

**LONELINESS IN LATER LIFE:
OLDER PEOPLE'S EXPERIENCES AND RESPONSES TO LONELINESS**

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Thesis submitted for the degree of Doctor of Philosophy

DECLARATION

I, Kalpa Kharicha, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Kalpa Vrajlal Kharicha

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On a personal note, I would like to thank my family and friends for their care and encouragement throughout the journey of this PhD; they will be proud and relieved. And most importantly, thanks to Conor, for his incredible support and to Freya and Calum, for their curiosity and sense of fun.

ABSTRACT

Background

Loneliness is a subjective experience; an emotional and unpleasant response to a lack of satisfactory companionship. In Western society, some consider this a major public health problem, however the evidence for effective interventions remains inconclusive. Loneliness can be socially stigmatised, and many people do not seek help. This research explores how community dwelling older people who self-identify as lonely describe their experiences of loneliness, their views on involving others, including community resources, and how they respond to loneliness themselves.

Methods

1. Systematic review and narrative synthesis of qualitative studies reporting strategies employed by older people to manage their loneliness, with model development.
2. Qualitative study comprising 28 in-depth interviews with older people in England who identified as lonely using two different loneliness measures. Data were collected between 2013-2014 and analysed thematically.

Findings

The review identified 11 studies. Strategies can be described by a model with two overarching and overlapping dimensions, one related to the context of coping (alone or with others), the other related to strategy type (prevention/action or acceptance/endurance of loneliness).

The circumstances and context of loneliness experiences were wide-ranging and loneliness was often inseparable from other distressing events.

Although generally knowledgeable about local resources, most did not consider these desirable or helpful. For many, loneliness was a private matter to be managed without external support. Multiple strategies, developed over time and shaped by individual coping styles and contexts, were used. They included managing thoughts, feelings, and behaviours

privately, within an 'inside world', or actively engaging with other people or places, in an 'outside world'.

Conclusion

Older people articulated strategies they used to deal with distressing feelings and can be regarded as active agents in managing their loneliness.

Understanding individual definitions of loneliness, coping styles and contexts are key to identifying acceptable and meaningful support.

IMPACT STATEMENT

The appointment of the first 'Minister for Loneliness' in January 2018 and the launch of the loneliness strategies for England and Scotland demonstrated a commitment to alleviating loneliness in the UK, despite limited research evidence for effective strategies to achieve this aim.

Loneliness is a subjective experience so engaging with older people who are lonely is important in understanding how they respond to loneliness and what support they consider desirable or appropriate. This thesis reports the experiences and responses to loneliness of older people who identified themselves as lonely.

I have disseminated my findings to a range of audiences including the academic community at both national and international primary care, geriatrics and gerontology conferences. I have also presented my findings to the Research and Policy Hub of the 'Campaign to End Loneliness', a national charity and campaigning organisation in the UK, attended by a range of third sector organisations, practitioners and researchers. I have been a member of the Hub during the course of my PhD which has been a space to share knowledge and insights with experts on loneliness. A further seminar to present my findings to older people is planned at the Health and Social Care Workforce Research Unit at King's College London.

To date, I have published two papers from this PhD. Firstly, the findings from my systematic review on strategies employed by older people to manage loneliness, from which a provisional model on self-management of loneliness was developed. A second paper reports older people's views on community services and activities for loneliness, including the role of primary care. Most research on loneliness interventions has reported the views of those already engaged with services; my paper adds the views of lonely older people who were not recruited via services or organisations providing support. It also reports older people's views on seeking support for loneliness from primary care which highlight potential barriers to the success of social prescribing schemes in general practice. A third paper on how older people manage

loneliness themselves in currently under review by a journal and I am responding to reviewers' comments.

I have drawn on my experience of the challenges of researching later life loneliness in my teaching on the post graduate Qualitative Research Methods in Health course at UCL.

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STATEMENT OF INTELLECTUAL PROPERTY/CONTRIBUTION

For this PhD, I recruited my sample from a wider primary care based study on health and wellbeing in later life. This statement is to help clarify my role and contribution across both the research study and my PhD.

The wider study was the Well-being Interventions for Social and Health needs (WISH) study, funded by the Medical Research Council under its Life Long Health and Well-being Phase 3 programme (LLHW G1001822/1) which ran from 2012-2013. As project manager and senior research fellow on this study, I led on gaining NHS ethics and research governance approval, recruiting practices and participants, data collection and analysis, and contributed to dissemination. I conceived the idea of undertaking a PhD on loneliness in older people which could build on the WISH study.

When I registered for the PhD, I gained agreement from the study team to integrate the sampling and recruitment for my proposed PhD within the WISH study. To help support my additional work on loneliness, we successfully applied for a grant from the National School for Primary Care Research (NSPCR) (April 2012-May 2015); I was a Co-Investigator on this grant. For the grant application, I reviewed the literature to identify an appropriate loneliness measure in terms of validity for community dwelling older people and feasibility for use within the postal questionnaires being used as part of the WISH study. The original WISH data collection instruments contained a single item question on loneliness, and for my PhD the additional loneliness scale was added. A substantial amendment to the ethics approval for the WISH study allowed me to invite WISH participants who reported being lonely to take part in an interview on loneliness and social support for my PhD. I undertook scoping reviews of the literature on loneliness and identified that self-management of loneliness was an under-explored field at that time. I carried out the recruitment, conducted all interviews and led the analysis and dissemination. The WISH study team contributed to the iterative development of my topic guide and data analysis;

data on responses to loneliness were analysed primarily in discussion with my supervisors.

CHAPTER 1: INTRODUCTION

This chapter introduces the context to this thesis' exploration of the impact of loneliness in later life. The prevalence and patterns of loneliness are outlined along with demographic and risk factors of loneliness. Outcomes of loneliness, in particular the associations between loneliness in later life (65 years and over) and morbidity, mortality and higher service use which have helped to raise the profile of loneliness, are then presented. The use of this evidence in responses to loneliness is then considered. Interventions for loneliness are presented along with evidence of their effectiveness. Individual coping strategies are then outlined and finally reasons why we need to better understand how older people manage their loneliness themselves are introduced.

1.1 Overview

Loneliness is considered a major public health problem in Western societies. Although loneliness is commonly associated with ageing it can be experienced at all stages of life and across cultures and societies (de Jong Gierveld and Havens, 2004). Loneliness is a subjective experience; an emotional and unpleasant response to a lack of satisfactory companionship. It has been described as a distressing occurrence, one that can be triggered by a lack of desired relationship (Weiss, 1973). Loneliness in later life is linked closely to other experiences associated with ageing, such as loss of family and friends and declining health, mobility and income, as well as socio-demographic factors and trends in wider society, such as people living longer and living alone for longer, more relationships ending in divorce or separation, a greater dispersion of families and changing communities due to greater mobility across countries (Age UK Oxfordshire, 2011; Bernard, 2013; Nicolaisen and Thorsen, 2014). Although loneliness is experienced by many people over different stages of the life course, the majority of older people do not report being lonely and it has been suggested that loneliness in later life has been 'pathologised' (Victor *et al.*, 2009). Furthermore, there is a stigma attached to admitting to loneliness due to a lack of satisfactory relationships; this is exacerbated in a society that values independence and

self-reliance and where ageism is the most commonly experienced form of prejudice in the United Kingdom (UK) and mainland Europe (Royal Society for Public Health, 2018). For many older people, loneliness may be a private matter which, on a day to day level, they manage themselves.

1.2 How common is loneliness in later life?

The majority of community dwelling older people do not report being lonely. In a recent study by the Office for National Statistics (ONS) on loneliness in England about 60% of those aged 65 and over were hardly ever/never lonely and about 40% reported loneliness occasionally/sometimes/often or always (Office for National Statistics, 2018). These proportions are similar to earlier reports from across the UK as well as Scandinavia, Australia, United States of America (US) and China. Based on survey data from Wales (Wenger and Burholt, 2004), Great Britain (Victor *et al.*, 2005), Finland (Savikko *et al.*, 2005), Australia (Steed *et al.*, 2007) and China (Yang and Victor, 2008), about a third of older people report experiencing loneliness. Some variation in the prevalence rates from the US have emerged; studies report a prevalence of 32% in those aged 60-69 years and 25% in the 70+ age group (Wilson and Moulton, 2010) or up to 43% in a sample aged 60 and over (mean age of 71 years) (Perissinotto *et al.*, 2012); both studies assessed loneliness using the UCLA loneliness scale (Russell, 1982).

Within those experiencing loneliness, the proportion of older people reporting severe loneliness is comparable across Western European and Scandinavian countries; between 3% and 13% of the UK older population say they feel lonely all or most of the time (Victor *et al.*, 2005; O'Lunaigh and Lawlor, 2008; Victor and Bowling, 2012; Office for National Statistics, 2018). In Australia 7% report that they are always or often lonely (Steed *et al.*, 2007); as do 12% of the Norwegian community dwelling older population (Tomstad *et al.*, 2017). A cross national study suggested that loneliness is higher in collectivist communities (which are family, community or society oriented) where sensitivity to social exclusion is higher than in more individualistic communities (Johnson and Mullins, 1987). However, North America which has a more individualistic society overall, reports higher

levels of loneliness than Europe. Within Europe, the levels of loneliness are lowest in the North and increase towards the South (van Tilburg *et al.*, 2004). Similarly, in their analysis of over 12,000 older adults across 14 countries in Europe, (Fokkema *et al.*, 2012) found that older adults in southern and central European countries were lonelier than their peers in northern and western European countries. However, caution may be required in the interpretation of the prevalence and experience of loneliness in different countries given that the measurement of loneliness is culturally and contextually bound (Peplau and Perlman, 1982); van Tilburg *et al.* (2004) concluded more research and theory are needed to understand the meaning of loneliness across different cultures.

The reported prevalence of loneliness in older people appears to have remained fairly stable over time. Comparative analysis of English data from three historical surveys between 1945, 1960 and 1999, with comparable data on loneliness, found that the overall prevalence of reports of loneliness ranged from five to nine per cent and showed no increase over time. This challenges the widespread presumption that loneliness has increased over time, due to the changes in family structure and living arrangements (Victor *et al.*, 2002).

Within those who are lonely, there does appear to be a change in the extent that those who are lonely some of the time are compared to those who are never lonely. More recent studies report between 31 and 44% of UK older people being sometimes lonely compared to earlier studies reporting between 13 and 25%, with a corresponding decrease in numbers reporting that they are never lonely over the five decades over which the research had taken place (Victor and Bowling, 2012). This includes findings from the ONS reporting about 36% were lonely some of the time/occasionally (Office for National Statistics, 2018). The changes in proportion of those who are never and sometimes lonely may be due to actual changes in the proportion of the population who are lonely or may be explained by a reporting bias due to a possible reduction in the stigma of loneliness over this time period. It may be

easier to report being lonely sometimes rather than admit to being lonely all the time (Tiikkainen and Heikkinen, 2005).

Within the older population, there is a mixed picture of the relationship between loneliness and increasing age. Some studies have reported an increase in prevalence and severity of loneliness with age (Tijhuis *et al.*, 1999; Dykstra *et al.*, 2005; Victor *et al.*, 2005; Beaumont, 2013); whilst others have reported a decrease in prevalence with age (Wilson and Moulton, 2010), with those aged 80 and over being twice as likely to report feeling lonely (a rating of 6 or more out of 10) than those aged 65 to 79 in the ONS Opinions and Lifestyle Survey (Office for National Statistics, 2015). Victor *et al.* (2005) reported that those aged 85 and over included the highest proportion of older people who were never lonely (58%) and suggested that advanced age may be a protective factor. They propose this may also be a survivor cohort effect, that is, those that are not lonely may have outlived the lonely.

1.3 Demographic factors and loneliness

There is a wealth of quantitative research on loneliness in later life from cross-sectional surveys and longitudinal cohort studies. This research typically identifies those who are lonely using scales or by a single-item question; some of the widely used measures are discussed in Chapter 4 (Section 4.2). These approaches assume a more positivist stance, that is, the experience of loneliness is understood to mean the same to different individuals, regardless of their individual differences, contexts, expectations or life experiences. Positivism is discussed in further detail along with other philosophical positions in Chapter 4 (Section 4.4). These studies commonly identify characteristics of 'at-risk' groups or protective factors against loneliness. Most research has focussed on older people living in the community in their own homes or supported housing (often termed extra care housing in the UK), rather than those in care homes or other locations.

There is a mixed picture of the experience of loneliness in those aged 65 and over as described by the prevalence reported among different older age groups, outlined above. Several large cohort studies have explored whether loneliness is related to ageing *per se* or factors associated with ageing. As might be expected, findings imply that an increase in prevalence of loneliness in older age is associated with the rising prevalence of the risk factors for loneliness rather than with an intrinsic ageing effect. A key risk factor that is consistently associated with loneliness is widowhood. Both cross-sectional analysis and longitudinal analysis report widowhood as the biggest factor affecting the incidence of loneliness over five years (Tijhuis *et al.*, 1999; Jylhä, 2004; Dykstra *et al.*, 2005; Golden *et al.*, 2009; Victor *et al.*, 2009; Nicolaisen and Thorsen, 2014).

The influence of early life events on the incidence of loneliness in older people has also been explored using a life course approach (Nicolaisen and Thorsen, 2014) in a Norwegian cohort of 1378 people aged 60-80 years. Adverse childhood events such as economic problems in the family, conflictual relationships between parents and being bullied over a lengthy period were associated with loneliness at baseline. There was a gender difference; men were more likely to be lonely having experienced conflicts in their parents' relationships and having been bullied over a lengthy period. They suggest this may result in developing a less resilient and more insecure self. For women, loneliness was influenced by economic problems in the childhood household. Those without a partner were also more likely to report being lonely. The authors concluded that early and later life events can influence loneliness, that many will experience the 'compound effects of several life stage transitions' (p10) and that there are both short and long term consequences which may influence loneliness.

Living alone is commonly associated with loneliness and a relationship between the two has been long reported (Bond and Carstairs, 1982; Tomstad *et al.*, 2017). However, as discussed in the next chapter about the variety of terminology in use, it is important to remember that those living alone may have a satisfactory network of relationships which means they do

not feel lonely. For example, Victor *et al.* (2005) found that greater loneliness was independently associated with an increased time spent alone, but not with living alone *per se*. Living alone is a social state whereas loneliness is a subjective experience.

Ejlskov *et al.* (2017) identified the combinations of characteristics and experiences associated with high levels of loneliness and their relative importance, with the aim of identifying 'high risk' groups. Using data from the Medical Research Council's National Survey of Health and Development (NSHD), which is a representative population sample from England, Scotland and Wales, their analysis was based on questionnaires completed between 2014 - 2015 by 2453 cohort members who were aged 68 years. They identified 42 variables which were conceptually or empirically correlated to loneliness, and which were grouped into the following 5 domains: personality characteristics, affective states, demographic characteristics, social relations and health. They examined the relative importance of different correlates of loneliness. The most importance correlates of being less lonely were positive mental well-being, personal mastery, identifying the spouse as the closest confidant (rather than marital status alone), being extrovert, and frequent informal social contact. Participating in organised groups and demographic correlates were less useful characteristics to identify those experiencing loneliness.

Loneliness in later life has been reported to be triggered or exacerbated by transitions common in later life such as retirement, moving to be closer to family members, becoming a carer, and divorce or separation. The associated change in network, support and/or role may contribute to feelings of loneliness but there is a lack of evidence to assess which transitions are impacting levels of loneliness in the UK and how they impact it (Jopling and Sserwanja, 2016). One transition that was not included in the above work is the move into a care home, about which research evidence is mixed (see Outcomes of Loneliness later in this Chapter). The breadth of cross-sectional associations reported in the literature highlights the physical, psychological

and social aspects of loneliness in community dwelling older people (Tomstad *et al.*, 2017).

1.4 Risk factors for loneliness and patterns of loneliness over time

Longitudinal studies have sought to identify both risk factors and protective factors against loneliness over time. They report that only a minority of older people are continuously lonely over time (Jylhä, 2004; Wenger and Burholt, 2004; Dykstra *et al.*, 2005; Victor and Bowling, 2012; Hawkey and Kocherginsky, 2018). Wenger and Burholt (2004) found that in a 20 year follow up of a population cohort in rural Wales almost all participants had changes in social isolation or loneliness including those that overcame loneliness. They explored characteristics of participants and specific events in relation to four patterns of loneliness and isolation. The main events related to loneliness without isolation and increases in both loneliness and isolation were related to loss - due to bereavements and other loss – of partners, other family and friends, and loss/deterioration of health and function. Other factors include difficult caring roles, long periods of time alone during the day, moving geographically and having a tendency not to ask for help. In their UK community cohort with a shorter follow-up period of eight years, Victor and Bowling (2012) followed up 287 of 999 older people from their original sample and explored changes in loneliness. A minority of 20-25% were persistently lonely, but their sample differed in that less than half reported changes in loneliness over time; 25% were less lonely over time and 15% were more lonely. The remaining 40-50% were never lonely. Changes in loneliness were associated with changes in marital status, living arrangements, social networks and physical health.

Other factors from longitudinal studies that are associated with greater loneliness are increasing disability and decreasing social integration (Jylhä, 2004) as well as strained relationships (Hawkey and Kocherginsky, 2018) findings that corroborate the qualitative evidence reported in the next chapter.

Whilst stability over the life course is argued as being a key factor in protecting against loneliness and social isolation by Wenger and Burholt (2004) they acknowledge that many of the contributing factors, such as widowhood and other deaths within families, friends and /or close neighbours, worsening health and caring roles, are beyond the control of the individual. Non-kin relationships were key in those who overcame loneliness or were not lonely despite being social isolated. They also suggest that conscious decisions to change lifestyle may help alleviate loneliness and isolation (Wenger and Burholt, 2004).

Other studies suggest that factors associated with a reduction in loneliness over time are the converse of risk factors for loneliness. These include an improvement in functional ability and physical health and an increased social network and improved social relationships (Dykstra *et al.*, 2005; Victor and Bowling, 2012). Victor and Bowling (2012) suggest that efforts to reduce loneliness should not be confined to social interventions such as befriending schemes but include attention to long-term health problems.

The findings of longitudinal studies of community cohorts are limited by the low response rates over time and likely representativeness of the survivor cohort; those not responding tend to be frailer and sicker, and less likely to be able to leave their homes. Studies in which loneliness is not the primary outcome measure can be underpowered. An example of this is Wenger and Burholt's (2004) 20 year follow-up study mentioned above. Of the original cohort of 543 people aged 65 and over, there were just 47 community dwelling and independently living survivors at final follow-up, which potentially compromises their findings. However, longitudinal studies can demonstrate the temporal nature of loneliness for the majority of older people who experience it. They also illustrate the dynamic nature of the loneliness experience, that loneliness may or may not be a cumulative phenomenon and that there may be key life events or transitions which increase an individual's vulnerability.

Whilst the majority of the risk factors outlined here are not modifiable, they can potentially help to identify groups or life events that may increase a vulnerability to loneliness. Engaging with older people to understand how they wish to respond to these feelings is important; in this exploratory and subjective area, qualitative work can provide a richer picture and greater understanding of what loneliness means to older people experiencing it, how they cope with and wish to manage their feelings of loneliness over time.

1.5 Outcomes of loneliness

There is a large body of work reporting the associations between loneliness, social isolation and both increased morbidity and risk of premature mortality. An overview of systematic reviews on the public health consequences of social isolation and loneliness across all ages identified 40 systematic reviews, 47 non-systematic reviews and 3 meta-syntheses (Leigh-Hunt *et al.*, 2017).

Depression and cardio-vascular health are the most researched outcomes in relation to social isolation and loneliness; others include quality of life, general health, biological markers of health, cognitive function and mortality (Courtin and Knapp, 2015). The overview of systematic reviews (Leigh-Hunt *et al.*, 2017) reported that meta-analyses identified a significant association between loneliness and mortality and there is consistent evidence linking loneliness to worsening cardio-vascular and mental health outcomes; the role of loneliness in other conditions is less clear.

A recent meta-analysis reported deficiencies in social relationships are associated with an increased risk of developing coronary heart disease and stroke (Valtorta *et al.*, 2016). The authors combined social isolation and loneliness within this study which should be borne in mind when interpreting these results. A further meta-analytic review (Holt-Lunstad *et al.*, 2015) of 70 prospective studies of 3,407,134 participants followed on average for 7 years (including 42/70 on those aged 60+ and 44/70 based in community settings) found that both social isolation and loneliness resulted in higher mortality. After adjusting for demographic variables and health status (to

account for reverse causality) they found that the increased risk of death was 26% for reported loneliness, 29% for social isolation and 32% for living alone. They add that these data indicate no difference between objective and subjective measures of social isolation when predicting mortality.

Their work builds on their earlier meta-analysis (Holt-Lunstad *et al.*, 2010) measuring the frequency of human interaction and tracked health outcomes. They reported that being connected with family or friends improves the odds of survival by 50 percent compared to those who have poor social relationships and networks. They add that the odds of survival for those in healthy relationships may be higher because the studies they analysed did not provide information on the quality of the relationships and so both negative and positive relationships were pooled together. Although not focussing on loneliness *per se* this research has been included in this chapter to acknowledge the breadth of the data in the review and the relationship between loneliness and social networks. However, it is important to reiterate that loneliness and social isolation are overlapping but distinct concepts.

Causal links and mechanisms to explain how loneliness may affect health are difficult to demonstrate (Courtin and Knapp, 2015). Three main pathways have been suggested; behavioural, psychological and physiological which correspond to the different disciplinary bases of those studying loneliness, as described in Chapter 2. Behavioural pathways suggest that health risk behaviours such as smoking and physical inactivity are associated with loneliness (Theeke, 2010; Shankar *et al.*, 2011) and those who are lonely are at risk of undernutrition; (van der Pols-Vijlbrief *et al.*, 2016; Tomstad *et al.*, 2017). Psychological and physiological research has focussed on those who are middle-aged and the 'young old' so its relevance may be limited to later life experiences of loneliness. Loneliness as a psychological experience has potentially adverse effects on biological stress processes that may be relevant to health based on research in the 47-59 year olds (Steptoe *et al.*, 2004). Several adverse biological/physiological factors have been associated to loneliness in older age in US research. This includes

loneliness and social isolation being associated with defective immune functioning, higher blood pressure and poor sleep (Cacioppo *et al.*, 2002; Hawkey *et al.*, 2010; Smagula *et al.*, 2016), increased likelihood of decline in activities of daily living and mobility, difficulties with upper extremity tasks and climbing stairs (Perissinotto *et al.*, 2012). A number of factors may limit the generalisability of these findings from the US to the older lonely UK population namely, small sample sizes and limited information on sample size calculations, limitations of data collected in laboratory settings and of diary data (for self-reported information on sleep patterns) and a younger age profile, typically between 50-68 years old.

As well as health outcomes of loneliness, research has explored the impact of loneliness on the move into care homes. The findings are mixed. Recent analysis of English Longitudinal Study of Ageing (ELSA) data reported that loneliness conveys an independent risk of relocating to a care home after adjusting for age, sex, social isolation, depression, memory problems including diagnosis of Alzheimer's disease, disability, long-term physical health, and wealth (Hanratty *et al.*, 2018). This contradicts earlier studies which have reported that the move is not associated with loneliness (Dykstra *et al.*, 2005). In addition, an earlier study in the Netherlands had found that in certain populations, namely the oldest old males (born pre 1920) who had declining health and had lost a partner, a move into a care home had been found to increase loneliness (Tijhuis *et al.*, 1999).

1.6 Loneliness and mental health

Given that being lonely is an unpleasant emotional experience, the relationship between loneliness and depression and other mental health problems is unsurprising and widely reported in the literature. Depression and loneliness in older people are strongly associated and often co-occur. Despite the overlap, loneliness and depression are considered distinct constructs, but ones that may act in a synergistic way to reduce well-being (Tiikkainen and Heikkinen, 2005; Cacioppo *et al.*, 2006b; O'Lunaigh and Lawlor, 2008). Loneliness both affected and was affected by depression and functional limitations over time (Luo *et al.*, 2012). The issue of reverse

causality between loneliness and depression is important; however analysis of longitudinal data has demonstrated mixed findings (Courtin and Knapp, 2015).

Evidence from a scoping review found that loneliness is an independent risk factor for depression in old age (Courtin and Knapp, 2015). Loneliness was found to be one of the strongest cross-sectional associates with depression in a study exploring the relationship between social support deficits, loneliness and life events as risk factors for depression in older people (Prince *et al.*, 1997). Other cross-sectional research with specific populations, such as people living in independent living retirement communities and older men (Alpass and Neville, 2003; Adams *et al.*, 2004), has also found that loneliness was significantly associated with depression. The detrimental effect of living alone on depression was more often due to loneliness for men than for women (Park *et al.*, 2012). In a study of loneliness, social support, mood and wellbeing in community dwelling older adults (Golden *et al.*, 2009), in which 8.8% of the population had depressed mood, it was unusual for depression to occur among those who were not lonely or socially isolated, with 74% of those with depressed mood also reporting loneliness. Furthermore, the risk of depression increased with the severity of loneliness and amongst those who were lonely over 80% of the risk of depressed mood was attributable to their loneliness.

Mental health outcomes were investigated in three studies, two exploring causal relationships over three years (Green *et al.*, 1992; Cacioppo *et al.*, 2006b) and the other being a 10 year longitudinal study (Heikkinen and Kauppinen, 2004) which found that loneliness is an independent risk factor for depression in older people. Loneliness and low social interaction are predictive of suicide in older age (Conejero *et al.*, 2018). The general mortality risk was doubled in those who were both lonely and depressed (Stek *et al.*, 2005).

Loneliness has also been associated with increased risk of Alzheimer's disease and cognitive impairment (Boss *et al.*, 2015). Specific aspects of cognition (psychomotor processing speed and delayed visual memory) were associated with loneliness after adjusting for depression, social networks and demographic factors, in community dwelling older adults (O'Luanaigh *et al.*, 2012). A three year follow-up study of 2173 community dwelling older people in the Netherlands without dementia found that lonely older people were more likely to develop clinical dementia than their non-lonely peers after adjusting for vascular disease, depression, functional status and socio-demographic factors (Holwerda *et al.*, 2014).

1.7 Cross-sectional associations of social and emotional loneliness

Most research identifying risk factors and associations has treated loneliness as a unidimensional concept. However there has been some work reporting risk factors associated with the different types of loneliness including social loneliness (the absence of a network of friends, family or community) and emotional loneliness (the lack of a confidante or a trusting, loving relationship, even within a good social network) as distinguished by Weiss (Weiss, 1973), and discussed in further detail in Chapter 2 (Section 2.2). Drennan *et al.* (2008) used the Social and Emotional Loneliness Scale for Adults (SELSA) scale (DiTommaso and Spinner, 1993) in a telephone survey to identify risk factors for social and emotional loneliness (the latter including elements of both family and romantic loneliness), in a community dwelling sample of 683 older adults in Ireland. Overall, levels of social and family loneliness were low and romantic loneliness was relatively high (Drennan *et al.*, 2008). Social loneliness was associated with increasing age, poorer health, rural location and lack of contact with friends. Association with family loneliness were rural location, male gender, lower income, being widowed, no access to transport, infrequent contact with family and being a carer. Romantic loneliness was predicted by marital status, in particular being widowed. The authors asserted that the least lonely were married, had regular contact with friends and family, relatively good incomes and access to transport. This makes instinctive sense and this picture is unlikely to be restricted to later life. Also of the three typologies, romantic loneliness was

most common emphasising the importance of close intimate relationships throughout adult life.

