	4.35 (0.95)***
Quartile 4	4.53 (0.96)***
Care recipients	
Adult-child	1.71 (1.07)
Parent or parent-in-law	-0.01 (1.09)
Other relative, friend or neighbour	-0.27 (1.20)
Lives with the care recipient	-0.51 (1.05)
Caregiving intensity	
High-intensity (≥20hpw)	-0.55 (0.85)
Round-the-clock care (168hpw)	-0.92 (0.96)
Multiple care recipients	2.94 (0.94)**
Number of close relationships (family and child)	0.32 (0.11)**
Number of close relationships (friends)	0.07 (0.13)
UCLA-LS Loneliness	-10.01 (0.83)***
CES-D: depressive symptomatology	-6.14 (0.84)***
Physiological health: chronic condition(s)	-2.09 (0.68)**
Health expectations	
Neither agrees nor disagrees	1.63 (0.81)*
Disagrees	1.44 (0.98)
Alcohol consumption ≥3days per week	2.63 (0.72)***

Notes: Linear regression, DV – CASP19; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

For caregiver characteristics, female caregivers reported QoL scores 1.4 points higher than male caregivers. The largest difference was observed between the wealthiest and poorest quartile, whereby wealthier caregivers QoL was 4.5 points greater than poorer caregivers. Alternatively, there were no significant associations between the caregiving relationship variables (care recipient or co-residential care) and QoL in the fully-adjusted model. However, in model one (Appendix T), co-residential care was negatively associated with QoL (B=-3.1, p<.05). The introduction of social network variables in model two attenuated this relationship, which suggests that close relationships were more strongly related to QoL after accounting for the caregiving relationship. Finally, when considering the caregiving role, QoL was 2.9 points higher among caregivers to multiple recipients, compared to a single recipient. However, caregiving intensity was not associated with QoL in any model. Evidence suggests that caregiving can provide feelings of fulfilment or satisfaction (Quinn *et al.*, 2009). Thus, providing care to multiple individuals may provide a heightened sense of gratification than to a single recipient, as they are helping two people, not just one. This increased sense of satisfaction may translate into positive wellbeing.

Caregivers either 'want to', 'have to', or are 'able to' provide care, and these attitudes, beliefs and barriers determine care provision (Broese van Groenou and de Boer, 2016). 'Wanting' to provide

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care is linked to feelings of altruism whereas ‘having’ to provide care may be more closely aligned with feelings of reciprocity and obligation. CASP19 considers aspects such as control and autonomy in relation to QoL. Therefore, it could be considered that individuals entering into caregiving roles because they ‘want to’, rather than because they ‘have to’, may experience greater feelings of control, contributing towards higher QoL. However, this may not directly link to the number of care recipients, nor was it accounted for within this analysis (i.e. it is unknown why caregivers in ELSA provide care). Verbakel *et al.* (2017) suggest that individuals with strong care attitudes are more likely to both provide care and provide care at higher intensities. Therefore, it could be deduced that caregivers with more altruistic motivations may be more likely to provide care to multiple recipients, which may be considered higher-intensity than a single recipient and, in turn, they may experience a greater return in fulfilment, increasing their QoL scores.

The negative association between loneliness and QoL was highly significant: QoL scores for lonely caregivers were 10 points lower than for non-lonely caregivers. Depressive symptomatology and poor physiological health were also negatively associated with QoL among caregivers. This aligns with previous literature, in that loneliness is known to reduce QoL among caregivers (Ekwall *et al.*, 2005; Vasileiou *et al.*, 2017). Furthermore, depression has been reported as the most common factor associated with reduced caregiver QoL (Farina *et al.*, 2017). In contrast, frequent alcohol consumption was associated with a 2.6 point increase in QoL score. As identified in section 5.3.2.1, the relationship between increased alcohol consumption and QoL among caregivers could be a coping mechanism. Thus, regular consumption of alcohol to relieve the stressors of caregiving may give the caregiver the illusion of higher QoL.

5.3.4.2 Caregivers’ life satisfaction

For life satisfaction, the fully-adjusted model was also significant ($F(23, 529)=15.88, p<.001$), with an R^2 of 0.41, accounting for 41% variance in caregivers’ life satisfaction (Table 27). This regression included 58% of the caregiving sample, 42% were excluded due to incomplete data. Significant positive associations were observed for cohabitation and wealth among the caregiver characteristics. However, neither of the caregiving relationship variables were significantly associated with life satisfaction in the fully-adjusted model (Appendix U). However, similarly to QoL, providing co-residential care was negatively associated with life satisfaction in model one ($B=-1.88, p<.05$), prior to the inclusion of social networks. This suggests that the conditional main effect of the care recipient relationship (e.g. spouse) does not directly impact life satisfaction after accounting for the caregivers’ close family and friendship networks. This would imply that regardless of who care is provided to, caregivers gain satisfaction from their friends and family.

Table 27: Fully-adjusted linear regression model examining how caregiving-specific variables affect caregivers' life satisfaction

Variables	B (std. error)
Constant	21.45 (1.38)***
Age	
60-69 years	0.47 (0.60)
≥70 years	0.50 (0.36)
Sex: female	0.84 (0.51)
Cohabitation	3.07 (0.69)***
In paid employment	0.16 (0.59)
Wealth	
Quartile 2	1.74 (0.71)*
Quartile 3	1.66 (0.74)*
Quartile 4	2.27 (0.76)**
Care recipients	
Adult-child	-0.33 (0.82)
Parent or parent-in-law	0.82 (0.85)
Other relative, friend or neighbour	-0.78 (0.94)
Lives with the care recipient	-0.92 (0.83)
Caregiving intensity	
High-intensity (≥20hpw)	0.47 (0.66)
Round-the-clock care (168hpw)	0.61 (0.75)
Multiple care recipients	1.76 (0.74)*
Number of close relationships (family and child)	0.11 (0.08)
Number of close relationships (friends)	-0.14 (0.10)
UCLA-LS Loneliness	-5.51 (0.65)***
CES-D: depressive symptomatology	-3.33 (0.66)***
Physiological health: chronic condition(s)	-0.60 (0.53)
Health expectations	
Neither agrees nor disagrees	1.38 (0.63)*
Disagrees	1.55 (0.76)*
Alcohol consumption ≥3days per week	0.78 (0.56)

Notes: Linear regression, DV – SWLS; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Furthermore, in the fully-adjusted model, care provision to multiple recipients was linked to 1.8 points higher SWLS scores than to a single recipient. However, again, caregiving intensity was not significantly associated with wellbeing. Research suggests that care to multiple recipients, in the form of sandwich caregiving, is often detrimental to wellbeing (Evans *et al.*, 2019). However, sandwich care reflects provision to older parents and young children, or grandchildren (Falkingham *et al.*, 2020). This form of caregiving is unlikely within this ELSA sample, because caregivers to grandchildren were excluded from the data (section 4.3.1.1). Moreover, due to the age range within the sample, care to a child likely represents that of dependent adult-children. Alternatively, compound caregivers (lifelong caregivers to disabled children who undertake additional caregiving responsibilities for another family member), are more likely to align with the ELSA sample. However, research with compound caregivers found no significant wellbeing differences for caregivers to individual and multiple recipients (Perkins, 2009). The results in this thesis suggest caregiving to multiple recipients is linked to higher life satisfaction, but, within this analytical sample, the most common caregiving combinations were multiple parents/parents-in-law and multiple others, which differs from the care provision of compound caregivers. Therefore, the literature on sandwich and compound caregiving may not be directly comparable to caregivers of

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multiple recipients in ELSA. Similar to the QoL findings (section 5.3.4.1), caregiving intensity was also not significantly associated with life satisfaction.

Finally, caregiver loneliness was negatively associated with life satisfaction, SWLS scores were 5.5 points lower than non-lonely caregivers. This is consistent with the findings from RQ1c, where the combined effect of caregiving and loneliness demonstrated a negative impact on life satisfaction (section 5.2.4.7). Moreover, among the health controls, depressive symptomatology was negatively associated with SWLS score ($B=-3.3$, $p<.001$), and caregivers who ‘disagreed’ that their health would get worse with age reported on average scores 1.6 higher on the SWLS than caregivers who ‘agreed’. This suggests that negative expectations, and depressive symptoms are linked to lower satisfaction. Within the literature, research highlights a connection between positive views and life satisfaction (Cummins and Nistico, 2002; Wu, 2009). Further evidence suggests that individuals reorganise their priorities within life according to their health status, which has sequential effects on improving satisfaction (Wu *et al.*, 2009). Relating this evidence to caregivers, it could be considered that while providing care, typically due to recipients’ poor health, the caregiver may be influenced to evaluate their own health and lifestyle. Thus, a caregiver may become more appreciative of their health status and consequently adopt a more positive outlook (positive health expectations) subsequently improving their life satisfaction.

5.3.4.3 *Summary: how does caregiving affect wellbeing?*

While there was some overlap in the findings for QoL and life satisfaction, there were also several differences (Table 28). Consistencies between the two wellbeing outcomes included: positive associations for wealth, providing care to multiple recipients and health expectations, and negative associations for depressive symptomatology and loneliness.

Other than wealth, the relationships between caregiver characteristics and wellbeing differed between the measures. For example, female caregivers showed higher QoL, but not life satisfaction, and cohabitation was positively associated with caregivers’ life satisfaction but not QoL. Furthermore, neither of the caregiving relationship variables (recipient or co-residential care) were significantly associated with wellbeing in the fully-adjusted models. Similarly, caregiving intensity was not associated with either wellbeing measure. However, providing care to multiple recipients was positively associated with both. These discrepancies highlight that QoL, and life satisfaction are separate constructs, representing different aspects of wellbeing.

Table 28: Summary of significant results for RQ2c: how does caregiving affect wellbeing?

Variables	Quality of life	Life satisfaction
Age: 60-69	NS	NS
≥70	NS	NS
Sex	*	NS
Cohabitation	NS	***
Paid employment	NS	NS
Wealth: quartile 2	***	*
Quartile 3	***	*
Quartile 4	***	**
Care recipient: adult-child	NS	NS
Parent or parent-in-law	NS	NS
Other relative, friend or neighbour	NS	NS
Lives with care recipient	NS	NS
Caregiving intensity: high-intensity (≥20hpw)	NS	NS
Round-the-clock care (168hpw)	NS	NS
Multiple care recipients	**	*
Close family relationships	**	NS
Close friendships	NS	NS
CES-D: depressive symptomatology	***	***
Physiological health	**	NS
Health expectations: neither agree nor disagree	*	*
Health expectations: disagree	NS	*
Alcohol consumption	***	NS
Loneliness	***	***

Notes: NS non-significant, *p<.05, **p<.01, ***p<.001, source: author's analysis of ELSA wave 8

5.3.5 Summary: how does caregiving affect loneliness, health, and wellbeing?

Research question two investigated how caregiving-specific variables impacted loneliness, health, and wellbeing among the sample of caregivers. These analyses were important to understand firstly, what factors may be contributing towards increased caregiver loneliness, and identify caregiving-specific determinants of loneliness. The results could also aid the explanation of differences observed between caregivers and non-caregivers in the health and wellbeing outcomes. Caregiver characteristics (age, sex, cohabitation, employment status and wealth), the caregiving relationship (care recipient and co-residential care) and the caregiving role (caregiving intensity and number of recipients) were analysed in relation to loneliness (RQ2a), SET health pathways (RQ2b), and wellbeing (RQ2c). The descriptive analyses (section 5.3.1) identified that caregivers were generally female, younger (aged 50-59), non-employed, and cohabiting. Additionally, the sample predominantly comprised spousal caregivers, and those providing co-residential care, or care at lower intensities (≤19hpw). Finally, there were substantially more caregivers to a single recipient, compared to multiple recipients.

It was hypothesised that due to the discrepancies in the determinants of loneliness between caregivers and non-caregivers observed in RQ1b (section 5.2.3), caregiving-specific variables would play a large role in explaining caregiver loneliness. However, there was little evidence to support this hypothesis, in that the only caregiving-specific variable significantly positively associated with loneliness was care provision to adult-children in comparison to spousal care. Otherwise, significant factors included sex, employment, friendship networks, alcohol consumption and QoL which largely replicates the findings from RQ1b. One discrepancy was the significance of alcohol consumption. Previously not a significant determinant of caregiver loneliness in RQ1b, after controlling for caregiving-specific variables, frequent alcohol consumption was positively associated with

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caregivers' loneliness. As discussed throughout the thesis, alcohol consumption is likely to be a coping mechanism among caregivers.

Moreover, the results indicated that caregiver loneliness was positively associated with frequent alcohol consumption, and negatively associated with QoL and life satisfaction, but not associated with physiological health or health expectations. However, simultaneity was present among the majority of the aforementioned relationships (alcohol consumption and QoL). To illustrate, loneliness was positively associated with frequency of alcohol consumption, but also frequent alcohol consumption was positively associated with loneliness, indicating relationships in multiple directions. In contrast, the relationship between life satisfaction and loneliness was not reciprocal. As such, loneliness was indicative of reduced SWLS scores, but life satisfaction was not significantly associated with caregiver loneliness. As with alcohol consumption and QoL, a level of simultaneity was expected between life satisfaction and loneliness. However, the observed results suggest that reverse causality may be present, in that rather than reduced life satisfaction leading to loneliness, loneliness was influential on SWLS scores. Conversely, further analysis (section 6.2.2) refutes this inference, by highlighting that both wellbeing measures at wave two were negatively associated with loneliness 12-years later (wave eight).

Finally, the results from RQ2 suggest the relationships between loneliness, health, and wellbeing among caregivers are multidimensional and complex. As such, being female was positively associated with loneliness, but negatively associated with frequent alcohol consumption. These results are slightly contradictory, considering that loneliness and frequency of alcohol consumption were positively related to one another (i.e. more frequent alcohol consumption among caregivers was linked to higher odds of loneliness and vice versa). Therefore, potential interactions may be present, for example, between sex and loneliness in relation to alcohol consumption. The complexity of the relationships will be investigated further in the following chapter: the follow-up analyses can clarify aspects such as the direction of some relationships.

5.4 Chapter summary

Chapter five presented the results of the cross-sectional analyses. A combination of binary logistic, multinomial logistic, and linear regressions were conducted to examine loneliness, health and wellbeing differences between caregivers and non-caregivers (RQ1) and among the caregiving sample at wave eight (RQ2). The findings from RQ1 suggest that caregiving is positively associated only with loneliness measured by UCLA-LS, not a direct question, but health and wellbeing controls accounted for the loneliness differences between caregivers and non-caregivers in the fully-adjusted model. There is evidence to suggest that the determinants of loneliness vary for caregivers and non-caregivers and that the impact of loneliness on health and wellbeing is different for caregivers across a number of health measures. Further analysis within the caregiving sample highlighted differences that arose within the caregiving group in relation to loneliness, health, and wellbeing. Predominantly,

these differences were impacted by caregiver characteristics, but there was evidence to suggest that aspects of the caregiving relationship and role also played a part. The following chapter (six) presents the follow-up analyses conducted between wave two and eight, and across waves two to eight, comparing longer-term effects on loneliness for both caregivers and non-caregivers, and identifying how changes to the caregiving relationship and role influence loneliness.

Chapter 6 Twelve year follow-up

6.1 Chapter outline

Chapter six reports the follow-up results, addressing the final research question: what are the longer-term effects of caregiving on loneliness? Section 6.2.1 discusses the descriptive analyses of the baseline variables (wave two), followed by the descriptive analyses of the caregiving sample (across all waves). **Bivariate analyses for the baseline variables in relation to wave eight loneliness, and for caregiving-specific variables in relation to loneliness occurring after the start of care provision are included in Appendices W-X.**

First, wave two caregivers and non-caregivers are compared (section 6.2.2), then caregivers at any wave with non-caregivers (section 6.2.3) to indicate whether caregiving has a longer-term (12-year) effect on loneliness, or whether the association is shorter-term. Finally, short-term, intermittent, and long-term caregivers are contrasted (section 6.2.4) to identify how changes throughout the caregiving experience can impact loneliness over a 12-year period.

6.2 RQ3: What are the longer-term effects of caregiving on loneliness?

6.2.1 Descriptive statistics for the longitudinally-weighted sample

6.2.1.1 *Characteristics of caregivers and non-caregivers*

This section discusses the descriptive statistics (Table 29), for the longitudinally-weighted sample of individuals that provided a response to the caregiving question (N=2954) at baseline (wave two). Moreover, the bivariate correlations with wave eight loneliness and loneliness at any wave are presented. Similarly to the cross-sectional analyses, checks were conducted between the predictors and DVs. For all variables, VIF and tolerance statistics were within accepted parameters (Field, 2013). Some moderate correlations were apparent between the variables, the strongest of which being the relationship between cohabitation and household size ($r=-0.62$).

Table 29: Descriptive statistics of the longitudinal sample at baseline (ELSA wave two)

		Non-caregivers N (%)	Caregivers N (%)
Care provision (wave two)		2566 (86.6)	389 (13.2)
Age (years)	50-59	1064 (41.5)	180 (46.3)
	60-69	984 (38.3)	139 (35.7)
	≥70	518 (20.2)	70 (18.0)
Sex	Male	1222 (47.6)	115 (29.6)
	Female	1343 (52.4)	274 (70.4)
Marital status	Married/civil partnership	1575 (61.4)	267 (68.6)
	Single, never married	115 (4.5)	8 (2.1)
	Remarried	316 (12.3)	39 (10.0)
	Divorced/legally separated	276 (10.8)	42 (10.8)
	Widowed	283 (11.0)	33 (8.5)
Cohabitation (spouse/partner)	No	573 (22.7)	73 (19.0)
	Yes	1949 (77.3)	312 (81.0)
Paid employment	No	1466 (57.2)	224 (57.7)
	Yes	1099 (42.8)	164 (42.3)
Wealth	Quartile 1 (poorest)	624 (24.6)	109 (28.3)
	Quartile 2	644 (25.4)	91 (23.6)
	Quartile 3	636 (25.1)	91 (23.6)
	Quartile 4 (wealthiest)	631 (24.9)	94 (24.4)
Household size	Single person household	488 (19.0)	47 (12.1)
	Dual-person household	1533 (59.7)	250 (64.3)
	Large household (≥3)	545 (21.2)	92 (23.7)
UCLA-LS	Not lonely	2123 (83.7)	315 (82.2)
	Lonely	414 (16.3)	68 (17.8)
Loneliness expectations	Agree	951 (37.7)	146 (38.2)
	Neither agree nor disagree	665 (26.3)	102 (26.7)
	Disagree	909 (36.0)	134 (35.1)
Physiological	No chronic CV conditions	1701 (66.3)	271 (69.8)
	≥1 chronic CV condition	864 (33.7)	117 (30.2)
Health expectations	Agree	1721 (68.6)	272 (70.5)
	Neither agree nor disagree	418 (16.7)	67 (17.4)
	Disagree	371 (14.8)	47 (12.2)
Alcohol consumption	<3 days per week	1596 (63.0)	249 (65.0)
	≥3 days per week	937 (37.0)	134 (35.0)
CES-D	No depressive symptomatology	2129 (83.6)	315 (81.6)
	Depressive symptomatology	417 (16.4)	71 (18.4)
Wellbeing	CASP19, mean (SD)	43.9 (8.1)	42.9 (8.2)
	SWLS, mean (SD)	26.6 (5.9)	25.7 (6.2)

Source: author's analysis of the longitudinal sample at ELSA wave 2

At baseline, 11% of the total sample were caregivers (N=389). Consistent with the literature (Dahlberg *et al.*, 2007; van Campen *et al.*, 2013), caregivers were predominantly female. Male presence is typically higher among older (aged >65) caregivers (Milligan and Morbey, 2016); however, within this thesis, there are fewer male caregivers, this is likely due to the age distribution. As such, the largest portion of caregivers were aged 50-59 (46%). Furthermore, most caregivers were cohabiting (81%), and commonly not in paid employment (58%). Among the non-caregivers (87%) at baseline, the sociodemographic characteristics were largely similar to caregivers. There were more females (52%) than males, although less of a female majority than amongst caregivers. The majority of non-caregivers were also cohabiting (77%), were aged 50-59 (42%) and not in paid employment (57%). A lesser proportion of non-caregivers were in the lowest wealth quintile (N=624, 25%) compared to caregivers (28%), suggesting that caregivers were slightly more socioeconomically disadvantaged. Among both caregivers and non-caregivers at baseline, it was more common to reside

in a dual-person household (64% and 60% respectively). Due to the high prevalence of married and cohabiting individuals, it is likely that the majority of the dual-person households represented couples.

As shown in Table 29, 18% of caregivers and 16% of non-caregivers were lonely at baseline. Furthermore, crosstabulation showed that loneliness altered over the 12-year period (Appendix V). Of the individuals lonely at wave two, 50% remained lonely at wave eight, whereas only 12% of respondents not lonely at wave two, were lonely at wave eight. This suggested that baseline loneliness may be linked to a higher likelihood of loneliness at follow-up. Additionally, almost as many respondents did not expect to become lonelier with age, as those that did. Descriptive analysis showed that, at baseline, 38% of both caregivers and non-caregivers ‘agreed’ that they expected to become lonelier with age, moreover, comparable percentages of both caregivers (35%) and non-caregivers (36%) ‘disagreed’.

Among both caregivers and non-caregivers, the majority of the sample appeared healthy at baseline. Most reported no chronic CV conditions (70% and 66% respectively) and did not consume alcohol frequently (≥ 3 days per week) (65% versus 63%). Additionally, the majority of both groups were without depressive symptomatology: 82% of caregivers and 84% of non-caregivers. However, a large percentage of both caregivers (71%) and non-caregivers (69%) demonstrated a negative perception on future health, whereby most agreed that they expected to experience poorer health as they grew older. Wellbeing at wave two was not substantially different between caregivers and non-caregivers. On average compared to non-caregivers, caregivers reported CASP19 scores 1 point lower, and SWLS scores 1 point lower. Overall, the baseline data suggested that caregiver health and wellbeing was not largely different, arguably only poorer than that of non-caregivers by negligible amounts; nevertheless, caregivers presented with a slightly higher prevalence depressive symptomatology, and marginally lower QoL and life satisfaction scores. Results from the bivariate analyses can be seen in Appendix W.

6.2.1.2 Characteristics of the caregiving sample

Table 30 shows the sample of caregivers who reported providing care at any point between waves two and eight; this represented 42% (N=1445) of the total longitudinally-weighted sample. Among the caregivers in the sample, most provided care in only one wave (N=633, 44%), or in two or more consecutive waves (N=594, 41%), although a minority reported providing care in two or more non-consecutive waves (N=218, 15%).