Some of these findings were corroborated by Dahlberg and McKee (2014) in a community survey of 1255 older people in Barnsley, UK, in which loneliness was dichotomised into social and emotional loneliness using the de Jong Gierveld 11-item scale (de Jong-Gierveld and Kamphuls, 1985). Significant associations specific to social loneliness were being male, having low contact with friends and family, low activity, low perceived community integration and receiving community or social care. Emotional loneliness was associated with high activity restriction (due functional impairment of instrumental activities of daily living) and no informal care. Being widowed, having low well-being, low self-esteem and lower income were associated with both social and emotional loneliness.

Schnittger *et al.* (2012) developed biopsychosocial models of social and emotional loneliness for community dwelling older adults in Ireland, using the de Jong Gierveld 6-item loneliness scale (de Jong Gierveld and van Tilburg, 2006). They collected data from 579 people using a battery of instruments across psychosocial, biological, cognitive and demographic domains and from the 82 variables found to be significant in bivariate analysis, they employed statistical techniques to reduce the number of false positives and derive the models. Psychosocial variables - higher levels of neuroticism, depression and perceived stress – and living alone and accommodation type were all significant indicators of increased emotional loneliness. Risk factors for social loneliness were neuroticism, perceived stress, lower levels of semantic fluency and fewer grandchildren.

This research on loneliness typologies extends Weiss's (1973) original work on differentiating social and emotional loneliness by empirically identifying characteristics specific to each type as well as illustrating that individuals may experience both simultaneously. Although it is interesting to tease out the different characteristics, there is by no means a clear picture emerging.

Furthermore, cross sectional analyses only generate associations and caution should be drawn in inferring causality from these findings.

The research outlined above on factors associated with loneliness, and risk factors for and outcomes of loneliness used different measures to identify those who are lonely and the extent of their loneliness. The use of different instruments makes comparisons difficult. To understand how loneliness and social relationships affect health it is important to understand what is being measured can affect whether meaningful conclusions be drawn about what response might be appropriate (Valtorta *et al.*, 2016). A discussion of the assessments and measures used to identify those who are lonely and the extent of their loneliness is presented in the Chapter 4 (Methods).

1.8 Loneliness and use of health services

The relationships between loneliness and health and well-being reported above have driven the research exploring loneliness and health service use. Early evidence reported that lonely relatively young (60 year old) primary care patients had twice as many consultations with their GP compared to those that were 'rarely' or 'never' lonely; these associations were significant after controlling for socio-demographic, socio-economic and health variables known to affect the frequency of GP consultations. However, the number of home visits by GPs was not associated with loneliness (Ellaway *et al.*, 1999) despite the association between impaired mobility and loneliness (for example, Wenger and Burholt, 2004). Survey data from the US (Gerst-Emerson and Jayawardhana, 2015) found that chronic loneliness (based on loneliness reported at two time points, 4-years apart) was significantly associated with a greater number of physician visits, but loneliness was not associated with physician visits at individual time points or greater hospitalisation. This latter finding contrasts with data from Ireland in which greater loneliness was independently associated with emergency (but not planned) hospitalisation among community dwelling older adults (Molloy *et al.*, 2010).

A recent systematic review of associations between social relationships and service use (Valtorta *et al.*, 2018) has challenged the perceived wisdom that in the absence of satisfactory relationships, older people consult their GP or primary care physician more often. Older patients with weaker social relationships were found not to place greater demands on ambulatory care (including physician visits and community- or home-based services) than warranted by their needs. They did experience increased rates of readmission to hospital. The authors argued their findings were important for public health because they challenge the notion that lonely older adults are a burden on all health and social care services. However, caution should be expressed in extrapolating the findings of this review to older people who are lonely as the absence of social relationships cannot be assumed to infer loneliness.

1.9 The use of evidence and the response to loneliness

The research evidence outlined above has been used for different means. Although most older people are not lonely (Office for National Statistics, 2018), the risk factors for loneliness (outlined above) which include common features of later life, have resulted in loneliness becoming inextricably linked with ageing. In addition, the associations between later life loneliness and morbidity, mortality and higher service use have contributed to loneliness being considered a public health and public policy concern. The headline of 'loneliness being as harmful for health as smoking 15 cigarettes a day' based on the findings of Holt-Lunstad *et al.*, (2010; 2015) has been used widely by the third sector, campaigning organisations in the media (for example Age UK Information and advice, 2018; Campaign to End Loneliness, 2018).

Loneliness is a subjective experience meaning different things to different people; the qualitative research on experiences of loneliness in later life is presented in Chapter 2. It has become a widely used term that describes a range of negative feelings associated with a breadth of experiences and circumstances. A lonely individual is unlikely to encounter all these experiences and circumstances and the importance of knowing what

loneliness means to individuals tends to be lost in the reporting of loneliness. It has been suggested that loneliness is being used as a concept to arouse interest and amplify arguments for other concerns (Agren, 2017). A review exploring how loneliness is constructed in the Swedish press found two dominant discourses; loneliness being used firstly to motivate the need for political change and allocation of resources for older people, and secondly to enhance the values of volunteer work and emphasise the risks associated with ageing (Agren, 2017).

Later life loneliness combines these discourses with ageist attitudes prevalent in Western societies (Royal Society for Public Health, 2018). Lonely older people are portrayed as vulnerable, neglected and excluded from society and loneliness is a problem to be solved. Alongside this the language used to describe the prevalence and impact of loneliness has often been emotive and alarmist. Loneliness is described as a 'public health epidemic' (Royal College of General Practitioners, 2018), 'Loneliness kills people and communities' and 'Lonely people are vulnerable. This is a safeguarding issue' (Joseph Rowntree Foundation, 2013), 'the hidden crisis of loneliness' (Jo Cox Commission on Loneliness, 2017), 'The problem can strike at any time and without warning to anyone' (Department for Digital Culture Media and Sport, 2018b). Seasonal messages from third sector organisations, especially over Christmas have included 'No one should have no one' (Age UK, 2016) and encouraged everyone to make a New Year's resolution to help an older, lonely person near them (Royal Voluntary Service, 2014). These descriptions imply that loneliness is a societal problem and that something must be done for or to the lonely older person regardless of their wishes. Although it is important not to deny the negative experience and impact of loneliness for many older people, the language used in these descriptions can in my view portray loneliness as pervasive and amplify ageist attitudes and stereotypes. The lack of consultation with older people who are lonely is a major omission in many of these descriptions, initiatives and the responses outlined below.

The raised profile of lonely older people has also undoubtedly in part been due to the work of lobbying groups such as the 'Campaign to End Loneliness'; established in 2011. This network of organisations and individuals shares evidence and ideas for action to tackle loneliness. It initially focussed on later life loneliness but has since broadened its scope in line with the evidence for loneliness affecting people across the life course. The Campaign provides information for individuals and organisations keen to address the problem, including several resources to help local government and NHS commissioners (including Health and Well-being Boards, Clinical Commissioning Groups, adult social care and public health teams) find ways to address loneliness in their locality (Local Government Association and Campaign to End Loneliness, 2012). More recently their work has included the promotion of initiating informal community exchanges; campaigns such as 'Be More Us' encourages people to strike up conversations to make friends and connections (Campaign to End Loneliness, 2018a). The name of the organisation suggests that loneliness is something that can (and should) be eradicated.

The Campaign is governed by five partner organisations which include prominent national (UK) third sector organisations for older people. Using the standpoint of Agren outlined above (Agren, 2017), it could be suggested that their focus on loneliness is a means to address other challenges faced by older people as well as loneliness, and to generate funds and increase the allocation of resources for older people.

This description has parallels with the experience of an on-going large programme of work called 'Ageing Better', which is a 6 year (2015-2021) Big Lottery funded programme working in 14 areas across England. This aims to work with people aged 50 and over and co-produce locally tailored projects to address social isolation and loneliness. Interim findings report on the development and impact of both community level initiatives to challenge negative perceptions of ageing and promote 'age-friendly' communities, and a broad range of locally tailored activities, including volunteering being provided by those who are lonely / isolated. The schemes have claimed that

they are successfully engaging with diverse groups including those who have been reported to engage less with initiatives promoting health and wellbeing, such as older people from minority ethnic and LGBT communities, socio-economically deprived neighbourhoods and carers (Liljas *et al.*, 2017; Big Lottery Fund, 2018). These groups, who may have increased risk of loneliness and isolation (Campaign to End Loneliness, 2014), are sub-groups of the older population who are more likely to have poorer health based on their socio-economic circumstances and inequities in access to health care across the life course (Pinquart and Sörensen, 2003; Marmot *et al.*, 2012; Fredriksen-Goldsen *et al.*, 2013; Evandrou *et al.*, 2016). As such, under the umbrella of loneliness and isolation, the initiatives within the 'Ageing Better' programme potentially address structural inequalities and wider socio-economic and political determinants of health and wellbeing. Interestingly, their interim findings report mixed outcomes in terms of self-reported loneliness in the 60,000+ people who have been involved in a broad range of activity. After participation in Age Better projects, a reduction was reported in those who were loneliest to start with, but there was an increase in loneliness in those who were less lonely at the outset (Big Lottery, 2018 page 7). Challenges of measuring loneliness are discussed further in Chapter 4 (Section 4.2).

1.9.1 A Minister and a strategy for loneliness

The research evidence and raised profile of loneliness are likely to have influenced recent developments in the UK. In January 2018, the first 'Minister for Loneliness' was appointed (formally the Minister for Sport and Civil Society within the Department for Digital, Culture, Media and Sport (DCSM)). This followed the recommendations in the Jo Cox Commission on Loneliness (2017) report based on the work of a cross-party Loneliness Commission which had been established by the late Jo Cox, MP.

The responsibilities of the 'Minister for Loneliness' are to (i) lead cross-government work on loneliness and develop a strategy on loneliness for England (see below); (ii) to develop the evidence-base around the impact of different initiatives in tackling loneliness, across all ages and within all

communities; (iii) establish appropriate indicators of loneliness across all ages, with the Office for National Statistics; and (iv) create a dedicated loneliness grant fund.

In line with this remit, a consultation was undertaken to gather expertise to inform a strategy for loneliness and £20 million new funding provided for charities and community groups (Department for Digital Culture Media and Sport, 2018a) to support programmes that have evidence demonstrating benefit to individuals and society that help make connections in their communities. The evidence on interventions for loneliness is discussed later in this chapter.

The scope of the UK government's strategy is loneliness over the life course including young people, people in poor health, carers, the unemployed and the bereaved, along with specific life events and times of transition which may increase the risk of loneliness; the aim being to identify times when preventative or early action could help. This remit was informed by the Office for National Statistics (ONS) Community Life Survey, 2016 to 2017, in England which reported in 2018 (Office for National Statistics, 2018). The research focused on the frequency of loneliness rather than degree of loneliness with the aim of preventing 'constant' loneliness and assessed loneliness using the question 'How often do you feel lonely?' with the following response options: often/always, some of the time, occasionally, hardly ever or never.

The main findings of the ONS survey are that 5% of adults (aged 16 years and over) report feeling lonely "often" or "always", the characteristics of those who are lonely more often are: 16 to 24 year olds compared to those in older age groups, women, those who are single or widowed, those in poor health, those renting their homes compared to homeowners, that is, of lower socio-economic status. In addition, those who feel a lack of belonging to their neighbourhood, and have little trust of others in their local area report feeling lonely more often. From this, three profiles of people at particular risk from loneliness were identified: (i) widowed older homeowners living alone with

long-term health conditions, (ii) unmarried, middle-agers with long-term health conditions and (iii) younger renters with little trust and sense of belonging to their area.

Although the policy emphasis has shifted away from an explicit focus on older adults, ‘triggers’ such as widowhood and worsening health will be most common in the older population. This change reflects the evidence that whilst loneliness in older people has remained fairly stable (see Section 1.2 earlier in this Chapter), loneliness in younger people has increased (Griffin, 2010; Office for National Statistics, 2018). The main parameters of the strategy have been determined by responses to a structured questionnaire which are limited in their breadth with pre-defined response options; caution is therefore needed in the interpretation of these findings.

The strategy ‘A connected society: a strategy for tackling loneliness – laying the foundations for change’ (Department for Digital Culture Media and Sport, 2018b) was launched in October 2018, and contains a foreword from the Prime Minister who reinforces loneliness as a public health concern describing it as a ‘growing social injustice which sits alongside childhood obesity and mental wellbeing as one of the greatest public health challenges of our time’ (Department for Digital Culture Media and Sport, 2018b page 2). The strategy, which is for England alone, has three main goals. Firstly, to improve the evidence base on causes, impact and interventions for loneliness. This draws on an overview of reviews of loneliness interventions across the life course led by the What Works Centre for Wellbeing (Victor *et al.*, 2018). The findings of this review are outlined in the Section 1.10 below. The need for more evidence is because earlier research has been difficult to compare as a variety of loneliness measures have been used. To establish prevalence and assess effectiveness of interventions, quantitative measurement of loneliness is proposed using a new ‘national measure’ which is made up of the single direct question: ‘How often do you feel lonely?’ together with the 3-item University of California, Los Angeles (UCLA) scale for adults which does not use the word ‘lonely’ in any of the

items; see Chapter 4 Section 4.2 for further discussion on loneliness measures.

The second goal is to embed loneliness as a consideration across government policy and promote partnerships with local government, the voluntary sector and businesses. A range of government departments is listed as having roles to play, including Health and Social Care, Digital, Culture, Media and Sport, Housing, Transport, Education and the Home Office amongst others, with different degrees of detail as to what the roles might be. This emphasis on partnership working may reflect the breadth of factors that can influence social exclusion and inequalities in health and wellbeing.

A range of initiatives is proposed including further investment in social prescribing via connector schemes across all health and social care organisations. This extends the reach of social prescribing beyond GPs as proposed in the recent 'Community Action Plan to Tackle Loneliness' from the Royal College of General Practitioners (RGCP) (Royal College of General Practitioners, 2018). This appears to be in response to the frequency of contact lonely older people are believed to have with their GPs, consultations that are attributed to loneliness rather than underlying health and well-being needs, despite a lack of evidence to support this. Social prescribing promotes primary care referrals to a range of local, non-clinical services and the use of 'directories' of local voluntary sector projects and schemes (Department of Health and Social Care, 2018).

The extension of social prescribing is despite the acknowledgement within the loneliness strategy that further evidence is needed on its impact (Department for Digital Culture Media and Sport, 2018b page 25). Inferences are based on a review of the evidence assessing impact of social prescribing on healthcare demand and cost implications, not the experience of loneliness (Polley and Pilkington, 2017). The evidence on whether older people consider health and social care organisations as appropriate or acceptable places to discuss their loneliness is lacking; older people's views

on primary care as a place to discuss loneliness have been explored as part of this thesis and findings are presented in Chapter 6. The views of health and social care practitioners are also largely unknown. Barriers to GPs discussing loneliness with their older patients from a recent qualitative study in England include GPs' feelings of powerlessness in their ability to 'fix' the problem and a need for more support and training on responding to social problems like loneliness (Jovicic, 2018). Furthermore, as well as 'connecting' older people to a range of initiatives (on which the evidence base for loneliness is mixed) social prescribing practice also needs to consider the barriers older people may need to overcome in order to engage and remain engaged over the longer-term. The strategy allocates new funds to support the initiatives which target groups who may be vulnerable (for example, at specific transition points) or disadvantaged for a number of reasons. Hence, funding for public services (provided by different sectors) for these groups is being allocated under the umbrella of loneliness.

Finally, the third goal is to build a 'national conversation' around loneliness, including campaigns to reduce stigma and working with businesses to reduce loneliness in the workplace. The subjectivity of the experience of loneliness should be part of this for the conversation to be meaningful; the strategy includes examples of loneliness experienced by diverse groups within the population ranging from school children to older adults, asylum seekers, new parents and victims of crime to name but a few.

There appears to be political cross-party and cross-sector acknowledgement of and commitment to address loneliness in the UK but little research to demonstrate effective strategies to alleviate loneliness (see Section 1.10). Victor *et al.* have argued that policy needs to distinguish between those who always been 'social isolates' from those who have recently become isolated (Victor *et al.*, 2009). It is also important to recognise that many lonely people (including older people) may not be in contact with health, local authority or third sector services and may be dealing with and managing their loneliness themselves.

1.10 Interventions for loneliness

An overview of the key types of intervention for loneliness is presented in this section along with evidence of effectiveness. Systematic reviews have reported very little high quality research into effective interventions to reduce loneliness in later life (Cattan *et al.*, 2005; Masi *et al.*, 2011; Cohen-Mansfield and Perach, 2015; Gardiner *et al.*, 2018). The subjectivity and heterogeneity of loneliness, both that experienced in later life as well as the experiences over the life course which may have shaped these feelings, may partly explain why a 'one size fits all' approach to interventions has produced disappointing results on the impact of interventions (Frost *et al.*, 2010).

Interventions and services to alleviate or prevent loneliness in 'at risk' groups have, for several decades in the developed world, been provided by the welfare state and voluntary sector groups (Means and Smith, 1998).

Currently in the UK, three main types of community-based services to alleviate loneliness are common. These may be 1) run by local government as part of social services or community resources, 2) run by local government or other public sector funded voluntary sector organisations, or 3) offered by self-funding community, self-help, and voluntary bodies that receive no/little state support but are linked to neighbourhood, leisure, self-help, educational, occupational, or faith groups (Moriarty and Manthorpe, 2012).

The activities undertaken may be individually or group focused; there is mixed evidence on whether group-based are more effective than one-to-one or solitary activities for loneliness (Gardiner *et al.*, 2018). Activities can be grouped into 4 main types: 1) information and sign-posting services, 2) one-to-one services, 3) group support services, and 4) services supporting or enabling community participation. Information and sign-posting include websites and directories of local services, telephone helplines and health and social support needs assessments which can be carried out by questionnaires (postal or internet based) or on home visits. Information is available on local government and voluntary sector organisations and

includes sign-posting to the services and activities described below. Information on how to alleviate loneliness and services that are available is likely to have limited effect on perceptions of loneliness.

One-to-one services most commonly refer to 'befriending'. These contacts may be face-to-face, by telephone or via the internet, and are based on the older person being matched with a volunteer who makes regular contact. One-to-one interventions can also include interventions including animals (either real or robotic). Most views on such interventions are from those already engaged with services (for example, Cattan *et al.*, 2003; Lester *et al.*, 2012). There is mixed evidence to support befriending. Befriending had a modest effect on depressive symptoms and emotional distress (Mead *et al.*, 2010). A recent systematic review and meta-analysis of befriending for a range of physical and mental health indications and patient relevant outcomes including loneliness, found no significant benefit on loneliness (Siette *et al.*, 2017). Fourteen trials and 2411 participants were included in the meta-analysis; 11 studies were randomised controlled trials (RCTs) and three were quasi-experimental studies. Loneliness was assessed in only five studies, of which three were rated high quality, one was medium and one was low quality (*ibid*). Both the latter two systematic reviews of trials included studies of adults and did not differentiate findings for older people. Other one-to-one interventions include using new technologies which have shown some promise in alleviating loneliness but the range of technologies are broad (for example, video conferencing, use of games consoles and robotic pets) so are difficult to compare and the studies were of small sample sizes (Hagan *et al.*, 2014; Cohen-Mansfield and Perach, 2015).

Group services are commonly either day centre type services, including lunch clubs, gardening groups or groups which aim to bring people together socially, with the aim of widening their social network. Within the caveat that the systematic review findings are based on a small number of trials of mixed quality and small effect size, there is some evidence to suggest potential benefit from group social or educational activities in specific populations (Cattan *et al.*, 2005; Cohen-Mansfield and Perach, 2015). In

addition interventions developed with a theoretical basis, groups offering social activity and/or support, and those in which older people are active participants have been shown to be effective for social isolation and loneliness (Dickens *et al.*, 2011; Gardiner *et al.*, 2018). An integrative review by Gardiner *et al.* (2018) included both quantitative and qualitative studies and used a descriptive thematic method for synthesising the data. Of the 39 included studies, six were RCTs, 21 were other quantitative studies, 10 were qualitative and two were mixed-methods. Only three of the 39 were of given the top score on quality appraisal; as with earlier reviews the quality of the studies included needs be born in mind when interpreting the findings. The highest quality studies were psychological therapies (for example, humour therapy, reminiscence therapy, and cognitive and social support interventions) delivered as group-based activities and which were successful in reducing loneliness. However, it is not possible to differentiate the individual factors contributing to the success of the intervention (Gardiner *et al.*, 2018).

The fourth type of intervention describes schemes that support older people to participate in existing activities within the wider community such as sport and leisure based facilities, libraries and museums, cultural and other interests. An example is social prescribing, as described earlier in this chapter. Although widely advocated, reviews of social prescribing have been limited to evaluations of small scale projects, and at the present time there is a lack of evidence to support its effectiveness or cost-effectiveness (Centre for Reviews and Dissemination, 2015; Bickerdike *et al.*, 2017). In addition a Dutch study found that whilst general practitioners acknowledged the importance of patients' feelings of loneliness, they had difficulty responding to these feelings (van der Zwet *et al.*, 2009).

Interventions delivered directly by health, allied health and/or social care professionals supporting older people, both one-to-one and group based, have had mixed results in alleviating loneliness. Interventions including enrolment into programmes of care delivered by a range of models were found to be effective to reduce social isolation and loneliness (Gardiner *et*

et al., 2018). However a randomised controlled trial of case management for frail older people delivered over 12 months with loneliness, depression symptoms and life satisfaction as primary outcome measures found no significant effects using an intention to treat analysis, but a significant difference (reduction) in loneliness at 6 months (but not 12 months) using complete case analysis (Taube *et al.*, 2018).

Overall, group based interventions were more common than one-to-one interventions (Cohen-Mansfield and Perach, 2015) but there were mixed findings about which format was more effective at reducing loneliness. Systematic reviews have reported that group based formats are more effective (Cattan *et al.*, 2005; Hagan *et al.*, 2014; Cohen-Mansfield and Perach, 2015) including those with an educational focus (Cohen-Mansfield and Perach, 2015). But Gardiner *et al.* (2018) found that when solitary interventions were included along with one-to-one interventions, they were more effective than group based interventions. Examples described by Gardiner *et al.* (2018) as solitary interventions have been included in earlier reviews as one-to-one interventions and comprised those that were computer based (such as video conferencing and internet use) and those involving animals. Therefore, although 'solitary' interventions did not include direct contact with other people, they appear to promote interaction.

A further meta-analysis sought to assess the strength of evidence of interventions to reduce loneliness (Masi *et al.*, 2011). It found pre-post and non-randomised comparison studies yielded larger mean effect sizes compared to randomised comparison studies. Also, in studies that used the latter design, the most successful interventions addressed maladaptive social cognition (negative perceptions of yourself and how other people perceive you). The findings are however limited by the lack of good trial evidence that fed into the meta-analysis.

From the qualitative studies in the integrative review (Gardiner *et al.*, 2018) three common characteristics of effective interventions were identified: (i) adaptability of an intervention to a local context in particular when

implemented by national organisations, (ii) a community development approach where older people were involved in the design and implementation and (iii) activities or interventions that supported productive engagement (ibid). The authors pointed to the need for tailoring and engagement with older people which resonates with the subjectivity of loneliness.

To inform England's loneliness strategy (Department for Digital Culture Media and Sport, 2018b), as noted above, an overview of systematic reviews was conducted by the What Works Centre for Wellbeing to identify the effectiveness of interventions to alleviate loneliness in people of all ages across the life course (Victor *et al.*, 2018). The review included both published and unpublished grey literature of studies using controlled study designs and measuring loneliness, between 2008-2018; all eligible literature focussed on older populations (55+years) so it is included here. A huge variety in the nature of interventions, settings and older populations were found in the studies, which also used a range of loneliness measures. The authors concluded that whilst there was no evidence of harm, results showed no effect on loneliness although they state that this does not mean loneliness is not alleviated at all by intervention. They also reported little evidence of interventions targeting those who are lonely/at risk of loneliness despite recognition that targeted interventions may be more beneficial. Proposals for policy include a focus on person-centred and tailored intervention, programmes to address the stigma of loneliness, and those that emphasise meaningful relationships and social connections in those that are lonely or at risk. Recommendations for conceptual clarity in loneliness work have been interpreted as the need for a quantitative 'national measure' for loneliness (see Section 1.9.1 above).

1.10.1 Economic benefits of loneliness interventions

In addition to the systematic reviews on effectiveness of interventions, a recent systematic review has scoped the evidence on cost effectiveness of interventions to prevent and/or tackle loneliness experienced by older people (McDaid *et al.*, 2017). Three groups of interventions were included (i)

befriending (both face-to-face and telephone), (ii) participation in social and healthy lifestyle activities, and (iii) signposting/ navigation services. Findings suggest that the economic evidence for both befriending initiatives and participation in social activities was very limited; evaluations reported both cost effective and cost ineffective interventions for both. Signposting / navigation services were however found to be potentially cost effective; one analysis suggested a positive return on investment of between £2 and £3 per £1 invested. The authors acknowledged the limitations of the review including that loneliness was a secondary outcome measure in most studies and none of the studies reported an incremental cost per change in loneliness score, measured using a validated instrument. However, those looking for evidence to strengthen the case for interventions for loneliness are likely to welcome these findings.

As well as interventions for loneliness provided by the government and voluntary sector described in this section, research has also explored the effectiveness of individual coping strategies for loneliness. This is summarised in the section below.

1.11 Coping strategies for loneliness

Several studies have investigated how different coping strategies may alleviate loneliness. Much of this work has focused on younger adult and university students from Canada (Rokach, 1990; Rokach and Brock, 1998) and studies which have aimed to explore strategies of coping with loneliness across the lifespan (Rokach, 2001) have failed to recruit sufficient numbers of older people to allow meaningful conclusions to be drawn. Coping strategies identified include: acceptance, self-development, increased social involvement, unhealthy behaviour, being comforted by religion, and solitary activities (Rokach and Brock, 1998).

Research on coping strategies in later life drawing on the work of Lazarus and Folkman (1984) and Folkman (2008), has proposed three broad coping strategies. Firstly, problem-focussed or active coping, which refers to the behaviours used to address the causes of stress. Secondly, emotion-

focused or regulative coping which describes the strategies used to diminish the emotional consequences of stressful events and thirdly, meaning-focused coping which describes how an individual appraises and responds to their stress drawing on beliefs, values and existential goals. This latter coping strategy is used to renew the coping process when other coping strategies have been unsuccessful. Based on the cognitive discrepancy model of loneliness (Perlman and Peplau, 1982), these coping strategies can be applied to loneliness as follows. Problem focused strategies would aim to improve relationships, emotion focussed strategies would include lowering expectations about relationships or comparing oneself to someone considered worse off, and meaning focused coping describes strategies such as telling yourself that everyone feels lonely at some time (Schoenmakers *et al.*, 2015). Studies have explored which type of coping strategies are used for addressing loneliness in later life, using predefined response options and vignettes describing different experiences of loneliness (*ibid*). The rationale given for using vignettes is to avoid the stigma of admitting to being lonely and avoiding social desirability bias in response. However, these findings can only describe how one individual might advise another to cope with loneliness rather than how they might respond if they were lonely. Also vignettes cannot capture the detail of context that might influence an individual's experience of loneliness. The researchers suggest that future work would benefit from a better understanding of the personal situation of the older person experiencing loneliness; arguably qualitative research methods would be most useful for this level detail to be gathered.