Table 30: Frequencies of caregiving-specific variables, and changes to mental health and loneliness expectations for caregivers in the longitudinal sample

		N (%)
Care provision	Caregiver (any wave)	1445 (100.0)
Duration of care	Short-term	633 (43.8)
	Intermittent	218 (15.1)
	Long-term	594 (41.1)
Care recipient	Ever cared for spouse	551 (38.1)
	Ever cared for adult-child	126 (8.7)
	Ever cared for parent/parent-in-law	382 (26.4)
	Ever cared for others	501 (34.7)
Co-residential care	Never lived with the care recipient	789 (54.8)
	Ever lived with the care recipient	651 (45.2)
Caregiving intensity	Ever provided low-intensity care	1075 (74.4)
	Ever provided high-intensity care	485 (33.6)
	Ever provided round-the-clock care	365 (25.3)
Number of care recipients	Never cared for multiple recipients	924 (63.9)
	Ever cared for multiple recipients	521 (36.1)
Loneliness expectations	Stable (always agrees)	196 (15.5)
	Stable (always neither)	71 (5.6)
	Stable (always disagree)	186 (14.6)
	Negative change	316 (24.9)
	Positive change	237 (18.7)
Changes to mental health	Fluctuating	262 (20.7)
	Stable (never reports depressive symptoms)	909 (67.1)
	Reduction in depressive symptoms	139 (10.3)
	Increase in, or persistent depressive symptoms	187 (13.8)
	Fluctuating	119 (8.8)

Notes: valid % of caregivers, source: author's analysis of ELSA waves 2-8

The most common care recipients were spouses (N=551, 38%), followed by others (N=501, 35%), parents/in-laws (N=382, 26%) and adult-children (N=126, 9%). The total percentages exceed 100% due to respondents providing to multiple recipients, or different recipients over their caregiving role. Less than half of caregivers reported ever living with the care recipient (N=651, 45%); this likely due to the high proportion of caregivers to others, which represents other relatives, neighbours, and friends.

Similarly to the care recipient dummy variables, the total percentage of intensity variables exceeds 100% due to multiple caregiving episodes and changes to intensity. Low-intensity care was the most commonly reported intensity, 1075 (74%) caregivers identified that they had provided care at ≤19hpw. However, around one third of caregivers (N=485, 34%) provided high-intensity care (≥20hpw) and one quarter (N=365, 25%) of caregivers provided round-the-clock care (168hpw). Across the waves, caregiving for a single recipient was more prevalent than to multiple recipients; just over one third of caregivers (N=521, 36%) reported ever providing care to multiple recipients.

Changes to loneliness expectations and depressive symptomatology were computed between three time-points (section 4.3.8). More caregivers changed their loneliness expectations (N=815, 64%) compared to those with stable expectations at each time-point (N=453, 36%). A quarter of caregivers reported a negative change in loneliness expectations (N=316, 25%), which indicated that as caregivers aged, they were more likely to expect future loneliness. Furthermore, changes to health were determined using the CES-D variable. Among the caregivers, the highest proportion never reported depressive symptoms (N=909, 67%). **Results from the bivariate analyses can be seen in Appendix X.**

6.2.2 RQ3a: is caregiving in wave two associated with loneliness at wave eight?

To determine if caregiving was associated with a longer-term effect on loneliness, a 12-year follow-up was conducted. In binary logistic regressions, caregiving at wave two was the main explanatory variable, with loneliness (UCLA-LS) at wave eight as the DV; all control variables were obtained at baseline (wave two). Two regressions were conducted to compare the results when (i) individuals who were lonely at baseline were excluded; and (ii) controlling for individuals who were lonely at baseline. Table 31 details the models applied in the analyses.

Table 31: Regression models for RQ3a: is caregiving in wave two associated with loneliness at wave eight?

Model number	Variables included in the model
1	Caregiving status (wave two)
2	Model 1 + loneliness*, loneliness expectations, sociodemographic characteristics, socioeconomic status and social networks
3	Model 2 + health and wellbeing

Notes: *in regression ii only, source: author's own

Model one included caregiving at wave two, **determining** whether providing care at baseline was associated with loneliness at the 12-year follow-up (wave eight). In model two, control variables were added for loneliness expectations, sociodemographic characteristics, SES, and social networks. Separate regressions were conducted excluding those lonely at baseline (i) and controlling for those lonely at baseline (ii); whereby comparison was drawn between the long-term effect of caregiving on 'new' loneliness, not present at the time of caregiving, and the long-term effect of caregiving on later loneliness, after accounting for those who had already reported loneliness at baseline. Finally, model three included baseline health and wellbeing variables; after controlling for health and wellbeing, any changes to the relationship between caregiving and loneliness would suggest that health and/or wellbeing had a stronger long-term association with loneliness, after controlling for caregiving and other factors. **All control variables in this regression were measured at baseline and thus treated as time-invariant.**

6.2.2.1 *The association between caregiving and loneliness over 12-years*

(i) excluding those lonely at baseline

A binary logistic regression was carried out to determine if caregiving was **linked to loneliness at** a 12-year follow-up. Respondents who identified as lonely at baseline were excluded from the analyses, **the remaining sample was based on a CCA, excluding 17% (N=496) of the longitudinally-weighted sample (N=2954).** Caregiving in wave two was not significantly associated with loneliness at wave eight in any model (Appendix Y); this would suggest that caregiving was not linked to long-term effects on loneliness over a 12-year period. In the fully-adjusted model (Figure 25), which controlled for loneliness expectations, sociodemographic characteristics, SES, social network, health, and wellbeing, only age, sex, and wellbeing (both QoL and life satisfaction) were linked to long-term loneliness outcomes.

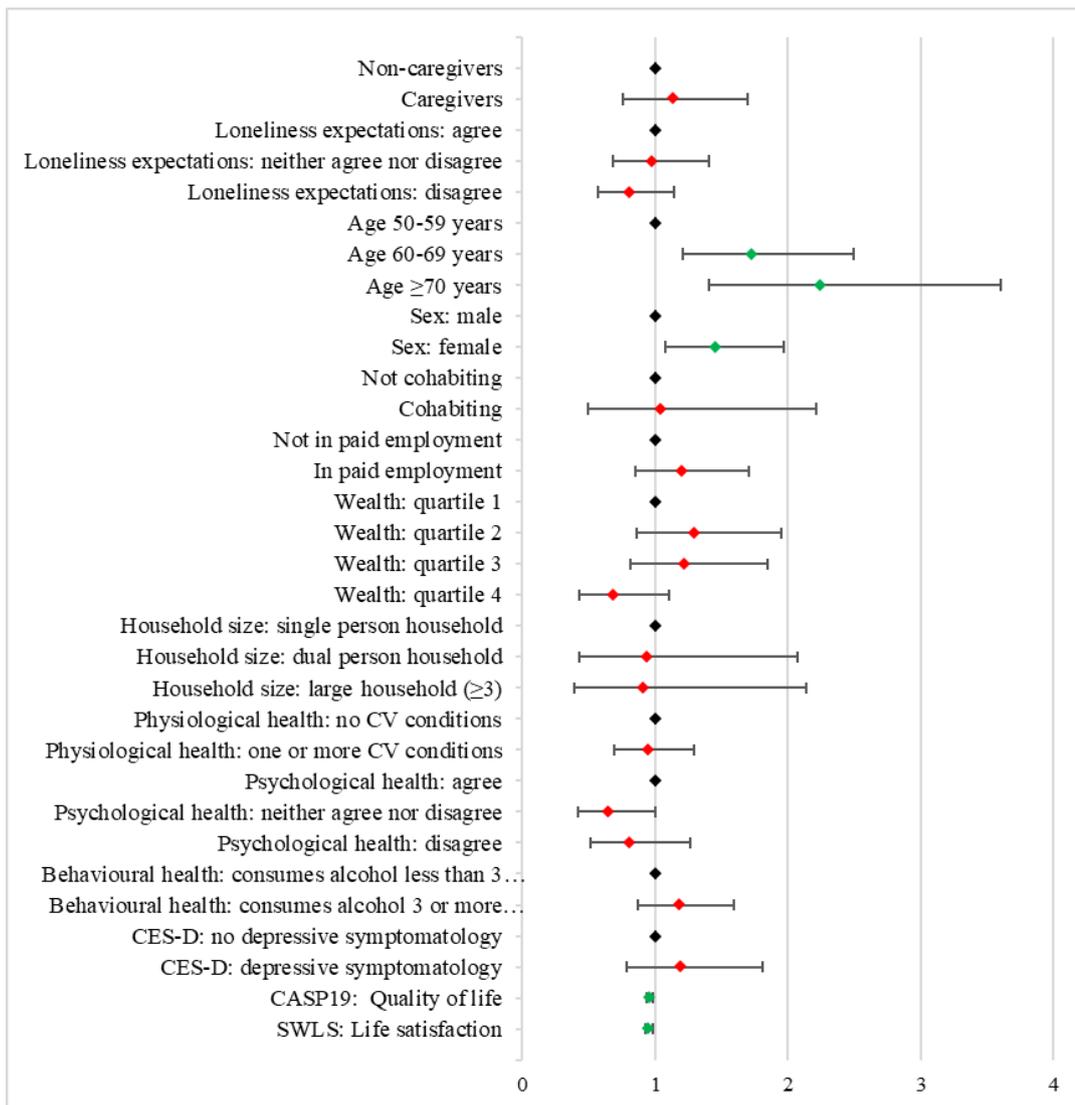


Figure 25: Odds ratio plot, wave two factors associated with wave eight loneliness, excluding baseline loneliness

Source: author's analysis of ELSA waves 2 and 8

Respondents aged 60-69 (OR=1.74, 95CI=1.21-2.50) and ≥ 70 (OR=2.25, 95CI=1.40-3.60) at baseline had significantly higher odds of reporting loneliness at wave eight than those aged 50-59. The respondents in these age categories at wave two would be aged 72-81 or ≥ 82 when reporting loneliness (wave eight). This contradicts the evidence from the cross-sectional analyses. As such, age was not significantly associated with loneliness among the full sample (section 5.2.2.2), nor was it a significant determinant of loneliness among caregivers or non-caregivers when analysed separately (section 5.2.3). Similarly, after controlling for caregiving variables, social networks, health, and wellbeing (section 5.3.2), age was not linked to loneliness among the cross-sectional caregiving sample. Particularly among caregivers, cross-sectionally age was not significant after controlling for the respondents' current health and wellbeing status. This suggested that previously significant loneliness differences between the age groups were explained by health and wellbeing differences. In the follow-up analyses, age was positively associated with later loneliness, after controlling for baseline health and wellbeing. However, health variables reported at baseline would

not account for changes to health experienced over the 12-year period between baseline and follow-up (see section 7.5.3 for further discussion of this limitation). Therefore, as older adults are more likely to experience poorer health, it could be health deterioration (e.g. health changes between waves two and eight) experienced by the older respondents that is contributing towards the significant positive association between age and loneliness. This would imply that poor health and loneliness may occur simultaneously, or that the effect occurs in a shorter time-period, rather than poor health leading to long-term loneliness outcomes.

Females had 46% higher odds of loneliness at follow-up than males (OR=1.46, 95CI=1.08-1.97). Previous evidence on sex differences and loneliness is largely inconclusive. Some literature suggests prevalence of loneliness is higher among females (Pinquart and Sörensen, 2001). However, seminal work evaluating the validity of the UCLA-LS suggested no sex differences when applying this loneliness scale, which was supported in an early review of sex differences between the UCLA-LS and direct measures, whereby few studies reported a significant difference, and of those that did, males appeared to be lonelier (Borys and Perlman, 1985). More contemporary evidence which utilised data from the BBC Loneliness Experiment also reported that males were lonelier than females (Barreto *et al.*, 2020). In the cross-sectional analyses, being female was a significant determinant of loneliness among caregivers, but not non-caregivers. Moreover, analyses on the full sample found no significant difference cross-sectionally for UCLA-LS loneliness between males and females (section 5.2.2.2). The positive association between sex and loneliness at follow-up, when excluding those lonely at baseline, suggests that over the 12-year period, females were more likely to become lonely than males, however this contradicts the cross-sectional result, which suggests that, at wave eight, among the full sample, being female was not associated with a higher likelihood of loneliness.

Additionally, as none of the wave two health controls (physiological health, health expectations, alcohol consumption or depressive symptomatology) were significantly associated with wave eight loneliness, this supports the aforementioned discussion that health does not appear to generate a long-term effect on loneliness, after accounting for sociodemographic and socioeconomic characteristics. Previous results suggest cross-sectional associations between loneliness and health, particularly for depressive symptomatology, which was not apparent in this follow-up analysis. In contrast, both wellbeing measures were significantly associated with long-term loneliness outcomes, those with higher QoL and life satisfaction at baseline were significantly less likely to be lonely at follow-up. This could suggest that wellbeing has a stronger and more enduring negative association with loneliness, than that of health.

6.2.2.2 The association between caregiving and loneliness over 12-years

(ii) controlling for loneliness at baseline

In contrast to the previous regression, whereby baseline lonely individuals were excluded, a further binary logistic regression was conducted controlling for baseline loneliness. This analytic sample represented 70% (N=2074) of the overall sample. This would determine whether caregiving, after controlling for baseline loneliness was associated with later loneliness. Caregiving in wave two was not significantly associated with loneliness at wave eight in any model (Appendix Z), however baseline loneliness was strongly positively associated with follow-up loneliness. In the fully-adjusted mode (Figure 26), individuals who were lonely at baseline, on average, were four times more likely to be lonely at follow-up (OR=4.13, 95CI=3.08-5.54). This suggests that loneliness may be persistent, or highly likely to reoccur, regardless of caregiving responsibilities, and that caregiving shows no link to long-term loneliness outcomes, even amongst those previously lonely.

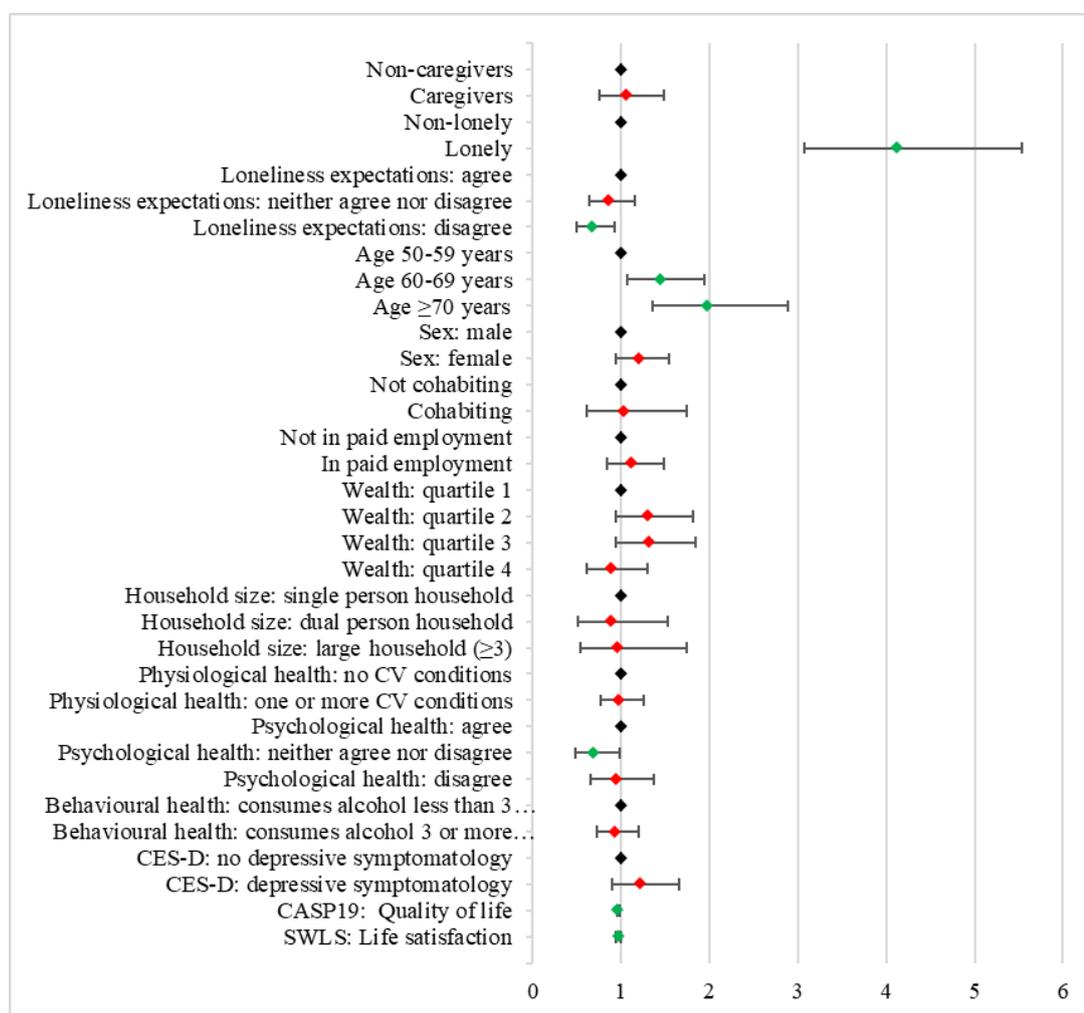


Figure 26: Odds ratio plot, wave two factors associated with wave eight loneliness, controlling for baseline loneliness

Source: author's analysis of ELSA waves 2 and 8

Respondents not expecting to get lonelier with age, when asked at baseline, were less likely to be lonely at follow-up than those who expected loneliness to occur (OR=0.68, 95CI=0.51-0.93). However, this negative association was not significant in the previous regression when baseline

lonely individuals were excluded (section 6.2.2.1). Loneliness expectations were more pertinent to lonely individuals. To illustrate, those already lonely may be more likely to have a negative perception on future loneliness than non-lonely individuals. This would explain why there was no significant difference in loneliness outcomes between the loneliness expectations categories when baseline lonely individuals were removed, i.e. a smaller percentage of individuals in the sample expected to become lonelier with age, because they were within the baseline lonely category, and therefore excluded. Crosstabulations support this (Appendix AA): among the respondents lonely at baseline, a substantially higher proportion of individuals expected to get lonelier with age than the non-lonely, 67% compared to 32%.

After controlling for baseline loneliness, being female was no longer positively associated with loneliness at follow-up. This suggests that the previously significant differences between males and females in RQ3a(i), may be accounted for by loneliness differences at baseline. As such, when lonely individuals at baseline were included, there were no significant differences in the loneliness outcomes between males and females. This might suggest that by removing the baseline lonely respondents, the balance of males and females within the sample was skewed, i.e. more females were lonely at baseline than males. Nevertheless, the lack of a significant relationship between sex and loneliness over the 12-year follow-up suggests that after accounting for caregiving, baseline loneliness, and all of the other factors, the occurrence of loneliness does not differ due to sex. However, after controlling for loneliness at baseline, age remained positively associated with loneliness at follow-up, respondents aged ≥ 70 were almost two times as likely to be lonely at follow-up, compared to respondents aged 50-59 (OR=1.98, 95CI=1.35-2.89). Baseline health remained non-significant, so it is reasonable to consider that, as discussed in the previous regression, health changes over the 12-year period which are likely to affect the older age groups more, could be contributing towards the significance seen between age and loneliness.

Wellbeing remained negatively associated with loneliness, after controlling for baseline loneliness. As such, individuals with higher QoL and life satisfaction were less likely to be lonely at follow-up, after accounting for the respondents who were experiencing loneliness at baseline. As well as asserting that a long-term relationship is present between wellbeing and loneliness, the results might also imply that loneliness and poor wellbeing are comorbidities. To illustrate, mean CASP19 and SWLS scores were considerably lower for lonely respondents at wave two, compared to non-lonely. Therefore, poor wellbeing, in conjunction with loneliness, could contribute towards a greater likelihood of persistent or reoccurring loneliness.

6.2.2.3 Summary: is caregiving in wave two associated with loneliness at wave eight?

When comparing the results from (i) excluding baseline loneliness with the results from (ii) controlling for baseline loneliness, the variance explained by the final models differs substantially.

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The Nagelkerke R^2 statistics demonstrate that the fully-adjusted models explained around 9% (i) and 23% (ii) of variance in wave eight loneliness, respectively. Given that the difference between the analyses was the inclusion of previously lonely individuals, the result suggests that baseline loneliness explains a large amount of variance in follow-up loneliness. However, both of the final models were deemed a good fit, from the Hosmer-Lemeshow test ($p=.109$ and $p=.062$ respectively). Table 32 contrasts the significant variables from each of the analyses.

Table 32: Summary of significant results for RQ3a: is caregiving in wave two associated with loneliness at wave eight?

Variables	RQ3a(i) Excluding baseline loneliness	RQ3a(ii) Controlling for baseline loneliness
Caregiving	NS	NS
Loneliness	-	***
Loneliness expectations: neither agree nor disagree	NS	NS
Loneliness expectations: disagree	NS	**
Age 60-69	**	**
≥70	**	*
Sex	*	NS
Cohabitation	NS	NS
Employment	NS	NS
Wealth Q2	NS	NS
Wealth Q3	NS	NS
Wealth Q4	NS	NS
Household: dual-person	NS	NS
Household: large (≥3)	NS	NS
Physiological health	NS	NS
Health expectations: neither	NS	**
Health expectations: disagree	NS	NS
Alcohol consumption	NS	NS
Depressive symptomatology	NS	NS
CASP19	**	*
SWLS	**	**

Notes: NS non-significant, * $p<.05$, ** $p<.01$, *** $p<.001$, source: author's analysis of ELSA waves 2 and 8

The positive association between baseline age and follow-up loneliness, and negative association between baseline wellbeing and loneliness at the 12-year follow-up remained consistent both when excluding, and accounting for, baseline loneliness, whereas the main differences were sex, loneliness, and health expectations. Being female was only positively associated with later loneliness when baseline loneliness was excluded, this implies sex differences in the experience of loneliness at baseline, which are then accounted for in the second regression, hence the attenuation of significance. Alternatively, expectations for future loneliness and health were only significantly negatively associated with follow-up loneliness after controlling for baseline loneliness. As discussed previously, respondents' perceptions on future loneliness appear to be linked to their current experience of loneliness, whereby the proportion of baseline lonely respondents expecting to become lonelier with age was over twice the proportion of non-lonely respondents with similar expectations (67% compared to 32%), therefore by deleting the baseline lonely respondents from the sample in RQ3a(i), this also removed a large number of respondents expecting to be lonelier.

In contrast, only respondents who 'neither agreed nor disagreed' that they expected their health to deteriorate with age significantly differed from those who 'agreed'. Neutral health expectations were linked to lower odds of loneliness when compared with negative expectations (agree), but no

significant difference was observed between agree and disagree responses. It is challenging to speculate or interpret the meaning of this result, because it is not evident what is meant when the respondent cannot agree or disagree with the health statement. As such, research suggests that the interpretation of this middle category differs substantially from neutral, to no opinion, to equal or both, to neither, and to unsure (Nadler *et al.*, 2015), and further, it should be interpreted differently to non-response or unknown (Baka *et al.*, 2012). When researched in the context of Greek local elections, the middle category was reportedly selected due to a lack of knowledge or indifference on the subject, indecisiveness, or ambivalence, or to challenge the assumptions of the statement (Baka *et al.*, 2012). In the context of the health statement, the latter seems unlikely because ‘disagree’ would inherently challenge the assumption that old age was linked to poor health. However, it is plausible that the respondents either felt they did not know enough to speculate on their future health, for example, they might consider advancements in medical healthcare, and consider whether recent or upcoming developments might impact themselves. Alternatively respondents might be undecided, they may have experienced periods of both good and poor health and therefore be uncertain about what the future may hold in regard to their health. Therefore, without accurately knowing why a respondent selected ‘neither’, it is difficult to draw conclusion about the link to loneliness.

Overall, there was no evidence to support a long-term association between caregiving at wave two and loneliness at wave eight. The strongest predictor of loneliness at follow-up appeared to be baseline loneliness, suggesting that loneliness was largely persistent or reoccurring. The subsequent section explores the relationship between caregiving and loneliness across all waves to determine if care provision is linked to experiencing later loneliness.

6.2.3 RQ3b: is caregiving at any wave associated with later loneliness?

The cross-sectional results suggested that prior to controlling for health and wellbeing (section 5.2.2.2), caregiving was positively associated with loneliness; this was under the circumstances where caregiving and loneliness were present at the same time-point. Moreover, subsequent to RQ3a, which examined whether caregiving at baseline (wave two) was associated with loneliness at follow-up (wave eight), this research question augments the previous analyses by questioning whether caregiving at any point over the 12-year period was associated with experiencing later loneliness. Duration of care was used as the primary explanatory variable when examining loneliness occurring after care provision, comparing short-term caregivers (only one wave) with long-term (two or more consecutive waves) and intermittent caregivers (two or more non-consecutive waves). All further controls were measured at baseline (wave two). Table 33 shows the models applied in the binary logistic regression for RQ3b.

Table 33: Regression models for RQ3b: is caregiving at any wave associated with ever being lonely?

Model number	Variables included in the model
1	Duration of care
2	Model 1 + loneliness expectations, sociodemographic characteristics, socioeconomic status and social networks
3	Model 2 + health and wellbeing

Source: author's own

Model one included only the duration of care variable, which characterised caregivers as short-term, long-term or intermittent. The purpose of this was to identify whether different durations of care provision were associated with experiencing later loneliness. Loneliness that occurred prior to or was first reported at the same time as caregiving was excluded to ensure all loneliness occurred after care provision. Model two controlled for sociodemographic characteristics, SES, and loneliness expectations. Individuals were asked at baseline whether they expected to get lonelier as they aged. Controlling for expectations tests the self-fulfilling prophecy theory in SET. In the final model, health and wellbeing variables at baseline were included to account for previous health and wellbeing, which may also be linked to the occurrence of loneliness over the waves. All control variables in this regression were measured at baseline and thus treated as time-invariant.

6.2.3.1 The association between caregiving duration and later loneliness

Long-term care provision was significantly positively associated with loneliness, compared to short-term care, when the data were examined over all waves (2-8) (Appendix BB). Of the 1445 respondents who indicated providing care in at least one wave, 507 (35%) were excluded due to loneliness occurring before, or starting in the same wave as care provision, leaving an analytic sample of 938 caregivers. Of those 938, a further 10% (N=92) were excluded from the regression analyses due to incomplete data. In the fully-adjusted model after controlling for loneliness expectations, sociodemographic characteristics, SES, household size, and health and wellbeing, odds of long-term caregivers experiencing loneliness were 1.8 times higher than short-term caregivers (OR=1.82, 95CI=1.17-2.85). In contrast to RQ3a, whereby no long-term association was found between caregiving and loneliness (section 6.2.2), this result suggested that the impact of caregiving on loneliness may be shorter-term, i.e. caregivers may experience loneliness during their role, or for a period succeeding their role, but this did not extend to the 12-year follow-up. The Nagelkerke R² statistic illustrated that the fully-adjusted model explains 15% of variance in loneliness across the waves, and the Hosmer-Lemeshow test confirmed that the model is a good fit for the data (p=.130).

In addition to duration of care, loneliness expectations were also significantly negatively associated with loneliness outcomes (Figure 27). Compared to respondents who agreed that they expected to become lonelier with age at baseline, caregivers who disagreed were 40% less likely (OR=0.60, 95CI=0.37-0.98) to be lonely after care provision. This supports the relevance of age-related stereotypes (Kornadt, 2016), and advocates that internalised stereotypes can become self-fulfilling prophecies with negative consequences (Levy *et al.*, 2009; Meisner and Levy, 2016).

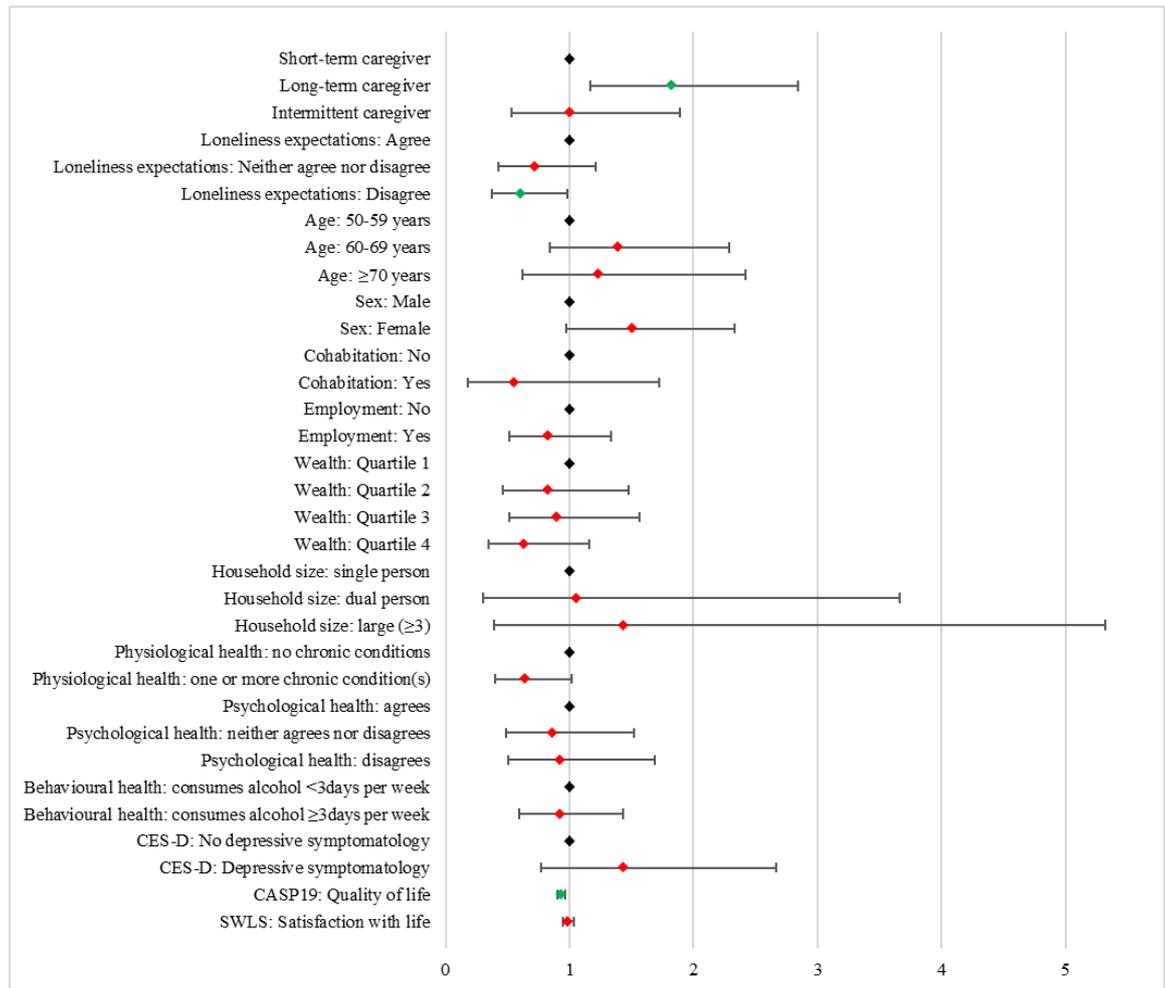


Figure 27: Odds ratio plot, associations between loneliness and duration of care
Source: author's analysis of ELSA waves 2-8

None of the included baseline controls, except QoL, were significantly associated with loneliness occurring after care provision. In some circumstances, variables may have changed between baseline (wave two) and the loneliness occurring (any wave) which could account for the lack of significant association. For example, in comparison to the 12-year follow up (section 6.2.2), age was no longer significantly positively associated with loneliness; compared to ages 50-59, there was no significant difference in prevalence of loneliness among the 60-69 or ≥70 age categories. This would suggest, as in the cross-sectional analyses, that there was no association between age and loneliness, or that this was better explained by other factors that may have changed over the 12-year period such as health. This could be considered a limitation of the approach to treat control variables as time invariant (section 7.5.3).

As indicated above, QoL remained negatively associated with loneliness, higher QoL scores at baseline were associated with a lower likelihood of loneliness occurring after the start of care provision (OR=0.93, 95CI=0.90-0.96). This is partially consistent with the literature and the previous regressions. To illustrate, in the previous research question, both baseline wellbeing measures were negatively associated with follow-up loneliness in the full longitudinally-weighted sample, whereas in this analysis, only baseline QoL was significant. Therefore, this would suggest that lower QoL is

linked to both shorter and longer-term effects on loneliness among caregivers and non-caregivers, whereas the evidence suggests that the link between life satisfaction and loneliness is apparent only among non-caregivers. As such, cross-sectionally, life satisfaction was not significantly associated with UCLA-LS among the caregiving sample (section 5.2.3.1 and 5.3.2.1) but was significantly negatively associated with UCLA-LS among the full sample (caregivers and non-caregivers, section 5.2.2.2) and non-caregivers (section 5.2.3.2); this appears to remain consistent in the follow-up analyses, whereby life satisfaction was previously significant (section 6.2.2) among the full sample, but not among the current caregiving sample.

6.2.3.2 Summary: is caregiving at any wave associated with later loneliness?

Duration of care provision was positively associated with UCLA-LS loneliness. Caregivers providing care for two or more consecutive waves (long-term) demonstrated higher odds of reporting loneliness than caregivers for a single wave (short-term). Alternatively, intermittent care was not associated with increased odds of loneliness compared to short-term care. Thus, loneliness was more likely to occur for long-term caregivers than for caregivers providing care over shorter periods of time, regardless of whether it was the caregivers' first episode of care provision or a subsequent episode of care provision at a later date. This emphasises that the positive association between caregiving and loneliness may be linked to continuing care provision over a prolonged period, rather than multiple caregiving episodes. Moreover, wave two caregiving was not significantly associated with wave eight loneliness (section 6.2.2). This suggests that loneliness may occur during the caregiving role particularly for long-term caregivers, or after the caregiving role and may persist for a short-term period, but there is little evidence to support long-lasting effects of caregiving on loneliness over periods such as 12-years.

Alongside duration of care, factors negatively associated with experiencing loneliness after care provision were negative expectations for future loneliness, and QoL, both measured at baseline. This result aligns with the theory of self-fulfilling prophecies and internalised age-stereotypes in SET, in that expecting to become lonelier was linked to an increased likelihood of a loneliness outcome. However, no significant associations were found for any of the health measures, indicating that, for example, presence of chronic CV conditions at baseline had limited influence on later loneliness. As identified previously, this could be a limitation of adopting time invariant controls, for full discussion see section 7.5.3. The following research question analyses the caregiving sample further, investigating how the caregiving relationship and role contribute to later loneliness and how changes to loneliness expectations and mental health impact loneliness.

6.2.4 RQ3c: how are the caregiving relationship, and role, associated with loneliness for short-term *versus* long-term, or intermittent caregivers?

Question 3c seeks to answer whether aspects of the caregiving relationship and role impact loneliness experienced by caregivers. As such, comparison is drawn between the duration of care provision, the caregiving relationships (relationship to the recipient and whether the caregiver lives with them), and the caregiving role (caregiving intensity and the number of care recipients). Table 34 shows the models applied in the binary logistic regression for RQ3c.

Table 34: Regression models for RQ3c: how do changes to the caregiving relationship and role impact loneliness among caregivers?

Model number	Variables included in the model
1	Duration of care
2	Model 1 + care recipient, co-residential care, caregiving intensity, and number of care recipients
3	Model 3 + changes to loneliness expectations and mental health

Source: author's own

In this regression, the main explanatory variable was duration of care. Caregivers who had provided long-term care (≥ 2 consecutive waves) and cared intermittently (≥ 2 non-consecutive waves) were compared with short term caregivers (caregivers providing care in only one wave). This will identify whether there is a difference in loneliness between caregivers providing care at one time point, those who care over consecutive waves for longer time-periods, and caregivers who provide care on multiple separate occasions. Model two introduces the caregiving relationship and role variables. As some of the caregivers had only provided care at one time-point, it was not possible to look at changes to these variables over the caregiving role; short-term caregivers would always be in the 'stable' categories, and this would likely affect the results. Therefore, the caregiving variables were measured as, for example, 'ever provided high-intensity care' or 'ever provided care to multiple recipients'. Significant results would indicate whether that particular aspect of caregiving was associated with loneliness after controlling for other caregiving-specific variables. In the final model, control variables were added for loneliness expectations, and changes to mental health (details in section 4.3.8). By controlling for changes to mental health and loneliness expectations over the 12-year follow-up, this identified whether, after accounting for caregiving variables, mental health and loneliness expectations were more strongly associated with loneliness.

6.2.4.1 The association between the caregiving relationship, and role, with loneliness.

The odds of loneliness were not significantly different for intermittent or long-term caregivers, in comparison with short-term caregivers in the fully-adjusted model (Figure 28). This could have been due to the smaller sample size (N=523), in this final regression analysis, 44% of the potential sample (N=938 caregivers, either non-lonely or loneliness occurring after care provision only) were excluded due to missing data. However in the initial model (Appendix CC), before controlling for other

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caregiving-specific factors, significant difference was observed between long-term and short-term care provision. Long-term caregivers were 1.9 times more likely to be lonely than short-term caregivers (OR=1.87, 95CI=1.16-3.00). This aligns with the result from RQ3b, in that longer periods of care were linked to increased odds of loneliness. However the attenuation of the significant result after controlling for variables related to the caregiving relationship and role suggest that other caregiving-specific factors were more strongly associated with caregiver loneliness after accounting for care duration. Overall, the result suggested that loneliness was not wholly dictated by the duration of the caregiving role. Intensity of care was also an influential factor. In the fully-adjusted model, odds of loneliness were significantly higher for caregivers providing high-intensity (OR=1.88, 95CI=1.11-3.19), or round-the-clock care (OR=1.94, 95CI=1.05-3.59) compared to low-intensity care.

Previous results from the cross-sectional analyses suggested that caregiving to an adult-child was linked to increased odds of loneliness (section 5.3.2.1), this positive association was not present in the follow-up analyses. Therefore, while care to an adult-child appeared to be strongly linked to loneliness that occurred simultaneously with the provision of care, the significant positive association between caregiving intensity, and previously caregiving duration, may better explain the longer-term relationship between care and loneliness. Moreover, Barnhart *et al.* (2020) indicates that caregivers to an individual with an intellectual or developmental disability (adult-child) are more likely to provide care over a longer duration (25-years compared to national US average of four-years) and at higher-intensity (57hpw compared to national US average of 24hpw). Thus the provision of high-intensity care, over longer durations is reflective of the care provided to adult-children, consequently the intensity and duration variables may account for the care relationship and have contributed towards the lack of significance.

The provision of co-residential care was not associated with loneliness among caregivers. As such, caregivers living with the care recipient did not experience a greater or lesser likelihood of loneliness in comparison to caregivers living separately from the care recipient. It is unknown from the data whether those providing co-residential care had additional support with the caregiving role; for example, caregivers living with and providing care to their spouse, whether they had adult-children outside, or within the home to assist with care needs. This would likely reduce the likelihood of loneliness if there were additional caregivers to share the burden. Caregivers who were ever required to give round-the-clock care indicated that their caregiving responsibility was constant, this suggests limited availability for social activities or breaks from the caregiving role. This would also require being available to meet care needs during the night and suggests co-residential care was highly likely. The significance between round-the-clock care and loneliness may account for this and explain why no significant difference was seen between co-residential care and loneliness. Finally, caregivers to multiple recipients were no more or less lonely than the caregivers to single recipients.

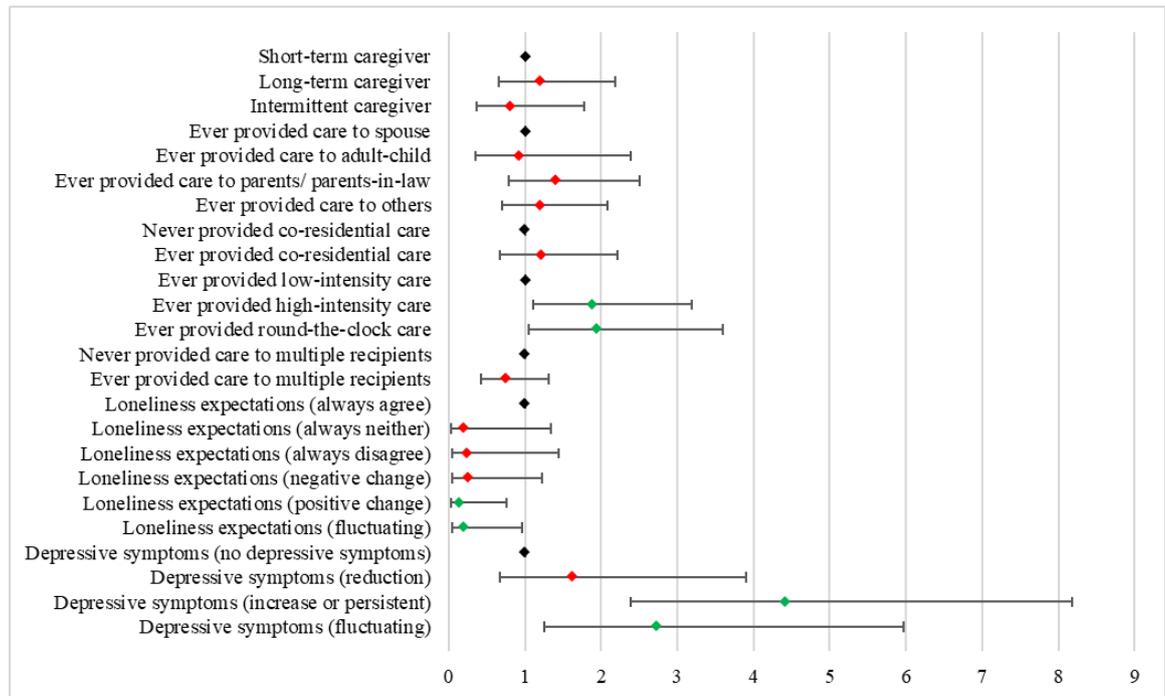


Figure 28: Odds ratio plot, associations between loneliness and duration of care, caregiving-specific factors and changes to loneliness expectations and mental health
 Source: author's analysis of ELSA waves 2-8

Changes to loneliness expectations were negatively associated with loneliness, and changes to mental health, as measured by depressive symptomatology, were positively associated with loneliness among caregivers. Compared to caregivers who always expected to become lonelier with age (always agree), those who demonstrated a positive change in expectations, or fluctuating change in expectations were less likely to experience loneliness. Interestingly, the odds of loneliness for caregivers always disagreeing, i.e. never expecting to grow lonelier with age, were not significantly different from those always agreeing, i.e. always expecting to grow lonelier with age.

When considering changes to depressive symptomatology over the 12-year period, compared to the reference group (stable: no depressive symptoms), persistent or an increase in depressive symptoms (OR=4.42, 95CI=2.39-8.17), and fluctuating (OR=2.73, 95CI=1.25-5.98) depressive symptoms were indicative of higher odds of loneliness. However, there was no significant difference in loneliness odds between caregivers who reported a reduction in depressive symptoms and the reference group. From these results, it is conceivable that depression and loneliness may be comorbid, and most frequently occur within similar time-periods, otherwise the 'reduction' group would also demonstrate heightened odds of loneliness due to having previously experienced depressive symptoms.

6.2.4.2 Summary: how do changes to the caregiving relationship and role impact loneliness among caregivers?

Overall, the results in RQ3c suggested that the main aspect of the caregiving relationship and role that influences loneliness was the caregiving intensity. Previously in the cross-sectional analyses the care recipient, predominantly caregiving for an adult-child appeared the most influential. However,

as discussed previously, recipient and intensity are likely be linked, as it is known that care to adult-children has a higher average of duration and intensity, compared to other care recipient groups. The Nagelkerke R^2 indicated that 16% of variance in caregiver loneliness was explained by the fully-adjusted model, and the Hosmer-Lemeshow statistic ($p=0.729$) suggested the model was a good fit for the data. Some of the unexplained variance may be accounted for by caregiver characteristics such as sex, age, or employment. In the cross-sectional caregiver-only analysis (section 5.3.2.1), sex was positively associated, and employment negatively associated with caregivers' loneliness. Additionally, in the previous follow-up regression analyses (sections 6.2.2 and 6.2.3), age has been shown to be significantly positively associated with loneliness over the 12-year period. Baseline caregiver characteristics were not controlled for in these analyses, due to the focus on changes to mental health and loneliness expectations; the small numbers of caregivers reporting change between the waves meant that splitting by sex or age category would prove unreliable, leaving much smaller subgroups for comparison or leading to overfitting of the regression model. Future research, to build on the contribution of this thesis, might consider a similar approach with a larger caregiving sample, which would permit additional controls.