The findings of this research have limited implications for the work of this thesis due to the assumptions made about the experience and response to loneliness that fit within a positivist paradigm. The findings of a recent systematic review (Deckx *et al.*, 2018) illustrate the limitations of the meaningful inferences that can be drawn. The review investigated the relationship between coping strategies and loneliness in adults, in which both were measured using validated scales and the association between both was assessed quantitatively. Studies on coping with loneliness and those that identified the lonely using a single-item question asking directly

about loneliness were excluded because of the perceived stigma of loneliness producing socially desirable answers. Only two of the 12 studies included older adults (mean or median age over 60 years) and results are not differentiated by sub-group; the heterogeneity across the studies included university students, lesbian, gay, bisexual or transgender (LGBT) groups, carers and clinical conditions and disorders ranging from obesity, paedophilia, cancer and HIV. Despite this, the researchers conclude that problem-focussed coping strategies were associated with lower levels of loneliness whilst emotion-focussed coping strategies were associated with higher levels of loneliness; hence problem-focussed coping strategies have potential within interventions for loneliness. However, this review fails to acknowledge the breadth of feelings and contextual factors associated with the term 'lonely', the dynamic nature and subjectivity of loneliness which may be defined differently at different times of life and so prompt varying responses (if any), as well as how earlier experiences of loneliness may shape the perception and response to later experiences.

1.12 Summary

Loneliness is experienced by many but not the majority of older people and is associated with a variety of adverse physical and mental health outcomes. It has gained increasing public and policy attention and services, particularly in the third sector, have sought to support vulnerable lonely older people. Despite a limited evidence base, several services are available for lonely older people which may be addressing needs other than loneliness. The prevalence of loneliness has remained largely static over recent decades. Many people may not seek support or approach services for help for a variety of reasons. A focus on designing better interventions fits the positivist medical model approach to alleviating loneliness. As well as the paucity of evidence on effective interventions, there is a lack of evidence on whether intervention of any kind is necessary at all. Qualitative work on understanding the why older people chose or chose not to take up formal services, as well as why they continue or not to stay in touch with these services would provide valuable information. Understanding these choices would help to answer the broader question of how older people experience,

understand and respond to their loneliness themselves, with or without the support of services or intervention.

CHAPTER 2: BACKGROUND

This chapter introduces the definitional debates and theoretical positions on loneliness and ageing. The qualitative research on older people's experiences of loneliness is then presented as well as the rationale for why a better understanding of how older people manage their loneliness themselves is needed. Finally, the research questions for this thesis are outlined.

2.1 Terminology and definitions

A range of terminology is used in the literature, sometimes interchangeably, when talking about lonely older people. This includes being alone, aloneness, solitude, social isolation and loneliness. These concepts differ in their meaning so it is important to distinguish between them. Being alone is simply a description of being by oneself. This can describe the physical state of being alone and is often used to describe people living on their own. It can also describe the social circumstance of feeling alone within a particular social context such as having a set of personal beliefs that are different to the mainstream. Being alone may be either a desired or undesired state. Similarly, aloneness and solitude may be desirable, even conducive to self-reflection, learning, creativity and concentration (O'Luanaigh and Lawlor, 2008). Solitude has been described as the sense and space of being with oneself and can be both a vibrant or sombre experience (Jackson, 2016).

Those 'living alone' are relatively easy to identify and living alone has been associated with a range of negative health and quality of life measures (Kharicha *et al.*, 2007). However, the objective measure of living alone has been taken as a proxy for isolation, exclusion and neglect and so those living alone are easily 'problematised' (Victor *et al.*, 2009). Victor *et al.* (2009) found that, although loneliness and isolation are more common in those that live alone or spend a substantial amount of time alone, there was no significant link between living alone or being alone and loneliness and isolation when other related factors such as widowhood were taken into account. A lack of social interaction between older people living with others

(usually children) has been reported as being more influential in predicting feelings of loneliness than living alone in some cultures (Ojembe and Kalu, 2018).

Similar definitional debates exist about social isolation, which is considered to be the objective experience of being alone and isolated from friends, family members, neighbours, the wider community or society on a broader level (Griffin, 2010; Roberts, 2014). It has also been described as a deprivation of social connectedness (Zavaleta and Samuel, 2014) leading some to conclude that 'social connections and relationships' should be among the dimensions taken into account for measurement of quality of life globally (ibid).

Assessments of social isolation include counting the contacts that an individual has with others, which is the number of individuals a person sees and/or the frequency and duration of that contact. However, this assumes that all contacts are equal in quality and that more is inherently better. It also tends to emphasise face-to-face contact above others, whereas research has highlighted the importance placed on highly-valued relationships which are maintained via phone contact (Victor *et al.*, 2009). Social isolation need not necessarily be a negative experience; it may facilitate solitude and be chosen.

Despite being distinct, loneliness and social isolation are related concepts. Early work by Townsend (1957) developed a typology to distinguish the conceptual difference and relationship between loneliness and isolation. Four groups were identified: lonely but not isolated, isolated but not lonely, lonely and isolated, neither lonely nor isolated; and this typology has since been used by other researchers (for example, Wenger and Burholt, 2004). Quantitative evidence corroborates this relationship between social isolation and loneliness. In an Irish community sample of 1299 older adults drawn from primary care, 40% of those who were socially isolated were also lonely, and similarly, 39% of those who were lonely were also socially isolated.

However, 32% of those with an 'integrated social network' were lonely, underlining the distinctness of the constructs (Golden *et al.*, 2009).

Social isolation and loneliness have long been identified as problems of later life and many factors are associated with both. Wenger *et al.* (1996) used data from their representative community dwelling sample of older people in rural North Wales to refine statistical models of isolation and loneliness and identify main explanatory variables. They reported that the key objective aspects of social isolation that predispose older people to loneliness are widowhood, living alone and support network type. Also that certain subjective correlates of loneliness may exacerbate social isolation, namely self-assessed poor health (which negatively affects mobility) and low morale.

2.2 Definitions and characteristics of loneliness

The terms associated with loneliness as described so far in this thesis can be viewed positively or negatively as well as in terms of voluntary (preferred) and involuntary states. Current definitions of loneliness describe a largely undesirable condition but historically and across different theoretical positions, loneliness has also been viewed as having dual states or as existing on a continuum of negative to positive states. Descriptions range from aversive, dissatisfied, alienating and terrifying to states associated with personal growth, creativity, discovery, meaning and freedom (Rosedale, 2007).

A plurality of definitions of loneliness exists, emanating from the multidisciplinary theoretical explanations of loneliness, as outlined later in this chapter. Widely used psychosocial definitions describe loneliness as a subjective experience which is unpleasant and distressing and which results from the lack of satisfying human relationships (Andersson, 1998). The latter characteristic has been further defined as the perceived dissatisfaction between the actual and the desired satisfaction with one's social relationships (Perlman and Peplau, 1982), both in terms of the number of existing relationships being smaller than desired as well as the level of intimacy being less than desired (de Jong Gierveld, 1998).

Loneliness has been conceptualised as both uni-dimensional and multi-dimensional. An established distinction is that proposed by Weiss (1973) between social and emotional loneliness, from which parallels can be drawn to the characteristics of loneliness described by de Jong Gierveld above (de Jong Gierveld, 1998). Weiss describes social loneliness as the absence of a network of friends, family or community and so most closely linked with social isolation. Emotional loneliness, on the other hand, is the lack of a confidante or a trusting, loving relationship, even within a good social network. Social and emotional loneliness are not necessarily mutually exclusive and may be overlapping and experienced to different extents at different times. Weiss described both social and emotional loneliness as motivating factors (for example, to find a partner or be part of a social network) which may improve survival and have an evolutionary function. Recent qualitative research exploring emotional loneliness for older people identified the factors that may underlie emotional loneliness were lost and unfulfilled relationships, including the loss or lack of a partner, the absence of a meaningful friendship, complex parenthood and troubling childhood experiences (Tiilikainen and Seppanen, 2017).

Other ways in which loneliness has been characterised are in terms of its duration: whether loneliness is short-lived, recurrent, reactive and possibly circumstantial and linked to certain events or periods of life, or whether it is a more long-standing experience. The former has been described as 'state' and the latter as 'trait' loneliness. Trait loneliness has been described as a personality-related form of loneliness, which may be as a result of early childhood and 'poor' parenting causing, for example, difficulties in early attachment (Bowlby, 1969; Weiss, 2006). It has been suggested that personality characteristics such as low self-esteem may cause unsatisfactory patterns of interaction and heighten loneliness. Long-term, chronic loneliness, rather than the situational or passing loneliness, may be harder to treat (Griffin, 2010), but the intensity or severity of the negative feelings that also characterise the lonely experience need to be borne in mind.

Given that loneliness is a subjective experience and that at different stages over the life course people have different expectations of their social network and relationships, loneliness can mean different things at different times of life. Most research on loneliness has focussed on later life; however recent survey data has found that loneliness is highest in younger adults compared to older adults (Griffin, 2010; Office for National Statistics, 2018) and Victor and Yang (2012) report a 'U' shaped distribution from European Social Survey data, with both those aged under 25 and those aged over 65 years reporting higher levels of loneliness than other age groups.

A rapid review of the evidence of loneliness across the life course concluded that it was not possible to make definitive statements about the age at which loneliness risk was highest or to assume reasonable consistency in the levels of loneliness across all ages (Jopling and Sserwanja, 2016). The authors also reported key transitions which can trigger loneliness and certain groups who may be at particular risk; these are discussed later in this chapter.

Given the myriad of ways that loneliness has been conceptualised it is important to look beyond the prevailing definition and ask what loneliness means to the individual.

2.3 Theories of loneliness and ageing

Several theoretical bases to loneliness have been proposed, most notably from the disciplines of psychology, sociology, biology, neuroscience, social gerontology, demography and philosophy.

In the current literature, psychosocial theories of loneliness predominate. Psychological viewpoints include cognitive theories of loneliness which emphasise the cognitive processes involved in how social phenomena such as loneliness are experienced. Two such approaches are self-discrepancy theory (Peplau, 1982) and attribution theory (Lunt, 1991), which both explain loneliness in terms of the gap between expectations of social relations and perceptions of experience. They contribute to a widely used definition of

loneliness which describes loneliness as arising from a mismatch of the actual quantity and quality of social relations experienced compared to the desired levels; the greater the discrepancy, the greater the loneliness (Perlman and Peplau, 1982; de Jong Gierveld *et al.*, 2006). It has been argued, however, that being discontent with interpersonal relationships may lead simply to dissatisfaction rather than loneliness. Also that this definition groups together all social relations, not allowing for the fact that one may be discontent with one aspect, for example, the number of friendships, but content with other aspects, for example the level of intimacy in other relationships (Stein and Tuval-Mashiach, 2015).

Attribution theory (Lunt, 1991) has also contributed to explanations of how loneliness may become chronic. According to this theory, lonely individuals attribute their loneliness and interpersonal deficits to uncontrollable external causes and exhibit dysfunctional attitudes such as fear of rejection and insecurity in interpersonal relations, social embarrassment in social interactions and high levels of social anxiety (Marangoni and Ickes, 1989). These explanations need to acknowledge that individuals may seek different types of relationships and closeness at different stages of life.

Sociological perspectives on loneliness are based on an understanding of the social context within which individuals develop, or do not develop, social relationships. The implicit theoretical assumption is that loneliness is a consequence of social isolation which itself is caused by a lack of a sufficient social network (Victor *et al.*, 2009). Whilst sociologists might argue that a sole focus on the individual can only offer a partial explanation of loneliness, a purely sociological theory of loneliness may fail to acknowledge individual cognitive and behavioural drivers.

Many social gerontologists would argue that that loneliness in later life is determined by the influence of socio-economic factors that impact negatively on older adults which are reinforced by broader ageism in society and reflected in social policy concerns for the socially excluded and dependent (Townsend, 1981). Within the discipline these views have been challenged

to reflect the experience of the quality and quantity of time within the spectrum of later life which is lived in good health and financial security by some, described by some as the 'Third Age' (Laslett, 1996; Gilleard and Higgs, 2000). The work of Victor *et al.* (2009) exploring the social world of older people also questioned the earlier deficit models or concerns with social support. They aimed to demonstrate that loneliness and social isolation are not an inevitable part of later life by examining the social environment of older people and exploring patterns of engagement as well as exclusion. Their findings describe social relationships as dynamic and rooted in the life history of individuals. Also that social engagement is influenced by the wider social context; health, mobility, income and transport both help and hinder the ability to maintain social links. They propose that a focus on these would enable older people to maintain their relationships and participate fully in society. Their qualitative findings on experiences of loneliness are discussed further in Section 2.4 below.

Research from social neuroscientists in the US has suggested that loneliness is a biological construct which has evolved as a trigger to behaviour change in a similar way to the experience of hunger, thirst or pain (Cacioppo *et al.*, 2006a). Cacioppo and colleagues asserted that the negative feelings experienced when lonely motivate us to be sensitive to potential social threats and to renew and maintain the social connections required to prosper. They suggested that when meaningful social relations are perceived as severed or unavailable, loneliness impacts deleteriously on cognition and behaviour increasing the likelihood of loneliness becoming chronic (Young, 1982; Cacioppo and Hawkley, 2009). This perspective focuses on the experience of loneliness at an individual level and takes little account of the social context in which people live or their own interpretations of loneliness. Furthermore, defining emotional states such as loneliness in terms of biological pathways has been criticised for being reductionist (Rosedale, 2007), pathologising and medicalising loneliness (Victor *et al.*, 2009) and treating loneliness as a set of problems to be solved.

An alternative philosophical view, termed existential loneliness, defines loneliness as a primary and inevitable condition of existence for which no permanent remedy can be found (Moustakas, 1961; Mijuskovic, 1977). Proponents of this believe that humans are born into a world essentially alone, that loneliness is a consciousness of a person's own isolation, a motivating factor for pursuing connection, truth and meaning, a vital aspect of critical life transitions and a bridge for new possibilities (Rosedale, 2007). Contrary to other theories, existential loneliness is not a deficit model of loneliness; it is not seen in terms of losses that may be experienced, but an approach that seeks to encourage people to overcome their fear of loneliness and to use loneliness positively. Although the approach does not deny the pain of loneliness for some, it does ignore the potentially negative effects of being alone for some (Weiss, 1973). Existential loneliness also contradicts evolutionary and psychological theories, such as attachment theory (Bowlby, 1969) which suggests that children are born pre-programmed to form attachments with others, most commonly the mother, because this is essential to survival. These experiences of attachment in infancy can also shape the development of future attachment styles which predict the adequacy of future relationships and propensity for loneliness.

The contrasting theoretical bases of loneliness described above concur only in that they all consider loneliness to be a subjective experience.

Later life experiences of loneliness can also be considered within theories of ageing, such as disengagement theory (Cumming and Henry, 1961), activity theory (Havighurst, 1963) and theory of successful ageing (Rowe and Kahn, 1997). It is noteworthy that, as described above, most theoretical stances consider loneliness as an undesirable state and as outlined below, theories of ageing largely focus on maximizing positive experiences of ageing.

One exception is disengagement theory. Despite its limitations as a theory of ageing (Bowling, 2007), it is interesting to consider it how it relates to loneliness. According to disengagement theory (Cumming and Henry, 1961) a process of withdrawal from social ties is considered to be a fundamental

part of ageing. As relationships with others are perceived less essential, time alone or solitude gains more significance. In terms of loneliness, a reduction in the 'mismatch' of actual and desired relationships may reduce the subjective experience of loneliness. Perlman (1988) has also suggested that older adults may place greater emphasis on the quality rather than the quantity of their relationships, which may explain why older adults are not as lonely a group as stereotypes suggest. Expectations and stereotyping of loneliness in old age and actual self-reported loneliness were explored using the English Longitudinal Study of Ageing (ELSA) in a sample of 4465 respondents aged over 50. Both stereotypes and expectations related to loneliness in old age were significantly associated with reported loneliness 8 years later. The authors argue that interventions aimed at changing age-related stereotypes in the population may have more impact on reducing loneliness than individually based services (Pikhartova *et al.*, 2016).

Activity theory (Havighurst, 1963) emphasises the link between activity and well-being and that ageing well means the ability to maintain the activities and roles of middle age into later life, or substitute them as appropriate and in line with age related changes and challenges. Elements of this position have relevance to the prevention of loneliness by placing an emphasis on maintaining engagement with others and the community more broadly. Activity theory does not address those who experience loneliness earlier in their lives or consider how recurrent episodes of loneliness might influence the experience and coping strategies employed to deal with later life loneliness. Furthermore these social theories ignore the restrictions on the individual due to the power structures and patterns of inequalities in society (Bowling, 2007).

Rowe and Kahn (1997) theory of successful ageing draws predominantly on biomedical models of ageing. They distinguish between 'usual ageing' and 'successful ageing' with the key components of the latter being an absence or avoidance of disease or risk factor for disease, maintenance of physical and cognitive functioning, and active engagement with life. 'Successful ageing' according to Rowe and Kahn (1997) places responsibility on the

individual to make healthy lifestyle choices and remain independent. There are two key drawbacks of this theory and related discourse. Firstly, the failure to take into account the lifetime experiences of those in poor health and low income or insecure employment, who reach later life less physically and financially able to age 'successfully', and secondly, the fact that an inevitable part of ageing is dying.

Psychosocial models of successful ageing emphasise satisfaction with life, social participation and functioning, and psychological resources including personal growth (Havighurst, 1963). Components of these models, such as continued social functioning, positive interactions or relationships with others and society more broadly might inform strategies to prevent loneliness underpinned by sociological theories of loneliness. However, this model can also result in a negative judgement on those who are lonely or considered to be lonely and hence not aged 'successfully'. They are considered to have not taken responsibility for or made 'bad' choices in terms of relationships and connections and roles during their life, which then impact on their health and wellbeing.

An alternative theory, which aims to incorporate the influence of structural inequalities to ageing well, is the capability approach to ageing (Stephens, 2017). This frames wellbeing in terms of capability to function in ways that are meaningful to the individual and shifts the focus of responsibility for health from the individual to society. This approach is rooted in the disciplines of economics and philosophy of wellbeing and quality of life and the work of Sen (1993). Elements of this approach are evident in a prominent model of successful ageing, that proposed by (Baltes and Baltes, 1990). They conceptualize ageing as a changing balance between gains and losses. Successful ageing occurs when individuals are able to compensate for losses and remain satisfied with their lives; underlying assumptions include the heterogeneity of ageing, the value of an assets-based approach and considering older people as active agents in their wellbeing. If successful ageing according to these models means the absence of or ability to cope with loneliness despite experiencing age-related losses, this

suggests that qualitative work to explore the subjective experience of loneliness with a focus on responses to loneliness may be useful.

Given the lack of consensus on successful ageing and the subjectivity of the term, qualitative research has explored lay perspectives of what it means to age well. A systematic review of qualitative studies was carried out to supplement the researcher driven theoretical models outlined above (Cosco *et al.*, 2013). Findings emphasised the multi-dimensionality and psychosocial elements of successful ageing, in particular social engagement and personal resources such as attitude, as integral components of successful ageing more often than 'physiological' components, such as longevity or physical functioning.

Advocates of lay models of successful ageing argue that the theoretical models outlined above are used uncritically, reflect the academic discipline of the researcher (Bowling and Dieppe, 2005) and underestimate the proportion of older people ageing well compared to older people's own criteria for successful ageing (Strawbridge *et al.*, 2002). Bowling and Iliffe (2006) tested five models of successful ageing – biomedical, broader biomedical, social functioning, psychological resources and lay model – on a British cross-sectional population survey of older people. The lay model was the most multi-dimensional model and the strongest predictor of perceived quality of life, in comparison to the other uni-dimensional models.

Bowling's work (Bowling, 2008) exploring older people's views of active ageing and comparison to the literature found overlap and differences between lay definitions and models of active ageing in the literature. Older people focussed on basic definitions such as social, physical and mental health and activity, but excluded frail older people from active ageing. From the literature, models of active ageing reflected current philosophies such as productivity, empowerment, dignity, human rights and the enabling features of environments, but not individual priorities. Given the subjectivity of both, it could be argued that a similar stance be adopted for loneliness, namely in order to understand experiences of loneliness (the lay models) as well as

what responses might be appropriate or welcomed by the older person means that eliciting views of individuals with loneliness is key.

Loneliness in later life can also be considered within life course theory which takes into account the influence of life events, social and structural contexts and social change on the lives of individuals (Elder, 1994). It emphasises the dynamic nature of life transitions and relationships over time rather than view experiences as static or any stage of life in isolation (Harevan and Adams, 1982). As such experiences and responses to loneliness would be shaped by a cumulative life events and contexts rather than being viewed as later life specific.

The resonance and implications of these theories of loneliness and ageing to the findings of the research for this thesis will be discussed in Chapter 8 (Discussion).

2.4 Older people's experiences of loneliness

A relatively small number of qualitative studies on the experience of loneliness have been carried out in comparison to the quantitative research summarised in Chapter 1. The qualitative studies enable a deeper exploration of the experience and meaning of loneliness to the individual, including the context of loneliness which may be shaped by cultural expectations as well as views of past, present and future episodes. They consider how loneliness may be transient or chronic and the impact of these different experiences. Most regard loneliness as a deficit condition but some also identify potential beneficial aspects of the experience (Graneheim and Lundman, 2010). The main themes from research literature on experiences of loneliness are described below; older people's experiences of how they respond to and manage loneliness are presented in the findings of the systematic review in Chapter 3. Studies in which loneliness was the focus of the article are included; research in which loneliness is a secondary issue, for example, studies of bereavement, living alone, experiences of ageing, and so on, have not been included here.

A broad range of contexts, life experiences and the subjective appraisal of these are described in the literature. Feelings of loneliness are conveyed by an array of negative emotions in all the papers identified. They include distress, painful feelings, an aversive state (Heravi-Karimooi *et al.*, 2010), anxiety, fear and sadness (McInnis and White, 2001), feeling abandoned (Graneheim and Lundman, 2010), as 'wrong and ugly' (Dahlberg, 2007), a feeling of 'lostness' and not being understood by others (Roos and Klopper, 2010) and feelings of helplessness and emptiness (Ojembe and Kalu, 2018). A few studies mentioned the positive aspects of loneliness in which people have described the experience as restful and creative (Dahlberg, 2007), enriching, living in confidence and feeling free amongst the oldest old (Graneheim and Lundman, 2010). Other characteristics of loneliness include the temporal nature of loneliness (Stanley *et al.*, 2010), differentiating between situational and chronic loneliness (Cattan and *et al.*, 2003) and a withdrawal process (Ojembe and Kalu, 2018).

Several studies reported on role of relationships and loneliness. Detailed accounts of the quality of relationships (Dahlberg, 2007; Stanley *et al.*, 2010) are given as well as the impact of a lack of satisfactory relationships or connections. The latter are described both as an isolation or fracture of important or intimate relationships as well as from networks and the community (McInnis and White, 2001; Cattan and *et al.*, 2003; Heravi-Karimooi *et al.*, 2010; Barke, 2017). Poor relationships with children (both co-resident and living separately) and a lack of reciprocity in intergenerational relationships in Nigeria led to feelings of loneliness associated with unfulfilled expectations of familial relationships (Ojembe and Kalu, 2018). A study exploring the definition of loneliness that is meaningful in rural Ghana found that loneliness was experienced when older people were denied what was regarded as proof of respect and companionship: others coming to them for their wisdom and advice (Van der Geest, 2004). The work of Victor *et al.* (2009) on the social world of older people in the UK placed great emphasis on the wealth of relationships older people have in later life. Counter to the position of other papers, the authors asserted the

richness of older people's social worlds and reiterate that only a small proportion of older people experience loneliness.

Despite this, many lonely older people describe loneliness as being inevitable and inextricable from the ageing process, due to increasing isolation, deteriorating health and the loss of relationships (Pettigrew and Roberts, 2008; Smith, 2012). Although perceived as an accepted part of ageing, this was not always negative. Older people were considered to have some control over their loneliness and articulated a need to be proactive in initiating contact with others and pastimes (Pettigrew and Roberts, 2008; Barke, 2017) and that it was an individual's responsibility to remain connected and maintain a sense of belonging (Sullivan *et al.*, 2016; Barke, 2017). Older identity, both in terms of the social construction of age in which older people are 'invisible', represented negatively or stereotyped, as well as how older people conceptualise their own older age also shaped how loneliness was experienced (Barke, 2017).

The narrative of loss was evident in many accounts of loneliness; the impact of loss as a contributing factor to loneliness, the adaption to loss, as well as loneliness being described as a loss of future and having nothing to live for (Graneheim and Lundman, 2010; Roos and Klopper, 2010; Kirkevold *et al.*, 2013; Davies *et al.*, 2016; Ojembe and Kalu, 2018). Victor *et al.* (2009) described the relationship between loneliness and very close loss, which is separated into two categories dependent on whether the loss has a direct or indirect effect on an individual's level of social interaction. Loss of a partner, confidante, child or best friend was described as having a direct reduction in social interaction through the loss of contact with that individual. Loss of health, mobility, financial independence, transport and paid employment and the change in the nature of the external environment or neighbourhood, were described as losses indirectly affecting the individual's propensity to loneliness by restricting their means of accessing social interaction. The loss of connection to the community, environment and the 'outside world' has been reported by others as contributing to loneliness (Roos and Klopper, 2010; Taube *et al.*, 2016; Barke, 2017). The loss of social interaction and

connection can also overlap with loss of meaningful contribution. This describes both 'contribution' that has ended, for example, following retirement and the end of working life (Barke, 2017) or expected contribution that is unrealised such as the intergenerational expectation of having others seek wisdom and advice from them in later life (Van der Geest, 2004) as described in an anthropological study of loneliness in Ghana. Lack of opportunity to be actively engaged in society in has been described as contributing to feelings of loneliness in older people in Nigeria (Ojembe and Kalu, 2018).

The personal and private nature of how loneliness is experienced is relayed in these accounts. They refer to the stigma of loneliness, the difficulty in talking about it, (Dahlberg, 2007; Stanley *et al.*, 2010) describing loneliness as a 'silent suffering' (McInnis and White, 2001) and using distancing or denial as an attempt at self-preservation (Sullivan *et al.*, 2016).

There is limited qualitative research exploring social and emotional typologies of loneliness. A recent small study by Tiilikainen and Seppanen (2017) explored how the experiences of emotional loneliness are embedded in the everyday lives and relationships of older people. In interviews with 10 older people who were lonely often or all the time, recruited from an earlier survey, they focus on emotional loneliness, described as lost and unfulfilled relationships. They identified four themes behind emotional loneliness: the loss or lack of a partner, the absence of meaningful friendship, complex parenthood, and troubling childhood experiences. Their findings describe a diversity of past and present life experiences that reflect loneliness in later life, and emphasise the influence of the quality rather than the quantity of relationships on emotional loneliness.

Methodological challenges of these studies needs to be considered. A major limitation of Dahlberg's study (Dahlberg, 2007) was that findings are not differentiated by age within a study that included participants ranging from 12-82 years in age. Studies included older people who were willing to talk about loneliness but who did not necessarily self-identify as lonely.

Recruiting older people to gather their views on loneliness in research can be challenging and the strengths and limitations of different approaches that have been used are discussed in the systematic review on how older people manage loneliness in Chapter 3 and the associated paper (Kharicha *et al.*, 2018). Most research has recruited older people from services (for example day centres), organisations or based on their living arrangements (such as supported housing or those living alone); there is little research which has successfully engaged lonely older people not via these routes.

Another methodological consideration is the stigma of loneliness (Rokach, 2013), which may elicit socially desirable responses from participants. Lack of friendships and social ties is considered socially undesirable and the perception of those who admit to being lonely is largely unfavourable (Rokach, 2013). Loneliness may carry a stigma that not only affects the behaviour of people who feel lonely, but also the attitude of others (Weeks, 1994).