6.2.5 Summary: what are the longer-term effects of caregiving on loneliness?

There were inconsistencies between the follow-up and cross-sectional findings among caregivers. Overall, the results within this thesis suggest that caregiving to an adult-child, was positively associated with loneliness when examined cross-sectionally. However, the follow-up analyses highlighted significant positive associations between both duration, and intensity, of care, and loneliness. Literature suggests a substantial overlap between these caregiving-specific factors, in that caregivers to adult-children provided care at higher-intensities and longer durations than other caregiving groups. Alternatively, this may be that the impact of caregiving intensity has longer-term effects on loneliness; for example, caregivers providing high-intensity or round-the-clock care may not experience loneliness at the same time as they are providing care (as would be indicated in cross-sectional analyses), but that this may develop over longer durations of care, or subsequent to the caregiving role due to diminished social circles while caregiving.

The initial follow-up analysis (RQ3a) suggested that the association between caregiving and loneliness does not extend over the 12-year period, indicating that the relationship may be shorter-term. There was no evidence of increased loneliness odds among the wave two caregivers after the 12-year follow-up. However, provision of long-term care at any point between waves two and eight was positively associated with loneliness occurring after care provision. A strong positive relationship was observed between loneliness at baseline and loneliness at follow-up, which would advocate loneliness as a trait characteristic, enduring rather than temporary like a state characteristic. Arguably, the positive association between caregiving and loneliness appeared to be short-term. Therefore, this suggested loneliness in itself may be more likely to be consistent or reoccurring,

irrespective of caregiving, but that caregiving does not appear to have long-lasting effects on loneliness.

Expectations for future loneliness appeared influential to long-term loneliness, particularly in the analysis controlling for baseline loneliness (RQ3a(ii)), and when examining loneliness occurring after the start of care provision (RQ3b). The results from this thesis support previous research into loneliness as a self-fulfilling prophecy, see Pikhartova *et al.* (2016).

The impact of sex was unclear, while significant in RQ3a(i), significance between sex and loneliness attenuated when baseline loneliness was controlled for in RQ3a(ii). Additionally when examined among caregivers over all waves (2-8), sex at baseline was not significantly associated with experiencing later loneliness (occurring after the start of care provision). This indicates that, overall, females may be more likely to be lonely, but that other factors such as loneliness or care provision may be stronger predictors of future loneliness than sex. As such, males who were previously lonely may be more likely to continue to be, or to be lonely again due to previous loneliness; sex would not be considered a protective factor for reoccurring loneliness among males. Moreover, although care provision was not associated with loneliness at 12-year follow up, there was evidence for shorter-term effects. Therefore, the significant positive association observed between females and loneliness in RQ3a(i) may be better explained by other factors occurring between the two time-points. For example, females have been shown to be more likely to be caregivers, therefore the females at baseline may become caregivers between waves three and eight, which could contribute towards the later reported loneliness.

Among caregivers, the duration of care was not statistically relevant for loneliness after controlling for other caregiving-specific factors such as intensity and the caregiving relationship (RQ3c). However, when controlling only for caregivers' sociodemographic characteristics, SES and health and wellbeing at baseline (RQ3b), characteristics long-term care provision was indicative of increased odds of later loneliness. The main factors influencing longitudinal loneliness among caregivers appeared to be caregiving intensity; the provision of high-intensity or round-the-clock care resulted in odds almost twice as high as low-intensity caregivers. The results from RQ3c also established that demonstrating a positive change in loneliness expectations, or even fluctuating expectations over the waves, had a beneficial impact on loneliness, in that caregivers with this aforementioned shift in expectations were less likely to become lonely. An increase in, or persistent depressive symptoms influenced loneliness as expected, with higher odds compared to never reporting depressive symptoms. However, the result for fluctuating depressive symptoms was less predictable; unlike for loneliness expectations, fluctuating symptoms resulted in higher odds of loneliness. This suggests that depression and loneliness may be comorbid, rather than one leading to the other, as it is plausible that loneliness occurred when depressive symptoms were present for those who were categorised as fluctuating.

6.3 Chapter summary

Chapter six has summarised the findings from the follow-up analyses. Four binary logistic regressions were carried out comparing loneliness among wave two caregivers and non-caregivers, and among short-term, long-term, and intermittent caregivers across waves 2-8. The results suggested that the positive association between caregiving and loneliness may be acute rather than chronic, highlighting a critical period for loneliness intervention (during the caregiving role). However, there is also evidence to suggest that loneliness, irrespective of caregiving, may be enduring. Therefore, both caregivers and non-caregivers who have been previously lonely, are at risk of chronic or reoccurring loneliness. The discussion in the subsequent chapter reflects on both the cross-sectional and follow-up results in relation to theory and literature, highlighting the original contribution of this thesis. Furthermore the final chapter reflects upon limitations of this thesis, considers the policy implications of the findings, and provides suggestions for future research.

Chapter 7 Discussion and conclusion

7.1 Chapter outline

This discussion chapter addresses the main aims of the thesis. It is structured as follows: the association between caregiving and loneliness (section 7.2), the determinants of loneliness (section 7.3), and the health and wellbeing consequences (section 7.4). Furthermore, the limitations of the thesis will be discussed (section 7.5), before concluding and providing policy and research recommendations (section 7.6.).

7.2 Association between caregiving and loneliness

When comparing caregivers with non-caregivers in the ELSA sample, the results of the cross-sectional analysis suggested that the **positive association** between caregiving and loneliness was conditional on the loneliness measure. As such, caregiving was not significantly associated with the direct loneliness question but **was positively associated** with UCLA-LS loneliness. Furthermore, the **positive association** between caregiving and UCLA-LS loneliness attenuated with the inclusion of health and wellbeing controls, which suggests that health and/or wellbeing are more strongly associated with loneliness, after accounting for caregiving. Nevertheless, in the unadjusted model, the odds of caregivers reporting loneliness were 1.35 times higher than non-caregivers. This finding is comparable with the ONS statistic, based on CLS data from 10,256 adults across England, which indicated that caregivers were around 37% more likely to report loneliness than non-caregivers (Pyle and Evans, 2018). Alternatively, caregivers' expectations for future loneliness did not significantly differ from non-caregivers; therefore despite the **positive association** between caregiving and loneliness, caregiving was not indicative of a negative outlook on future loneliness. As such, caregivers were no more, or less, likely than non-caregivers to expect loneliness as they age. Previous evidence using ELSA data demonstrated that loneliness expectations were linked to future loneliness (Pikhartova *et al.*, 2016), although this was not compared for caregivers and non-caregivers. However, there was no current evidence found whereby loneliness expectations were the outcome variable. Therefore, the knowledge around what contributes towards future loneliness expectations is limited. But the findings from this thesis suggest that caregiving is not a contributing factor. This would imply that the loneliness experienced by caregivers is not the result of an internalised stereotype and may be related to factors specifically associated with caregiving.

However, when examining caregiver characteristics, the caregiving relationship, and the caregiving role in relation to loneliness, the cross-sectional results suggested that role factors (e.g. intensity or number of recipients) may play a lesser part than caregivers' sociodemographic and socioeconomic characteristics or relationship with the care recipient. Once controlled for social networks, health, and wellbeing, female caregivers compared to male, **non-employed** compared to employed, and

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caregivers to a dependent adult-child compared to spousal caregivers, had higher odds of loneliness. Whereas caregiving intensity and number of care recipients were not significantly associated with caregiver loneliness in any model. These findings align with certain aspects of caregiver literature, but also give additional insight into how these caregiving factors tie together. As such, caregiving literature suggests female caregivers are more likely to be lonely (Beeson, 2003; Vitaliano *et al.*, 2003; Soylu *et al.*, 2016). However, in previous literature this was not examined simultaneously with other caregiver characteristics, or factors relating to the caregiving relationship and role.

Within the literature on caregiver loneliness, the discussion is centralised around sex, with a large body of evidence (e.g. Beeson, 2003; Soylu *et al.*, 2016; Victor *et al.*, 2020) indicating that female caregivers are lonelier than males (section 3.4.2.1). Alternatively, only evidence from Bramboeck *et al.* (2020) was found to dispute this, suggesting male caregivers were lonelier. The results from this thesis also suggested female caregivers were lonelier than males, when examined among other traditional loneliness determinants (section 5.2.3.1), and caregiving-specific factors (section 5.3.2.1) supporting the majority of previous evidence. The literature review also identified co-residential care, and caregiver-recipient relationships as important factors related to loneliness. Bramboeck *et al.* (2020) found co-residential caregivers to be lonelier than non-residential, and Victor *et al.* (2020) reported that spousal caregivers were lonelier than caregivers to other family members or friends. Within this thesis co-residential care was only significantly positively associated with caregiver loneliness before controlling for social networks, suggesting that an external network outside of the caregiving role, particularly close relationships with friends, may be vital for those providing care to someone within their household. Moreover, the results suggest that after controlling for other caregiving-specific factors, and caregivers' health and wellbeing, those providing care to adult-children experienced greater loneliness than spousal caregivers. Literature suggests that caregivers to adult-children provide care at considerably higher intensities (Barnhart *et al.*, 2020), and over longer durations (Anderson *et al.*, 2018), which may account for the heightened loneliness.

However, in comparison to research into caregiver characteristics (sex), the body of evidence examining the links between factors related to the caregiving relationship or role and loneliness is substantially smaller. Evidence from this thesis conflicts with previous evidence on the caregiving relationship and role highlighting a need for further robust research into these areas and less emphasis on sex differences which are well-established. Additionally, among caregiving literature, intensity is a substantial factor linked to caregivers' health and wellbeing, but much less is reported about the effects of caregiving intensity on loneliness. This thesis found no significant association between caregiving intensity and loneliness cross-sectionally but found evidence of significant longer-term associations. However, the significance of adult-child caregiving may account for some of the intensity differences between the caregivers, i.e. if the majority of caregivers to adult-children were providing high-intensity or round-the-clock care, this significant difference may explain why no significant difference was seen for the caregiving intensity variable. Nevertheless, caregiving duration, arguably another method of determining caregiving intensity, was significantly positively

associated with loneliness. Thus specific studies examining the impact of caregiving intensities on loneliness, both short-term and long-term are vital to further clarify the relationships between these variables.

When considering the long-term associations of caregiving and loneliness, the findings suggest that the positive association between caregiving and loneliness may be more acute than chronic. As such, caregiving was not associated with loneliness at 12-year follow-up, but long-term caregiving (for two or more waves) over the 12-year period was positively associated with loneliness occurring after care provision. No published literature was found reporting the lasting effects of caregiving, therefore little comparison can be drawn between these findings and other data sources. Moreover, there is a substantial lack of clarity about how long during, or after the caregiving role caregivers might experience loneliness. This thesis provides an insight suggesting that the impact of caregiving on loneliness is less than 12-years, but further research is essential to identify whether the effects are lasting, and how long for. Nevertheless, the findings highlight the need for immediate intervention, or prevention strategies to ensure loneliness does not endure, nor reoccur, as previous loneliness among caregivers was shown to increase the odds of loneliness at 12-year follow-up by over four times.

7.3 Determinants of loneliness

Investigation into the determinants of loneliness identified that largely, the factors related to loneliness among caregivers are different to non-caregivers. However, loneliness expectations, an indicator of SET psychological health, was a significant determinant of loneliness for both caregivers and non-caregivers. The cross-sectional results indicated that those who did not expect to be lonelier with age, were also less likely to be lonely at the same time-point. Moreover, there was evidence of longer-term effects; positive loneliness expectations at baseline were negatively associated with loneliness scores 12-years later when controlled for baseline loneliness. Pikhartova *et al.* (2016) have previously demonstrated using ELSA data that expecting to be lonelier with age was positively associated with loneliness 2-6 years later. Therefore, this thesis augments this conclusion by demonstrating that loneliness expectations are also associated with more immediate impact on loneliness and showing the impact of loneliness expectations persists over longer time-periods. SET suggests that age-stereotypes relate to a range of health-related areas (Levy, 2009; Meisner and Levy, 2016), predominantly research considers stereotypes of physical and mental health decline. Aside from the cited work from Pikhartova *et al.* (2016), limited research has been conducted on internalised loneliness stereotypes and the implications of loneliness expectations. Thus, this thesis provides additional context of the impact of loneliness expectations over both shorter and longer time-periods.

The determinants of loneliness exclusive to non-caregivers were predominantly health and wellbeing related. In contrast, factors associated with loneliness among caregivers included sex, employment,

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and closer relationships with friends. Largely, the determinants match previous literature; however there is limited literature in caregiving samples, so little comparison can be drawn. The discrepancies between caregivers and non-caregivers could aid the identification of those at higher risk of loneliness. As such, female and non-employed caregivers are more likely to be lonely, and similarly non-caregivers living alone with poor mental health. These individuals are most likely to experience loneliness and thus would benefit from loneliness interventions. The findings also emphasise a clear need for further research, as anticipated from the literature review, the majority of determinants of loneliness for caregivers were different from the non-caregivers, less prominence appears to be placed on health and wellbeing as determinants of loneliness for caregivers. Among dementia caregivers, previously reported determinants of loneliness were social networks, cohabitation, depression, life satisfaction and QoL (Victor *et al.*, 2020). These findings were almost mirrored in the present thesis, with the exception of depression and life satisfaction, which were only positively and negatively (respectively) associated with loneliness among non-caregivers, and the significance of employment for caregivers. Although arguably, the impact of employment on caregiver loneliness may be related to the social network which accompanies being employed. Results demonstrated that a larger network of close friends was negatively associated with loneliness, whereas a larger network of close family members was not significantly associated with loneliness. Research on relationships (section 3.2.2) and social networks (section 3.2.3) highlights the importance of relationship quality, and it was suggested by Stephens *et al.* (2011) that the individuals making up the network was also relevant for loneliness. Family-based networks have been linked to an increased risk of loneliness, as they provide little other social support (*ibid*); moreover, family networks may be indicative of a restricted network, whereby the individual may have reduced connections with the wider network due to health. Therefore, the finding that close friends have a significant positive impact on loneliness, but close family do not, aligns with the conclusion of Stephens *et al.* (2011) that family networks may provide minimal social support.

A key theme identified within the literature review was the importance of SES as a determinant of loneliness. Overall, previous evidence suggested that lower SES was positively associated with loneliness, whereby loneliness was highest among the poorest (Pinquart and Sørensen, 2001; Niedzweidz *et al.*, 2016), non-employed (Algren *et al.*, 2020), and least educated (Pinquart and Sørensen, 2001; McRae *et al.*, 2009). The results of this thesis generally upheld these conclusions in that poorer and non-employed respondents demonstrated higher odds of loneliness. Employment was negatively associated with loneliness among the full sample and amongst caregivers when examined separately. However, the relationship between wealth and loneliness appears to be moderated by health and wellbeing. Among caregivers (sections 5.2.3.1 and 5.3.2.1) the negative association between wealth and loneliness attenuated after the inclusion of health and wellbeing controls. Furthermore among the full sample, health and wellbeing controls affected the direction of the relationship between wealth and loneliness. Initially, those in lower wealth quartiles were lonelier than wealthier respondents (section 5.2.2.2), which aligns with the published evidence. However,

after controlling for health and wellbeing effects, this ceased to apply. The results demonstrated that, without the additional health and wellbeing consequences that are typically associated with poverty (for example, due to healthcare inaccessibility, or other unattainable health-promoting lifestyle factors, such as healthier diets), poorer respondents were less lonely in comparison to wealthier individuals. Thus implying that the connection between SES and loneliness is not necessarily direct, but that poverty-related health and wellbeing inequalities may have a substantial influence on loneliness among those in lower socio-economic brackets. This implication may have been less apparent using only employment as an indicator of SES, the conclusion may have been that health and wellbeing were stronger determinants of loneliness rather than considering health as a moderator in the relationship between SES and loneliness. Thus the emphasis placed on the importance of appropriate context-specific SES variables in the literature review (section 3.2.4) is confirmed, but also the results of this thesis would advocate for the use of multiple SES indicators and the inclusion of health-related factors when examining SES and loneliness.

The long-term factors associated with loneliness over the 12-year period also differed from the cross-sectional findings. Baseline age was positively associated with, and QoL and life satisfaction at baseline were negatively associated with, loneliness at follow-up, both when controlling for and excluding those lonely at baseline. Age was not significantly associated with loneliness in the fully-adjusted models of any of the cross-sectional analyses, typically any significant association attenuated once controlled for health and wellbeing. This is likely because poor health is often more common with older age groups, therefore the inclusion of health in the cross-sectional analysis likely accounts for the positive association between age and loneliness. However, in the follow-up analysis, baseline health and wellbeing are controlled for, rather than health status concurrent with the experience of loneliness. Thus, because baseline health was not associated with later loneliness, this implies that poor health may be more likely to co-occur with loneliness, not precede over such a long period, therefore age may be reflective of later health decline which is then linked to loneliness. To clarify, the long-term positive association with age may only be significant because health data were not included at follow-up, which is likely to have attenuated the significant result, as was evident in the cross-sectional analysis. Furthermore, the results suggested that over a 12-year period, wellbeing (QoL and life satisfaction) were stronger long-term predictors of loneliness than health. This suggests that wellbeing could have long-term effects on loneliness, whereas the evidence does not suggest the same for health. Cross-sectional results found wellbeing was negatively associated with loneliness, and loneliness was negatively associated with wellbeing, indicating that poor wellbeing and loneliness may also be comorbid.

When considering the results over all waves (section 6.2.3), QoL continued to be negatively associated with loneliness, but no other health or wellbeing measure was significant. As baseline depressive symptoms were not significant in predicting loneliness 12-years later, nor over a shorter-period (loneliness occurring in any wave, but after care provision) this suggests a simultaneous experience of depression and loneliness, which highlights a need for immediate intervention for both

caregivers and non-caregivers with depressive symptoms as they demonstrate higher likelihood of experiencing loneliness at the same time. Nevertheless, this further supports the conclusion that wellbeing is a stronger long-term predictor of loneliness than health. Additionally, age was not significantly associated with loneliness in RQ3b, indicating that age had significant long-term impact on loneliness, but may not be associated with loneliness over a shorter time-period. As previously discussed, this significant relationship may be attributed to age-related health changes which occurred between baseline and follow-up.

7.4 Health and wellbeing consequences of loneliness

One of the key findings from applying SET as a health theory was the significant negative association between loneliness and frequent alcohol consumption. The interpretation that increased frequency of alcohol consumption actually represented socialisation, more than the impact of alcohol itself, was further supported by the positive association between QoL and alcohol consumption. Evidence from Dunbar *et al.* (2017) corroborates these findings, they found those who drank frequently, particularly those drinking in the same establishment ('their local'), experienced substantial social benefits and enhanced wellbeing compared to non-drinkers. Alternatively, the impact of loneliness on alcohol consumption was different for caregivers and non-caregivers, in that caregivers were overall less likely to drink frequently, but loneliness among caregivers was positively associated with frequent alcohol consumption. This implies that, for caregivers, alcohol may be a coping mechanism. There is little evidence on the connection between caregiving and alcohol, but no literature was found on alcohol consumption among lonely caregivers. Evidence from Gottschalk *et al.* (2020) demonstrated caregivers had more responsible drinking habits, but did not examine the additional impact of loneliness, as within this thesis. Moreover, Rospenda *et al.* (2010) suggested that alcohol was consumed by caregivers due to stress from caregiving; their results indicated social burden (relationship strain outside of the caregiving role) and emotional burden (negative emotions towards the care recipient) were the main factors related to alcohol consumption among caregivers. Particularly, social burden could be linked to experiences of loneliness, which supports the findings from this thesis that lonely caregivers were more likely to report frequent alcohol consumption.

Among the full sample, loneliness was associated with all three SET health pathways prior to controlling for wellbeing; positively associated with poor physiological health, and negatively associated with frequent alcohol consumption, and neutral or positive health expectations, suggesting that wellbeing was a stronger predictor of health after accounting for loneliness. However, given that the CASP19 measure for QoL contains several health-related questions, a strong relationship could have been expected. Furthermore, after controlling for wellbeing (QoL and life satisfaction), loneliness was negatively associated with reporting LLTIs. This suggests that wellbeing may account for the previously observed negative association between LLTIs and loneliness, which also implies that the connection between wellbeing and health may be stronger than that of loneliness and health.

The findings identify strong relationships between wellbeing and loneliness, and loneliness and wellbeing, and highlight the existence of simultaneous relationships between health and wellbeing. However, the relationships between loneliness and health, and health and loneliness, appear to be largely influenced by wellbeing. Further analysis is required to clarify the relationships between loneliness and health in a longitudinal context and to examine the mediating effects of wellbeing.

Finally, the caregiving-loneliness interaction suggested that the impact of loneliness on health and wellbeing often differed for caregivers and non-caregivers. Where caregivers appeared healthier than non-caregivers, a healthy caregiver effect was proposed, in that caregivers may be able to provide care because their health permits them, those with poorer health may be less likely to demonstrate a capacity to care. Moreover, with the example of LLTIs, it could be considered that non-lonely non-caregivers may have less of an awareness of their health in comparison to caregivers, therefore illnesses may have been under-reported in this group. Whereas in contrast, because loneliness is known to be linked to poor health, non-caregivers who were lonely may become increasingly aware of their health and therefore more likely to report LLTIs. In contrast, the combined effect of caregiving and loneliness was indicative of greater negative consequences for mental health and wellbeing. These findings were consistent with the caregiver-only analysis. The implications of these results are that the impact of caregiving and loneliness appear to have greater impact on mental health and wellbeing in comparison to the physical health measures. This aligns with previous discussion in this thesis, that the relationship between loneliness and wellbeing is stronger than that of loneliness and health. Moreover, these findings expand on previous literature which indicates that, separately, caregiving (section 3.4.2.2) and loneliness (section 3.4.1) are **positively associated** with negative health and wellbeing outcomes, by highlighting a greater impact on health and wellbeing when caregiving and loneliness are combined.

7.5 Limitations

One of the main considerations of this section is justifying the decision to conduct the analysis using ELSA data. As identified in section 4.2.2.1, ELSA was deemed more appropriate than comparable UK surveys (e.g. UKHLS), due to the longitudinal availability of loneliness data. The advantages of ELSA were the cross-sectional and longitudinal capacity to examine caregiving, loneliness, health, and wellbeing, with little variance in the measurement tools between the waves. However, there are recognised limitations to the ELSA dataset, which will be addressed in relation to the variables (section 7.5.1), the sample (section 7.5.2), and methods (section 7.5.3).

7.5.1 Variable limitations

Within this thesis, caregiving was measured based on provision during the past week; in early waves (2-5) there was a prerequisite question about caregiving in the past month (section 4.3.1), which was not consistent with later waves. One limitation with caregiving over the past week, is that there may

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be a likelihood of undetected caregivers providing care less often (e.g. less than once per week), or those who had not provided care recently (i.e. more than a week ago). But debatably, this demographic of caregivers may firstly, be less likely to experience the negative outcomes related to caregiving due to a reduced intensity, and secondly, for those who had provided care, but not recently, it would be difficult to relate the caregiving to other variables. As such, in cross-sectional analysis, the collected data are occurring within the same time-point, if the respondent was lonely at the point of interview, but had provided care over a month ago, these are, arguably, not occurring simultaneously. In contrast, in the CLS, care responsibilities were not measured exclusively, and were categorised under informal volunteering (Gov.UK, 2020), which is less frequent than ELSA, and no supplementary data was available on caregiving intensity and recipients. Moreover, HSE only included caregiving responsibilities in the most recent wave (2019) (NHS Digital, 2019), which would restrict any longitudinal analysis from being conducted.

Another limitation that arose from the caregiving variable, was the inability to distinguish between short- and long-term caregivers in the cross-sectional analyses. While this was computed in the longitudinal analyses by checking the caregiving variable across all waves, there were no data collected on the duration of care provision for use cross-sectionally. Additionally, the method used to compute duration of care accounts only for those providing care within the week of data collection at each ELSA wave, therefore it is unknown whether care provision continued consistently, or intermittently during the two-year period between each wave. Furthermore, as described in section 4.3.8.2, the loneliness occurring after care provision variable was computed for the regression analyses in RQ3b and RQ3c. The implications that arose from the creation of this variable, such as the exclusion of lonely caregivers in wave two and any caregivers in wave eight, resulted in further reductions to the sample size. Additionally, due to the time gaps between data collection waves (i.e. two-years), it was not possible to control for changes that occur between reporting caregiving in one wave, then loneliness in the next. For example, other lifestyle changes may have occurred, such as bereavement which could contribute towards loneliness more so than the caregiving, so while caregiving occurred chronologically before loneliness, it cannot be guaranteed that the caregiving was the sole contributor.

Limitations could also be identified for some of the health variables, namely LLTI and alcohol consumption. As such, for LLTI, as a self-reported long-standing illness, there is potential for significant discrepancies between respondent interpretations. As no further information was collected on what this illness was: what respondent A considers to be a limiting illness may be considerably different to respondent B. Additionally, no guidance was given regarding 'long-standing', what one recipient might report after a month, another might not report until a year. The results from RQ1 also suggested that it is not explicitly clear what the LLTI variable represents. As such, LLTI was negatively associated with QoL and life satisfaction, but was also negatively associated with both directly reporting loneliness and UCLA-LS. Furthermore, LLTI was positively associated with non-caregiver loneliness prior to controlling for wellbeing, then negatively associated once controlling

for wellbeing. Simultaneously, loneliness was linked to higher odds of LLTI until controlled for wellbeing, then the odds were significantly lower. This could indicate an interaction effect between wellbeing and LLTI, which would require further investigation to fully understand the variable.

Alcohol consumption was determined by how often the respondent had an alcoholic drink in the past 12 months. When asking respondents to recall behaviour over such a long period, there will be an element of recall bias, or particularly for sensitive topics such as alcohol consumption, respondents may provide a more socially desirable answer. It could be considered that frequency of alcohol consumption may not reflect poor behavioural health in the same way that quantity of alcohol might, as such, one respondent might more drink frequently, but in small quantities, and another might drink on fewer occasions, but in considerably larger amounts. Data were collected from around 53% of the total sample in wave eight on quantities of alcohol consumed over the past week, but in previous waves (e.g. wave two), the data collected on alcohol consumption differed substantially, asking about specific beverages (sherry, spirits, beer, and wine) but this was based on their 'heaviest' day and would not be comparable with the wave eight data. Moreover, generalising alcohol consumption based on one 'heavy' day in the past week would arguably not accurately reflect typical alcohol consumption in the way that average frequency over a year would. Similarly, limitations arose by using only alcohol consumption to reflect behavioural health, rather than a range of behavioural health factors for example smoking and exercise. As identified in section 4.3.3.1 problems arose in the analyses when including an aggregated behavioural health variable. However, future research might consider focussing solely on behavioural health aspects, excluding variables such as LLTI and physiological health to allow for a more in-depth analyses of the relationships between loneliness, caregiving and behavioural health. Additionally, in this analysis, the alcohol variable may have been a proxy for social interaction, as the correlations with loneliness might suggest. Therefore, the frequency of alcohol consumption, although largely not representative of typical health-related alcohol measures, was still a valid variable to analyse alongside loneliness.

Additional variable limitations have been highlighted throughout the thesis, particularly in relevant methodology sections. For example, within the physiological health variable, which was computed to represent CV conditions relevant to SET, dementia was incorporated due to evidence that dementia can be CV-related (section 4.3.3.1). However, it could be argued that dementia should not have been included as it is not exclusively a CV condition. To align with other SET research, CV responses such as specific heart rate and blood pressure measurements could have been analysed alongside CV conditions. However, further constraints with the ELSA data restrict the ability to include this information. While nurse data were collected in wave eight, including a range of blood pressure readings, this was only available for a subset of the sample (N=3525), around 42% of those who completed the main questionnaire (N=8445) (ELSA, no date [c]), which would have been largely detrimental to the sample size within this thesis.

Limitations also arose for the social network control variables, whereby only the size of the network could be accounted for rather than other important aspects such as relationship quality. Relationship quality was highlighted as an important factor influencing loneliness, but other than identifying individuals that the respondent was 'close' to, or shared a household with, no further inference could be drawn about the quality of each relationship and no further data were available. Other studies that examined relationship quality (e.g. Hsieh and Hawkley, 2018) considered elements of relationship quality such as support and strain. Typically these would refer to spousal relationships, but collecting data on strain within caregiving relationships would provide insight towards levels of burden experienced by caregivers.

Finally, within this thesis it was not possible to capture information on caregiving burden. As proposed in the conceptual framework, experiences of burden are likely to mediate caregivers feelings of loneliness. It could be hypothesised that those reporting higher levels of burden would feel more isolated and unsupported in their caregiving role and thus more likely to be lonely. However, no formal measures of burden are included in the ELSA data. It was intended that feelings of achievement within the caregiving role and appreciation from others would be applied as proxy measures of burden, but the small proportions of caregivers feeling under-appreciated or dissatisfied with achievement, restricted the inclusion of this variable in any of the analyses (section 5.3.1.4). Thus constituting a limitation within this thesis, as aspects of burden could not be examined or controlled for in the regression models.

7.5.2 Sample limitations

As identified in section 4.3.5, a lack of ethnic diversity is a significant limitation of the ELSA dataset, the majority (>95%) of the total sample are White, and all other ethnic categories are combined as non-White. This limits the generalisability of the results to White England residents aged ≥ 50 . Although evidence from 2011 Census data suggests that in England, 93% of over 50s were of White ethnicity (author's own calculation from Nomis, 2011), therefore the ELSA sample may be reflective of the general population, but the small number of ethnic minorities grouped together leave limited scope for analysis.

Furthermore, as discussed throughout the literature review (chapter three) and caregiving theories (chapter two), caregiving appraisal, including aspects such as satisfaction and burden are key elements when researching the impact of caregiving. Depicted in Table 20 (section 5.3.1), only 3% of caregivers were dissatisfied with what they had gained from caregiving, and 8% did not feel adequately appreciated. Although not typical caregiver appraisal measures (e.g. Zarit burden interview), these variables were to be considered a proxy measure for burden. However, the small sample sizes meant that conducting robust statistical analyses was not possible, therefore the current results could not be controlled for burden and the implications of burden within the ELSA caregiving sample could not be researched. To examine the impact of caregiver burden on loneliness, health and

wellbeing, an alternative data source would need to be used, or additional questionnaire items included in later waves of ELSA. Finally, when computing the change variables (section 4.3.8) for RQ3c, the majority of caregivers did not change their co-residential status, intensity, or recipient number between the measured waves. However, this does not necessarily mean unequivocally that no changes occurred. For example, ELSA data are collected every two-years, therefore several changes may have taken place between data collection points. Moreover, due to caregivers providing care to multiple recipients, and the complexity of the variable over the multiple waves, it was not possible to accurately compute changes in care recipient, therefore the results from RQ3c regarding changes should be interpreted with caution.

7.5.3 Methodological limitations

Due to the CCA approach, in some cases, large percentages of the samples were excluded from analyses due to data being missing or incomplete. As such, as high as 64% of the sample were removed from RQ3c (section 6.2.4). However, on average, the percentage excluded were much lower, as few as 8% were excluded from a regression analysis in RQ1c (section 5.2.4.7). Nevertheless, in all circumstances, the sample sizes were deemed sufficient enough to conduct the proposed analyses. Alternative methods were considered, for example imputation, however, the lack of certainty around the mechanisms behind the missing data, i.e. at random or not at random, raised concerns of bias when applying imputation methods. Furthermore, arguably, due to the subjective nature of some of the variables (e.g. expectations for loneliness and health), imputation could be considered less appropriate, in that other variables within the model may not be able to accurately predict an individual's opinion.

Another methodological limitation was the treatment of all control variables in the follow-up analyses as time-invariant. This method is common in similar research using the same data source and is typically employed to avoid overly complex regression models. In RQ3a and RQ3b, all controls were measured at baseline, this meant that changes to variables such as cohabitation or employment were not accounted for. For example, those who were cohabiting, or in employment at baseline may have divorced or retired during the period between baseline and follow-up, which likely would contribute to loneliness. Future research examining the longer-term effects of caregiving on loneliness should aim to account for changes to sociodemographic and socioeconomic variables in addition to changes to mental health and loneliness expectations (as in RQ3c). This identified limitation may explain the lack of significance between control variables and the outcome variable, in that responses provided to, for example, cohabitation or health status, 12-years prior to the follow-up were no longer accurate or relevant.

7.5.4 Limitations summary

Overall, although there are some limitations to the ELSA dataset, in comparison with other UK-based datasets (e.g. UKHLS, HSE, CLS) it was the most suitable for conducting the proposed analysis. Furthermore, the identified limitations with selected variables are likely to be evident in most SDA projects due to the authors' inability to design data collection tools to fit their research questions exactly. This, however, is outweighed by the advantages of SDA (section 4.2.1.1), whereby a large representative sample is readily available for analysis. Quality of data could be improved by alterations to ELSA variables in later waves, but broadly, when using self-completion questionnaires the interpretation of respondents will likely always differ and therefore the clarity of more generic questions, such as LLTI could always be questioned. **In contrast, the methodological limitations could be addressed in future research, applying imputation methods, and accounting for different change variables, or time-varying controls to determine the effects on the overall results.**

7.6 Conclusion

This thesis addressed three key research questions. Firstly, how does loneliness differ for caregivers and non-caregivers? Overall, the findings indicated that caregiving was **positively associated** with loneliness, but the loneliness measure was important; caregivers were more likely to be lonely on the UCLA-LS but not to directly report loneliness. Moreover, the determinants of loneliness were different for caregivers and non-caregivers, for example the relationships between health and loneliness were significant among non-caregivers but not caregivers. Due to the large discrepancy in determinants identified in RQ1, it was hypothesised that caregiving-specific variables played a larger role in **explaining caregivers' loneliness**. However, the caregiver results (RQ2) confirmed the importance of sociodemographic and socioeconomic characteristics, sex and employment as **determinants**, and only the inter-personal relationship between caregiver and care recipient was found to significantly impact loneliness, not co-residential care, caregiving intensity or number of recipients.

Secondly, how did caregiving affect loneliness, health, and wellbeing? Caregivers demonstrated reduced odds of poor physiological and behavioural health, which have been discussed throughout as a healthy caregiver effect. However, the odds of depressive symptoms were considerably higher for caregivers, and they experienced significantly lower QoL and life satisfaction. This suggests that the impact of caregiving may be more substantial for mental health and wellbeing than for physical health.

Finally, what were the longer-term effects of caregiving on loneliness? Over a 12-year period **caregiving at baseline was not significantly associated with loneliness at follow-up**, which suggests that the impact of caregiving is acute rather than chronic, highlighting a need for early intervention to prevent the possibility of detrimental effects on health and wellbeing that were indicated in the

cross-sectional analysis. However, further research is essential to determine the longer-term effects of loneliness on health and wellbeing among caregivers. **There was a strong positive association between previous loneliness and loneliness at follow-up**, indicating that loneliness is likely to endure or reoccur over an individual's lifetime. Again, this provides a precedent for early intervention, or prevention strategies for loneliness, as initial development of loneliness becomes a risk factor for loneliness in the future.

Largely, the findings in this thesis aligned with the conceptual framework proposed initially (section 2.2), whereby relationships were evident between caregiving and loneliness directly and through other factors, and both loneliness and caregiving impacted health and wellbeing, including through the interpretation of the SET pathways. However, as discussed throughout the thesis, caregiving was often negatively associated with poor health outcomes, which were interpreted as a healthy caregiver effect. In essence, caregivers may have better health initially, permitting them to undertake a caregiving role, rather than caregiving having a positive impact on health. An additional arrow has therefore been included in the conceptual framework (Figure 29) to demonstrate this effect, but further analysis (detailed ahead) would be required to clarify this theory.

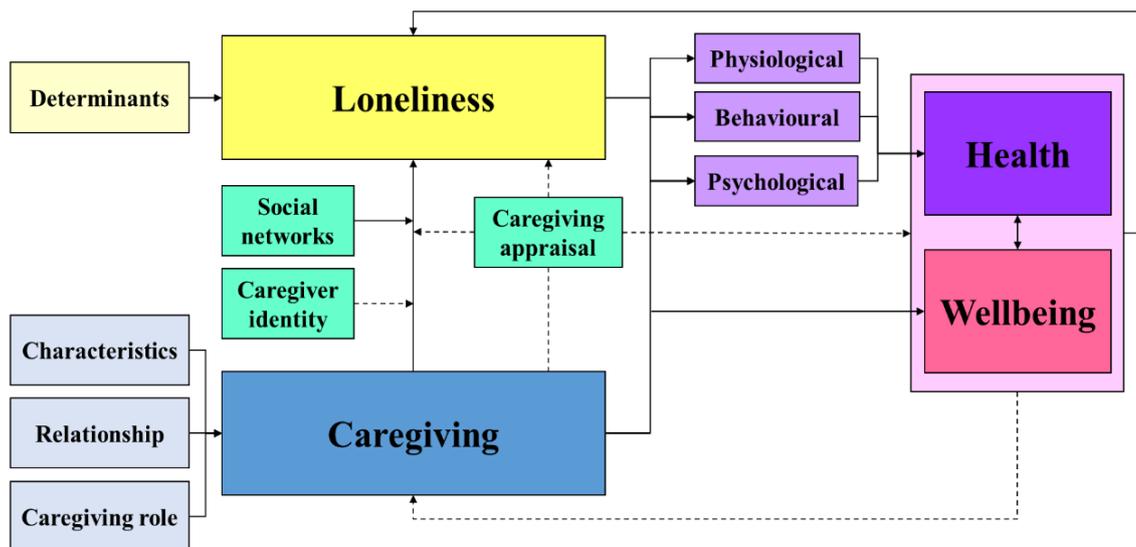


Figure 29: Amended conceptual framework

Source: author's own

7.6.1 Original contribution

As outlined initially in section 3.5.1.1, this thesis makes a significant contribution to current caregiving and loneliness knowledge in several ways. Firstly, the results demonstrate that determinants of loneliness are substantially different for caregivers than non-caregivers, as identified in the research gaps (section 3.5.1), there was limited investigation into the determinants of loneliness for caregivers. Victor *et al.* (2020) also highlighted this limitation and contributed by examining prevalence and predictors of loneliness in dementia caregivers; however, this thesis expands on those findings by conducting a direct comparison of **loneliness determinants** in caregiving and non-caregiving samples and including a greater range of caregivers, i.e. not limited to dementia

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caregivers, and providing a more detailed division of care recipients. The comparison with non-caregivers emphasises the substantial difference between the two subgroups and highlights a need for further research into the determinants of loneliness among caregivers to clarify the current findings.

Additionally, evidence suggested that the reliability and validity of loneliness measures differs by sociodemographic characteristics, such as age and sex (Pinquart and Sörensen, 2011; Nicolaisen and Thorsen, 2014a), but there is no evidence attesting to the use of direct or indirect loneliness measures among caregivers. Research on loneliness among caregivers uses a range of direct and indirect measures, including common scales such as UCLA-LS and DJGLS with differing results. The results from this thesis confirm that among the same sample of caregivers, loneliness prevalence significantly differs depending on the measure applied. This identifies that it is not sociodemographic characteristics alone, that influence the likelihood of directly reporting loneliness, but that further consideration should be made into which loneliness measure is used within caregiving samples.

Finally, as discussed within the literature review (section 3.4.2), literature tends to examine the impact of caregiving on loneliness, health, and wellbeing separately, despite a large body of evidence in non-caregiving populations (section 3.4.1) identifying connections between loneliness and health, and loneliness and wellbeing. Little was known about the impact of loneliness on health and wellbeing among caregivers, and more research is required to identify the impact of health and wellbeing on loneliness among caregivers (section 7.6.3). This thesis highlighted through use of a caregiving-loneliness interaction that the relationships between loneliness and alcohol consumption, depressive symptomatology, LLTI, QoL and life satisfaction differed for caregivers and non-caregivers. Moreover, because the relationship between loneliness and health, and loneliness and wellbeing differ for caregivers, loneliness, health, and wellbeing should be researched simultaneously rather than generic health and wellbeing implications of loneliness from non-caregiving populations being applied to caregivers.

7.6.2 Contribution to theory

CIT demonstrates how a caregiver's identity changes throughout the caregiving role; as the role becomes more complex, the caregiver identifies less with the original relationship they once held with the recipient, and more with their role as caregiver (section 2.1.1.1). While identity could not be directly examined in this thesis, due to limitations within ELSA data, it was considered that caregiving intensity may serve as an appropriate alternative, representing caregiving context (Montgomery and Kosloski, 2009). As such, those providing higher-intensity, or more specifically round-the-clock care are more likely to be in later phases of CIT whereby they would be expected to associate more as a caregiver than a spouse, for example. In relation to this thesis, it was postulated that those in later CIT phases may experience heightened loneliness due to the feeling of losing the significant attachment (emotional loneliness) that was present in the pre-caregiving relationship.

Largely, the results from this thesis demonstrate that CIT is applicable to caregiver loneliness. In the cross-sectional, caregiver-only analysis (section 5.3.2.1), although caregiving intensity was not significantly associated with loneliness, care provision to an adult-child was positively associated with loneliness. As discussed previously (section 7.2), care to adult-children is known to be of higher-intensities, therefore it is possible that the relationship between caregiver-recipient relationships and loneliness accounts for some of the relationship between intensity and loneliness. Additionally, caregivers to adult-children may find that they associate less with the parental relationship, and more with being a caregiver, as their child reaches adulthood; this would be when typical child-care tasks usually cease, but for these individuals care requirements continue, if not escalate. Thus caregivers to adult-children may be representative of caregivers in later phases of CIT. With regard to the longitudinal results, the provision of long-term care was significantly positively associated with loneliness, whereas intermittent care was non-significant (section 6.2.3.1). This could indicate caregivers moving through the phases of CIT. Those providing short-term care, or intermittent care may be less likely to experience contextual changes within the caregiving role, due to the shorter time-periods; thus their identity as a caregiver, and the caregiver-recipient relationship, remain relatively stable. Finally, in section 6.2.4.1 'ever providing' high-intensity, or round-the-clock care was positively associated with loneliness. While the caregivers may not currently be providing this level of care, the phases of CIT are not exhaustive, in that caregivers can experience the phases in different orders. Caregivers who had previously, or were currently providing, higher-intensity care represent the later phases of CIT and demonstrated higher odds of loneliness. The literature on CIT highlights implications for supporting caregivers (Montgomery, 2009), but the focus is on the congruence of identity, not instrumental support with their role. However, interpretations from this thesis imply that the CIT phases may be useful, if implemented in caregiving support services. For example, as a self-rated monitoring tool to observe changes to caregiver identity, and highlight those at higher risk of loneliness, and potentially other detrimental health and wellbeing consequences (later CIT phases) to relevant service providers.

Moreover, SET provides a health framework (section 2.1.2), indicating that internalised stereotypes can have consequences, in the form of self-fulfilling prophecies, for physiological, psychological, and behavioural health pathways (Levy, 2009; Meisner and Levy, 2016). Throughout this thesis health measures have been included for all three pathways. However, caregiving specifically does not appear to be strongly linked to increased likelihood of internalised negative stereotypes. Cross-sectionally, caregiving was not significantly associated with loneliness expectations (section 5.2.2.2) nor health expectations (section 5.2.4.3). Alternatively, caregiving was linked to more positive outcomes related to physiological and behavioural health pathways and the caregiving loneliness interaction indicated that the relationship between loneliness and behavioural health was significantly different for caregivers and non-caregivers. As discussed throughout the thesis these results have been attributed to a healthy caregiver effect, or for example, the use of alcohol as a coping mechanism for caregivers, *versus* alcohol as a social activity for non-caregivers.

This thesis examined health and loneliness related age-stereotypes on loneliness. There was evidence of longer-term impacts of stereotypes and expectations particularly for loneliness. Longitudinally, among the full sample negative loneliness expectations (disagree) at baseline were positively associated with loneliness 12-years later. However, the results for health expectations were less clear when linked to loneliness outcomes, further research is required to determine the long-term effects of health expectations on health-related outcomes. Additionally, there was evidence of long-term self-fulfilling loneliness prophecies among the caregiving sample. Negative loneliness expectations at baseline were positively associated with loneliness occurring after the start of care provision, and changes to loneliness expectations, both positive and fluctuating, were negatively associated with later loneliness. This would suggest that any form of positive expectation may have the ability to counteract previous negative beliefs. While SET provided a clear framework for examining health outcomes among caregivers and non-caregivers, the results from this thesis do not provide enough evidence to indicate a strong affiliation between caregiving and all of the SET pathways. To clarify, from the caregiving-loneliness interaction analyses, only the impact of loneliness on behavioural health was found to differ between caregivers and non-caregivers. This is applicable only to alcohol consumption and further research should be conducted to examine other aspects of behavioural health before drawing further conclusions about the connection between caregiving, loneliness, and SET. Finally, the occurrence of negative age-stereotypes and self-fulfilling loneliness prophecies appeared common among both caregivers and non-caregivers. Additional research examining loneliness expectations as an outcome, with caregiving-specific factors as explanatory variables would aid to explain if caregiving influenced the development of specific age-stereotypes.