Experiences of loneliness across different cultures in these accounts include data from Finland (Tiilikainen and Seppanen, 2017), Sweden (Graneheim and Lundman, 2010; Taube *et al.*, 2016), Iran (Heravi-Karimooi *et al.*, 2010), South Africa (Roos and Klopper, 2010), Nigeria (Ojembe and Kalu, 2018), Ghana (Van der Geest, 2004), Australia (Pettigrew and Roberts, 2008; Stanley *et al.*, 2010), New Zealand (Davies *et al.*, 2016), US (McInnis and White, 2001; Smith, 2012), UK (Cattan and *et al.*, 2003; Victor *et al.*, 2009; Sullivan *et al.*, 2016; Barke, 2017), and a secondary analysis of three country data originally from Australia, Norway and UK (Kirkevold *et al.*, 2013). There is limited discussion within these papers of how of individual cultural beliefs and practices might influence definitions and experiences of loneliness and it is not possible to draw culturally-based inferences based on the data from each country. Culturally bound meanings add to the diversity of the experience of loneliness, further reiterating the subjectivity of loneliness.

2.5 Summary

Loneliness is a subjective experience which may be persistent over the life course, situational and related to losses common in older age or both.

Loneliness itself is a complex phenomenon and multiple theories exist.

Loneliness can be a private and possibly debilitating experience which is socially stigmatised. Whether or not people choose to seek support from services, there are likely to be times when lonely older people manage their loneliness by themselves. A better understanding of how older people ameliorate their loneliness themselves is needed. Chapter 3 will systematically review and appraise the available literature on self-management of loneliness.

2.6 Research questions

This qualitative study aims to add to the evidence on loneliness in later life by exploring in depth how community dwelling older people, who self-identify as lonely, explain the causes and experiences of their loneliness, and their attitudes towards involving others in ameliorating their loneliness, including using services and taking up social activities. In particular, these accounts will aim to understand how older people respond to and manage their loneliness themselves. The specific research questions that will be addressed are presented below.

1. How do lonely community dwelling older people understand their loneliness and its causes and consequences?
2. What are the views of this group towards involving others in their loneliness, including community based services and activities?
3. How do older people respond to and manage loneliness themselves?

A greater focus is given to the third research question as the evidence base is least developed in this area. This informed the rationale for the systematic review of the qualitative evidence on older people's responses to loneliness in this PhD, which is presented in the following chapter.

CHAPTER 3: STRATEGIES EMPLOYED BY LONELY OLDER PEOPLE TO MANAGE LONELINESS THEMSELVES: A NARRATIVE SYNTHESIS WITH MODEL DEVELOPMENT

This chapter presents the systematic review and narrative synthesis of the published literature of qualitative studies on strategies used in response to loneliness by community dwelling older adults. The review has been published (Kharicha *et al.*, 2018), see Appendix 5. Details of the review and synthesis that could not be expanded upon in the published paper due to word limitations are presented in this chapter. For pragmatic reasons, this systematic review was conducted after data collection and overlapped with data analysis of the interviews.

3.1 Background

3.1.1 *Alleviating loneliness*

The experiences of loneliness as well as the links between loneliness and health have been presented in Chapters 1 and 2. Interventions for loneliness and the evidence base for their effectiveness have also been outlined in Chapter 1 (Section 1.10). Systematic reviews have reported the effectiveness of community based interventions to reduce loneliness in later life (along with social isolation in some instances) but the quality of the evidence reviewed has been mixed and findings inconclusive (Frost *et al.*, 2010). The systematic reviews were largely limited to quantitative outcome studies (Cattan *et al.*, 2005; Hagan *et al.*, 2014; Cohen-Mansfield and Perach, 2015). An integrative review of interventions to reduce loneliness and social isolation in older people including both qualitative and quantitative studies reported reasons why interventions might be successful and explored effectiveness where feasible (Gardiner *et al.*, 2018). Their qualitative data reported that when solitary interventions were included with one-to-one interventions, they were more effective than group-based interventions for loneliness and social isolation (Gardiner *et al.*, 2018). ‘Solitary interventions’ included animal based and computer based interventions. In contrast to the other systematic reviews which have largely focussed on interventions provided by services or organisations, these

‘solitary interventions’ may be activities initiated and carried out independently by the individual. However the majority of studies of solitary interventions (two out of three animal based interventions and five out of six computer based interventions) were initiated by the research team as an ‘intervention’ rather than initiated by the older person themselves as solitary pursuits. The use of the term ‘solitary’ is also debateable as they are not strictly carried out ‘alone’; they include others, that is, pets or those people that they engage with via the computer.

Although this review (Gardiner *et al.*, 2018) reported its findings after this PhD was started and hence did not influence the development of the research questions, the review findings point to the importance of exploring ways in which older people alleviate loneliness by ‘interventions’ they initiate themselves which are not necessarily provided by services or organisations.

3.1.2 Individual responses to loneliness

It is likely that whether or not lonely older people are engaging with formal interventions, there are times when they deal with their loneliness themselves. The stigma of loneliness may be a further deterrent to seeking support. The broader strategies older people themselves employ to cope with feelings of loneliness have been less researched and not systematically reviewed. Given the subjective nature of the loneliness experience, qualitative data is key to understanding individual meanings and context of the loneliness experience as well as the response to these feelings.

The aim of this review is to systematically identify and review strategies employed by community dwelling lonely older people to manage feelings of loneliness themselves.

3.2 Method

3.2.1 Design

A systematic review of qualitative studies was carried out using a narrative synthesis approach, which followed Economic and Social Research Council (ESRC) guidelines. The synthesis included data extraction and tabulation, thematic analysis and conceptual model development (Popay *et al.*, 2006). The 21 items of the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement have been addressed in this review (Tong *et al.*, 2012).

3.2.2 Databases and search terms

The following seven electronic databases were searched: Medline, Embase, PsychInfo, CINAHL, Web of Science, Social policy and practice, ASSIA. Guidance on searching electronic databases was sought from university librarians to develop and refine the search. Endnote 7 software was used to manage the references.

Frameworks for search strategies include PICO(S) which stands for Populations, Interventions, Comparison, Outcomes (Study type) and the more recent SPIDER: Sample, Phenomenon of Interest, Design, Evaluation, Research type (Cooke *et al.*, 2012). The use of these frameworks for qualitative reviews has been debated (Methley *et al.*, 2014). In this research, the following inclusion and exclusion criteria were used.

3.2.3 Inclusion/exclusion criteria

Papers which met the following inclusion and exclusion criteria were searched for:

Inclusion criteria:

- People aged 65 years and over
- Identified or self-identified as lonely
- Living in the community, including assisted housing arrangements/supported care

- Report coping strategies for loneliness
- Loneliness is the focus of the study

Exclusion criteria:

- Living in residential/nursing care/long-term care facilities
- In hospital settings
- Those who are terminally ill/receiving palliative care

The review was limited to qualitative research only as the most appropriate methodology to address the review question.

Papers from 1990 onwards were included for two reasons. This date reflects a change in provision of community based health and social care services in England (NHS and Community Care Act, 1990). Also older people aged at least 65 and over in research conducted after this date represent a post-World War cohort who will have experienced major social and political changes which may have had an impact on their coping strategies to adversity.

Search terms addressing the following three areas were developed: (1) older people, (2) loneliness and (3) coping strategies. A full list is included in Appendix 1.

Scoping searches were run in June 2016 and November 2016. Broad search terms were used initially funnelling to a more focused search. Medical Subject Headings (MeSH) terms and subject headings for keywords were used where possible and adjusted for different databases as appropriate. Search terms for social isolation and loneliness were included in the initial searches; although they are recognised as distinct concepts, there is an overlap in meaning and they are sometimes used interchangeably. Search terms used in earlier systematic reviews (see Section 1.10) were referred to for guidance. Additional search terms for the coping strategies were identified, agreed with supervisors and incorporated. The final search was run at the end of January 2017. From the list of identified papers, I removed any

duplicates and then screened all titles and abstracts to identify those that met the study inclusion criteria. Full text review was then carried out to identify eligible papers; papers on social isolation alone and not loneliness, were excluded at this stage.

Citation tracking and reference lists of eligible papers were checked to identify any papers that may have been missed. I reviewed all full texts and a random sample over 10% of full papers was reviewed by a second reviewer (ND). Eligibility of final papers included and any papers where there was disagreement were discussed with input from supervisors and a consensus reached.

3.2.4 *Rationale for narrative synthesis*

There are debates about the appropriateness of synthesising qualitative data. It has been argued that key methodological and epistemological features of qualitative data, including issues of generalizability and qualitative data being specific to a particular context, time and group of participants, that are lost in synthesising individual studies and that findings from the synthesis process are de-contextualised (Dixon-Woods *et al.*, 2005). The value of synthesising qualitative research to inform the evidence base of effective and appropriate health care is also recognised (Thomas and Harden, 2008).

A range of different methods for synthesising qualitative research exist, many of which share basic similarities in their core approach to synthesising the data (Barnett-Page and Thomas, 2009). Synthesis of qualitative data aims to achieve a greater understanding and reach a conceptual or theoretical development beyond that attained in any individual empirical study (Campbell *et al.*, 2003). To achieve this, synthesis is considered to be more than the description and summarising associated with narrative literature review. Like secondary analysis, synthesis can involve re-interpretation of findings but the difference with secondary analysis is that published findings are used rather than primary data (Campbell *et al.*, 2003).

Different methods of synthesis were considered for this review. Meta-ethnography is a method of meta-synthesis first introduced in the education sector by Noblit and Hare to synthesise qualitative research (Noblit and Hare, 1988). Many newly developed synthesis methods, including thematic synthesis, draw on methods from meta-ethnography. Fundamentally, they involve the process of translating, which is taking concepts from one piece of work and finding these concepts in another study. Following on from this a line of argument is developed based on the theories and evidence presented within these concepts. The method has developed many times since then (Barnett-Page and Thomas, 2009), however, some argue it remains poorly described and understood (Atkins *et al.*, 2008).

Thematic synthesis (Thomas and Harden, 2008) was also considered. This method has three stages: i) 'line by line' coding of verbatim findings of each study, ii) the developments of 'descriptive' themes, and iii) the generation of analytic themes – the stage which 'goes beyond' the findings of the primary studies and is comparable to the 'third order interpretations' of meta-ethnography. The strengths of this approach however support hypothesis generation, which was not the aim of this review. Furthermore, having identified the eligible papers for this review, it was considered that to limit the analysis to verbatim findings alone would be restrictive as detailed accounts written as text, predominantly in the findings sections of papers but also in the conclusions, would have been excluded.

Narrative synthesis was considered a more appropriate method for the purpose of this review and the identified primary papers. Popay *et al.* (2006) describe it as a broader review process which includes a systematic approach to searching, appraising as well as synthesising evidence.

Narrative synthesis is an interpretive rather than integrative synthesis as the synthesis is conceptual both in process and output, and the main product is theory rather than aggregated data (Dixon-Woods *et al.*, 2005). Integrative synthesis is more appropriate for well-defined phenomena, unlike the subjective experience of loneliness. Narrative synthesis is useful when there

is a diversity of studies to be synthesised, for example a range of different settings, types of participants, or methods used, and considered more likely to make transparent the heterogeneity between studies and issues of quality appraisal, than thematic synthesis (Lucas *et al.*, 2007).

The Economic and Social Research Council (ESRC) has produced detailed guidance for conducting a narrative synthesis (Popay *et al.*, 2006) in response to criticisms of a lack of consensus on the individual elements within the method and a lack of a systematic and transparent approach. The ESRC guidance focusses and gives worked examples on the use of narrative synthesis for two types of reviews: questions of effects of interventions and/or factors shaping the implementation of intervention. However, they recognise that narrative synthesis can be used in a variety of research questions including the needs and preferences of particular population groups. They propose a generic framework with four elements which should be applied iteratively and as applicable to individual reviews. The ESRC guidance recognises that some of the recommended stages and tools listed may not be applicable for some review questions, as is the case in the current review. To answer the current review question in this thesis the ESRC guidance was used with deviation at points which are detailed and explained below.

The four elements to the narrative synthesis process are described below; they are not necessarily linear or sequential in approach.

- a. Developing a theoretical model of how the interventions work, why and for whom. This is a way of devising the review question and finding the appropriate papers to include in the review. This step is not included in the current review as it is considered useful for assessing effectiveness of interventions and developing a 'theory of change'.
- b. Developing a preliminary synthesis to organise all the data from the papers and develop an initial description of the findings of the

included studies. The report suggests a variety of methods and tools to help with the preliminary synthesis. For the purpose of the current review, data were extracted into a predefined table with the following headings: participants, study aims, exclusion criteria, sample site(s) and recruitment method/by whom, sample size and sampling method(s), data collection method, role of the researcher within the setting, data analysis method, key findings, implications (policy and practice), conclusion. A summary table of data containing a subset of these headings (author, year, country, study design, number / type of participants, analysis and main themes related to older people's views of coping with loneliness) was used for the preliminary synthesis of the narrative synthesis (see Table 1).

A brief textual description is then given of the included studies which draws out methodological differences in recruitment and how lonely older people are identified. Then a thematic analysis was conducted of the text from the findings and conclusions from the individual papers. Thematic analysis (Corbin and Strauss, 2008) was chosen as a technique for synthesising the data from the included studies as it allows the reviewer to identify commonalities and group the key findings of all studies; gaps in the literature can also be identified.

- c. Exploring relationships in the data is the third stage. The ESRC guidance provides a series of different approaches to begin to explore these relationships which moves a step further than the simple description of studies provided in the preliminary synthesis. These include developing conceptual models and conceptual mapping. For this thesis a conceptual model was developed to represent the main themes and the interaction between them.
- d. The final element from the ESRC guidance is the assessment of the robustness of the synthesis. The guidance defines the robustness of the study based on the quality of the included papers as well as the trustworthiness of the product of synthesising of these. For this

review, the Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme (CASP), 2018), was used to critically reflect on the included studies.

3.3 Results

The search process to identify eligible papers is presented in the PRISMA flow chart in Figure 1. Eleven papers were identified.

3.3.1 Quality appraisal

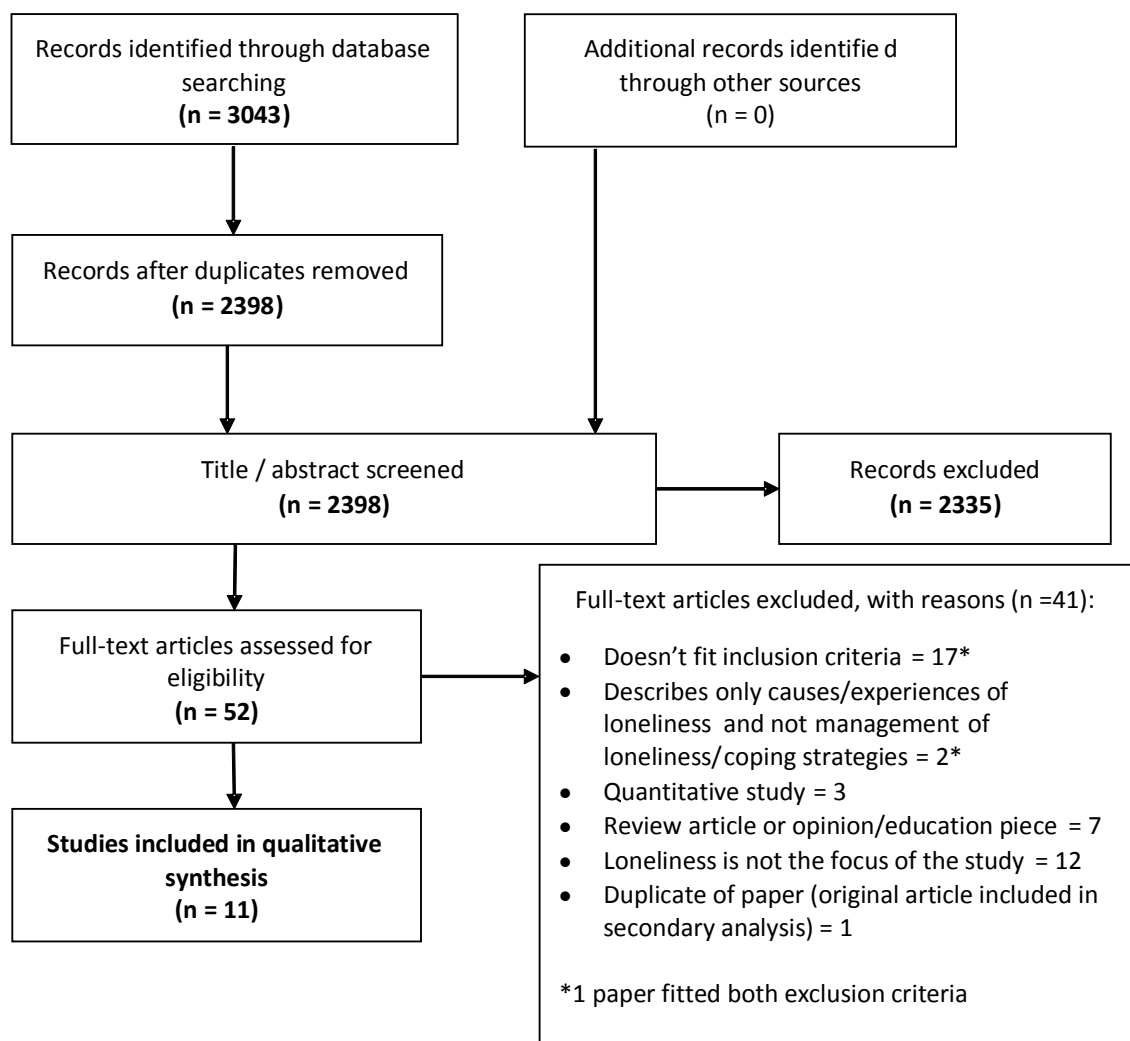
The CASP tool (CASP, 2018) developed for the appraisal of qualitative literature was used in this review. None of the eleven eligible studies were excluded based on the results of their quality appraisal; the tool was used to develop discussion of the included studies. Overall the studies were of mixed quality. Some of the detail lacking especially in the methods section may be due to the word limits on publications (Blignault and Ritchie, 2009). The data reported in the papers are appraised below.

In line with the inclusion criteria, all studies used a qualitative methodology, appropriate for exploratory research on subjective topics such as loneliness. The nine studies that collected primary data all used one-to-one, face-to-face interviews, either semi-structured or in-depth. Within these studies, two also used focus groups to gather the views of professionals (Cattan and *et al.*, 2003; Stanley *et al.*, 2010), and one was a mixed method study that also collected quantitative data (Smith, 2012). The two studies that did not collect primary data (Kirkevold *et al.*, 2013; Sullivan *et al.*, 2016) conducted secondary analysis of interview data. Most interviews took place in the participant's organisations (Cattan and *et al.*, 2003); there is no discussion about the potential impact of the environment on discussing sensitive topics like loneliness.

The aims of the research were clearly stated in all but one paper. Sullivan *et al.* (2016) described the foci of the two primary studies from which their data

is drawn, but the aim for the secondary analysis reported in the included paper is less clear. This is an exploratory discussion paper and the aim, ‘to discuss selected findings from a qualitative exploration of loneliness in the lives of older people’, is only stated at the beginning of the concluding comments section (Sullivan *et al.*, 2016 p175).

Figure 1: PRISMA flow chart



All studies sought appropriate ethical approval for primary data collection. In the two papers reporting secondary analyses, the authors do not state whether ethical approval was sought in the primary studies for the data to be used for secondary analysis.

The description of the data analysis was variable in the included papers. A mixture of analysis approaches were used with thematic analysis being the most commonly used (Pettigrew and Roberts, 2008; Stanley *et al.*, 2010; Kirkevold *et al.*, 2013; Davies *et al.*, 2016; Sullivan *et al.*, 2016), although this was inferred from the description in two papers rather than being stated explicitly (Pettigrew and Roberts, 2008; Kirkevold *et al.*, 2013).

Two papers described the possible influence of the researchers on the data collection by reporting the researchers' backgrounds and any previous knowledge of the study participants (Davies *et al.*, 2016; Taube *et al.*, 2016). One (Roos and Klopper, 2010) recognised the importance of being wary of researchers' views of loneliness whilst interviewing. Two studies (Cattan and *et al.*, 2003; Pettigrew and Roberts, 2008) involved participants in respondent validity (by sharing transcripts or early themes) but did not report if the analysis or interpretation were shaped by this. Two papers referred to having used the COREQ checklist (Tong *et al.*, 2007) for reporting (Davies *et al.*, 2016; Taube *et al.*, 2016).

Results were mostly well presented with core themes and verbatim quotes. However, authors' reflections were not consistently backed by data (Sullivan *et al.*, 2016), or quotes were merged within the descriptive text without accompanying demographic data for information or to gauge the spread of participants' views (Roos and Klopper, 2010). Two papers reported the hierarchy of themes (Roos and Klopper, 2010; Taube *et al.*, 2016). However, one paper combined data from older people attending community groups, with those attending who were thought to be lonely by the staff, not differentiating between the two data sets in their findings (Cattan and *et al.*, 2003).

Two papers reported culturally bound interpretations, specific to Hong Kong Chinese and South African culture (Roos and Kloppe, 2010; Lou and Ng, 2012) respectively. There was no discussion of cultural differences in the secondary analysis of the three-country dataset by Kirkevold *et al.* (2013).

3.3.2 Description of included studies

A summary of the 11 studies is presented in Table 1. Given the extensive published literature on the experience of loneliness in later life and how it might be alleviated, it was interesting to find that papers identified in this review on strategies to self-manage loneliness are limited to only 11 in number and all except one have been published within the last 10 years, so are relatively recent. The earliest paper (Cattan and *et al.*, 2003) contains limited information on older people's own strategies as the focus is on services for loneliness. In others, the focus is on the experiences of loneliness, but there is some indication in people's accounts of how they respond which can be interpreted as a way of managing the feelings and so the papers have been included (for example Stanley *et al.*, 2010).

In line with the inclusion criteria, all studies included older participants aged 65 and over, although a breadth of older age ranges was reported from those aged 55-94 (Cattan and *et al.*, 2003) to between 85 and 103 years (Graneheim and Lundman, 2010). Similarly all studies included community dwelling older people living either in their own homes or living independently in retirement villages or independent living units. Two studies also recruited older people living in more supported housing including long-term care (Stanley *et al.*, 2010) and residential care facilities (Roos and Kloppe, 2010). Findings are not differentiated either by age band or by the type of housing or support/care the participants were receiving, including whether or not participants required assistance to leave their homes, both potentially able to impact on an individual's ability to manage their loneliness.

The papers are predominantly from Western countries: England/UK (n=3), Australia (n=3) and New Zealand (n=1), Sweden (n=2) and Norway (n=1) and USA (n=1) with the exception of two papers that report different cultural

experiences of managing loneliness from Hong Kong, China (n=1) and South Africa (n=1). Few studies collected or reported information on ethnicity. Cattán and *et al.* (2003) acknowledge that due to the small number of people from ethnic minority groups included, their findings may not be applicable to the alleviation of social isolation and loneliness among ethnic minority older people. Lou and Ng (2012) identify their model as being a cultural model specific to Hong Kong, China. Living alone is not culturally desired or expected for older people and is considered to be a risk factor for loneliness. Older adults living alone but not experiencing loneliness are presumed to have a resilience or ability to manage their loneliness. Hence, in this study, older adults are eligible if, they live alone in the community but do not report feeling severe loneliness as assessed by the de Jong Gierveld Loneliness Scale Chinese version (a score below six). Roos and Klopper (2010) recruited an almost equal number of Afrikaans speaking and Tswana people who were able to speak English; they acknowledge that the Tswana-speaking people may have been limited in their ability to describe deeper meanings in English.

In all studies where gender was reported (all except Cattán *et al.*, 2003) the majority of the sample was female except Davies *et al.* (2016) who employed stratified purposive sampling to recruit an equal number of men and women. Other socio-demographic data reported included living alone/with others, marital status notably being widowed or divorced, urban/rural living, health status - usually physical and cognitive health, being in receipt of care, education level, having family or significant others including children or not, still driving or not. But no sub-group analyses were presented to illustrate any variation by socio-demographic factors.

Nine of the 11 eligible papers report primary analysis of data and two report secondary analysis with one of these combining both secondary and primary analyses of data. All data from the older participants in the studies was collected by face-to-face interviews, either semi-structured or in-depth; in addition one of the studies was mixed-methods and quantitative data was collected during the semi-structured interview (Smith, 2012). Two studies

also collected the views of practitioners (Cattan and *et al.*, 2003) or support/service providers (Stanley *et al.*, 2010) but the findings were reported separately in the papers and excluded from this review, which focusses on the views of older people alone.

3.3.3 Methodological issues

3.3.3.1 Identifying older people who are lonely

Four different approaches were used to identify older people who were lonely.

Older people **self-identified** as lonely in a variety of ways. Smith (2012) interviewed those who gave a positive response to the question of “Have you experienced loneliness within the last six months?” although it is unclear whether this initial question was asked verbally or presented in written form. Others had reported being ‘lonely’, ‘sometimes lonely’ or given an indication of strength of loneliness feelings in an earlier study from which they were then purposively sampled for interview (Sullivan *et al.*, 2016; Taube *et al.*, 2016) or stated being lonely or sometimes lonely during the course of an interview (Sullivan *et al.*, 2016).

Others had not necessarily identified as lonely but simply that they were **willing to talk about loneliness**, (Pettigrew and Roberts, 2008; Roos and Kloppe, 2010; Stanley *et al.*, 2010; Kirkevold *et al.*, 2013) and several studies **relied on practitioners** at community based organisations running groups or activities for older people, elder care or retirement village managers, to identify potential participants ie older people they thought were lonely or at risk of loneliness and likely to be interested in participation (for example Cattan *et al.*, 2003; Pettigrew and Roberts, 2008; Lou and Ng, 2012). Other studies used a range of **‘risk factors’ as proxy measures** for loneliness, such as being widowed (Davies *et al.*, 2016) or being very old (85 years and over) and living alone (Graneheim and Lundman, 2010), to explore coping strategies. Participants in these studies may or may not have been lonely themselves and may have given both their own views and experiences as well as those of ‘others’; combining these views may be problematic when loneliness is subjective experience.

3.3.3.2 *Recruiting participants*

Recruitment approaches are reported in most papers reporting primary data but little detail is reported in the two papers reporting secondary analysis in which the original sources are referred to. Recruitment strategies include distribution of written material about the study in centres used by older people Stanley *et al.* (2010) and recruitment via practitioners for example via practice nurses (Davies *et al.*, 2016).

Some studies employed several strategies at once, for example information being placed on notice boards of residential care facilities for all older persons to read and engaging both managers and practitioners to recruit potential participants (Roos and Klopper, 2010). And Stanley *et al.* (2010), report using newsletters and flyers distributed in partner care organisations as well as using key contacts within the organisation to inform older people about the study.

Others changed their recruitment approach after failing to recruit sufficiently, for example Smith (2012) reports that after initial unsuccessful recruitment using flyers at senior centres, a protocol change was necessary to allow recruitment via personal contact which was more successful as 'colleagues and friends were able to hand out flyers to those adults they perceived to be at risk for loneliness' (p296). The total sample size was 12 but there is no information on how many were recruited by each route. No data was reported in any of the papers on response rates to the different strategies, either individual or multiple, employed. Furthermore, in studies which employed more than one strategy, information is rarely given on the relative success of each.

In their secondary analysis of three country data, Kirkevold *et al.* (2013) no details on recruitment are not reported other than sampling, recruitment and interview guides were the same across all countries. Other studies recruited participants from larger preceding studies on ageing which either ask directly about loneliness (Taube *et al.*, 2016) or collect data on 'risk factors' for loneliness (Graneheim and Lundman, 2010) but no information is given on

how potential participants were approached. Some papers reported no details on recruitment (for example Cattin *et al.*, 2003) and others only the individuals responsible, for example elder care agencies and retirement village managers (Pettigrew and Roberts, 2008).