7.6.3 Recommendations for policy and further research

Several policy recommendations can be deduced from the results of this thesis. Namely, the use of SET as a health theory identified specific areas of health associated with caregiving and loneliness among caregivers. This allowed for more tailored policy recommendations regarding the health of caregivers. The impact of caregiving on alcohol consumption differed depending on whether they were lonely or not. It is considered that this increased frequency of alcohol consumption among lonely caregivers is likely to be a coping mechanism as evidence has previously linked caregiver burden with unhealthy drinking behaviours (Rospenda *et al.*, 2010). This, therefore, is a specific area of behavioural health shown to be particularly relevant in caregiving populations; caregivers should have access to support and guidance promoting alternative, healthy coping strategies. For example, signposting towards relevant support groups, and access to professional services. These may help address specific issues such as alcohol consumption, or more generally, for concerns they have about their caregiving role.

A recent briefing paper on informal care (Powell *et al.*, 2020) suggested that caregivers who were more likely to experience physical ill health were those providing round-the-clock care, palliative care, or caregivers with socioeconomic difficulties. However, there was limited detail as to what

physical ill health entailed. Whereas, the results of this thesis would suggest that specific areas such as physiological health are particularly relevant to caregiving samples, but broader measures such as LLTI were not significantly associated with caregiving. A 2018/19 NHS mandate detailed that caregivers were to be identified and given access to information and advice about support (Powell *et al.*, 2020). However, this support appears limited, as in the case of caregivers to disabled children, their local authorities needed only consider services the caregiver is assessed for (*ibid*). Thus, if the advice and support to caregivers is provided around more general health, and caregivers are assessed using broad health measures, rather than more specific areas such as physiological or behavioural health (e.g. alcohol consumption) as identified, these support services are likely to be ineffective. It is recommended that caregivers have a more thorough health screening to identify which services should be recommended. Alternatively, the results from this thesis suggested that caregivers of adult-dependent children were more likely to be lonely than spousal caregivers, additionally, caregiving as a whole was only significantly **positively associated** with UCLA-LS loneliness, not the direct question. Relating these findings to the aforementioned policy, if the caregivers' loneliness is assessed by a direct measure, and the individual is therefore not identified as needing loneliness support, the advice and support services would not be considered. It is recommended that when caregivers are identified, they are given access to information about all of the available support services and how to access these, regardless of an assessment. This would give the caregivers all of the available knowledge and reduce the need for caregivers to be reassessed each time that support may be needed.

Moreover, in the carers action plan 2018-2020, research was outlined for areas including the cost and benefit of informal care, the experiences of caregivers and factors that might influence propensity to care (Department of Health and Social Care (DHSC), 2018). Moreover, it was identified that caregivers should be considered in the cross-government loneliness strategy: they were identified as a vulnerable group for loneliness and £500,000 funding was pledged to build caregiver-friendly communities, services, and interventions via the Carer Innovations Fund (DCMS, 2018). This funding was extended to £5 million, to support projects with positive effects on health, wellbeing, employment, loneliness, and respite (DHSC, 2019), but was later suspended in 2020 with the intention to "support carers via other means in due course" (Carers UK, 2020, paragraph 1). Additionally, in the Loneliness Annual Report, published January 2020, little update was provided on the support for caregivers other than work from Sport England and Carers UK, targeting barriers around sport and physical activity for lonely caregivers (HM Government, 2020). While physical activity is arguably important for loneliness, as such, Shankar *et al.* (2011) identified that lonely individuals were less likely to be physically active. This is not limited to caregivers, as evidence from Gottschalk *et al.* (2020) found caregivers to be more physically active. In contrast, both physiological health and alcohol consumption were found, in this thesis, to be related to caregiving, alongside depressive symptoms and QoL. Therefore, it is recommended to reinstate funded projects to support caregiver loneliness, health, and wellbeing through methods aside from physical activity.

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Furthermore, to expand upon the contribution of this thesis, recommendations can also be made for further research. Such research could determine the long-term effects of caregiving on health and wellbeing outcomes to supplement the information gathered on long-term effects of caregiving on loneliness. Moreover, within this thesis, wave two health and wellbeing variables were used as baseline controls for wave eight loneliness. To further disentangle the relationships between caregiving, loneliness, health, and wellbeing, additional longitudinal research could be conducted using previous loneliness and wellbeing to examine future health, and previous loneliness and health to determine future wellbeing in caregiving samples. This would clarify the directions of the relationships and aid researchers to map out which aspect occurs first, i.e. loneliness, poor health, or reduced wellbeing.

Furthermore, there was limited evidence from these analyses to suggest that loneliness persisted 12-years after care provision, additional research using alternative methods, for example, survival analysis, could determine the length of caregiving effects. To clarify, this could estimate how long after initiating caregiving roles, the onset of loneliness or poor health and wellbeing might occur. Alternatively, similar research could be conducted to identify how long these consequences persist. Finally, as discussed previously, a healthy caregiver effect may have been observed in several of the analyses, additional longitudinal analysis examining the health and wellbeing of caregivers prior to undertaking a caregiving role, for example, examining health and wellbeing in the wave prior to the first wave of care, would aid to confirm this theory.

Appendix A Confirmation of ethical approval



Thu 02/11/2017 13:31

ERGO <ergo@soton.ac.uk>

Your Ethics Submission (Ethics ID:30736) has been reviewed and approved

To Davison L.

Submission Number: 30736

Submission Name: Carers and loneliness in the English Longitudinal Study of Ageing (SDA - Secondary Data Analysis)

This is email is to let you know your submission was approved by the Ethics Committee.

Comments

None

[Click here to view your submission](#)

Coordinator: Lisa Davison

ERGO : Ethics and Research Governance Online

<http://www.ergo.soton.ac.uk>

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Appendix B Bivariate associations between sociodemographic characteristics, socioeconomic factors, social networks, loneliness, health, wellbeing and the UCLA-LS and direct loneliness question in the full sample

	UCLA-LS			Direct loneliness		
	χ^2	df	Sig.	χ^2	df	Sig.
Age	15.80	3	.000	27.68	1	.000
Sex	4.68	1	.030	17.78	1	.000
Cohabitation	451.16	1	.000	606.98	1	.000
In paid employment	19.86	1	.000	62.72	1	.000
Wealth	181.94	3	.000	147.32	1	.000
Household size	230.01	2	.000	412.46	2	.000
UCLA-LS				1339.95	1	.000
Loneliness expectations	417.12	2	.000	327.28	2	.000
LLTI	135.27	1	.000	142.63	1	.000
Physiological health	21.62	1	.000	39.17	1	.000
Health expectations	69.34	2	.000	47.24	2	.000
Alcohol consumption	39.02	1	.000	26.62	1	.000
CES-D	632.37	1	.000	1064.69	1	.000
	r		Sig.	r		Sig.
Close relationships with family	-0.11	.000		-0.06	.000	
Close relationships with friends	-0.11	.000		-0.09	.000	
CASP19	-0.44	.000		-0.31	.000	
SWLS	-0.42	.000		-0.30	.000	

Source: author's analysis of ELSA wave 8

Appendix C RQ1a is caregiving associated with directly reporting loneliness?

Variables	Model 1			Model 2			Model 3			Model 4		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper									
Constant	0.102***			0.439***			0.682			4.216**		
Caregiving	0.921	0.662	1.279	1.041	0.732	1.482	1.130	0.790	1.615	0.829	0.552	1.246
Age												
60-69 years				0.839	0.588	1.199	0.831	0.577	1.198	1.095	0.725	1.653
≥70 years				0.714	0.484	1.054	0.700	0.465	1.054	0.964	0.601	1.549
Sex, female				0.844	0.648	1.098	0.870	0.667	1.135	0.763	0.562	1.036
Cohabitation				0.136***	0.103	0.180	0.162***	0.109	0.241	0.254***	0.161	0.399
In paid employment				0.552**	0.391	0.779	0.543**	0.383	0.769	0.898	0.603	1.336
Wealth												
Quartile 2				1.052	0.755	1.465	1.125	0.804	1.574	1.895**	1.275	2.816
Quartile 3				0.816	0.570	1.169	0.866	0.602	1.245	1.926**	1.250	2.967
Quartile 4				0.684	0.459	1.019	0.748	0.499	1.122	1.761*	1.094	2.834
Household size												
Dual-person household							0.710	0.473	1.066	0.507**	0.318	0.809
Large household (≥3)							0.811	0.496	1.325	0.467*	0.261	0.835
Number of close relationships (family and child)							0.942*	0.895	0.991	0.965	0.914	1.019
Number of close relationships (friends)							0.918**	0.863	0.977	0.952	0.890	1.017
LLTI										0.711*	0.506	0.999
Physiological health: chronic CV condition(s)										1.139	0.837	1.550
Health expectations												
Neither agrees nor disagrees										0.772	0.483	1.234
Disagrees										1.020	0.617	1.684
Alcohol consumption ≥3days per week										0.866	0.615	1.218
CES-D: depressive symptomatology										7.041***	5.058	9.801
CASP19										0.956***	0.933	0.980
SWLS										0.952**	0.923	0.982

Notes: binary logistic regression, N=3236, DV – direct loneliness question; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix D RQ1a is caregiving associated loneliness on the UCLA loneliness scale?

Variables	Model 1			Model 2			Model 3			Model 4		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.189***			0.554***			1.273			682.407***		
Caregiving	1.349*	1.066	1.707	1.454**	1.131	1.869	1.463**	1.132	1.892	1.014	0.743	1.385
Age												
60-69 years				0.800	0.615	1.039	0.844	0.643	1.107	1.151	0.831	1.593
≥70 years				0.635**	0.469	0.859	0.734	0.534	1.010	0.824	0.556	1.222
Sex, female				0.964	0.788	1.179	1.007	0.821	1.236	1.177	0.920	1.505
Cohabitation				0.247***	0.199	0.306	0.167***	0.122	0.229	0.259***	0.178	0.379
In paid employment				0.722*	0.560	0.931	0.725*	0.560	0.940	1.124	0.820	1.540
Wealth												
Quartile 2				0.666**	0.511	0.868	0.692**	0.528	0.908	1.196	0.861	1.662
Quartile 3				0.567***	0.429	0.749	0.593***	0.446	0.787	1.443*	1.020	2.040
Quartile 4				0.602***	0.453	0.800	0.667**	0.498	0.894	1.894**	1.317	2.723
Household size												
Dual-person household							1.640**	1.157	2.324	1.219	0.805	1.847
Large household (≥3)							1.785**	1.196	2.663	1.001	0.620	1.615
Number of close relationships (family and child)							0.934**	0.897	0.972	0.966	0.924	1.010
Number of close relationships (friends)							0.901***	0.858	0.945	0.976	0.927	1.029
LLTI										0.632**	0.478	0.837
Physiological health: chronic CV condition(s)										0.939	0.731	1.207
Health expectations												
Neither agrees nor disagrees										1.169	0.834	1.638
Disagrees										0.994	0.662	1.492
Alcohol consumption ≥3days per week										0.760*	0.578	0.998
CES-D: depressive symptomatology										1.681**	1.253	2.254
CASP19										0.869***	0.851	0.887
SWLS										0.939***	0.916	0.962

Notes: binary logistic regression, N=3213, DV – UCLA-LS; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix E RQ1a does caregiving impact loneliness expectations?

Variables	Model 1						Model 2					
	Neither agree nor disagree			Disagree			Neither agree nor disagree			Disagree		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		LCI	UCI		LCI	UCI		LCI	UCI		LCI	UCI
Caregiving	0.995	0.841	1.177	1.034	0.874	1.223	0.976	0.823	1.158	0.992	0.836	1.177
Age												
60-69 years							1.146	0.968	1.356	1.218*	1.025	1.447
≥70 years							1.026	0.846	1.245	1.294*	1.063	1.575
Sex, female							0.911	0.802	1.033	1.005	0.885	1.142
Cohabitation							1.374***	1.187	1.591	1.643***	1.414	1.909
In paid employment							0.939	0.798	1.104	1.023	0.867	1.207
Wealth												
Quartile 2							1.166	0.973	1.396	1.071	0.895	1.282
Quartile 3							1.147	0.957	1.373	0.941	0.784	1.129
Quartile 4							0.998	0.831	1.198	0.842	0.701	1.012

Notes: multinomial logistic regression, N=3259, DV – loneliness expectations; LCI – Lower confidence interval, UCI – Upper confidence interval; *p<.05, **p<.01, ***p<.001, source: author’s analysis of ELSA wave 8

Abbreviations

RQ1a does caregiving impact loneliness expectations? (continued)

Variables	Model 3						Model 4					
	Neither agree nor disagree			Disagree			Neither agree nor disagree			Disagree		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		LCI	UCI		LCI	UCI		LCI	UCI		LCI	UCI
Caregiving	0.934	0.747	1.166	0.980	0.784	1.224	1.000	0.790	1.266	1.154	0.900	1.481
Age												
60-69 years	1.113	0.890	1.392	1.311*	1.043	1.648	1.022	0.808	1.292	1.213	0.941	1.564
≥70 years	0.957	0.734	1.247	1.315*	1.002	1.726	0.866	0.651	1.153	1.361	0.997	1.856
Sex, female	0.862	0.731	1.018	0.906	0.766	1.071	0.832*	0.696	0.995	0.798*	0.660	0.965
Cohabitation	1.214	0.887	1.661	1.824**	1.294	2.572	1.184	0.840	1.670	1.530*	1.022	2.290
In paid employment	0.881	0.714	1.089	1.061	0.856	1.315	0.742*	0.593	0.930	0.872	0.684	1.110
Wealth												
Quartile 2	1.075	0.847	1.363	0.971	0.765	1.232	0.844	0.650	1.095	0.628**	0.476	0.828
Quartile 3	1.062	0.834	1.351	0.955	0.750	1.215	0.829	0.636	1.081	0.578***	0.437	0.765
Quartile 4	0.850	0.666	1.085	0.712**	0.557	0.911	0.640**	0.487	0.842	0.390***	0.292	0.523
Household size												
Dual-person household	1.335	0.933	1.909	0.891	0.607	1.307	1.206	0.823	1.769	0.933	0.601	1.449
Large household (≥3)	1.276	0.863	1.886	1.022	0.677	1.541	1.236	0.811	1.883	1.200	0.749	1.923
Number of close relationships (family and child)	1.024	0.993	1.056	1.076***	1.045	1.108	1.022	0.989	1.056	1.060**	1.025	1.096
Number of close relationships (friends)	1.046**	1.012	1.081	1.095***	1.061	1.130	1.029	0.995	1.064	1.057**	1.023	1.093
LLTI							1.159	0.934	1.438	1.728***	1.373	2.174
Physiological health: chronic CV condition(s)							1.213*	1.009	1.459	1.126	0.924	1.372
Health expectations												
Neither agrees nor disagrees							1.548***	1.223	1.959	1.711***	1.340	2.183
Disagrees							1.528**	1.127	2.072	3.254***	2.447	4.326
Alcohol consumption ≥3days per week							0.987	0.818	1.191	0.917	0.750	1.120
CES-D: depressive symptomatology							0.517***	0.394	0.680	0.600**	0.438	0.822
CASP19							1.036***	1.020	1.053	1.111***	1.091	1.131
SWLS							0.985	0.966	1.005	0.991	0.969	1.014

Notes: multinomial logistic regression, N=3259, DV – loneliness expectations; LCI – Lower confidence interval, UCI – Upper confidence interval; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix F RQ1b what are the determinants of caregivers' loneliness?

Variables	Model 1			Model 2			Model 3			Model 4		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.189***			0.217***			0.669			269.295***		
Age												
60-69 years	0.601	0.341	1.060	0.461*	0.241	0.882	0.476*	0.240	0.943	0.715	0.319	1.598
≥70 years	0.627	0.355	1.106	0.359**	0.178	0.727	0.426*	0.199	0.914	0.626	0.249	1.576
Sex, female	1.029	0.632	1.676	1.373	0.808	2.331	1.685	0.964	2.945	3.061**	1.487	6.303
Cohabitation	0.565*	0.326	0.979	0.718	0.389	1.326	0.404*	0.176	0.926	0.770	0.270	2.190
LLTI	1.685*	1.012	2.805	1.299	0.754	2.236	1.311	0.747	2.302	0.653	0.322	1.326
Loneliness expectations												
Neither agrees nor disagrees	0.776	0.470	1.279	0.732	0.432	1.241	0.801	0.464	1.382	1.316	0.681	2.543
Disagrees	0.079***	0.032	0.196	0.088***	0.035	0.219	0.100***	0.039	0.255	0.182**	0.061	0.538
Public transport use												
1-3 times per month	0.789	0.448	1.391	0.763	0.414	1.408	0.758	0.402	1.427	0.994	0.474	2.084
1-3 times per week	1.593	0.805	3.155	1.192	0.572	2.484	1.063	0.494	2.284	1.093	0.441	2.711
Every day or nearly everyday	2.022	0.884	4.628	1.092	0.431	2.766	0.727	0.254	2.078	0.583	0.137	2.487
In paid employment				0.238***	0.124	0.458	0.227***	0.113	0.455	0.398*	0.180	0.878
Wealth												
Quartile 2				0.524	0.257	1.069	0.644	0.305	1.364	0.857	0.346	2.126
Quartile 3				0.378**	0.176	0.810	0.448*	0.203	0.988	0.953	0.363	2.498
Quartile 4				0.403**	0.191	0.850	0.522	0.239	1.137	1.405	0.539	3.660
Household size												
Dual-person household							1.597	0.505	5.056	0.729	0.181	2.937
Large household (≥3)							2.273	0.669	7.720	1.188	0.270	5.226
Number of close relationships (family and child)							0.887*	0.790	0.995	0.961	0.852	1.084
Number of close relationships (friends)							0.803**	0.691	0.934	0.843*	0.718	0.990
Physiological health: chronic CV condition(s)										1.627	0.816	3.244
Health expectations												
Neither agrees nor disagrees										0.593	0.228	1.540
Disagrees										1.122	0.360	3.497
Alcohol consumption ≥3days per week										2.051	0.990	4.249
CES-D: depressive symptomatology										0.839	0.394	1.788
CASP19										0.854***	0.808	0.902
SWLS										0.943	0.886	1.003

Notes: binary logistic regression, N=503, DV – UCLA-LS; *p<.05, **p<.01, ***p<.00; source: author's analysis of ELSA wave 8

Appendix G RQ1b what are the determinants of non-caregivers' loneliness?

Variables	Model 1			Model 2			Model 3			Model 4		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.145***			0.132***			0.192***			199.159***		
Age												
60-69 years	0.958	0.717	1.280	1.071	0.778	1.473	1.139	0.818	1.587	1.416	0.964	2.080
≥70 years	0.707*	0.521	0.959	0.846	0.578	1.238	0.980	0.657	1.462	1.049	0.655	1.678
Sex, female	0.965	0.760	1.227	0.972	0.764	1.237	0.982	0.770	1.252	1.040	0.783	1.380
Cohabitation	0.208***	0.162	0.267	0.227***	0.176	0.294	0.147***	0.100	0.217	0.214***	0.137	0.334
LLTI	1.938***	1.507	2.492	1.864***	1.434	2.424	1.863***	1.431	2.425	0.709*	0.507	0.990
Loneliness expectations												
Neither agrees nor disagrees	0.273***	0.206	0.361	0.269***	0.203	0.356	0.270***	0.204	0.359	0.297***	0.215	0.410
Disagrees	0.120***	0.084	0.173	0.116***	0.080	0.167	0.120***	0.083	0.174	0.210***	0.139	0.318
Public transport use												
1-3 times per month	0.853	0.644	1.129	0.856	0.644	1.136	0.876	0.658	1.166	1.045	0.751	1.455
1-3 times per week	0.907	0.639	1.286	0.929	0.654	1.321	0.922	0.647	1.313	1.033	0.683	1.561
Every day or nearly everyday	1.175	0.772	1.788	1.148	0.752	1.752	1.165	0.760	1.786	1.448	0.885	2.370
In paid employment				1.206	0.871	1.669	1.180	0.849	1.640	1.435	0.974	2.113
Wealth												
Quartile 2				0.751	0.543	1.038	0.753	0.541	1.049	1.004	0.684	1.472
Quartile 3				0.702*	0.501	0.985	0.718	0.510	1.011	1.392	0.933	2.077
Quartile 4				0.650*	0.458	0.923	0.684	0.478	0.979	1.468	0.961	2.244
Household size												
Dual-person household							1.702*	1.123	2.580	1.397	0.872	2.239
Large household (≥3)							2.002**	1.233	3.251	1.215	0.698	2.116
Number of close relationships (family and child)							0.965	0.923	1.010	0.977	0.929	1.027
Number of close relationships (friends)							0.947	0.897	1.000	1.009	0.951	1.072
Physiological health: chronic CV condition(s)										0.861	0.644	1.153
Health expectations												
Neither agrees nor disagrees										1.740**	1.174	2.578
Disagrees										1.415	0.891	2.246
Alcohol consumption ≥3days per week										0.607**	0.443	0.833
CES-D: depressive symptomatology										1.910***	1.351	2.700
CASP19										0.884***	0.862	0.906
SWLS										0.925***	0.899	0.952

Notes: binary logistic regression, N=2701, DV – UCLA-LS; *p<.05, **p<.01, ***p<.00; source: author's analysis of ELSA wave 8

Appendix H RQ1c how does the interaction between caregiving and loneliness affect the relationships between caregiving, loneliness and physiological health?