Table 1: Description of studies included, in chronological order

	Authors	Year / country	Study design	Number / type of participants	Analysis	Main themes related to older people's views of coping with loneliness
1	Cattan M, Newell C, Bond J & White M	2003 / England	Semi-structured interviews & focus groups	23 staff members from voluntary sector run health promotion projects targeting loneliness and social isolation in older people, 22 focus groups with 145 older people who participated in project activities, 25 interviews with older people who participated in project activities whom project staff considered to be socially isolated and lonely.	Framework analysis	i) Perceptions and experiences of social isolation and loneliness, ii) Coping strategies, iii) Perceptions and experiences of services and activities, iv) Solutions

2	Pettigrew S & Roberts M	2008 / Australia	Semi-structured interviews	19 older people living in retirement villages or on their own.	Thematic analysis (though not stated)	i) Social interaction: a) Interacting with others, b) Eating and drinking rituals; ii) Solitary activities: a) Reading, b) Gardening and c) Television.
3	Granheim UH & Lundman B	2010 / Sweden	Interviews	30 people aged 85 and over, who lived alone in their own homes, or apartments in houses for older people.	Content analysis	Themes related to loneliness are intertwined with themes related to experiences of ageing whilst living alone. Four main themes: i) Living with losses: Suffering from bodily decline; Being dependent; Mourning significant others; Missing zest for life; Longing for meaning. ii) Feeling abandoned: Feeling set aside; Feeling invisible. iii) Living in confidence: Feeling safe and secure; Leaving everything in God's hands; Feeling content; Accepting the loneliness.
4	Roos V & Klopper H	2010 / South Africa	In-depth interviews	31 older people, 4 lived in residential care, 3 lived with their children, 1	Phenomenological approach to identifying themes	3 themes: expressions of loneliness, causes of loneliness and coping with loneliness.

				lived in own home, rest (n=23) in own house/flat in a retirement village.		Coping with loneliness: Self-awareness and preferred style of interaction; Humour; Preparations for and dealing with losses; Meaningful interpersonal contact; Religion; Active engagement with life.
5	Stanley M, Moyle W, Ballantyne A, Jaworski, Corlis M & Oxlade D	2010 / Australia	Focus groups and semi-structured interviews	8 focus groups with approximately 64 support / service providers for older people, and interviews with 60 older people living in long-term care, independent living units and the community.	Thematic analysis	Key themes describing loneliness, as: i) Private, ii) Relational, iii) Connectedness, and iv) Temporal. Within these themes, descriptions of loneliness experience are given as well as coping strategies.
6	Lou VWQ & Ng JW	2012 / Hong Kong, China	Semi-structured interviews	13 community dwelling adults, living alone and not severely lonely	Interpretive approach	A cultural specific model: relationship-oriented resilience to senses of loneliness in a Chinese context. 3 primary themes: i) Cognitive resilience: a) Cognitive

						<p>pragmatics, b) Everyday competence</p> <p>ii) Self and personality: a) Interdependent self, b) Open and accommodating,</p> <p>iii) Social relations: a) Social affiliation, b) Social companionship.</p>
7	Smith JM	2012 / USA	Mixed methods (quantitative & semi-structured interview)	12 older people, either attending senior centers or (the majority) via personal contact from colleagues and friends.	Interpretative phenomenological approach including thematic analysis	<p>i) Sustaining connections with others: a) Reaching out to others, b) Helping those in need (volunteering), c) Seeking companionship with pets.</p> <p>ii) Finding comfort in television and other hobbies.</p>
8	Kirkevoid M, Moyle W, Wilkinson C, Meyer J & Hauge S	2013 / Australia, Norway & UK	Secondary analysis of in-depth interviews	78 older people: 26 lived in long-term care, 19 in an independent living unit, and 33 in private homes.	Thematic analysis (though not stated)	<p>Impact of losses was closely related to loneliness experience. Four central themes related to losses were dichotomised by 'not lonely' / 'lonely' groups as follows:</p> <p>i) Accepting losses and moving on vs. being overpowered by accumulating losses,</p> <p>ii) Staying committed to activities vs.</p>

						<p>unable to carry on with activities,</p> <p>iii) Staying connected to other people vs. being isolated from other people,</p> <p>iv) Creating a meaningful life in one's own company vs. a life alone is an empty life.</p>
9	Davies N, Crowe M & Whitehead L	2016 / New Zealand	Narrative inquiry	40 older widow/widowers	Thematic analysis	<p>Three broad themes: Experiencing the absence, Loss of routine connection and Establishing new routines, which describe the experience of loneliness following widowhood from an acute phase of experiencing an absence and the associated loss of routine connection to the establishment of new routines that provided new connections and a new sense of identity as an individual rather than a couple. The process was facilitated by keeping active and having access to mobility. The participants also described having to manage the social norms associated with what behaviours others expected</p>

						from a widow or widower. This was not a linear trajectory and many of the participants continued to experience periods of loneliness.
10	Taube E, Jakobsson U, Midlov P & Kristensson J	2016 / Sweden	Semi- structured interviews	12 older people purposively selected from a larger intervention study (randomized controlled trial)	Content analysis	<p>Overall theme: Being in a Bubble</p> <p>3 themes with subthemes within this:</p> <p>i) Barriers:</p> <p>a) The ageing body, b) Fear, c) The influence of losses, d) No one to share daily chores with</p> <p>ii) Hopelessness:</p> <p>a) A constant state, b) Feeling sad, empty and anxious, c) Being invisible to others, d) Losing the spirit</p> <p>iii) Freedom:</p> <p>a) Having time to reflect and reload, b) Being free to make decisions, c) Being able to create meaningfulness, d) Having a social belonging, e) Being protected from disappointment</p>

11	Sullivan MP, Victor CR & Thomas M	2016 / England, UK	<p>Secondary analysis of in-depth interviews from study 1 informed the development of primary data collection using in-depth interviews in Study 2</p>	<p>Study 1) 25 older people who identified as lonely / sometimes lonely in a larger mixed methods study on loneliness and social isolation in later life.</p> <p>Study 2) 12 older people participating in a mixed methods pilot longitudinal study on temporal variations in loneliness.</p>	Thematic analysis	<p>Findings separate the accounts of those who talked 'openly' about loneliness from those who found it harder to talk about, emphasising the dynamic and multi-dimensional aspects of loneliness.</p> <p>Coping strategies include internal factors eg acceptance, finding, inner strength, keeping loneliness hidden, and external factors eg reading, 'keeping busy', having routines, maintaining and activating social networks</p>
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3.3.4 Main findings of the synthesis

Thematic analysis of the findings and conclusions of eligible papers identified a range of strategies older people use to manage their loneliness. I have described these findings in full in my paper with quotes of supporting data (see Appendix 5) and summarise them in brief here.

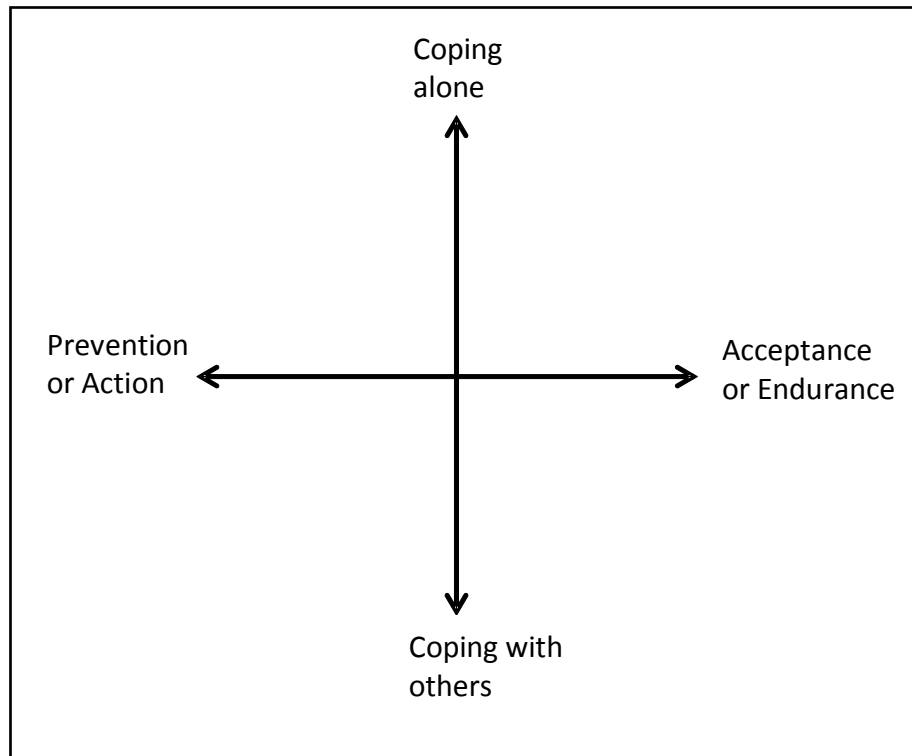
The themes can be grouped into two overarching dimensions. Firstly, the context of coping, that is, whether people coped alone or by involving others, either directly or in reference to others, that is, the strategies employed were carried out with others in mind. The context of coping highlighted individual preferences of involving others in responding to loneliness and the desire, by some, to manage loneliness privately.

The second dimension described the type of strategy used and included prevention or action in response to loneliness and acceptance or endurance of loneliness. Prevention of loneliness or protection against loneliness included both actual strategies practised in an attempt to deter loneliness as well as 'hypothetical' strategies; the latter may be related to how older people were identified as being lonely (see Section 3.3.3.1) or the difficulty in talking about personal experiences of loneliness. Actions were the strategies performed to alleviate distress. Acceptance describes strategies that people had used to come to terms with their experience of loneliness. An extension of these strategies is described as endurance in which the challenges of coping with loneliness are a feature of the strategy. Acceptance and endurance largely describe cognitive strategies used to manage loneliness. They overlap to some extent in their definition but differ in that acceptance implies an adequate resolution to the experience of loneliness and endurance explains how the unpleasant feelings continue and are 'lived with'.

The two overarching dimensions are overlapping. I have presented these as a conceptual model of managing loneliness (see Figure 2). An individual

could be placed on these continuums based on their desire to involve others in their loneliness and their preference of strategy type within the spectrum.

Figure 2: A model for managing loneliness in later life



The themes within the dimensions are presented (in *italics*) below. Some themes – *personality related strategies, shifting the focus away from yourself, planning and creating a structure or routine, going outdoors regularly, religion and spirituality and comparative thinking* - spanned more than quadrant of the model and are described first. Themes describing strategies specific to coping alone or coping with others are then presented.

Within the context of coping alone, *personality related strategies* straddled both prevention/action and acceptance/endurance strategy types. These strategies were underpinned by the belief that it was an individual's responsibility to manage their loneliness (Roos and Klopper, 2010; Stanley

et al., 2010; Sullivan *et al.*, 2016). Strategies included having to be determined and motivated to stay active, focusing on the positive, taking pride in yourself and your environment, an ability to draw on 'inner strength' (Roos and Klopper, 2010; Stanley *et al.*, 2010; Lou and Ng, 2012; Kirkevold *et al.*, 2013) and, amongst the very old, was described as having a 'fateful' approach and living in the moment (Taube *et al.*, 2015; Graneheim and Lundman, 2010).

Within the context of coping with/in reference to others the theme of *shifting the focus away from yourself* spanned both prevention/action and acceptance/endurance strategy types. Examples of activities included volunteering, caring responsibilities and socialising for the sake of others (Pettigrew and Roberts, 2008; Smith, 2012; Kirkevold *et al.*, 2013; Roos and Klopper, 2010; Taube *et al.*, 2016). In terms of acceptance/endurance, this strategy described how individuals adjusted their own expectations for the sake of a 'collective well-being', for example, by living alone rather than expressing the desire to live with family (Lou and Ng, 2012; Kirkevold *et al.*, 2013).

Making the effort *to plan and create a structure or routine* was a prevention/action strategy that was practised within both the contexts of being alone and with others. Daily patterns were practiced by those who had been alone for some time, those adjusting to life alone after bereavement as well as those planning for loneliness perceived as inevitable in the future (Lou and Ng, 2012; Sullivan *et al.*, 2015; Roos and Klopper, 2010; Kirkevold *et al.*, 2013; Davies *et al.*, 2016). Plans and structures in relation to others included both formal and informal exchanges most commonly related to food and drink rituals (Pettigrew and Roberts, 2008; Lou and Ng, 2011; Smith, 2012). A common aspect of routines was *going outdoors regularly* and this was carried out both alone (for example Roos and Klopper, 2010; Lou and Ng, 2012) as well as with the hope of initiating chance encounters or exchanges with others (Lou and Ng, 2012; Cattán *et al.*, 2003; Sullivan *et al.*, 2016).

Similarly, *religion and spirituality* were described as preventative or actions that helped people cope both alone (Graneheim and Lundman, 2010; Roos and Klopper, 2010) and with others who shared their beliefs (Roos and Klopper, 2010).

Comparative thinking was an acceptance/endurance type strategy that was used both alone and in relation to others. When used alone, the strategy described how later life loneliness was accepted or endured by comparing it to times in their earlier life which had been difficult to bear emotionally (Graneheim and Lundman, 2010; Lou and Ng, 2012; Sullivan *et al.*, 2016). In relation to others, people described how they came to terms with their own situation by comparing themselves to other people or situations that were perceived to 'worse' (Cattan and *et al.*, 2003; Taube *et al.*, 2016).

Coping alone

Other themes within coping alone which were specific to prevention/action included *keeping busy*, and described solitary pastimes - both those which were considered more engaging or meaningful such as reading or gardening as well as those that were more passive and a distraction from loneliness such as watching the television (Pettigrew and Roberts, 2008; Roos and Klopper, 2010; Lou and Ng, 2012; Smith, 2012; Kirkevold *et al.*, 2013; Sullivan *et al.*, 2016; Taube *et al.*, 2016).

Strategies within acceptance/endurance of loneliness also included perceiving *loneliness as inevitable*; considering loneliness as commonplace helped people to come to terms with their own experience (Pettigrew and Roberts, 2008; Graneheim and Lundman, 2010; Roos and Klopper, 2010). The *temporal nature of loneliness* and learning from previous experiences that acute distress can pass, was a means of accepting or enduring the feelings in the moment (Green *et al.*, 1992; Roos and Klopper, 2010; Stanley *et al.*, 2010). This strategy could be drawn on to bring temporal relief and was not described as a 'cure' for loneliness. Also described was a *re-framing*

of *loneliness* in which the advantages and freedom of being alone, such as the opportunity to reflect and do what one wanted, were emphasised (Graneheim and Lundman, 2010; Roos and Kloppe, 2010; Taube *et al.*, 2016). In response to loneliness that was persistent and managed privately, the *constant effort to fight feelings* acknowledged the challenges of managing chronic loneliness alone and efforts to find small relief where possible (Taube *et al.*, 2016).

Coping with/in reference to others

Coping strategies that involved others and can be described as prevention/action strategies are outlined first. The importance of *establishing, maintaining, nurturing, repairing relationships and connections* was widely reported, most commonly in reference to family and friends but also included pets (Smith, 2012) and care workers (Graneheim and Lundman, 2010). The nature of the interaction varied from 'simple' contact to having confidantes. The importance of having boundaries around what is shared within these groups in order to maintain relationships was also raised (Pettigrew and Roberts, 2008; Roos and Kloppe, 2010; Stanley *et al.*, 2010; Lou and Ng, 2012; Smith, 2012; Kirkevold *et al.*, 2013; Davies *et al.*, 2016; Sullivan *et al.*, 2016; Taube *et al.*, 2016). Another strategy which was described as challenging and a reluctant necessity was *being open to new experiences* such as clubs or activities; those that had tried this described the benefits they had experienced after the effort to engage (Cattan and *et al.*, 2003; Lou and Ng, 2012; Kirkevold *et al.*, 2013; Davies *et al.*, 2016).

Another coping strategy related to acceptance/endurance was *keeping loneliness hidden or a secret*. Employing this strategy entailed denying personal feelings of loneliness so that they did not impact on relationships with others. This was based on the perception of admitting loneliness being seen as a failure (Stanley *et al.*, 2010; Lou and Ng, 2012; Sullivan *et al.*, 2016).

3.4 Summary

This systematic review and narrative synthesis of the qualitative data identified a range of strategies employed by community dwelling lonely older people to manage feelings of loneliness themselves. The subjective and dynamic nature of loneliness was echoed in a range of coping mechanisms drawing on individual coping styles and preferences. Strategies highlighted the effort put into managing and filling time, contacting others, keeping loneliness hidden and cognitive strategies to re-frame negative feelings to make them more manageable or help shift the focus from the present time or themselves.

The findings of the review provide a broader perspective on responses to loneliness than earlier systematic reviews which have predominantly focussed on interventions provided by services and to increase contact with others. Several strategies described how people responded to their loneliness alone and, in some instances, preferred to manage privately. Caution is needed regarding the positive framing of coping with loneliness in this review; it appears as if most people have successful coping strategies. The views of those who felt they were not coping are likely to be under-represented.

The challenges of identifying and recruiting participants to talk about a distressing experience such as loneliness were highlighted in this review. Given the subjectivity of loneliness it is important to differentiate between those who self-identify as lonely and those willing to talk about it who may or may not be lonely.

This review has highlighted the need to engage with older people who self-identify as lonely to explore how older people understand their experiences of loneliness, how it affects them and what responses to loneliness they consider appropriate. It has also emphasised the limited evidence from older people who are not using services or taking part in social activities; community dwelling older people who are lonely and do not engage with

these may have different views on how they wish to respond to their loneliness including involving others. These gaps in evidence have informed my PhD which aims to explore how older people who self-identify as lonely, understand the causes and consequences of their loneliness and how they respond to and manage their loneliness themselves. The qualitative study carried out for this PhD is presented in the following chapters. The next chapter (Chapter 4 Methods) includes details of how a sample of community dwelling older people who self-identified as lonely was recruited. Findings corresponding to the three research questions of this thesis (see Chapter 2 Section 2.6) are then presented in the Findings chapters (Chapters 5, 6 and 7). The themes identified from my interviews have been mapped onto the model for managing loneliness developed in this systematic review and are presented in Chapter 8 (Section 8.2.4.1).

CHAPTER 4: METHODS

In this chapter I firstly outline an earlier study, the Well-being Interventions for Social and Health needs (WISH) study, from which the sample for this thesis was drawn. The role of Public and Patient Involvement (PPI) members in this research is then outlined. I will then present the philosophical debates in qualitative research, the stance I have adopted and the justification for using qualitative research methods in this study. The stages of recruitment, data collection and analysis are then described, followed by reflections on data collection and analysis.

4.1 Overview of the Well-being Interventions for Social and Health needs (WISH) study

For this thesis I purposively sampled participants from the Well-being Interventions for Social and Health needs (WISH) study that had been funded by the Medical Research Council under its Life Long Health and Well-being (LLHW) Phase 3 programme (2012-2013). My role in the WISH study is outlined in the Statement of intellectual property/contribution on page 17 and a brief overview of the study is given below.

The WISH study explored the feasibility and costs of embedding a primary care intervention to promote the health and well-being of older people. The intervention was the Multi-dimensional Risk Appraisal for Older people (MRAO) (Iliffe *et al.*, 2010). This is a comprehensive multi-domain questionnaire which works with an 'expert' software system to generate personalised feedback based on questionnaire responses to identify needs and signpost individuals to local or national resources. Details of the study processes are reported elsewhere (Walters *et al.*, 2017).

4.1.1 Study setting and recruitment

The WISH study took place in two English localities, the London Borough of Ealing in West London and the County of Hertfordshire. These areas were selected to enable comparisons between urban and semi-rural locations and

for their diversity in terms of socio-economic characteristics and proportions of minority ethnic groups within the older population. The study population was recruited from NHS general practices; three general practices in Ealing and two in Hertfordshire. Recruitment was facilitated by local NHS Research Networks and contacts within the locality Clinical Commissioning Groups (CCGs) in both areas.

4.1.2 *WISH study population and eligibility criteria*

The GP practices identified eligible patients using inclusion and exclusion criteria. The inclusion criteria were: adults aged 65 years and over, who were community dwelling, permanently registered with participating GP practices and living in the local authority area. Patients were excluded if they had a severe incapacitating, life-threatening or terminal illness, were unable to provide informed consent (for example, had moderate to severe dementia/learning disability), or those for whom an assessment would be considered burdensome at the time of recruitment (for example, bereavement within 3 months, life-threatening illness in family member).

Searches to identify eligible patients and exclude ineligible patients were carried out in two stages: (i) using practice-specific search terms on the electronic patient record, and (ii) manual review of this list by GPs or practice nurses to ensure that patients had not been missed in the first stage and were not inappropriately contacted, based on their knowledge of the patient.

4.1.3 *Recruitment and data collection*

General practices wrote to eligible older people to invite them to participate in the study. A covering letter signed by the practice lead for the study was posted along with a patient information leaflet, consent form, an opt-in reply slip and a pre-paid return envelope addressed to the practice. Practices were asked how they engaged with patients who had difficulty reading, writing or with spoken English so that these methods could be employed in recruiting those for whom English was not their first language, and for those with sight or literacy problems. Written materials were available in large print

versions and could be translated into other languages as necessary, but this was not requested by the practices or by patients. Patients were encouraged to discuss the study with their friends and family and to contact the research team if further information might help inform their decision to participate.

Consenting participants were posted questionnaires at baseline, three and six months. A written reminder was sent to non-responders after two weeks. Assistance was available from the research team over the telephone for anyone unable to complete the written questionnaires or for other research-related queries.

4.1.4 *WISH study data relevant to this thesis*

Key data from the WISH study for this thesis included:

- a. Socio-demographic and economic data including age, gender, ethnicity, education, household composition (living alone or living with others), marital/civil partnership status (single, divorced or separated, widowed, married or in civil partnership or living with partner), caring responsibilities and whether they found this difficult, recent life events such as bereavement and ill health. Health and well-being data included whether the older person had difficulty looking after themselves, leaving their home or using transport, co-morbidities including physical and mental health problems, their social network and their recent use of local services and organisations.
- b. Responses to the single question on loneliness contained within the MRAO, which is phrased as follows: 'Do you feel lonely much of the time?' and to which the response options are 'Yes' or 'No'.
- c. The de Jong Gierveld 6-item loneliness scale (de Jong Gierveld and van Tilburg, 2006), which was added to the supplementary booklet of questionnaires for the purpose of this thesis' data collection and was not part of the original WISH study protocol. The shorter version, rather than the 11-item scale (de Jong-Gierveld and Kamphuls, 1985), was used to minimise participant burden. Reasons for the choice of this loneliness measure are outlined later in this chapter (Section 3.2).

4.1.5 Postal questionnaires in the WISH study

Structured postal questionnaires were used in the WISH study as a relatively low-cost method of accessing information about a large sample of people and are widely used in health services research (Bowling, 2014).

Questionnaires can be completed over more than one sitting so may be less onerous than face-to-face interviewing particularly for older people. A key limitation is in the use of pre-coded response choices which may not accurately reflect participants' views. Postal questionnaires eliminate interviewer bias and are useful for sensitive subjects on account of the added anonymity. However, this method is only useful when the topic and questions are straightforward (Bowling, 2014). Although loneliness can be considered a sensitive topic and participants may be more likely to disclose loneliness in a postal questionnaire than if asked directly, only a partial understanding of the loneliness experience can be gathered using pre-defined response options. Therefore, although useful in identifying a sample of lonely older people, supplementing them with exploratory qualitative methods may assist in gaining a deeper understanding of the topic. The advantages and disadvantages of sampling participants from the WISH study are reported in Chapter 8 (Discussion Section 8.3.3).

4.2 Measuring loneliness / identifying those who are lonely

Given the subjective nature of loneliness, identifying those who are lonely and the extent of their loneliness relies on self-report. Assessments and measures of loneliness vary from the use of a single question to multi-item scales. Single item questions typically include the term 'lonely' in the wording and invite either a yes/no response or choice from a range such as from 'never' to 'always'. Such assessments are simple to administer both for research purposes and in clinical settings but there are several drawbacks. Using the word lonely may be problematic for some, if they are reluctant to self-identify as a 'lonely older person' for reasons discussed. Further, asking about loneliness as a unidimensional concept would assume that the loneliness felt by someone who has experienced the loss of their partner and confidante is equivalent to the loneliness felt by someone who has recently

retired. The single item question may identify those who are lonely, but does not give any indication of what loneliness means to that individual which might influence how they wish to respond to it. Differentiating between different types of loneliness may be helpful when considering therapeutic interventions (O'Luanaigh and Lawlor, 2008). It would follow that the emotional loneliness experienced by the recently bereaved older person who has lost their partner may not be alleviated by attending social support groups but that this may be helpful for those who are socially lonely and in other contexts.

Several multi-item scales or questionnaires have been developed to measure loneliness, both as a uni-dimensional and multi-dimensional concept. It should be noted that several of these scales have been developed and validated for use with younger, adolescent and university age populations. Two widely used scales are the University of California Los Angeles (UCLA) Loneliness Scale (Russell *et al.*, 1978) and the de Jong Gierveld 11-item loneliness scale (de Jong-Gierveld and Kamphuls, 1985), which both derive from a psychological base and have been validated for use with an older population as well as a younger adult population (van Tilburg and de Leeuw, 1991).

The most widely used self-report loneliness measure is the uni-dimensional UCLA Loneliness Scale (Russell *et al.*, 1978) originally a 20-item scale, which was then revised to a 10-item version (Russell *et al.*, 1980), and then further simplified to Version 3 of the UCLA Loneliness Scale, (Russell, 1996). The scale has response options hardly ever / some of the time / often, and distinguishes between social and emotional loneliness. Its widespread use means that population norms are available for different populations but there are clear limitations of the use of a scale developed on US college students to a UK older population. It has been critiqued as reflecting the interests of social psychologists, namely loneliness as a personality trait or a state-related entity (Victor *et al.*, 2009).

Unlike the UCLA Loneliness scale, the de Jong Gierveld loneliness scale measures loneliness as both a single as well as a multi-dimensional construct, distinguishing between social and emotional loneliness as described by Weiss (Weiss, 1973). It is based on a cognitive theoretical approach to loneliness and the discrepancy between what one wants in terms of interpersonal affection and intimacy, and what one has; the greater the discrepancy, the greater the loneliness. The scale addresses three dimensions associated with loneliness: firstly, feelings and emotions related to the absence of an intimate attachment, such as emptiness and abandonment. Secondly, how loneliness is interpreted by the individual, and thirdly, the scale alludes to a range of emotions including sorrow, sadness, shame, guilt or frustration. It can be argued, however, that these negative emotions might also be due to factors or distress other than those associated with loneliness.

The de Jong Gierveld loneliness scale was originally developed as a 34-item multidimensional scale of loneliness (de Jong Gierveld and Raadschelders, 1982), from which an 11-item unidimensional scale was developed (de Jong Gierveld and Kamphuls, 1985), as well as a shorter 6-item version for use in larger surveys which was later developed and validated (de Jong Gierveld and van Tilburg, 2006). It was designed for use with older people and the shorter 6-item version has been tested for reliability and validity in seven countries, including the Netherlands, France, Russia and Japan (de Jong Gierveld and van Tilburg, 2010). Its use in rural Ghana has been challenged based on qualitative work which sought to describe what loneliness meant to older people; the emerging definitions of being denied respect and a source of wisdom were not represented in the scale (Van der Geest, 2004). The UCLA and de Jong Gierveld loneliness scales are the most commonly used measures of loneliness; a recent assessment of both scales has shown the relative superiority of the de Jong Gierveld for the study of middle-aged and older adults (Penning *et al.*, 2014). The 6-item de Jong Gierveld scale is the most widely used with an older population which informed the decision to use it in the research for this thesis (see Appendix 2).