Variables	Model 1			Model 2			Model 3			Model 4		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper									
Constant	0.760***			0.769***			1.085			4.515***		
Caregiving	0.753***	0.648	0.875	0.699***	0.590	0.829	0.750**	0.626	0.898	0.712***	0.594	0.854
Loneliness	1.442***	1.256	1.656	1.360***	1.169	1.582	1.232*	1.044	1.453	0.881	0.732	1.060
Caregiving-loneliness				1.423	0.983	2.062	1.466	0.996	2.159	1.340	0.905	1.982
Age												
60-69 years							1.631***	1.393	1.909	1.729***	1.473	2.028
≥70 years							3.365***	2.809	4.033	3.383***	2.815	4.065
Sex, female							0.674***	0.600	0.758	0.694***	0.616	0.781
Cohabitation							0.935	0.813	1.075	0.917	0.794	1.059
In paid employment							0.738***	0.636	0.856	0.800**	0.688	0.929
Wealth												
Quartile 2							0.719***	0.608	0.851	0.816*	0.687	0.969
Quartile 3							0.646***	0.546	0.764	0.748**	0.629	0.888
Quartile 4							0.484***	0.407	0.575	0.595***	0.498	0.711
CASP19										0.960***	0.951	0.970
SWLS										1.012	0.998	1.025

Notes: binary logistic regression, N=5275, DV – physiological health chronic CV conditions; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix I RQ1c how does the interaction between caregiving and loneliness affect the relationships between caregiving, loneliness and alcohol consumption?

Variables	Model 1			Model 2			Model 3			Model 4		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper									
Constant	0.564***			0.570***			0.639			0.298***		
Caregiving	0.791**	0.674	0.930	0.733**	0.613	0.876	0.765**	0.635	0.921	0.780**	0.648	0.940
Loneliness	0.629***	0.538	0.735	0.586***	0.493	0.696	0.706***	0.587	0.850	0.844	0.689	1.034
Caregiving-loneliness				1.541*	1.021	2.326	1.689*	1.104	2.585	1.790**	1.167	2.744
Age												
60-69 years							1.024	0.873	1.202	0.998	0.850	1.172
≥70 years							0.926	0.768	1.118	0.925	0.765	1.118
Sex, female							0.519***	0.459	0.586	0.509***	0.450	0.576
Cohabitation							1.076	0.925	1.252	1.058	0.906	1.236
In paid employment							1.129	0.968	1.316	1.098	0.940	1.282
Wealth												
Quartile 2							1.309**	1.081	1.585	1.230*	1.013	1.493
Quartile 3							2.030***	1.688	2.441	1.893***	1.569	2.283
Quartile 4							3.306***	2.753	3.971	2.995***	2.480	3.618
CASP19										1.015**	1.004	1.025
SWLS										1.006	0.992	1.020

Notes: binary logistic regression, N=5239, DV – behavioural health frequency of alcohol consumption; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix J RQ1c how does the interaction between caregiving and loneliness affect the relationships between caregiving, loneliness and health expectations?

Variables	Model 1						Model 2					
	Neither agree nor disagree			Disagree			Neither agree nor disagree			Disagree		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
	LCI	UCI		LCI	UCI		LCI	UCI		LCI	UCI	
Caregiving	0.979	0.810	1.184	1.053	0.850	1.304	1.051	0.856	1.291	1.121	0.894	1.406
Loneliness	0.606***	0.502	0.732	0.425***	0.333	0.542	0.648***	0.529	0.794	0.459***	0.353	0.596
Caregiving-loneliness							0.639	0.367	1.111	0.606	0.294	1.247
Variables	Model 3						Model 4					
	Neither agree nor disagree			Disagree			Neither agree nor disagree			Disagree		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
	LCI	UCI		LCI	UCI		LCI	UCI		LCI	UCI	
Caregiving	1.098	0.892	1.351	1.115	0.887	1.403	1.208	0.974	1.500	1.168	0.912	1.496
Loneliness	0.663***	0.536	0.820	0.461***	0.351	0.606	1.112	0.863	1.433	0.967	0.704	1.328
Caregiving-loneliness	0.685	0.393	1.196	0.612	0.296	1.266	0.515	0.259	1.022	0.819	0.386	1.734
Age												
60-69 years	1.155	0.952	1.401	0.926	0.739	1.160	1.063	0.868	1.302	0.904	0.712	1.148
≥70 years	1.483**	1.186	1.854	1.158	0.898	1.493	1.490**	1.174	1.891	1.261	0.958	1.659
Sex, female	0.939	0.814	1.083	1.034	0.878	1.218	0.875	0.752	1.017	0.978	0.822	1.164
Cohabitation	0.884	0.745	1.049	1.057	0.865	1.292	0.882	0.732	1.062	1.012	0.814	1.258
In paid employment	1.342**	1.115	1.615	0.971	0.782	1.206	1.188	0.978	1.444	0.872	0.693	1.098
Wealth												
Quartile 2	1.370**	1.115	1.684	1.197	0.952	1.505	1.256*	1.004	1.572	0.977	0.763	1.251
Quartile 3	1.182	0.957	1.459	0.996	0.787	1.260	0.985	0.784	1.237	0.697**	0.540	0.899
Quartile 4	1.361**	1.104	1.677	0.936	0.736	1.190	1.050	0.836	1.320	0.625***	0.482	0.812
CASP19							1.067***	1.052	1.081	1.082***	1.065	1.100
SWLS							0.998	0.980	1.016	1.005	0.984	1.027

Notes: multinomial logistic regression, N=5275, DV – health expectations; LCI – Lower confidence interval, UCI – Upper confidence interval; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix K RQ1c how does the interaction between caregiving and loneliness affect the relationships between caregiving, loneliness and mental health (CES-D)?

Variables	Model 1			Model 2			Model 3			Model 4		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.109***			0.105***			0.136***			24.193***		
Caregiving	1.717***	1.418	2.079	2.029***	1.617	2.547	1.975***	1.560	2.501	1.791***	1.389	2.310
Loneliness	5.899***	5.023	6.928	6.527***	5.455	7.810	5.425***	4.471	6.583	1.774***	1.414	2.226
Caregiving-loneliness				0.598*	0.400	0.895	0.473**	0.309	0.723	0.340***	0.209	0.551
Age												
60-69 years							0.613***	0.490	0.765	0.788	0.617	1.006
≥70 years							0.519***	0.408	0.661	0.589***	0.450	0.770
Sex, female							1.602***	1.359	1.890	2.057***	1.714	2.468
Cohabitation							0.816*	0.681	0.978	0.861	0.703	1.055
In paid employment							0.331***	0.265	0.413	0.430***	0.339	0.547
Wealth												
Quartile 2							0.577***	0.466	0.715	0.824	0.650	1.044
Quartile 3							0.470***	0.376	0.586	0.759*	0.595	0.968
Quartile 4							0.341***	0.267	0.435	0.683**	0.523	0.892
CASP19										0.890***	0.878	0.903
SWLS										0.974**	0.957	0.992

Notes: binary logistic regression, N=5245, DV – CES-D; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix L RQ1c how does the interaction between caregiving and loneliness affect the relationships between caregiving, loneliness and limiting long-term illness?

Variables	Model 1			Model 2			Model 3			Model 4		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.373***			0.368***			0.655***			33.617***		
Caregiving	1.085	0.926	1.272	1.171	0.979	1.400	1.253*	1.036	1.515	1.124	0.920	1.373
Loneliness	2.190***	1.901	2.524	2.318***	1.984	2.707	1.883***	1.587	2.235	0.767*	0.627	0.937
Caregiving-loneliness				0.717	0.491	1.047	0.603*	0.405	0.900	0.444***	0.287	0.687
Age												
60-69 years							1.221*	1.019	1.463	1.515***	1.250	1.837
≥70 years							1.541***	1.267	1.875	1.667***	1.351	2.058
Sex, female							0.953	0.839	1.082	1.056	0.923	1.209
Cohabitation							0.746***	0.645	0.863	0.717***	0.612	0.840
In paid employment							0.352***	0.296	0.417	0.415***	0.347	0.497
Wealth												
Quartile 2							0.546***	0.457	0.651	0.717**	0.594	0.867
Quartile 3							0.468***	0.392	0.559	0.664***	0.549	0.803
Quartile 4							0.349***	0.290	0.421	0.588***	0.481	0.718
CASP19										0.904***	0.894	0.915
SWLS										1.011	0.996	1.026

Notes: binary logistic regression, N=5275, DV – LLTI; *p<.05, **p<.01, ***p<.001; source: author’s analysis of ELSA wave 8

Appendix M RQ1c how does the interaction between caregiving and loneliness affect the relationships between caregiving, loneliness and QoL?

Variables	Model 1				Model 2			
	Unstandardised		Standardised	Sig.	Unstandardised		Standardised	Sig.
	B	Std. Error	Beta		B	Std. Error	Beta	
Constant	43.964	0.129		0.000***	43.862	0.131		0.000***
Caregiving	-1.791	0.293	-0.072	0.000***	-1.162	0.327	-0.047	0.000***
Loneliness	-11.699	0.276	-0.500	0.000***	-11.161	0.302	-0.477	0.000***
Caregiving-loneliness					-3.212	0.737	-0.062	0.000***
Variables	Model 3				Model 4			
	Unstandardised		Standardised	Sig.	Unstandardised		Standardised	Sig.
	B	Std. Error	Beta		B	Std. Error	Beta	
Constant	38.167	0.389		0.000***	41.263	0.384		0.000***
Caregiving	-1.269	0.312	-0.051	0.000***	-0.819	0.278	-0.033	0.003**
Loneliness	-10.105	0.299	-0.431	0.000***	-7.506	0.276	-0.320	0.000***
Caregiving-loneliness	-2.616	0.703	-0.050	0.000***	-3.077	0.625	-0.059	0.000***
Age								
60-69 years	1.594	0.277	0.082	0.000***	1.466	0.247	0.076	0.000***
≥70 years	0.040	0.161	0.004	0.805	0.042	0.146	0.004	0.775
Sex, female	1.127	0.209	0.061	0.000***	1.485	0.188	0.081	0.000***
Cohabitation	0.368	0.252	0.018	0.144	-0.125	0.224	-0.006	0.577
In paid employment	2.065	0.267	0.110	0.000***	0.425	0.242	0.023	0.079
Wealth								
Quartile 2	3.334	0.298	0.155	0.000***	2.152	0.266	0.100	0.000***
Quartile 3	4.063	0.299	0.192	0.000***	2.600	0.269	0.123	0.000***
Quartile 4	5.645	0.301	0.269	0.000***	3.674	0.276	0.175	0.000***
LLTI					-3.850	0.218	-0.193	0.000***
CES-D: depressive symptomatology					-6.218	0.272	-0.253	0.000***
Physiological health: chronic CV condition(s)					-1.058	0.195	-0.057	0.000***
Health expectations								
Neither agrees nor disagrees					2.378	0.247	0.098	0.000***
Disagrees					2.972	0.284	0.107	0.000***
Alcohol consumption ≥3days per week					0.864	0.201	0.044	0.000***

Notes: linear regression, N=5366, DV – CASP19; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix N RQ1c how does the interaction between caregiving and loneliness affect the relationships between caregiving, loneliness, and life satisfaction?

Variables	Model 1				Model 2			
	Unstandardised		Standardised	Sig.	Unstandardised		Standardised	Sig.
	B	Std. Error	Beta		B	Std. Error	Beta	
Constant	26.960	0.092		0.000***	26.917	0.094		0.000***
Caregiving	-0.463	0.210	-0.026	0.027*	-0.196	0.235	-0.011	0.405
Loneliness	-7.671	0.196	-0.468	0.000***	-7.448	0.215	-0.454	0.000***
Caregiving-loneliness					-1.298	0.519	-0.036	0.012*
Variables	Model 3				Model 4			
	Unstandardised		Standardised	Sig.	Unstandardised		Standardised	Sig.
	B	Std. Error	Beta		B	Std. Error	Beta	
Constant	21.944	0.280		0.000***	23.254	0.298		0.000***
Caregiving	-0.399	0.227	-0.023	0.079	-0.117	0.217	-0.007	0.591
Loneliness	-6.231	0.215	-0.380	0.000***	-4.913	0.213	-0.300	0.000***
Caregiving-loneliness	-1.103	0.499	-0.031	0.027*	-1.379	0.476	-0.038	0.004**
Age								
60-69 years	1.181	0.201	0.086	0.000***	1.025	0.193	0.075	0.000***
≥70 years	0.795	0.116	0.117	0.000***	0.699	0.113	0.103	0.000***
Sex, female	0.697	0.150	0.054	0.000***	0.917	0.146	0.071	0.000***
Cohabitation	2.383	0.181	0.165	0.000***	2.157	0.173	0.150	0.000***
In paid employment	0.589	0.194	0.044	0.002**	-0.184	0.188	-0.014	0.328
Wealth								
Quartile 2	1.451	0.215	0.096	0.000***	0.906	0.207	0.060	0.000***
Quartile 3	1.932	0.216	0.129	0.000***	1.252	0.209	0.084	0.000***
Quartile 4	2.660	0.218	0.179	0.000***	1.753	0.215	0.118	0.000***
LLTI					-1.347	0.169	-0.096	0.000***
CES-D: depressive symptomatology					-3.535	0.211	-0.205	0.000***
Physiological health: chronic condition(s)					-0.230	0.151	-0.018	0.129
Health expectations								
Neither agrees nor disagrees					1.106	0.192	0.064	0.000***
Disagrees					1.454	0.221	0.074	0.000***
Alcohol consumption ≥3days per week					0.459	0.156	0.033	0.003**

Notes: linear regression, N=5482, DV – SWLS; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix O Bivariate associations between caregivers' characteristics, the caregiving relationship, caregiving role, social networks, loneliness, health, wellbeing, and loneliness (wave eight) in the caregiving sample

	χ^2	UCLA-LS df	Sig.
Age	7.18	2	.028
Sex	0.00	1	.967
Cohabitation	55.48	1	.000
In paid employment	13.51	1	.000
Wealth	43.82	3	.000
Cares for a spouse	0.26	1	.608
Cares for an adult-child	8.14	1	.004
Cares for parents or in-laws	5.98	1	.014
Cares for others	0.35	1	.557
Co-residential care	9.07	1	.003
Caregiving intensity	5.35	2	.069
Number of care recipients	0.06	1	.801
Caregivers' perceived appreciation	25.74	1	.000
Caregivers' role satisfaction	20.93	1	.000
Household size	7.05	2	.030
Loneliness expectations	57.92	2	.000
Physiological health	8.77	1	.003
Health expectations	24.52	2	.000
Alcohol consumption	0.001	1	.981
CES-D	62.58	1	.000
	r		Sig.
Close relationships with family	-0.19		.000
Close relationships with friends	-0.24		.000
CASP19	-0.49		.000
SWLS	-0.42		.000

Source: author's analysis of ELSA wave 8

Appendix P RQ2a how does caregiving affect loneliness on the UCLA Loneliness Scale?

Variables	Model 1			Model 2			Model 3		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.230**			1.185			273.879***		
Age									
60-69 years	0.400**	0.213	0.750	0.363**	0.189	0.700	0.640	0.289	1.419
≥70 years	0.264***	0.134	0.520	0.257***	0.126	0.521	0.527	0.212	1.312
Sex, female	1.505	0.892	2.540	1.630	0.948	2.801	3.126**	1.515	6.451
Cohabitation	0.522	0.268	1.019	0.426*	0.215	0.844	0.575	0.239	1.383
In paid employment	0.229***	0.121	0.434	0.207***	0.107	0.403	0.438*	0.201	0.955
Wealth									
Quartile 2	0.613	0.311	1.209	0.727	0.356	1.482	0.939	0.382	2.310
Quartile 3	0.325**	0.157	0.674	0.383*	0.180	0.815	1.152	0.442	3.007
Quartile 4	0.499	0.248	1.007	0.598	0.286	1.251	1.535	0.584	4.031
Care recipients									
Adult-child	2.102	0.988	4.472	2.536*	1.165	5.516	2.550*	1.012	6.425
Parent or parent-in-law	0.786	0.334	1.852	0.636	0.257	1.572	0.665	0.225	1.969
Other relative, friend or neighbour	1.826	0.712	4.681	1.325	0.495	3.545	1.085	0.307	3.830
Lives with the care recipient	2.744*	1.243	6.057	1.934	0.833	4.491	1.358	0.490	3.762
Caregiving intensity									
High-intensity (≥20hpw)	0.890	0.457	1.730	0.772	0.387	1.541	0.928	0.400	2.154
Round-the-clock care (168hpw)	1.031	0.509	2.089	1.166	0.557	2.442	1.290	0.549	3.033
Multiple care recipients	0.721	0.317	1.643	0.911	0.398	2.084	1.413	0.482	4.143
Number of close relationships (family and child)				0.931	0.837	1.035	0.985	0.874	1.110
Number of close relationships (friends)				0.750***	0.650	0.865	0.797**	0.680	0.933
CES-D: depressive symptomatology							0.587	0.275	1.254
Physiological health: chronic CV condition(s)							1.552	0.793	3.036
Health expectations									
Neither agrees nor disagrees							0.682	0.261	1.782
Disagrees							0.517	0.166	1.610
Alcohol consumption ≥3days per week							2.369*	1.145	4.904
CASP19							0.852***	0.808	0.898
SWLS							0.954	0.896	1.016

Notes: binary logistic regression, N=498, DV – UCLA-LS; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix Q RQ2b how does caregiving affect physiological health?

Variables	Model 1			Model 2			Model 3		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper
Constant	2.369			2.646			7.718*		
Age									
60-69 years	2.670***	1.563	4.560	2.680***	1.569	4.579	3.374***	1.919	5.932
≥70 years	2.690**	1.484	4.878	2.711**	1.492	4.925	3.374***	1.785	6.379
Sex, female	0.416	0.273	0.633	0.417	0.273	0.634	0.425***	0.276	0.656
Cohabitation	0.610	0.346	1.077	0.610	0.346	1.078	0.630	0.345	1.151
In paid employment	0.434**	0.266	0.706	0.434**	0.266	0.706	0.524*	0.316	0.870
Wealth									
Quartile 2	0.905	0.497	1.647	0.911	0.500	1.659	1.109	0.597	2.059
Quartile 3	0.636	0.350	1.156	0.642	0.353	1.167	0.929	0.492	1.756
Quartile 4	0.533*	0.290	0.980	0.533*	0.289	0.984	0.775	0.404	1.486
Care recipients									
Adult-child	0.678	0.337	1.362	0.683	0.339	1.373	0.695	0.339	1.423
Parent or parent-in-law	0.517	0.241	1.113	0.513	0.238	1.107	0.526	0.242	1.142
Other relative, friend or neighbour	1.116	0.498	2.505	1.089	0.481	2.464	1.065	0.463	2.451
Lives with the care recipient	1.414	0.697	2.872	1.376	0.671	2.822	1.253	0.606	2.591
Caregiving intensity									
High-intensity (≥20hpw)	1.613	0.931	2.793	1.603	0.925	2.778	1.610	0.914	2.833
Round-the-clock care (168hpw)	0.951	0.515	1.758	0.955	0.516	1.766	0.875	0.465	1.646
Multiple care recipients	0.958	0.506	1.812	0.958	0.506	1.816	1.014	0.528	1.947
Number of close relationships (family and child)				0.985	0.918	1.058	1.010	0.939	1.086
Number of close relationships (friends)				0.995	0.917	1.079	1.034	0.950	1.125
UCLA-LS: Loneliness							1.551	0.844	2.851
CASP19							0.939**	0.905	0.974
SWLS							1.042	0.993	1.093

Notes: binary logistic regression, N=505, DV – physiological health chronic CV conditions; significance *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix R RQ2b how does caregiving affect alcohol consumption?

Variables	Model 1			Model 2			Model 3		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.892			0.588			0.029***		
Age									
60-69 years	1.414	0.833	2.403	1.391	0.818	2.367	1.332	0.770	2.305
≥70 years	0.966	0.500	1.865	0.908	0.467	1.767	1.006	0.503	2.013
Sex, female	0.586*	0.374	0.919	0.577*	0.367	0.907	0.527**	0.329	0.843
Cohabitation	0.844	0.446	1.598	0.840	0.441	1.597	0.872	0.442	1.720
In paid employment	1.024	0.612	1.712	0.994	0.592	1.669	1.090	0.633	1.879
Wealth									
Quartile 2	3.515**	1.604	7.704	3.561**	1.623	7.815	2.747*	1.245	6.060
Quartile 3	3.593**	1.626	7.943	3.571**	1.610	7.920	2.289*	1.015	5.161
Quartile 4	7.624***	3.535	16.442	7.582***	3.497	16.439	5.049***	2.294	11.115
Care recipients									
Adult-child	0.342*	0.141	0.828	0.320*	0.131	0.781	0.310*	0.124	0.774
Parent or parent-in-law	0.797	0.371	1.709	0.836	0.390	1.791	0.813	0.367	1.803
Other relative, friend or neighbour	0.466	0.208	1.047	0.475	0.210	1.077	0.446	0.193	1.034
Lives with the care recipient	0.513	0.240	1.094	0.559	0.261	1.196	0.596	0.269	1.322
Caregiving intensity									
High-intensity (≥20hpw)	0.712	0.374	1.355	0.714	0.374	1.364	0.737	0.377	1.441
Round-the-clock care (168hpw)	1.663	0.847	3.264	1.593	0.808	3.143	1.637	0.800	3.349
Multiple care recipients	1.916*	1.036	3.547	1.912*	1.031	3.546	1.592	0.839	3.020
Number of close relationships (family and child)				1.026	0.951	1.107	1.007	0.931	1.089
Number of close relationships (friends)				1.067	0.981	1.161	1.055	0.967	1.150
UCLA-LS: Loneliness							2.594**	1.270	5.296
CASP19							1.087***	1.041	1.135
SWLS							0.982	0.931	1.036

Notes: binary logistic regression, N=503, DV – behavioural health frequency of alcohol consumption; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix S RQ2b how does caregiving affect health expectations?

Variables	Model 1						Model 2						Model 3						
	Neither agree nor disagree			Disagree			Neither agree nor disagree			Disagree			Neither agree nor disagree			Disagree			
	Exp (B)	95% CI		Exp (B)	95% CI		Exp (B)	95% CI		Exp (B)	95% CI		Exp (B)	95% CI		Exp (B)	95% CI		
		LCI	UCI		LCI	UCI		LCI	UCI		LCI	UCI		LCI	UCI		LCI	UCI	
Age																			
60-69 years	1.150	0.737	1.794	1.317	0.784	2.212	0.973	0.553	1.710	1.758	0.825	3.744	0.976	0.521	1.828	1.750	0.781	3.921	
≥70 years	1.038	0.595	1.811	1.382	0.760	2.513	0.987	0.497	1.959	2.246	0.976	5.168	1.210	0.556	2.631	1.908	0.758	4.804	
Sex, female	1.152	0.796	1.667	1.090	0.720	1.649	1.113	0.687	1.803	0.940	0.530	1.668	1.108	0.654	1.877	0.994	0.534	1.853	
Cohabitation	1.289	0.745	2.230	2.115*	1.140	3.924	1.097	0.541	2.223	1.542	0.683	3.481	1.361	0.569	3.254	1.236	0.511	2.992	
In paid employment	1.956**	1.257	3.045	0.901	0.535	1.519	1.907*	1.089	3.338	1.470	0.737	2.931	2.023*	1.082	3.783	1.249	0.595	2.620	
Wealth																			
Quartile 2	1.031	0.600	1.774	0.768	0.426	1.385	1.330	0.668	2.651	1.118	0.501	2.498	1.588	0.712	3.543	0.610	0.254	1.469	
Quartile 3	1.528	0.887	2.632	1.086	0.610	1.934	2.025*	1.003	4.089	2.025	0.937	4.375	2.138	0.929	4.921	1.194	0.528	2.703	
Quartile 4	1.144	0.663	1.975	0.697	0.383	1.266	1.452	0.715	2.949	0.813	0.334	1.978	1.595	0.706	3.606	0.452	0.176	1.161	
Care recipients																			
Adult-child	0.417*	0.203	0.856	1.304	0.677	2.512	0.393*	0.161	0.958	1.274	0.530	3.065	0.102**	0.021	0.492	1.873	0.726	4.835	
Parent or parent-in-law	0.436	0.223	0.854	0.841	0.397	1.781	0.608	0.256	1.447	0.480	0.156	1.478	0.513	0.199	1.320	0.416	0.128	1.352	
Other relative, friend or neighbour	0.742	0.374	1.471	1.960	0.926	4.152	0.686	0.265	1.775	1.829	0.621	5.385	0.560	0.200	1.568	2.000	0.632	6.334	
Lives with the care recipient	1.037	0.572	1.878	1.228	0.639	2.361	1.319	0.570	3.054	1.155	0.428	3.117	1.218	0.472	3.145	1.368	0.472	3.962	
Caregiving intensity																			
High-intensity (≥20h/w)	0.810	0.474	1.385	1.803*	1.044	3.113	0.960	0.499	1.845	2.016	0.946	4.299	1.295	0.650	2.578	2.119	0.953	4.713	
Round-the-clock care (168h/w)	1.448	0.862	2.433	2.251**	1.259	4.026	1.284	0.655	2.517	2.258*	1.001	5.093	1.144	0.527	2.485	2.600*	1.072	6.309	
Multiple care recipients	1.676	0.958	2.933	1.396	0.741	2.630	0.771	0.350	1.701	1.672	0.739	3.783	0.673	0.287	1.579	1.469	0.602	3.583	
Number of close relationships (family and child)							1.002	0.927	1.084	0.945	0.847	1.055	0.972	0.892	1.060	0.924	0.819	1.041	
Number of close relationships (friends)							1.040	0.949	1.139	1.026	0.920	1.143	1.032	0.938	1.136	0.991	0.881	1.116	
UCLA-LS: Loneliness													0.586	0.242	1.420	0.391	0.132	1.165	
CASP19													1.048*	1.002	1.097	1.041	0.986	1.098	
SWLS													0.994	0.936	1.054	1.066	0.989	1.149	

Notes: multinomial logistic regression, N=538, DV – health expectations; LCI – Lower confidence interval, UCI – Upper confidence interval; *p<.05, **p<.01, ***p<.001; source: author’s analysis ELSA wave 8

Appendix T RQ2c how does caregiving affect QoL?

Variables	Model 1				Model 2				Model 3			
	Unstandardised coefficients		Standardised coefficients	Sig.	Unstandardised coefficients		Standardised coefficients	Sig.	Unstandardised coefficients		Standardised coefficients	Sig.
	B	Std. Error	Beta		B	Std. Error	Beta		B	Std. Error	Beta	
Constant	30.738	1.903		0.000***	26.377	2.013		0.000***	36.009	1.761		0.000***
Age												
60-69 years	2.962	0.952	0.138	0.002**	2.768	0.927	0.129	0.003**	1.495	0.765	0.070	0.051
≥70 years	1.623	0.565	0.149	0.004**	1.470	0.551	0.135	0.008**	0.463	0.458	0.043	0.313
Sex, female	0.885	0.809	0.043	0.274	0.622	0.789	0.030	0.431	1.428	0.649	0.069	0.028*
Cohabitation	2.237	1.115	0.087	0.045*	2.259	1.084	0.088	0.038*	0.280	0.879	0.011	0.750
In paid employment	3.989	0.931	0.194	0.000***	3.929	0.906	0.191	0.000***	0.879	0.753	0.043	0.244
Wealth												
Quartile 2	5.954	1.148	0.255	0.000***	5.710	1.118	0.245	0.000***	3.602	0.909	0.155	0.000***
Quartile 3	8.320	1.178	0.358	0.000***	7.936	1.148	0.341	0.000***	4.353	0.950	0.187	0.000***
Quartile 4	8.143	1.178	0.357	0.000***	7.859	1.151	0.345	0.000***	4.534	0.964	0.199	0.000***
Care recipients												
Adult-child	-0.129	1.338	-0.004	0.923	-0.456	1.305	-0.015	0.727	1.706	1.073	0.055	0.112
Parent or parent-in-law	-0.076	1.378	-0.003	0.956	0.552	1.346	0.025	0.682	-0.006	1.086	0.000	0.996
Other relative, friend or neighbour	-1.474	1.493	-0.062	0.324	-0.567	1.470	-0.024	0.700	-0.270	1.196	-0.011	0.821
Lives with the care recipient	-3.064	1.316	-0.153	0.020*	-1.803	1.300	-0.090	0.166	-0.509	1.049	-0.025	0.628
Caregiving intensity												
High-intensity (≥20hpw)	-0.852	1.074	-0.035	0.428	-0.659	1.046	-0.027	0.529	-0.547	0.845	-0.023	0.518
Round-the-clock care (168hpw)	-0.976	1.210	-0.036	0.420	-1.219	1.182	-0.045	0.303	-0.922	0.955	-0.034	0.334
Multiple care recipients	2.879	1.183	0.104	0.015*	2.868	1.153	0.104	0.013*	2.940	0.937	0.106	0.002**
Number of close relationships (family and child)					0.472	0.132	0.143	0.000***	0.316	0.107	0.096	0.003**
Number of close relationships (friends)					0.443	0.157	0.113	0.005**	0.067	0.128	0.017	0.603
UCLA-LS Loneliness									-10.014	0.829	-0.402	0.000***
CES-D: depressive symptomatology									-6.141	0.840	-0.235	0.000***
Physiological health: chronic condition(s)									-2.086	0.680	-0.102	0.002**
Health expectations												
Neither agrees nor disagrees									1.631	0.809	0.062	0.044*
Disagrees									1.440	0.981	0.046	0.143
Alcohol consumption ≥3days per week									2.629	0.716	0.116	0.000***

Notes: linear regression, N=540, DV – CASP19; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix U RQ2c how does caregiving affect life satisfaction?

Variables	Model 1				Model 2				Model 3			
	Unstandardised coefficients		Standardised coefficients	Sig.	Unstandardised coefficients		Standardised coefficients	Sig.	Unstandardised coefficients		Standardised coefficients	Sig.
	B	Std. Error	Beta		B	Std. Error	Beta		B	Std. Error	Beta	
Constant	17.659	1.301		0.000***	16.275	1.411		0.000***	21.451	1.383		0.000***
Age												
60-69 years	1.257	0.655	0.086	0.055	1.190	0.653	0.081	0.069	0.469	0.600	0.032	0.435
≥70 years	1.248	0.386	0.169	0.001**	1.216	0.386	0.165	0.002**	0.504	0.359	0.068	0.161
Sex, female	0.457	0.556	0.032	0.412	0.388	0.554	0.027	0.484	0.837	0.508	0.059	0.100
Cohabitation	4.174	0.762	0.243	0.000***	4.181	0.759	0.243	0.000***	3.073	0.685	0.179	0.000***
In paid employment	1.794	0.639	0.128	0.005**	1.797	0.637	0.128	0.005**	0.158	0.587	0.011	0.789
Wealth												
Quartile 2	2.983	0.786	0.189	0.000***	2.932	0.783	0.186	0.000***	1.738	0.709	0.110	0.015*
Quartile 3	3.725	0.809	0.235	0.000***	3.648	0.807	0.230	0.000***	1.661	0.743	0.105	0.026*
Quartile 4	3.949	0.817	0.252	0.000***	3.935	0.818	0.252	0.000***	2.273	0.763	0.145	0.003**
Care recipients												
Adult-child	-1.395	0.899	-0.068	0.121	-1.488	0.897	-0.072	0.098	-0.326	0.819	-0.016	0.691
Parent or parent-in-law	0.893	0.949	0.060	0.347	1.073	0.949	0.072	0.259	0.817	0.853	0.055	0.338
Other relative, friend or neighbour	-1.183	1.028	-0.074	0.250	-0.816	1.036	-0.051	0.431	-0.782	0.938	-0.049	0.404
Lives with the care recipient	-1.880	0.908	-0.138	0.039*	-1.502	0.919	-0.110	0.103	-0.920	0.826	-0.068	0.266
Caregiving intensity												
High-intensity (≥20hpw)	0.462	0.736	0.028	0.531	0.550	0.734	0.033	0.454	0.470	0.661	0.029	0.477
Round-the-clock care (168hpw)	0.516	0.833	0.028	0.536	0.470	0.832	0.026	0.572	0.613	0.748	0.034	0.413
Multiple care recipients	1.556	0.823	0.081	0.059	1.568	0.821	0.082	0.057	1.764	0.744	0.092	0.018*
Number of close relationships (family and child)					0.199	0.092	0.088	0.031*	0.112	0.083	0.050	0.175
Number of close relationships (friends)					0.052	0.110	0.019	0.637	-0.141	0.100	-0.053	0.158
UCLA-LS Loneliness									-5.507	0.650	-0.328	0.000***
CES-D: depressive symptomatology									-3.332	0.658	-0.189	0.000***
Physiological health: chronic CV condition(s)									-0.602	0.531	-0.043	0.258
Health expectations												
Neither agrees nor disagrees									1.383	0.616	0.079	0.025*
Disagrees									1.552	0.762	0.073	0.042*
Alcohol consumption ≥3days per week									0.777	0.561	0.050	0.167

Notes: linear regression, N=553, DV – SWLS; *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA wave 8

Appendix V Crosstabulation of UCLA loneliness responses at waves two and eight

UCLA-LS Wave 2	UCLA-LS Wave 8	
	Not Lonely N (%)	Lonely N (%)
Not Lonely	2988 (88.4)	275 (11.6)
Lonely	234 (49.8)	236 (50.2)

Notes: % of UCLA at wave two, source: author's analysis of ELSA waves 2 and 8

Appendix W Bivariate associations between baseline (wave two) variables and wave eight loneliness in the longitudinally-weighted sample

Baseline (wave two) variables	UCLA-LS (wave 8)		
	χ^2	df	Sig.
Caregiving	0.39	1	.533
Age	12.24	2	.003
Sex	13.62	1	.000
Cohabitation	58.22	1	.000
In paid employment	8.77	1	.007
Wealth	36.52	3	.000
Household size	43.85	2	.000
UCLA-LS	394.58	1	.000
Loneliness expectations	75.41	2	.000
	<i>r</i>		Sig.
CASP19	-0.27	.000	
SWLS	-0.25	.000	

Source: author's analysis of ELSA waves 2 and 8

Appendix X Bivariate associations between the variables computed for the follow-up analyses and loneliness occurring after the start of care provision, in the longitudinally-weighted caregiving sample

	UCLA-LS (loneliness occurring after the start of care provision)		
	χ^2	df	Sig.
Duration of care	7.97	2	.019
Ever provided care to an adult-child	11.94	1	.001
Ever provided care to parents or in-laws	0.12	1	.726
Ever provided care to others	0.94	1	.332
Ever provided co-residential care	2.22	1	.137
Ever provided high-intensity care	6.95	1	.008
Ever provided round-the-clock care	10.04	1	.002
Ever provided care to multiple recipients	0.48	1	.490
Changes to loneliness expectations	14.01	5	.016
Changes to depressive symptomatology	125.43	3	.000

Source: author's analysis of ELSA waves 2-8

Appendix Y RQ3a(i) is caregiving associated with loneliness 12-years later, excluding those lonely at baseline

Variables	Model 1			Model 2			Model 3		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.122***			0.112***			1.472		
Caregiving (wave two)	1.231	0.840	1.803	1.179	0.796	1.746	1.137	0.763	1.696
Loneliness expectations									
Neither agree nor disagree				0.854	0.604	1.207	0.982	0.687	1.405
Disagree				0.608**	0.437	0.846	0.809	0.571	1.148
Age									
60-69 years				1.435*	1.004	2.050	1.735**	1.206	2.495
≥70 years				1.654*	1.045	2.617	2.248**	1.404	3.600
Sex, female				1.354*	1.013	1.809	1.461*	1.081	1.973
Cohabitation				0.975	0.471	2.018	1.049	0.498	2.210
In paid employment				1.047	0.745	1.472	1.209	0.855	1.708
Wealth									
Quartile 2				1.044	0.704	1.548	1.295	0.859	1.952
Quartile 3				0.988	0.666	1.466	1.226	0.813	1.849
Quartile 4				0.505**	0.323	0.790	0.686	0.427	1.103
Household size									
Dual-person household				0.876	0.403	1.903	0.941	0.428	2.070
Large household (≥3)				0.868	0.377	1.998	0.917	0.392	2.143
Physiological health: chronic CV condition(s)							0.953	0.698	1.294
Health expectations									
Neither agrees nor disagrees							0.649	0.419	1.004
Disagrees							0.807	0.514	1.267
Alcohol consumption ≥3days per week							1.182	0.875	1.596
CES-D: depressive symptomatology							1.196	0.789	1.813
CASP19							0.961**	0.939	0.985
SWLS							0.956**	0.927	0.987

Notes: binary logistic regression, N=2458, DV – UCLA-LS (wave 8); *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA waves 2 and 8

Appendix Z RQ3a(ii) is caregiving associated with loneliness 12-years later, controlling for loneliness at baseline

Variables	Model 1			Model 2			Model 3		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.208			0.126***			0.882		
Caregiving (wave two)	1.105	0.820	1.488	1.101	0.794	1.526	1.064	0.762	1.484
UCLA-LS Loneliness				6.136***	4.684	8.039	4.130***	3.080	5.538
Loneliness expectations									
Neither agree nor disagree				0.783	0.590	1.041	0.864	0.646	1.156
Disagree				0.577***	0.431	0.772	0.685*	0.505	0.928
Age									
60-69 years				1.242	0.931	1.657	1.445*	1.075	1.941
≥70 years				1.594**	1.103	2.302	1.976***	1.352	2.887
Sex, female				1.180	0.933	1.493	1.206	0.944	1.540
Cohabitation				0.981	0.589	1.634	1.029	0.608	1.740
In paid employment				1.002	0.759	1.323	1.121	0.845	1.488
Wealth									
Quartile 2				1.139	0.831	1.560	1.312	0.948	1.814
Quartile 3				1.119	0.808	1.550	1.315	0.939	1.841
Quartile 4				0.679**	0.474	0.973	0.893	0.611	1.304
Household size									
Dual-person household				0.905	0.533	1.537	0.888	0.517	1.527
Large household (≥3)				1.025	0.576	1.823	0.970	0.538	1.749
Physiological health: chronic condition(s)							0.978	0.764	1.252
Health expectations									
Neither agrees nor disagrees							0.690*	0.482	0.989
Disagrees							0.948	0.653	1.376
Alcohol consumption ≥3days per week							0.935	0.725	1.205
CES-D: depressive symptomatology							1.220	0.898	1.656
CASP19							0.970**	0.951	0.989
SWLS							0.973*	0.949	0.997

Notes: binary logistic regression, N=2074, DV – UCLA-LS (wave 8); *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA waves 2 and 8

Appendix AA Crosstabulation of responses to loneliness expectations and UCLA-LS loneliness at wave two

UCLA-LS Wave 2	Loneliness expectations Wave 2		
	Agree N (%)	Neither agree, nor disagree N (%)	Disagree N (%)
Not lonely	768 (31.9)	654 (27.1)	988 (41.0)
Lonely	319 (67.4)	104 (22.0)	50 (10.6)

Notes: % of UCLA-LS , source: author's analysis of the longitudinal sample at baselines (ELSA wave 2)

Appendix BB RQ3b is caregiving at any wave associated with later loneliness?

	Model 1			Model 2			Model 3		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.186***			0.259**			9.428**		
Caregiving duration (reference: short-term)									
Long-term	2.088**	1.376	3.167	1.954**	1.272	3.003	1.823**	1.167	2.847
Intermittent	1.221	0.678	2.199	1.093	0.595	2.009	1.007	0.536	1.893
Loneliness expectations									
Neither agree nor disagree				0.658	0.401	1.082	0.722	0.430	1.213
Disagree				0.489**	0.309	0.772	0.604*	0.373	0.979
Age									
60-69 years				1.163	0.720	1.878	1.389	0.844	2.287
≥70 years				1.076	0.564	2.054	1.230	0.624	2.422
Sex, female				1.425	0.939	2.162	1.505	0.973	2.328
Cohabitation				0.660	0.228	1.904	0.557	0.180	1.721
In paid employment				0.754	0.474	1.199	0.826	0.513	1.331
Wealth									
Quartile 2				0.667	0.386	1.152	0.830	0.465	1.480
Quartile 3				0.703	0.415	1.192	0.896	0.513	1.565
Quartile 4				0.444**	0.252	0.784	0.634	0.345	1.163
Household size									
Dual-person household				0.925	0.286	2.992	1.060	0.306	3.668
Large household (≥3)				1.256	0.364	4.331	1.439	0.389	5.324
Physiological health: chronic CV condition(s)							0.639	0.402	1.015
Health expectations									
Neither agrees nor disagrees							0.864	0.492	1.517
Disagrees							0.925	0.507	1.686
Alcohol consumption ≥3days per week							0.923	0.594	1.434
CES-D: depressive symptomatology							1.433	0.770	2.669
CASP19							0.931***	0.901	0.962
SWLS							0.988	0.944	1.035

Notes: binary logistic regression, N=846, DV – UCLA-LS (loneliness occurring after the start of care provision); *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA waves 2-8

Appendix CC RQ3c how are the caregiving relationship, and role, associated with loneliness for short-term *versus* long-term, or intermittent caregivers?

	Model 1			Model 2			Model 3		
	Exp(B)	95% CI		Exp(B)	95% CI		Exp(B)	95% CI	
		Lower	Upper		Lower	Upper		Lower	Upper
Constant	0.253***			0.165***			0.251***		
Caregiving duration (reference: short-term)									
Long-term	1.867*	1.160	3.004	1.317	0.746	2.325	1.194	0.654	2.181
Intermittent	1.162	0.576	2.345	1.017	0.488	2.118	0.811	0.370	1.775
Ever provided care to... (reference: spouse)									
Adult-child				0.980	0.383	2.507	0.919	0.352	2.394
Parents /in-law				1.190	0.688	2.058	1.406	0.788	2.508
Others				1.144	0.673	1.945	1.203	0.693	2.087
Ever provided co-residential care				1.069	0.608	1.881	1.219	0.672	2.210
Ever provided... (reference: low-intensity care)									
High-intensity care				1.707*	1.033	2.821	1.880*	1.108	3.192
Round-the-clock care				2.109*	1.177	3.778	1.943*	1.050	3.593
Ever provided care to multiple recipients				0.786	0.462	1.336	0.745	0.425	1.306
Changes to loneliness expectations (reference: stable – always agree)									
Stable – always neither							0.193	0.028	1.333
Stable – always disagree							0.233	0.038	1.443
Negative – disagree to agree/neither OR neither to agree							0.250	0.051	1.230
Positive – agree to neither/disagree OR neither to disagree							0.144*	0.028	0.756
Fluctuating							0.198*	0.041	0.960
Changes to CES-D (reference: stable – never reports depressive symptoms)									
Reduction in depressive symptoms							1.622	0.673	3.908
Increase in or persistent depressive symptoms							4.422***	2.393	8.174
Fluctuating							2.734*	1.251	5.975

Notes: binary logistic regression, N=523, DV – UCLA-LS (loneliness occurring after the start of care provision); *p<.05, **p<.01, ***p<.001; source: author's analysis of ELSA waves 2-8

Glossary of Terms

Capacity to care	Caregivers' physical ability to care (e.g. due to adequate health, or availability).
Caregiver	An individual who provides unpaid assistance to someone (typically a family member, friend or neighbour) with disabilities, or chronic physical or mental health conditions.
Caregiver characteristics	The sociodemographic and socioeconomic characteristics of caregivers.
Caregiving relationship	The inter-personal relationship between caregiver and care recipient, and whether the care provided is co-residential or non-residential.
Caregiving role	The intensity of the care provided and the number of care recipients a caregiver provides care to.
Compound caregiver	Caregivers who undertake an additional caregiving role (e.g. to a spouse, or sibling) alongside providing care to a dependent child with developmental or intellectual disabilities.
Co-residential care	Care provided to a care recipient living within the same household.
Filial care	Care provided by an adult-child to an older parent.
Healthy caregiver effect	Caregivers demonstrating better health than non-caregivers because, principally, their health permits them to provide care, not exhibiting good health due to their caregiving role.
Healthy worker effect	Employed individuals demonstrating better health than non-employed because, principally, their health permits them to work, not exhibiting good health due to their employment.
High-intensity care	Care provided for 20 or more hours per week.
Invisible care	Observations or unseen tasks related to caregiving (e.g. monitoring symptoms).
Low-intensity care	Care provided for less than 20-hours per week.
Non-residential care	Care provided to a care recipient living in a different household.
Parental care	Care provided by parents to their children, typically adult-children with developmental or intellectual disability.
Round-the-clock care	Care provided 168-hours per week, i.e. 24-hours per day, 7 days per week.
Sandwich caregiver	Caregivers to both a surviving parents and a young child or grandchild.
Spousal care	Care provided to a spouse.
Visible care	Caregiving behaviours or actions which are more easily perceived by others (e.g. provision of personal care tasks).

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