Measurement tools are useful to quantitatively determine the prevalence of loneliness as well as cross-sectional associations and causality over time in cohort studies after controlling for predefined potential confounders. However, they have limitations. As well as the risk of under-reporting described above related to the stigma of loneliness and the comprehensibility of the language used, the tools may also fail to capture individuals whose experience of loneliness may fluctuate over time. Current measures on the whole do not capture the distinction between 'state' (short-term) or situational loneliness and trait (long-term or enduring) loneliness which may also be related to personality traits (Heinrich and Gullone, 2006). Victor *et al.* (2009) argued that measurement tools need to be reviewed to ensure that they capture older people's understanding of these concepts as well as incorporating the dynamic element and distinguishing between the different types of loneliness in later life. A key limitation for using measurement tools to explore subjective phenomena such as loneliness is that they have predefined responses which may fail to capture the meaning of loneliness for individuals, acknowledge the wider context of their loneliness, or the cause or consequence of their loneliness.

To address the lack of conceptual clarity in terminology to describe loneliness and isolation, Valtorta *et al.* (2016) proposed a way of classifying instruments to better enable comparison across disciplinary boundaries. They identified 54 measures of social relationships and classified them according to whether instruments cover structural (quantitative) or functional (qualitative) aspects of social relationships and the degree of subjectivity asked of respondents based on how questions are phrased. As might be expected, instruments measuring loneliness (for example, the UCLA Loneliness Scale and the de Jong Gierveld Loneliness Scale) were based on more subjective questions, whereas social network indices primarily use more objective measures. Interestingly, loneliness measures focussed exclusively on the functional aspects of relationships, which challenge the widely used definition of loneliness as resulting from the lack of satisfactory quantity as well as quality of their relationships (Perlman and Peplau, 1982).

If the functional (qualitative) and subjective elements of loneliness measures are identified as being key (Valtorta *et al.*, 2016) this lends weight to the argument that qualitative research methods are in fact the most appropriate method as they allow exploration of subjective experiences such as loneliness.

4.3 Patient and Public Involvement (PPI) in this study

Involving members of the public in research is considered a core element of health and social care research. It is supported by government policy (NHS England, 2017) and the National Institute for Health Research (NIHR) Advisory group INVOLVE; the premise being that involving the public as participants, not just as subjects of research, produces more meaningful research findings and aligns with the broader principles of citizenship, accountability and transparency (INVOLVE, 2012).

The two PPI members in the WISH study were invited to participate in my follow-up study on loneliness. PPI in research on sensitive subjects can help in the development of research questions and interpretations that are more meaningful to their peers (Iliffe *et al.*, 2010; Goodman *et al.*, 2011). I drew on guidance from INVOLVE for this work and PPI members were regarded as co-researchers (INVOLVE, 2012). Both PPI members were older people with relevant prior professional and/or personal experience on the topic of this thesis. One had worked in the voluntary sector and for a local authority and maintained contact with organisations working to support older people who were lonely. The other had experience as a social worker outside the UK and a keen interest in mental health and well-being in later life.

Both PPI members were co-applicants on the NIHR SPCR grant which funded my PhD and provided comments on the application. They were actively involved throughout the study, attending regular team meetings, contributing to the stages of recruitment, analysis and dissemination. More specifically, they commented on and helped develop the participant recruitment materials and interview topic guide before submission for ethical

review and advised on appropriate language. They read and annotated interview transcripts, helped identify patterns and themes in the data and were actively engaged in discussions about the data with the rest of the team, adding rigour to the analysis process (Mays and Pope, 1995). They commented on abstracts submitted to conferences and manuscripts for publication in academic journals (Kharicha *et al.*, 2017).

Several steps were taken to facilitate engagement. Suitable transport arrangements were made and costs reimbursed. Documents shared outside of meetings were printed and posted as the PPI members preferred paper copies when reading long documents rather than working on computer screens and this also avoided them incurring printing costs. A preferred style of communication was established, for example, via email rather than telephone as one PPI member had significant hearing impairment. A hearing loop was used in meetings and all participants were asked to take turns to speak, and to do so in the direction of the PPI member to enable lip-reading. I arranged pre-meetings in advance of main meetings to clarify any concerns or questions related to the agenda. I also met one member to explain the principles and practice of qualitative analysis as this person had less experience of and confidence in reading transcripts but was keen to take part in the analysis.

Both brought valuable insights to the research process and analysis and interpretation data that were different to those of other members of the multi-disciplinary team. For example, reflections on the 'cohort effect' of their generation who had lived through different socio-economic and political times, different traditional gender roles, and the impact of these life experiences on coping mechanisms.

There were also challenges and assumptions to address in involving PPI members as co-researchers. One PPI member, who had close working links with organisations supporting lonely older people, seemed reluctant to accept participant accounts that critiqued the role of 'services for loneliness' in this study. A balance was also needed to maintain boundaries between

facilitating involvement and friendship. As other studies have reported, working with PPI members is time consuming and requires careful planning (Goodman *et al.*, 2011). Major challenges and frustrations included arrangements for financial reimbursement of the PPI members for their time and contribution. Although I was guided by NIHR INVOLVE (INVOLVE, 2016), and sought advice from this body, one member elected not to be paid because of the impact payment would have on their benefits.

4.4 Philosophical debates in qualitative research and research paradigms

Driving the decisions on which research methods to use are philosophical debates on the nature of the social world and our understanding of 'reality', known as ontology, and the basis of our knowledge, known as epistemology (Guba and Lincoln, 1994). The ontological and epistemological position and beliefs of the researcher determine the research paradigm and hence the research design and analysis, and interpretations of the findings (Kelly, 2009).

Social sciences have been dominated by two opposing philosophical positions: positivism and constructivism. Positivism asserts the existence of a single reality which can be known and which exists independently of the actions of researchers. Within this paradigm, loneliness would be considered to have a single accepted definition which would be the same for all those experiencing it, regardless of their personal circumstances such as age, gender and ethnicity, and context including life experiences. On the contrary, the ontological assumptions of constructivism would be the existence of multiple realities rather than a single reality, and that individuals construct their own reality and which is further shaped in the research process by the interaction of researchers and participants (Guba and Lincoln, 1994). Within this relativist ontology loneliness would be considered to be a subjective experience, shaped by individual circumstances and over time, and the expression and meaning of loneliness may be influenced by the interaction between the person and the researcher.

These debates are important as they have implications for the methodological decisions that are made in research. Social scientists who take a stance akin to positivism consider the phenomenon of loneliness to be objective and measureable, and researchable without participants and/or researchers being influenced by the process (Guba and Lincoln, 1994). Researchers are likely to use quantitative research methods, for example, to understand the extent of loneliness within different populations or identify risk factors with a view to prevention or intervention (Victor *et al.*, 2009). Implicit in these research methods is a deductive or 'top down' approach to knowledge, in which the starting point is established, then theory/theories and hypotheses are tested based on observations of the world.

Those adopting a constructivist stance query if objectivity is possible and instead embrace the interaction between the researcher and participant which shape the findings along with the values and assumptions both bring to the research process. These principles are aligned with qualitative research methods which assume an inductive 'bottom up' approach, shaped by observations of the world and from which theories are developed (Barbour, 2014; Ormston *et al.*, 2014).

In terms of these philosophical debates, this thesis fits most closely to a relativist ontology in which loneliness is a subjective phenomenon and exists as multiple realities constructed by individuals over time and influenced by their context. The epistemological position draws on a constructivist research paradigm.

However, I would argue that rather than being led by a particular philosophical position, the stance I have adopted for this thesis has been based on a pragmatic decision to identify the most appropriate research method to answer the research question. Pragmatism as a theoretical stance is commonly used in applied research in health and social care where researchers are led by practical issues as well as concerns of

research quality and rigour rather than philosophical position (Murphy *et al.*, 1998; Ormston *et al.*, 2014).

In my opinion, the research question of this thesis, namely to explore how older people experience and respond to loneliness, is best addressed by qualitative research methods. These methods lend themselves to providing an in-depth understanding of the meanings people attach to their experiences of the social world and how they make sense of that world, their experiences, perspectives and histories (Pope and Mays, 2006; Ormston *et al.*, 2014). They are naturalistic and interpretative approaches, which explore phenomena from the participant's perspective (Flick, 2009) and ask 'what, why and how' questions rather than the 'how many' questions (Pope and Mays, 2006).

4.5 Interviews

Qualitative research includes a broad range of methods and approaches, including interviews which were chosen as the data collection method best suited to the topic of enquiry for this thesis (Silverman, 2011), that is, to capture the subjective nature of loneliness and the exploratory nature of the study. Interviews are an effective way of exploring how participants construct and experience their lives (Yeo *et al.*, 2014).

Interviews vary in the extent to which they are directed by the researcher (Green and Thorogood, 2009). At one end of the spectrum is the structured interview in which the interviewer must follow a specified set of questions, in a specified order for each interview to generate comparable answers from each participant. At the other end are the 'naturally occurring' conversations as described by Lewis and McNaughton Nicholls (2014). In between are the most commonly used interview types in qualitative health research: semi-structured, in-depth and narrative interviews. In semi-structured interviews, the topics to be covered are set by the researcher but participants' responses determine the kinds of information produced about those topics and the relative importance of them. In-depth interviews are more

participant-led, in that the participant is encouraged to develop their own account of the matters that are important to them and greater time is allowed to facilitate this. Narrative interviews aim to facilitate participants to tell their 'story', for example, about their health and illness (Green and Thorogood, 2009). Further details of the interview type used in this study are given in the topic guide section below (Section 4.9).

4.6 Ethical approval and considerations

London-East Research Ethics Committee approved the WISH study (reference 11/LO/1814). A substantial amendment was applied for and approved for the qualitative follow-up study that informed this PhD. It was anticipated that taking part in an interview about the experience of loneliness could be potentially distressing and so the following steps were taken: the recruitment materials were piloted to check the clarity of the purpose of the research, the information sheet stated that the interviews would be carried out by a researcher experienced in interviewing older people about sensitive topics, time and care were taken during interviews to ensure participants were able to share their views as fully as they wished, confidentiality and anonymity were reiterated, and a follow-up letter of thanks was sent to all participants. Further details of these steps are given below. Also, a risk protocol was written which detailed how I should respond if, during the course of the interview, the participant disclosed any matters giving cause for concern about their safety. The lone worker policy at UCL was followed and details of the time, place of the interview were left with a member of the research team, who was contacted when the interview had been completed. University photo ID was carried and shown to all participants.

4.7 Sampling

My PhD qualitative study was carried out immediately after the WISH study was completed. After excluding those who had withdrawn or were no longer eligible (deceased, no longer registered with the practice, clinician review of current health and well-being recommended no contact), a purposive sample of all remaining participants who had reported loneliness at either baseline

or 6 months follow-up, in either the single item question 'Do you feel lonely much of the time?' or those who scored 2 or more in the validated 6-item de Jong Gierveld loneliness scale (de Jong Gierveld and van Tilburg, 2006), were invited to interview.

Interviewing continued until data saturation had been reached, that is, when additional interviews did not add anything that would aid interpretation or any major new themes. It was anticipated that approximately 20-25 interviews would be necessary. However, in order to try and achieve maximum diversity in the sample, I oversampled and interviewed all those who volunteered.

4.8 Recruitment

Recruitment materials incorporated the WISH study logo to help link the work and clarified how potential participants had been identified. Those eligible were posted an invitation letter with an opt-in reply slip (giving the options to accept, decline or ask the research team for further information about the study and space to provide contact details), an information sheet and pre-paid return envelope addressed to me at the research site.

The wording in the participant information sheet and covering letter thanked them for their involvement in the WISH study and informed them that additional funding had been secured for a follow-up study to which they were being invited to participate. Also, that based on responses to WISH study questionnaires, a sub-group of participants was being invited to interview to explore the topics of social networks and loneliness in greater detail. The word 'lonely' was used in the description, but it was couched within a broader description of who the research was aimed at, that is, 'older people who may have few people they can turn to for support, who may feel lonely at times or have little social contact with others', so those who had difficulty admitting they were lonely or had not considered their circumstances in this way, might be less deterred from taking part (see Appendix 3 for Participant information sheet and covering letter).

Those who returned a reply-slip stating they were interested in participation or wanted further information about the study, were telephoned within office hours or at a given time if this was indicated on the reply slip. A convenient time and place for interview were arranged and a time to telephone the participant to re-confirm arrangements (usually the morning of the planned interview) was agreed.

4.9 Development of interview topic guide and pilot interview

The topic guide was developed from the initial scoping of literature I had performed for the funding application for my PhD and in consultation with co-investigators (see Statement of intellectual property/contribution p 17). It was refined iteratively as the interviews were conducted and with on-going discussion with the multi-disciplinary team.

Questions in the topic guide were open-ended and designed to address key topics to be covered rather than as a series of questions to be asked in a predefined order. Associated probes and prompts were also included. It was anticipated that, although there were key topics to address in line with the study objectives, the interview would be led by the participant and their responses would determine subsequent questions. Within this flexibility, the opening and ending questions of the interviews were largely fixed.

Introductory questions referred to the WISH study, asked participants about their own health and well-being in later life and served to connect the two pieces of research as well as allowed time to develop a rapport with a more neutral, less potentially stigmatising topic.

If the subject of social networks or loneliness did not arise during the initial part of the interview, it was introduced by referring back to the participant's responses to the loneliness questions in the WISH study questionnaire. The participant was reminded of how they had responded at the time and asked to reflect on why that might have been and whether they still felt that way. Questions on loneliness were not introduced until an appropriate level of

rapport and trust had been established between the researcher and participant. The line of enquiry was participant-led but broad areas were included in most interviews, namely how the individual felt when they were lonely, their response to these feelings, what support they desired or considered helpful, and how they managed their loneliness.

Towards the end of the interview, all participants were asked for their views on services or support for loneliness, if these had not been discussed already. Finally, given that participants may have found the experience of talking about loneliness distressing, it was important to end with discussion that moved away from the personal experience to a more general viewpoint (Yeo *et al.*, 2014).

The first draft of the interview schedule had been closer to the format of a semi-structured interview, with several pre-defined questions. Following pilot testing and early interviews, it became apparent that the interviews needed less structure to explore the subjective and sensitive topics in greater depth. The topic guide provided an overall structure which was tailored to individual discussions; it allowed for additional topics to be covered within the interviews giving participants the freedom and flexibility to discuss topics which were important to them.

The interviews in this study are best described as being between semi-structured and in-depth in nature. Discussions about services and support were closer to a semi-structured style of questioning whilst the exploration of experiences and management of loneliness were more in-depth in style. This follows the pragmatic approach that I adopted in this research.

A pilot interview was arranged with an older PPI member who had previously participated in research within our ageing research group at the University. Although she had not self-identified as lonely she had potential risk factors for loneliness (including being widowed, living alone and being over 75 years of age) and volunteered to participate. She gave informed consent; the

interview took place at her home, was audio-recorded and transcribed. This pilot allowed for the wording of key questions to be checked, for example, that the wording had been understood as intended. It gave the opportunity to practise the use of prompts and probes, introduce the topic of loneliness and end the interview appropriately, and determine a more accurate idea of the length of the interview. This data did not contribute to my sample.

The first two interviews were then carried out with study participants. Transcripts of the pilot and first two interviews were shared with the research team. Further changes to the wording of questions and prompts included asking 'How do you maintain morale?' or 'How do you manage?' rather than 'How do you cope?' and using 'maintaining' rather than 'improving'.

The early interviews highlighted the difficulty participants may have in talking about loneliness and the challenge of eliciting a deeper discussion of the subject of the topic whilst managing potential participant distress. The final version of the topic guide is in Appendix 4.

4.10 Preparation for interviews

Prior to each interview, the questionnaires and the feedback report sent as part of the WISH study were read through and the interview topic guide was annotated with relevant information. This allowed a detailed picture of the individual to be formed based on their socio-demographic characteristics and health and well-being at the time of questionnaire completion. Relevant data as listed earlier (see Section 3.1.4) and responses to the loneliness measures, both the single item question and the 6-item de Jong Gierveld scale (de Jong Gierveld and van Tilburg, 2006) were recorded on all topic guides and used as prompts during the interview as necessary.

Given that such detailed information had been volunteered by participants in the WISH study, I considered it appropriate and respectful that, when participants were followed up for a face-to-face interview, I was aware of their health and wellbeing profiles as captured by the MRAO schedule.

Questionnaire responses were not enquired about directly but served as useful prompts during the interview. Furthermore, it allowed a rapport to be built more easily within the interview as I was able to refer back to and incorporate information that the participant had already shared.

A maximum of two interviews per day were arranged given the travel time required, likely length of interviews and their potentially emotive nature. Arrangements for de-briefing after interviews were made with supervisors. Given that I had experience of interviewing similar groups of older people in their homes about sensitive topics, it was initially agreed that I would contact my supervisors as necessary after interviews. However, following an early interview which I found particularly distressing, it was agreed that I would routinely contact my lead supervisor after each interview.

4.11 Data collection

Participants were given the option of being interviewed in their home, at the research department or in a local community venue of their choice. Time was taken at the start to build rapport with the participant; if refreshments were offered, they were accepted and this allowed time for conversation. As far as possible, interviews were held in a quiet room without others present. When interviewing in participants' homes, there were occasions where I had to request that other family members not be in the same room, or that a door was closed to reduce the chance of the conversation being overheard. On one occasion, a spouse was present at the far end of the room for the first half of the interview with her husband and on occasion he referred to her, but she then left the room and went upstairs.

The purpose of the research was reiterated whilst referring to the participant information sheet. The participant was given time to ask questions about the research and clarify what their involvement would mean. Permission was sought to audio-record interviews. Participants were then asked to give informed consent by completing the consent form. They were reassured that

their responses would be confidential to the study team and that transcripts would be anonymised so that individuals were not identifiable.

Key skills and attributes suggested by Yeo *et al.* (2014) for interviewers carrying out in-depth interviewing include employing active listening, in which the interviewer tries to hear beyond the spoken words the actual meaning of what has been said, demonstrating confidence, interest and a degree of humility to encourage the participant to 'open up' and talk at a deeper level than normal conversation and allow exploration of the factors that underpinned participants' answers. During the course of the interview I made every attempt to be attentive and to remember what had been said throughout the interview, to be non-judgemental and not make assumptions about responses, to remain neutral, and to avoid using affirming (for example, nodding expressively) or disapproving gestures or speech. After being asked a question the participant was given adequate time to think about their response and silences were not filled with other questions. Probing was used to encourage participants to elaborate further on initial responses, to provide fuller explanations or clarification as well as to challenge inconsistencies in a non-confrontational way. Attention was also paid to non-verbal communication, including being sensitive to tone and body language, and asking relevant follow-up questions appropriately.

It was anticipated that, despite having volunteered to participate, taking part in an interview about loneliness could be challenging and upsetting for the participants. Green and Thorogood (2009) highlight the importance of making people feel 'safe' to reveal their stories and views, which is pertinent to topics such as loneliness. Time was taken to reassure those who displayed a level of anxiety about discussing private matters or having the interview recorded and they were reminded of the confidential nature of the research. Several participants became distressed, upset or tearful during the interview; again reassurance and empathy were conveyed, and time was taken before checking that the participant was happy to proceed. The risk protocol was referred to as needed.

At the end of the interview, participants were thanked for their contribution. No financial incentives had been given for their participation, but details of local groups for older people were left with the participant if they were interested in them. Prior contact had been made with the groups to check eligibility criteria, length of waiting time and that contact details were correct. A letter of thanks was sent to participants after the interview, and if particular information had been requested this was researched and enclosed; examples included details of local numeracy courses for older people on low incomes and Alexander technique practitioners.

As soon after interviews as possible, field notes were written, as recommended by (Silverman, 2013). These included my reflections about the interview and observations that would not have been audio recorded, such as participant behaviour, relevant details about the environment in which the interview had taken place, for example, any interruptions, and a summary of any conversation that had taken place whilst the audio recorder was not on.

All interviews were recorded on a digital audio recorder. Interviews were transcribed verbatim by an experienced external transcriber who was known to the research team with whom a contract had been signed to comply with data confidentiality protocols. Files were transferred via a secure website, along with an anonymised email summarising any relevant contextual information (for example, background noise or interruptions during the interview) and a copy of the interview topic guide was shared. The transcriber was given instruction on the level of detail required in transcripts, such as, to indicate pauses, any emotion conveyed such as laughter or distress or changes in tone which might change the meaning of the spoken words, such as sarcasm. The transcriber was also asked to highlight sections of text that were inaudible. Transcribing is an interpretive act rather than simply a technical procedure, and the close observation that transcribing entails can lead to both a change in the meaning of an utterance

as well as noticing unanticipated phenomena (Bailey, 2008). If the participant talked at length about topics which were considered totally unrelated to the interview (for example, details of car insurance quotes being considered, or care arrangements that had been in place for a relative who had died some time ago), the transcriber was asked to summarise these sections of the interview.

4.12 Analysis

4.12.1 Analysis approach

Thematic analysis was used to analyse the data in this study. It is the most common method of qualitative analysis used in health research (Pope, 2006) and core elements of thematic coding are used in other analysis methods. The decision to use this approach rather than others is given in the section below. Thematic analysis includes a process of identifying and reporting patterns and clusters of meaning both within individual cases (interview transcripts) as well as across cases. Codes (descriptive text) are applied to summarise and break the data into simple components. These are then grouped with similar data from across the dataset, moving from data-driven descriptive to more conceptual themes. This allows an in-depth analysis and interpretation of the data. Codes are derived both inductively, that is, are data-led using the language and terms of participants and deductive, reflecting the specific areas of enquiry within the topic guide derived from the literature and aims of the study (Spencer *et al.*, 2014). Thematic analysis allows for multiple realities to be presented in line with the relativist ontology and epistemological assumptions of this work. The process of thematic analysis enables the social worlds of research participants to be captured, portrayed and explained by initially remaining close to the original data before a moving through stages of abstraction and interpretation (Spencer *et al.*, 2014).

4.12.1.1 *Alternative qualitative analysis approaches*

Analysis approaches vary to reflect the aims of the analytic process. Those that focus on capturing and interpreting meaning in the data in order to

understand the social worlds of participants are known as 'substantive' approaches. Examples include grounded theory, thematic framework analysis, interpretative phenomenological analysis (IPA) and thematic analysis. Approaches that are concerned with the language and construction of the interaction are known as 'structural' or 'constructionist' approaches, and include discourse analysis and conversation analysis (Spencer *et al.*, 2014). Understanding the meaning of loneliness to participants is central to the research questions of this thesis, hence different substantive approaches were considered, namely thematic framework analysis, grounded theory, IPA and thematic analysis.

4.12.1.2 *Thematic Framework Analysis*

Central to thematic framework analysis (Ritchie and Spencer, 1994) is the use of a matrix developed from the thematic framework in to which all data is systematically apportioned during the analysis process. It is designed to make the analysis process transparent and has been used widely in health services and policy research. However, it takes a more deductive approach to the data than appropriate for the exploratory and inductive nature of this study. The deductive approach is reflected in the use of a more structured topic guide to address the research questions than suitable for in-depth interviewing. In contrast the topic guide used in this study was developed iteratively and designed to be used within a participant-led interview which facilitated the exploration of the subjective topic of loneliness. Also, the summarising of data into charts and matrices is carried out early in the analysis process. This can create a distance between the summarised and charted text from the original narrative which may result in loss of context, emotion and richness of data. In this study, I found that referring back to original full transcripts helped to explain meaning and ensure participant expression was not lost.

4.12.1.3 *Grounded theory*

Grounded theory is a method of theory development, starting with a broad research question and iteratively building concepts and ideas throughout the process (Strauss and Corbin, 1994). Although the iterative development of concepts and interpretation of data are common elements of grounded theory and other qualitative analysis methods, grounded theory differs in its aim to develop theory at the end of the process. Strengths of the approach are that it offers a systematic way analysing data in depth which goes beyond simply describing the data (Strauss and Corbin, 1994). However, conducting grounded theory can be time consuming and it has been questioned whether what it creates is in fact 'theory' (Thomas and James, 2006). Grounded theory was not used in this study as the research questions were to explore older people's experiences and responses, rather than to explicitly develop a theory about loneliness in later life.

4.12.1.4 *Interpretative Phenomenological Analysis*

Interpretative phenomenological analysis (IPA) (Smith and Osborn, 2003; Smith *et al.*, 2009) aims to generate rich and detailed descriptions of how individuals experience the phenomena under investigation. It focuses on depth rather than breadth; fairly homogeneous and small samples are recruited to allow detailed and time consuming case-by-case analysis. Some have suggested that for students doing IPA for the first time, an appropriate sample size is three (Smith and Osborn, 2003). Good communication skills and the ability to articulate nuances of experiences are required. This study aimed to generate a detailed understanding of the experience of loneliness; however, participant accounts were influenced by the challenges of talking about loneliness, both due to the distressing nature of loneliness as well as social stigma. IPA has been critiqued as being suited to more 'eloquent individuals' (Willig, 2008). The exploratory nature of this study would have been further limited by sample sizes commonly used in IPA. Loneliness is a subjective experience which is further influenced by context; the balance between breadth and depth needed to address the research questions of

this study mean that a broader base (rather than a small, homogenous sample) is more appropriate. Furthermore contrary to other qualitative analysis methods considered here, IPA does not promote constant comparison or search for deviant cases during analysis (Pietkiewicz and Smith, 2014). In this study this would have limited explorations of those who denied loneliness during the interview. Pragmatically, the time consuming nature of IPA would have influenced the extent to which the wider team and PPI members could have contributed to the process; the involvement of the multi-disciplinary team is a strength of this study. IPA has also been criticized for being fraught with ambiguities (Giorgi, 2010) and that it is mostly descriptive and not sufficiently interpretative (Brocki and Wearden, 2006; Larkin *et al.*, 2006).

4.12.2 Analysis process

A step-by-step account of the analysis process is now given. I led the analysis process but met regularly with my supervisors and the wider multi-disciplinary team including PPI members. Adopting a team approach to analysis is a key element to ensuring rigour within qualitative research (Mays and Pope, 1995). It can reduce the potential bias any one researcher may have about the data, especially in this study where I collected it all. Involving co-researchers offers an opportunity to reflect on the data as well as discuss thoughts and ideas about their meaning and interpretation (Lewis and McNaughton Nicholls, 2014).

Interviews were transcribed within a few days of being carried out. I read the transcripts as they were returned by the transcriber, and checked for accuracy by listening to the recording whilst reading the text. Transcripts were read several times and field notes referred to, to increase familiarity with the data prior to interpretation. Paper copies were annotated and a data analysis note book was used to record areas of interest and potential codes. An example of annotated transcript is included in Appendix 5. After three interviews, the transcripts were shared and discussed with the wider team. This introduced the wider team to the data that was being collected, initiated

discussions and thoughts on the analysis and identified areas that needed greater or lesser emphasis in future interviews.

To increase rigour, a spread of transcripts reflecting a variety of experiences and circumstances of loneliness was shared with all members of the team; my supervisors each read over half of the transcripts. Initial codes were generated for as much data as possible and organised into a preliminary coding framework which was discussed and agreed at a team meeting. I independently and systematically assigned the data from all transcripts to this coding framework, using the computer software Nvivo 10 to assist with data management.

After coding was complete, I met with my supervisors and the wider team including public members over several meetings to discuss clustering the codes into provisional higher and lower themes. The data within each theme was read, considered and revised iteratively. Outlying data (or deviant cases) were searched for and examined for disconfirming evidence and to ensure the themes were supported (Mays and Pope, 2000). Examples of deviant cases include participants who stated they were not lonely in the interview when asked directly or those with depression or anxiety which overlapped with their experiences of loneliness. An iterative process was taken where transcripts were revisited throughout the process of refining codes and developing themes to ensure that the themes were robust and firmly grounded in the data over several meetings with team members. An example of data that informed the theme 'Reciprocity and boundaries' is included in Appendix 6. Themes were classified into a framework which was further refined by examining the relationship between themes and the final version was agreed in discussion with my supervisors. The final version of the thematic framework is included as Appendix 7.

Each theme was then reported with a description of the theme and illustrated with direct quotations, and this was shared with the wider team. The final stage of analysis involved moving from thematic description to interpretation

and a more conceptual analysis of the data. Identifying patterns beyond the surface level of data can reveal the complexity of phenomena such as loneliness and is a key strength of qualitative research (Kelly, 2009). Conceptual themes were discussed and agreed with my supervisors and the wider team. For the example, the conceptual themes of 'outside' and 'inside' worlds were developed from the range of strategies participants described to manage their loneliness. Coping in an 'outside world' described strategies to find meaningful engagement, connection and belonging to people and place. The 'inside world' described cognitive strategies in which loneliness was managed privately, kept hidden or re-framed to make the feelings more manageable.

For pragmatic reasons in this part-time PhD, the timing of systematic review and narrative synthesis reported in Chapter 3 overlapped with data analysis of the participant interviews. Therefore, the findings of the review will have also informed the analysis of the empirical data. The findings from the participant interviews are presented in Chapters 5, 6 and 7; themes from the thematic framework have been grouped to correspond to each of the three research questions of this thesis. I have also explored how the strategies used to respond to loneliness identified in my interviews correspond to the model for managing loneliness in Chapter 8 (Section 8.2.4.1).

4.13 Reflexivity

In this PhD I have strived to maintain a position of 'empathic neutrality' by making a conscious effort to be non-judgemental and impartial in my approach whilst acknowledging that qualitative research is not value free and hence assumptions, biases and values need to be made transparent (Ormston *et al.*, 2014). In qualitative research there is a necessary and complex inter-play between the researcher, the participant and the wider context of the exchange. A critical look at how data is co-produced and the likely influence on the data is known as reflexivity (Green and Thorogood, 2009).

Participants were recruited from the WISH study that preceded this work and are likely to have been influenced by their experiences of the former study and the focus of that research which was a preventative intervention for health and well-being in later life. This may have encouraged participants to talk about positive coping strategies although I did ask directly about how people managed. Further discussion of the impact of the sampling on the findings is presented in Chapter 8 (Discussion Section 8.3.3).

My knowledge of their responses to the WISH questions (see Section 4.10) was helpful in prompting and probing during the interview and developing rapport. Participants reflected on their experiences of completing questionnaires for the WISH study and the responses they had given at the time and this provided a useful link to the work of this study. I did, however, need to be mindful of my assumptions of how factors such as living alone or being in a relationship might influence their experiences of loneliness. For example, among those living alone and single, I did not know whether they had any significant relationships with others which had not involved marriage/civil partnership. For those who were widowed, I did not know how long ago their partner had died or the extent of their grief. And for those who were widowed or still living with a partner, I had no knowledge of the quality of those relationships. There was an unexpected level of disclosure about unsatisfactory relationships with partners in some of these interviews, which on some occasions were relayed when the partner was in the home. I found this difficult to start with, but learnt to ask whether the participant was happy to continue and if a door needed to be closed.

Establishing rapport was an important element of the interviews. I spent time talking to participants before the interview was started, for example about the journey to the interview and accepted drinks if they were offered or offered drinks to those who came to the university department. I did not question participants' views until further into the interview when a comfortable level of rapport was felt. A balance had to be struck within the 'empathically neutral' approach, so that I could probe and challenge

participants without making them feeling uncomfortable or threatened (Yeo *et al.*, 2014). When reading earlier interviews, I was aware that I had been more cautious with probing than I could have been. I summarised participant responses but could have asked participants to expand or explain their responses further.

The setting is likely to have had an impact on the interview. The majority took place in participants' homes, which added a level of informality compared to those that took place in the university department. However, the chance of interruption was higher due to phone calls and other people within the home or leaving/entering the home. A few participants had pets that mostly remained in the same room which I found distracting. Five participants chose to come to the university and we sat at a table in a meeting room. Three of these participants were retired professionals and talked about their working lives at some length.

I introduced myself in the same way at all interviews - as a researcher (they were all aware of my involvement in the WISH study) and that the interviews were part of my PhD. I had to clarify to some participants that I was not a clinician due to the confusion between the name of the university, a local hospital and their prior involvement in the WISH study, to which they had been recruited via their general practice. Reassurances of confidentiality were important as some participants were keen that information was not shared with their GPs. Not having a clinical background appeared to put participants at ease in 'opening up' about the subject of loneliness and other experiences of distress. Several participants said they had not spoken about their loneliness to anyone before. Many appeared to value the opportunity to discuss their feelings and reflect on their lives; the therapeutic value of interviews has been reported by others (Rossetto, 2014).

It is important to consider how characteristics such as my age, gender, ethnicity and class were perceived by participants and their potential effect on the research (Britten, 1995). Most alluded to the difference in my age to

theirs, with statements like 'well when you get to my age...'. Most participants were White British / White Other and some asked about my ethnicity and cultural background. One participant was from the same ethnic group as me, which was acknowledged both indirectly by making assumptions about shared cultural views and then directly once the interview was over. On occasion I was asked about details of my own life, for example, whether I had children when participants had been talking about their own children and grandchildren, I responded truthfully but then steered discussion back to the focus of the study. This felt appropriate in the moment to maintain rapport; a focus on neutrality and distance between researcher and participant have been criticised as reinforcing power imbalance in interviews (Yeo *et al.*, 2014).

Participants disclosed difficult and distressing episodes of their lives. My previous research experience interviewing older people on sensitive topics helped with the interviews for this study. However, I found one early interview particularly challenging personally in which the participant described several traumatic episodes, from childhood to recent events before asking me to turn the recorder off as he did not want his account of the effects of the trauma and how he managed to be recorded. The anger and frustration felt by the participant made the exchange confrontational and challenging and left me feeling distressed. I spoke to my clinical supervisors (KW and SI) and we agreed that following subsequent interviews I would routinely contact one of them to de-brief as dependent on availability.

The difficulty of talking about loneliness was evident in these interviews; the stigma associated with loneliness is well documented (Rokach, 2013). Participants talked of loneliness in others rather than themselves. At times it was difficult to disentangle accounts of loneliness from other emotional issues or depression and anxiety. A balance had to be struck in seeking clarity in these instances to avoid upset and I used the language of participant in the interviews as much as possible. The risk protocol was followed after an interview in which a participant caring for a partner

described thinking of ending both their lives and how this might be done. With participant consent I contacted their GP who followed up with the participant and discussed management with one of my clinical supervisors (KW).

Reflexivity in the analysis and interpretation process, as well as earlier stages, needs to acknowledge the prior assumptions brought to the study by the team. For several years before beginning this PhD and throughout it, I have worked as a mixed-methods health services / social science researcher on ageing in particular on health and wellbeing promotion in later life. Whilst working in a Department of Primary Care and Population Health, I have worked with multi-disciplinary academic partners and cross-sector organisations in ageing which has influenced my interest in the broader aspects of ageing. Much of my work has focussed on ageing well and maintaining independence which may have shaped how I approached the study of older people's responses to loneliness. On a personal level my prior assumptions about social connectedness and loneliness have built on my experiences and observations of family and friends of forming and maintaining relationships over time. In particular, those of my family who migrated to this country as refugees and my grandparents whose experiences ranged from living within a large extended family to living alone for over 20 years after being widowed.

The multi-disciplinary team members have backgrounds in general practice, social care, nursing, public health and mental health in later life. One member brought topic knowledge of loneliness and interventions for loneliness in later life. During analysis and interpretation discussions, members drew on their individual disciplinary views of loneliness and appropriate responses to it. The views of PPI members emphasised both coping strategies influenced by the 'cohort effect' of this age-group and the challenges of critiquing services supporting lonely older people due to involvement with organisations (see Section 3.3 earlier in this chapter). The

diversity of background was a strength and included loneliness being considered as a 'treatable entity' to the social construction of loneliness.

4.14 Summary

This chapter has outlined the rationale for the methods used in this thesis and described how they were employed. The research paradigm for this work is rooted in a relativist ontology which aligns epistemologically to constructivism as loneliness is considered to be a subjective phenomenon existing as multiple realities in the experience of older people. The choice of qualitative in-depth interviews reflects a pragmatic decision to use the research method most suited to an exploratory study of a subjective topic. The stages of recruitment, sampling, data collection and analysis are presented including a discussion of reflexivity. The strengths of the study include the ability to sample and recruit older people who self-identified as lonely, using two measures of loneliness, to take part in interviews; the systematic review for this thesis (Chapter 3) identified the challenges other researchers have faced with this. A further strength is the active involvement of PPI members throughout the process. The findings from the interviews are presented in the following three chapters, corresponding to the research questions for this thesis.

CHAPTER 5. FINDINGS 1: PERCEPTIONS OF LONELINESS, ITS CAUSES AND CONSEQUENCES

This chapter is the first of three chapters in which the interview analysis is presented. Each chapter addresses one of the three research questions of this thesis, with a greater focus given to the third research question on responses to loneliness (Chapter 7) as the evidence base is least developed in this area. Chapter 5 begins with an outline of participant characteristics and is followed by the themes that emerged from participants' descriptions and experiences of their loneliness and its causes and consequences.

5.1 Participants

One hundred and fifty eight older people were identified as lonely from their responses to either one or both of the loneliness items in the WISH study questionnaires (see Chapter 4 Section 4.1.4); 28 were interviewed between June 2013 and May 2014. Data collection was continued until data saturation was reached and no new major themes emerged from the interviews. All interviews were conducted face-to-face and lasted between 75-135 minutes. Five participants preferred to meet at the University department, the remaining 23 were interviewed in their own homes.

Participant characteristics and self-rated loneliness based on questionnaire responses to the earlier study (Walters *et al.*, 2017) are given in Table 2. Almost two thirds of the sample was female. A spread of older age bands was represented although the majority of participants were aged between 65 and 75 years; five participants were aged 75-84 and four aged 85 or over. Participants ranged in age from 65 to 90 years old. Twenty five participants identified as White UK according to the Census 2011 ethnic groups (Office for National Statistics, 2011); the remainder identified as Irish, Indian or White Other. Eleven participants had basic education up to the age of 15 or 16 years and the other 17 had continued their education beyond the age of 17 years, with 10 of the 17 remaining in education at 21 years or over. Thirteen participants lived with others, all long-term partners.

Table 2: Characteristics of participants and self-rated loneliness

		n
Gender:	Female	18
	Male	10
Age:	65-74	19
	75-84	5
	85+	4
Ethnicity:	White UK	25
	Other (Irish, Indian and White Other)	3
Education:	Up to 16 years old	11
	17 years and over	17
Living arrangements:	Lives alone	15
	Lives with others	13
Self-rated loneliness*:		
Responded 'yes' to 'Do you feel lonely much of the time?'		9
Scored 2 or more on de Jong Gierveld 6-item scale*		27

* 8/28 participants were lonely on both measures

In their prior questionnaire responses, nine participants had reported being lonely much of the time. The de Jong Gierveld 6-item scale scores of these participants ranged from one to six, with eight of these with a score of 2 or above, the threshold for loneliness (de Jong Gierveld and van Tilburg, 2006). Therefore, eight participants were lonely on both measures; five out of the eight were moderately lonely (scores between 2 and 4) and three were severely lonely (scores of 5 or 6). Nineteen of the 28 participants were lonely based on their responses to the de Jong Gierveld 6-item scale alone with scores ranging from two to six; 16 were moderately lonely and 3 severely lonely. Based on responses to the two loneliness measures, a range of experiences in terms of severity of loneliness is included in this study.

All participants were able to leave their home independently although a few had difficulty in going any distance alone and used mobility aids, such as

walking sticks, or required assistance to travel further. All had capacity to consent to take part in the interview based on clinician review (see Chapter 4 Section 4.7).

5.2 Definitions and descriptions of loneliness

Loneliness is a term used to describe a broad range of feelings and experiences. When participants described their experience of loneliness, they acknowledged that loneliness means different things to different people and that their description may not be meaningful to others.

Across the sample, definitions of loneliness were often polarised, for example, loneliness was described as a lack of contact with people, comparable with isolation, as well as loneliness experienced in a crowd:

Some sort of contact with people, even with one person. If I go all day and have no contact with anybody at all, then I don't feel good at all. (Interview 1, female aged 89)

Maybe that's at the base of it all ...feeling isolated amongst a group, other people are talking and that. (Interview 11, male aged 71)

Loneliness was described as common and experienced by everyone at some stage as well as being an extreme state of desperation and isolation and having no one at all:

I think everybody experiences loneliness pretty much to the same extent, I think just different people deal with it or fail to deal with it differently (Interview 15, female aged 65).

Those who ascribed severity to their feelings of loneliness included those who were grieving the loss of a partner, those who described difficult times and traumatic events in their past that had shaped their lives and continued to affect them, and those with mental health problems such as depression or

anxiety. Several participants cried during interviews, but all were content to continue the interview after taking a moment to compose themselves. One participant requested that the audio recorder be turned off when he talked about the extremity of his loneliness experience (see Chapter 7 Section 7.2.3 for further examples and quotations). Descriptions of more severe loneliness were predominantly provided by those living alone but also included those living with others:

I just get depression sometimes. ...That's been there a long time that has, a long time; just sitting indoors and doing nothing, watching the same rubbish on telly. You think to yourself, is it worth it, you know?
(Interview 7, male aged 68, living alone)

But still there are days when there's a vacuum, there's a blank
(Interview 5, male aged 71, living with another)

5.3 Social and emotional typologies of loneliness

Social and emotional typologies of loneliness (Weiss, 1973) were evident in participant accounts of their perceptions of loneliness. Social loneliness is the absence of a network of friends, family or community and most closely linked with social isolation. Emotional loneliness is the lack of a confidante or a trusting, loving relationship, even within a good social network. Social and emotional loneliness are not necessarily mutually exclusive; they may be overlapping and endured to different extents within an individual's experience of loneliness.

Most accounts were of emotional loneliness which was described most often in individuals grieving the loss of a partner:

She died in 2002...I still find it hard to talk about but I found it very difficult at first, and really I guess it's the support of my children that helped, helped me to get through things, but I still miss her dreadfully,

and I guess that always stays, it doesn't change. (Interview 16, male aged 65)

Emotional loneliness was also apparent in descriptions of on-going but difficult relationships with partners.

It's that sense of support really. I don't want help, I feel I'm competent, but I do like to share what I'm doing without being ridiculed for getting it wrong, or feeling a failure for getting it wrong. And even if it's trivial, to validate is not the word, my sense of satisfaction for getting it right. And to keep things in proportion as well; if you've got somebody else there, it keeps things in proportion doesn't it? I think that's the best thing about having somebody there, and that's the thing that I miss. (Interview 15, female aged 65)

The connection between emotional loneliness and the role of a key relationship, not necessarily with a partner, was raised by many. Several examples were given of participants who felt lonely although they were not alone:

It's funny, with all the people around you and the family I've got, sometimes you feel lonely. I think what you miss most is being not special to one person; you miss your husband really, even after all these years. I don't think that will ever go away. (Interview 13, female aged 84)

For others the role provided by the 'key relationship' of a partner seemed less essential:

It's just the fact that you've got somebody in the house, to say, "Do you want a cup of tea?" or "What are we going to have for dinner tonight?" and I think once you haven't got that, then I think loneliness can easily build up, I would imagine. But some people are quite

happy in their own company, aren't they? (Interview 19, female aged 69)

Those still grieving described the 'nurturing' required to establish other meaningful relationships and feelings of emotional loneliness that could only be ameliorated by another relationship:

So I mean, you can see people without kind of getting close to them. I mean, it does take a long, long time to kind of build things. (Interview 22, female aged 70)

It's just that loss really and there is a big hole. ... There just is no answer; it's just impossible really, so perhaps if I met another person and had a new relationship, maybe that would be different, but ... I don't know. (Interview 16, male aged 65)

There were also descriptions of the changing need for confidantes over time and experience. A woman who had outlived two husbands and a son described this as:

I don't really want to be responsible for anyone ... I wouldn't do that to anyone now. The ladies that I know are all lovely and they're very, very nice; absolutely nothing against them. One or two you have to be careful what you say! ... I can't be bothered, I don't like all that. I mean, I just don't get involved really. (Interview 13, female aged 84)

Social loneliness in later life was related to decreasing circles of friends and family as they died or moved away as well as health problems limiting the ability to engage with others:

Well, (slight sigh), I have a friend – they're all dying of course (slight laugh) you know, that's the other thing (Interview 22, female aged 70)

Within the context of social loneliness, living alone provided a particular challenge for some:

So I think that's where my feeling of isolation comes from, it's being on my own. If I didn't make an effort, I wouldn't see anybody or I wouldn't talk to anybody, but sometimes it's difficult to even make that effort (Interview 3, female aged 71)

Social loneliness is also described as an absence of community (Roberts, 2014). Rich descriptions of the neighbourhoods in which participants lived and the level of integration they felt were shared. These were complex as described by this participant who, despite having lived in the same street for over 40 years, explained her feelings about involving her neighbours in her life:

You know, you'd say hello in the street and have a little chat, and that sort of thing, but it doesn't go any further than that. And there's a sort of unspoken consensus that they don't want it; do you see what I mean? ... I think it takes a long time to build a community; it can take a generation and a bit really.... We're protective of our base, aren't we really? Or some people are; I am. We don't want people knowing too much even if we've got nothing to hide (slight laugh). It's ridiculous, isn't it? But that's very common. (Interview 15, female aged 65)

Geographical re-location to be closer to children and grand-children was considered by a few participants and two had moved to be closer their families. The social loneliness experienced in the absence of established networks was described:

... so filling in the time was initially the problem, coming to strange places where there were less friends and things like that.... We had a

good life there, and then you come here and all of that has gone suddenly. (Interview 5, male aged 71)

Many described circumstances of over-lapping social and emotional loneliness, most commonly in relation to partners (past and present) and other acquaintances. This participant, who described emotional loneliness, was cautious of letting those feelings impact on her social network:

I think that is something else that I hold back a bit on sharing with friends, because I don't want to burden them with my worries. (Interview 18, female aged 78)

Partners also influenced the ability to maintain wider networks for a variety of reasons which are discussed in further detail later in this chapter. This participant, who was grieving the loss of her partner and confidante, described how his controlling nature had led to a reduction of her social circle:

...he was quite gregarious in a sense. A bit of a bully, looking back now, and didn't like any of my friends. So in that sense, that cut me off and I wasn't strong enough to stop him doing it, really, but I could have done, if I'd realised what was happening, but I didn't understand the scenario at all until much later on. (Interview 22, female aged 70)

The complex inter-play of social and emotional loneliness in the accounts of these participants reflects the breadth of the loneliness experience described earlier.

5.4 State and trait typologies of loneliness

Other ways in which loneliness has been characterised are in terms of its duration and frequency (Victor *et al.*, 2009). Episodes of loneliness may be short-lived, recurrent, circumstantial, linked to certain events or periods of life, or loneliness may be a more long-standing experience not linked to

situations. The former has been described as 'state' and the latter as 'trait' loneliness (O'Luanaigh and Lawlor, 2008).

State and trait typologies are also identifiable in the narratives of the older people in this sample. The duration, frequency and recurrence of loneliness varied enormously between participants illustrating the transient nature of loneliness which some were skilled at managing:

Evenings, I think, are the hardest. (Interview 16, male aged 65)

Well, I think as you get older and your own family gets older, their needs are different and sometimes, especially at the weekend, and I know a lot of widowed people say that the weekend is the worst, sometimes you just sort of feel, (slight sigh) it's just nobody needs you anymore. (Interview 19, female aged 69)

I have what I call my Celtic glooms, (slight laugh) but they'll pass, they do pass. (Interview 22, female aged 70)

Episodes of state loneliness were experienced at different points of their lives. Earlier experiences were compared and contrasted to more recent ones both in terms of how they had made them feel at the time as well as how they had influenced their later years and decisions. The following examples illustrate first how being a lonely only child had influenced a participant's decision to have a larger family of his own and second the 'state' loneliness of parenting a small child:

No, I'm an only child, and it was because I was an only child that I felt that I was a bit lonely as a child, that having a large family would be beneficial for the children, as well as being beneficial for me. (Interview 14, male aged 67)

I think when you've got a new baby you can feel quite lonely, and your husband is out at work all day and you're left with this little thing that doesn't really do anything much, (Interview 19, female aged 69)

Divergent views on loneliness in later life were expressed; loneliness was felt more keenly at earlier stages of life for some whereas others found loneliness harder as they had become older:

... yes, I think things would be much more difficult for me from the point of view of being on my own in other periods of my life than they are at the moment (Interview 1, female aged 89)

I think it's harder now, because, like I say, I'm getting older. I'm getting older now and I think it's getting more difficult to try and control it, put it that way. Sometimes I'm lying in bed and I feel really depressed and I think, oh, sod it! Well, how deep is the [canal]? (Interview 7, male aged 68)

Although state loneliness describes loneliness that is circumstantial, it is not necessarily time limited and some participants remained very distressed long-after the precipitating event:

[Husband had died] in 2004, so that's why I kind of think it's time for me to really let go. (Interview 22, female aged 70)

The transition of retirement and associated change of lifestyle and reduced income contributed to state loneliness for many participants. The majority of the participants were aged between 65 and 74 years and reflections on their working life were common. Some had experienced early or unplanned retirement following workplace disputes, recession-related redundancies or due to health reasons. Others had worked for as long as they could and carefully planned their retirement but nevertheless found the transition challenging:

Since retiring and I was quite late in retirement, I mean 70, I have felt more isolated and more ... it's because I think I still haven't got a structure to my life, you know, when you work all your life, you have a structure, because I've never had children. So you have a structure to your life and then all of a sudden that goes and you think, oh, gosh! (Interview 3, female aged 71)

Trait or long-standing loneliness was commonly and at times inextricably described alongside co-existing mental health problems such as depression and anxiety. These were experienced as both long-standing and short-term but recurrent episodes, which many participants were skilled in managing.

... let's try taking you off of these [medication] again and it's alternate days and every three days and all the rest of it. And I'll be off of them and then something else comes on, gives me a shove and I'll fall off the precipice and off I go again. (Interview 9, female aged 66)

This participant with long term depression going back to early adult life and which was managed with medication, was very aware of potential triggers, her need to keep a distance from others and the impact this had on the quality of her social network and feelings of being alone and lonely:

And there's the difference because I cannot get interested in everything and everyone. But I think part of me about not being interested in other people who've got things wrong with them is because I'm frightened. I was aware of this quite a long time ago; why do I hold back if somebody is really, really ill or needs my support? And it's because I'm frightened, I'm frightened of the depression. If I see that person in a state, I take that home with me and then I get depressed. So as I go on in life, I hold back a lot and it looks selfish, but as I say to my family, I have to look after myself, you know? (Interview 3, female aged 71)

Some participants recounted painful childhood experiences which had affected their mental health or shaped their personalities, coping strategies and relationships in later life. The distress of these experiences had left them feeling alone, unwanted, confused or an 'outsider' as illustrated by these quotations:

...I was only eleven at that time. So I lost a father, lost a mother and never regained my mother, because she was delusional and was paranoid, and so forth, I had to think for myself. I think I've therefore always been a bloody-minded awkward person, probably rather harsh because, and I've survived so I don't need to trust anybody, I can trust myself, right? I don't have that need. (Interview 20, female aged 78)

When I was young, my parents didn't really want me.... I was fostered out when I was about six years old for a few years and I was sent to boarding school... I was beaten when I was ten years old for not going to sleep... So all this was accumulative, and that caused me to have bad relationships... The Hoarder Next Door (slight laugh) that's me! That is me, and I was trying to analyse it myself, I can never throw anything away. I guess that's all down to childhood insecurity (Interview 2, male aged 68)

Yeah, I can remember times in childhood when I felt just absolutely overwhelmed, almost with terror, and didn't know why. My sister is the same, she takes tablets, and my brother is a complete recluse. So whether it's the way we've been brought up or what, I don't know.... it would help us if we actually knew why our mother hated so much. And she did hate! (Interview 9, female aged 66)

One of the feelings of loneliness I think is the question of religion because although my mum was brought up as C of E [Church of

England], she never had my brother or me christened, so we were sort of outsiders. (Interview 10, male aged 70)

Trait loneliness was also linked to personality type in the absence of distressing life events by some. Due to the length of time loneliness had been experienced some participants described a familiarity with the feelings:

I think it probably depends very much on what sort of people they are to start with, how sociable they are, how much they depend on the company of people before they got to this point...I've never been that sociable. I've never been a very sociable person, you see. (Interview 1, female aged 89)

I suppose I'm used to being some distance emotionally from people, so I've got quite accepting of it really. (Interview 21, female aged 65)

5.5 The place of loneliness within other matters in life

Within the narratives of participants, loneliness was discussed alongside a variety of life events and emotions. The complexity and interplay of these were common features and at times it was difficult to isolate the feelings of loneliness from other distress. This participant describes the interaction of several factors that influence her life, including long-term depression and anxiety, retirement, living alone, filling the time and limited finance:

Before that I was working and I handled the depression and the anxiety, perhaps a lot better than I do now because I'm retired and because I live on my own, I've got to find things to do to keep me occupied and to keep my brain intact really, which is not easy when you're retired to keep ... you know, especially if you have a certain amount of money to live on, you know? (Interview 3, female aged 71)

Health problems were, for some, the over-riding concern in their lives. As well as depression and anxiety, declining mobility and major diagnoses such

as stroke and cancer contributed towards the feelings of isolation and loneliness:

Now, I can walk so far but not far, and unless I've got a friend who can get this [mobility aid] in their car, I can't go. There's lots of places I can't go and that's just it (Interview 6, female aged 90)

Having a stroke was an absolute turning point, the support was zero, absolutely zero. (Interview 25, female aged 68)

...but then to be confronted with that and that word 'cancer' it's just a terror for everyone. And that sort of clouded everything else. Until then I'd been resiliently independent and very happily so; I just like my own company. But then when I needed people, the only person I had was a cousin, I had only seen twice in about 50 years. (Interview 2, male aged 68)

Difficult relationships with partners and wider family were the context of some participants' distress. In these examples the first participant describes her controlling husband and the second participant describes the lack of involvement with wider family particularly grand-children:

My husband is not supportive at all, but that doesn't mean we're at loggerheads or anything; that's just the way he is and I'm the way I am. I mean, he doesn't welcome people to the house so that's a big barrier, not to be able to invite your friends in for a cup of coffee. I mean, I could insist, but what would that do? So, yeah, I'm aware of that, but I live with it (Interview 26, female aged 78)

Because there are lots of things that one can be helpful with, but I think it's mainly that, a sense of not being able to contribute as I would like, you know, just helping with the children or whatever. But

anyway, it doesn't happen, and I find that hurtful. (Interview 22, female aged 70)

For some there were specific experiences from their early life which continued to affect them and remain important to them. These are different to the traumatic childhood events described earlier under trait loneliness and describe losses which participants have had to live with.

But what I would like, but you can't get it down our way, because I've never accomplished nothing in my life and I tried to sign up for school so I could learn maths. ... Yeah, but it's too expensive now. I mean, I can't afford it.... yeah, I'd just like to accomplish something, you know? (Interview 7, male aged 68)

People talk about their family and my friends now, they all talk about their grandchildren and it's lovely to hear about them, but I would like to talk about mine, but I haven't got any. (Interview 18, female aged 78)

5.6 The language of loneliness

All the participants in this study had been invited to take part based on their responses to questionnaires which had indicated that they were lonely. However, within the group, there was a subset of participants who, at the interview, said that they were not lonely.

This may have been due to a number of reasons. The social stigma of admitting to being lonely may have been difficult to overcome in an interview setting; it may have been easier to report in a postal questionnaire. Some said it must have been how they felt at the time they completed the questionnaire, perhaps reflecting the transient nature of loneliness and others commented on the limitations of questionnaire response options:

...but I just ticked the boxes or answered how I felt at that moment. I suppose maybe my emotions go up and down a little bit, and you might have caught me at a moment when I didn't feel quite so positive. (Interview 14, male aged 67)

Yeah, difficult isn't it? I think that was one where I didn't feel I could answer positively yes, or positively no, and it was somewhere in-between. (Interview 18, female aged 78)

...but they're mixed emotions, I think you'll find, that people put down; it's all 'sometimes' because you're not static, nobody is. (Interview 6, female aged 90)

Maybe I was answering those questions on the basis of am I alone, rather than am I lonely, because I am quite frequently alone, but I don't feel lonely, no. (Interview 26, female aged 78)

The breadth of loneliness experience articulated by participants has been described earlier in this chapter. The subjectivity of loneliness is reflected in the range of language used to describe these feelings. For some participants their idea of a 'lonely older person' did not reflect their own experience:

I suppose I perceive lonely as people who have nobody. You know, having nobody at the end of the phone, not being able to go out, not having a social life; maybe that's what I perceive as loneliness. (Interview 27, female aged 66)

Some described loneliness as an absence having anything to do:

I don't think I'm lonely, because I read, there's so many things that I can do if I want to. So I don't know that lonely is something that I understand actually. (Interview 25, female aged 68)

No, I don't feel lonely. I don't feel lonely at all actually. There's always something to do. (Interview 20, female aged 78)

Participants who had been identified as lonely on the basis of their responses to the de Jong Gierveld questionnaire (de Jong Gierveld and van Tilburg, 2006) were prompted to reflect on their responses. The scale does not use the word 'lonely' but includes statements about 'trust' 'emptiness' and 'rejection' which participants were prompted to reflect on:

Well, I trust my sons and I'm quite comfortable with other members of my immediate family, but I only trust myself. (Interview 20, female aged 78)

It's not empty; we used to have such a lot to look forward to, whereas now we haven't. (Interview 17, male aged 70)

It depends what you mean by emptiness, doesn't it, too. I think it's all tied up with this business of being alone, or not having family. There is an emptiness because there's nobody there, there's no family there. (Interview 18, female aged 78)

Well, I think the fact that your own children don't need you so much, or feel the need to pop in and see if you're OK. Or even phone you, but I think as I get older and more dependent, that will change, but at this time of your life when they can see you're still able and capable...And I think that's how you do begin to feel a little bit rejected like that. (Interview 19, female aged 69)

Loneliness may have been difficult to disclose or articulate, difficult to disentangle from other feelings or distress or easier to talk about in others. When asked what loneliness meant to them, those that did not consider themselves to be lonely were able to describe the 'types' of people who they thought might be. Some participants had not reflected on their

circumstances in such depth before the interview and towards the end of the discussion, one participant went on to say:

But maybe my perception of loneliness is wrong, I don't know.

(Interview 27, female aged 66)

5.7 The role of family and friends

Relationships and contacts with family and friends over time were discussed to provide the context of participants' loneliness. Relationships with partners formed a significant part of the narrative of this group in which 13 of the 28 participants were living with long-term partners, but also among those currently living alone. Within difficult relationships that had lasted several decades, an emotional loneliness stemming from not feeling understood or valued or feeling unloved was described. Partners also influenced the ability to maintain wider networks due to personality traits, 'controlling relationships' or caring responsibilities which limited contact with others and meant neglected friendships were harder to re-establish after time. Several accounts of difficult relationships were described in which participants had decided to remain:

And that makes a difference, having a friend who is up for doing stuff.

I mean, a lot of people would be doing things with their husband, but that doesn't work in my case (Interview 19, female aged 69)

The death of a partner resulted in smaller networks due to the loss of that individual or no longer feeling comfortable within social groups comprising couples. Themes on how participants managed this within their past and present relationships and expectations of relationships are described further within Chapter 8 on managing loneliness.

All the participants in this study, except one, could identify someone they could call on if necessary; a safety net that for most provided some

reassurance that they were not alone although the unease of having to initiate that contact was also apparent:

We're social animals, I think it's really fundamental and I think it's a curse to anybody, to be honest; very, very few people are natural loners, we all need somebody. (Interview 15, female aged 65)

So there is this umbrella, but it's only used when it's absolutely 100% necessary. (Interview 20, female aged 78)

For those living alone, this role was usually filled by children, friends including those that lived some distance away, as well as local acquaintances and neighbours. Six of the 15 participants who lived alone had neither a current partner nor children of their own. All but one was female and they had developed relationships with others over time that filled the role of 'family' in their lives. These included members of shared interest groups they had participated in for many years, other members of a shared religion, neighbours, as well as a cleaner whose relationship had developed to one that provided both practical and emotional support to one of the participants over 15 years:

And then I have a friend who comes and helps with cleaning, she's a kind of carer to me, she's very helpful. She comes and calms me down, and that's something, you know, and says, "Oh, don't worry it will be all right. I'll phone them up and see what they mean." and that sort of thing. ...She's been coming to me for 15 years. I met her in the local shop when she was looking for a job for house cleaning (Interview 6, female aged 90)

These wider networks were also described as important by those who lived with others in less satisfactory relationships:

You see golf clubs are really good that the ladies are very supportive of the ladies and if one of them has got a really unpleasant illness and is

having to cope with it, you know, they gather round, 'Are you all right?' you know and send cards, and that sort of thing. That gives you a feeling that you've got a bigger family that's at least interested in you. (Interview 26, female aged 78)

5.8 Reciprocity and boundaries

Both reciprocity and boundaries were themes within relationships with family and friends. Amongst the participants who had children/step-children and grandchildren, several participants expressed the desire to have greater involvement with them whilst recognising that their families' lives were busy with work commitments and raising children:

Obviously my children, but at the moment, that relationship there is I feel one more of me supporting them. Although they do support, I can have conversations with my daughter but then again they've got work, families, they don't live next door so, you know, there's a geographical remoteness as well as anything else... We look after the grandchildren from time to time which is super, but that's supporting not supportive. (Interview 15, female aged 65)

The loss of an 'empty nest' was expressed alongside sadness and frustration that their children did not appear to recognise their desire for a closer relationship. Several commented that this was because the children perceived their parent(s) were managing as they remained independent, but did not consider their broader needs or wishes:

*I know this sounds absolutely crazy, but there are times when I feel as though I am not really here.
[Uh huh, what do you mean?]
Surplus to requirements. I do an awful lot for my daughters, and I don't begrudge what I do, I do it very, very willingly, but there are times when I think, well, why can't you put yourself out for me? ...*

Yeah, I do, I just feel as though everybody is using me, but it doesn't turn round the other way. (Interview 9, female aged 66)

Those with much less contact than they desired with family also expressed similar sentiments; this participant struggled to maintain a relationship with her deceased husband's family and children, who appeared to set the boundaries to their relationship and left her feeling a burden on them:

My stepson is the one I see most of, maybe two or three times a year and Christmas, but I feel like the charity case at Christmas, you know? (Interview 22, female aged 70)

Within friendships participants were keen to ensure reciprocity of relationship and to not 'overstep the mark' as described by this participant with a very limited social network:

...my Alexander [technique] teacher said that I can ... talk to him, ring him up and have a chat. But you don't really like to ... well, I feel like I'm sort of, you know, making use of people in a way if I do that. (Interview 1, female aged 89)

Those who had described several losses of close friends and family members were cautious of forming close connections with others and had consciously set different expectations of friendships over time:

I mean, I have a friend, we go to [local stately home] for a Sunday morning conference, and we have a meal afterwards and that's great, and we do that about four or five times a year, and in-between, we don't meet at all, right? And that sort of friendship I like very much because it doesn't commit me to anything except on that particular thing. (Interview 20, female aged 78)

It was evident in these accounts that there was a diverse range of experiences and the description, context and meaning of loneliness was highly individual. A summary of the findings of participants' experiences of loneliness is presented at the start of the Discussion chapter (Chapter 8 Section 8.1.2.2).

CHAPTER 6. FINDINGS 2: PARTICIPANTS' VIEWS ON COMMUNITY BASED SERVICES AND SUPPORT FOR LONELINESS, AND INVOLVING OTHERS.

This chapter reports participants' views on services and other avenues of support for older people who may be lonely or at risk of loneliness. Themes have been grouped by the types of community services and support that have been used or recommended, including one-to-one services and group based activities both hobby or interest based, and purely social. Participants were also asked for their views on the role of primary care services as these are increasingly seen as places that could address loneliness for example, through social prescribing. Broader reflections on involving others to alleviate loneliness emerged from participant accounts and are described below. The findings reported in this chapter expand on those that have been published (Kharicha *et al.*, 2017), see Appendix 5.

6.1 One-to-one services such as befriending

One-to-one befriending services, delivered either face-to-face or by telephone were on the whole not popular with participants, both within those that considered themselves to be lonely and those that did not. Several people were not aware of the existence of such a service and asked for details about them; none of the participants had experience of befriending services.

Among some there was a strong antipathy to using befriending services. Particular features of the service that people felt uncertain about included the personality and compatibility of the individual delivering the service, the idea of a stranger coming to their home, and concerns about what one would actually talk about:

People I don't know I wouldn't know what to talk about, and how would I handle it? (slight laugh) Would I not feel it was an intrusion

that this was going to happen weekly or whatever? You know?
(Interview 26, female aged 78)

Those more amenable to the idea of one-to-one services described either a future scenario when they were more disabled and unable to leave their homes or 'other people' for whom the service might be appropriate:

Mmn, possibly, but at the moment, no. I mean, that could well happen in the future, yes. I know exactly what you're saying and I know these people exist, and I know they do very good work, but at the moment, I don't feel that I have those sort of problems. (Interview 18, female aged 78)

... but what I'm saying is, ten years down the line, I might think that's a really good idea. At the moment, I'm saying it's not for me, but if I was isolated in this house and couldn't get out, yeah, I think that would be a lovely idea, but just not at the moment. I think I have to find my own way at the moment of doing things. (Interview 3, female aged 71)

None of the participants said they would consider a befriending service delivered by phone, stating either that they did not particularly like that type of communication or that they would phone someone they knew instead.

6.2 Shared interest or hobby based groups

By and large, the participants of this study were well informed about local groups and services. A breadth of views and circumstances was shared about how and why people decided to engage or not. These included the detailed planning, using internet searches, by a widow living alone as she planned her retirement, to another widow living alone, in her nineties, who described the complexities of deciding which group to go to, and weighing up the pros and cons within her limited budget and transport reliant options.

As with interest or hobby based groups attended at any stage of life, they were largely judged by the subjective quality of the group activity.

There was an awareness of the positive impact of group activities, both directly and indirectly:

I sprained my back and so thought Pilates or anything like that would be good for that, so I went to this class and not only is it a little community, it actually made me feel physically better and consequently psychologically better as well; because I was having to go out and do something on my own, it prompted me to be more confident I suppose. (Interview 15, female aged 65)

Several people attended groups based on long-standing interests at adult education colleges and courses provided by the local council but some had joined groups that were more focussed on activities or interests directed at older adults. The University of the Third Age (U3A) was well known and popular with many although a few had tried attending its events and decided not to continue:

...basically all through the U3A, which is a very good organisation, you know, one which I think fits your study down to the ground really, helping people. (Interview 11, male aged 71)

I can remember going to a lecture and I wasn't very thrilled, but that was some time ago.... I forget what the lecture was about, I can't remember. Anyway, I decided not to have another go at them, but that's just my experience; maybe I should have kept on and it might have got better, things might have got better. (Interview 1, female aged 89)

As well as the quality of the group activity, another factor in attending interest based groups was the opportunity to socialise and meet people:

And I go to this class which is this balance class. Well, they're all older women and some of them I've known for years and years. It's a nice class, but I go for the company. (Interview 6, female aged 90)

Others mentioned organisations and clubs that they went to, albeit infrequently, but where they could turn to for support, usually practical but sometimes emotional, if needed. This included a local ex-armed services club and a golf club.

Two participants who had re-located to be closer to their children had debated whether to join shared interest groups as a means to create new networks. However, both had decided against it, as described by this participant:

So he [son] keeps on saying why don't you go to the local gym and then you can make friends there. But I don't want to go in order to make friends, you know? So somehow I don't feel comfortable with that, just going there and hoping to make friends (Interview 5, male aged 71)

The social aspect was described as a fortunate but secondary reason for going and participants were uncomfortable about going primarily to make friends as this was perceived as having an air of desperation about it.

Challenges of attending group based activities were raised; these included going to a new group on your own or following bereavement of a partner if they had previously attended together:

If I had somebody to go with, I probably would. As I say, if my sister lived nearer, then probably, because we're bit of stick in the muds, you know? I hate going anywhere on my own, this is the trouble. (Interview 4, female aged 74)

I've done all that, just standing in a corner by yourself. Yeah, I always went with my wife, yeah. (Interview 11, male aged 71)

Attendance was particularly problematic for those with mental health problems. Two participants describe their mixed feelings about attending groups, the latter not feeling able to do so:

So, I belong to a local art group and stuff like that, I've just done that and that's fine, but I kind of feel that I'm doing what I should do (Interview 22, female aged 70)

But I know I should, I should maintain interests and do things. (Interview 2, male aged 68)

6.3 'Social' groups

Views on groups that come together for purely social reasons such as lunch clubs and coffee mornings, were comparable to those given for one-to-one befriending services, rather than the views given on groups with a shared interest or hobby. The latter were seen as not necessarily specific to later life or overtly for those who were lonely, whereas the one-to-one service and social groups were perceived to be for those who were older and more dependent, with very limited networks for support.

Of the 28 participants, three attended social groups fairly regularly; of them two enjoyed them and one had mixed feelings. All three were widowed women in their 80s or 90s, living alone. Two further participants held positive views on these groups; for one this was based on the experience of her mother, for the other, her views were as a service provider for older people. Two more said they would be open to suggestion in the future; one of these was in relation to a social group arranged by the U3A. All of the above mentioned were women who mostly did not consider themselves to be lonely:

Well, they're all for the elderly, ... we'll play Rubik cube or dominoes, or cards....Well, I enjoy it anyway; it's nothing special, you know, it's just a get together really. There's always food down there too; as I say, they cook them what looks like a nice dinner. We just mostly play Rubik cube, have a chat and a laugh at the same time. (Interview 23, female aged 85)

... the U3A have what they call social groups which meet on a Sunday, they go out for Sunday lunch, go to the pictures or something like that, and I imagine that I would get involved in that. (Interview 19, female aged 69)

Most, however, expressed reservations about this type of activity. For some it was simply a matter of personal preference and not the usual way of forging meaningful relationships. Strong negative opinions were expressed by both those who had tried such activities and those that had not:

Someone told me to go to the old people's luncheon club and I thought that's a good idea, maybe I can talk to people. But everyone else was the same as me, all they wanted to do was talk about themselves, and what they did was of zero interest to me and vice versa; it was Pinter conversation, you know? Everyone is talking about themselves and it was not a good way to spend time! (Interview 25, female aged 68)

I mean, the thought of sitting with a cup of tea and playing bingo is my worst nightmare. ... And also I don't know, do I feel a stigma even?, well, that people would laugh at me.

[But what is it about those services that you are not keen on?]

I think probably of going to them and being classed as an idiot. (Interview 3, female aged 71)

6.4 'Types' of people or circumstances when services for loneliness might be appropriate

Participants, including those that described themselves as lonely and had very limited networks, described the type of the people they thought went to such groups and why they would not go themselves:

To tell you the truth, I'm not really interested in that. I don't want to sit down there and listen to Mrs Jones and her rheumatism, and old Fred Bloggs talking about his bleedin' lumbago! (Interview 7, male aged 68)

Because all these people, I'm put with these and they're far worse than I am! No, I don't think so, not for me. No, not groups to try and help you, no. (Interview 8, male aged 85)

The perception that such groups were for those whose needs were much greater than their own was held by most participants, perhaps reflecting that all were able to leave their home independently and the majority were aged between 65 and 74 years:

A lot of these resources though are for people that really, really need ... I'm talking about really elderly people that don't see anybody for weeks on end. (Interview 3, female aged 71)

If your question is 'would I ever?' I suppose I can't rule it out. But if I felt dissatisfied with what I've got and I had to look around for some other way of filling the gaps, then I suppose I'd consider it, but I never have. (Interview 14, male aged 67)

6.5 Tailoring of services– not just for ‘old people’

The need for services to be better tailored to individuals was important for many:

We’re all very different and we’ve got different needs and so the support mechanisms have got to be completely flexible to take into account every individual, and they are all individual needs, aren’t they really? (Interview 16, male aged 65)

Activities enjoyed in later life were often interests established in earlier life that participants were able to continue doing. Those that did not have specific interests to continue with and looked for groups to join in later life were not enamoured of groups that were badged as being for older people. Sometimes this was due to their chronological age not matching how old they felt, because they preferred the company of younger people or because they were in good physical health:

I know I’m old but I don’t want to sit there with a load of old men; I’m not like that, it’s not me. My eldest son now is 47 and I prefer mixing with his mates (Interview 17, male aged 70)

For those unable to continue interests because they had moved away from their networks, the difficulty in finding new interests, re-establishing themselves or the lack of fit were particularly pertinent:

I’m neither a young man nor an old man where you are staggering to walk with a frame, and you can’t speak if you have a stroke and somebody just has to help you and nurses come. ... I still drive, we don’t require any social services help as yet, but I dread this will happen one day... I need support in sort of social life and things like that, but then it’s not that desperate at this stage where you’re cut off because you can’t get out. (Interview 5, male aged 71)

6.6 Group welcome and arrangements

As well as over-arching views on services and groups for loneliness, participants went on to describe specific features of these that they liked and did not like. These views were based on having experienced group based activities (some related to later life and others interest specific) both as members and as organisers.

The nature of the welcome into the group by those who run the group was important for many:

I think when people are advertising, in the broad sense, these groups, they need to make it clear that they understand the obstacles, I think. Quite often the obstacles can be psychological, like mine in my previous years of thinking I don't deserve to do this. (Interview 15, female aged 65)

I prefer people to come to me rather than me to go to them, and if you're like that, I think if you go up to it, and you're standing there like a ... (Interview 11, male aged 71)

Knowing others in the group made a big difference; it made local groups more attractive and helped overcome the fear of attending alone for some:

I probably would have gone to the [local] one on my own, because I do know a lot of people [locally] anyway, when I go I always see people up there that I know. I'm not sure that I would have gone to the [nearby town] one on my own, because I don't really know people there. I know people now to nod to and say hello, but they're not people that I know as well as [locally]. (Interview 19, female aged 69)

One who had been anxious about joining a new group described how she planned ahead to make the first visit easier:

I went on my own, because two people I know were on holiday, but I phoned the lady who runs it and she introduced me to some people. (Interview 27, female aged 66)

Basic hospitality and being generous both in attitude and with refreshments were important and yet could be perceived differently, as described by one participant as a group member but also another participant who had volunteered (once and many years ago) and whose experiences had deterred her from going along as a member:

They're always coming round, "Would you like a biscuit? Would you like a sausage roll? Cakes?" and there's always tea and coffee available.... Yes, it is very good, very generous. (Interview 23, female aged 85)

I just didn't like the atmosphere at all. I mean, these people who were the volunteers making the tea and giving out the cakes, just seemed to be so in control of these people and it should have been the other way around really.... I'd hate to go along to one of these and people not treat me kindly, as if I was a nuisance. ...I think they were impatient and I think with very elderly people, you've got to be really patient. And I think maybe I saw the impatience of, "You've had two cups of tea already!" I mean, whose business is that if she wants ten cups of tea! You know, and I just had the feeling, no, you know, it's not for me. (Interview 3, aged 71)

As well as recommendations for those who run groups, suggestions were made about how to approach groups when you first join, and being sensitive to the existing group dynamic:

... if you said, well, I'll join the club and go in there and you gradually work your way in. If you go into places and say you're lonely, people

can say, “Bit forceful, isn’t he, he’s just joined!” No, it’s very difficult. (Interview 8, male aged 85)

One participant in the study, who ran a popular exercise group for older people, had a keen understanding of group dynamics and shared many techniques she employed to tailor her approach:

That’s why with some of my ladies, I’ve known them so well for so long, that when they become widowed, I just make sure I ring them up, send them cards, ‘We miss you. When are you coming back?’ you know? Because it would be so easy for them. I’ve got one at the moment who is just not coping very well at all. I ring her and say, “Come along, because I can have a laugh with you!” (Interview 28, female aged 67)

Several participants were also wary of seeming overly critical:

I don’t want to sound negative, because there are a lot of good people out there trying to help. (Interview 14, male aged 67)

6.7 Role of primary care for loneliness

Participants were asked whether they thought primary care services, that is their GP or practice nurse, had a role to play in alleviating their loneliness. The following themes emerged from their responses.

6.7.1 ‘Appropriateness’ of contact with primary care regarding loneliness

For most people approaching primary care was not the route they would seek for support with their loneliness and many had not considered this as an option before being asked their opinion in the interview. Reasons included a perceived lack of understanding among primary care practitioners of health matters other than physical health problems and that talking to the

GP or nurse about emotional problems would be wasting their time as other problems were considered more pressing:

No, I've never thought of it in that sort of capacity really. I mean, it's different if you feel you've got depression or something of that kind, or stress, perhaps you could go to the doctor and then these issues would come out. But if I'm feeling healthy, to go along and start talking about loneliness, I'd feel that perhaps I'm wasting their time as it's not a health problem, currently. (Interview 21, female aged 65)

Those with mental health problems, such as anxiety or depression, and particularly those who had long-standing mental health problems for which they took prescribed medication, were more likely to consider talk about feelings of loneliness with primary care practitioners, albeit indirectly:

But while I've got a GP that understands that and keeps me straight, I'm fine (Interview 9, female aged 66)

Well, for instance, coming up two years ago, my doctor put me down for a sort of refresher in CBT. ... Yeah. I mean, he's very good; he's spent a lot of time with me. (Interview 10, male aged 70)

But for others, often who described a poorer relationship with the primary care team this was not the case, as reported by this participant with long-standing anxiety about taking medication:

Oh, good heavens, no! I just get prescription renewal (Interview 25, female aged 68)

Some participants stated that they would have valued talking to their primary care team but did not because they thought they would be prescribed medication. This was illustrated by one participant who said he was depressed and very lonely:

... well, really, there's nobody to talk to really, is there? You can't talk to your doctor about it, because they'll just turn around and say, "Here's a tablet". And I take enough of them now, and that's about all; there's nobody actually to talk to really. (Interview 7, male aged 68)

Some expressed concern that if a problem was medicalised by seeking help from the GP or nurse, this may lead to getting drawn into the health care system inappropriately. This participant was very fearful of the treatment of older people that had been reported in the press at the time of the interview:

Because I don't want to end up on some pathway, because I go into hospital for an earache or something! I know I'm exaggerating but this is how they frighten people, you know? ... I don't want to be sucked in, I won't be able to get out or anything, and told, "Oh, she's going senile or something, and we'll do this, we'll do that!" So I just think carry on and try and help myself as best I can. (Interview 3, female aged 71)

6.7.2 Doctor or nurse - patient relationship

The relationship participants had with particular members of their primary care team determined whether or not they had sought help from them for loneliness or would consider doing so in the future:

Well, that would be the last place I'd want to go, you see; they're not very sympathetic. (Interview 4, female aged 74)

Others described a positive relationship that had been developed over time and with their wider family:

Yeah, I might do, yes, because I've known them all for a long time, since we first moved here. And for various reasons, we've had quite a bit to do with them (Interview 19, female aged 69)

But for one woman the relationship meant being given her prescription when she needed it so that she could take the tablets as she felt necessary, not necessarily as prescribed:

I have a very understanding GP and she, or they, know me quite well, and they know I can sort of manage my own feelings, and they know if I ask for a prescription for Prozac because of my anxiety, they give it to me, because they know that I can manage it. (Interview 3, female aged 71)

6.7.3 Appointments and access

Within participants' views and experiences of primary care, themes emerged about the appointment systems and access, including time constraints, which were not specific to their experience of loneliness. These themes are briefly outlined here to provide a context of participants' experiences of primary care.

Not being able to see a practitioner of choice was a frustration for many:

... and the trouble with GPs of course now it's always difficult; you don't have your own GP, you have a practice, don't you? So that's all right if I can wait a fortnight to go and see him (Interview 18, female aged 78)

Navigating appointment systems was considered to be complex, particularly for participants who were registered with one general practice whose system for booking appointments changed during the course of the study. Having to describe symptoms to receptionists who then relayed these on to doctors

before the GP's decision on whether an appointment was necessary was very unpopular.

... it's like a conveyor belt in there. You've got to phone up and make an appointment. The receptionist want to know what's the matter with you and you've got to tell her, and then she says, "The doctor will phone you back." And then they say that those tablets are waiting for you, or come and see me. You never know what you're going to get. (Interview 7, male aged 68)

Booking an appointment was further complicated if the participant needed assistance to get to the practice:

Well, you see it's all very well for them to say that, but this is the problem, I've got to arrange an appointment that my friend can take me, you see? I just keep putting it off. You can't just phone up and say, "When do you want to see me?" I've got to arrange it when somebody can take me. (Interview 6, female aged 90)

The length of the consultation was for most too short, particularly when the issues were complex, of an emotional rather than physical nature, and the person may be feeling quite low or desperate by the time they reached the practice:

There are many times when I would have liked to have had a discussion, but the appointments are just 10 minutes (Interview 25, female aged 68)

One participant, however, who had long standing anxiety, stemming from her childhood and who had sought help from other therapies, described a different expectation of her GP with whom she had a good relationship:

I'm not sure I do need a bit more time, because I can think my way through it myself, and I think that actually will make me the stronger. You know, if I actually work the problem out for myself, that is the way that I'm going to actually cure it. (Interview 9, female aged 66)

6.8 Involving others in your loneliness

Most views about involving others in their experiences of loneliness were raised in relation to services to support people who are lonely and have been reported earlier under those sections. Other themes emerged about disclosure of loneliness that was not specific to services.

Participants' unease with using services stemmed from the perceived stigma of admitting they were lonely and needing services for support. For many, loneliness was a private matter that they would not consider talking to anyone about:

I know I've said, you know, I feel alone and isolated, but I'm not sure whether it would help me to talk about it. I think I know why I feel alone and isolated. I think I know, I don't need somebody to tell me if you like. (Interview 3, female aged 71)

Others alluded to wanting support but felt unable to ask for a variety of reasons including not wanting to appear unable to cope as well as not wanting to burden others, in particular their children:

I would be showing that I was not able to depend on myself. And it's also a masculine thing, but I hope I'm not that kind of person. But to depend on somebody, then suppose that person isn't there, you form a relationship and then they're not there. I'd rather be on my own than depend on somebody I find I can't depend on. (Interview 2, male aged 68)

... it's always been me who is like the matriarch of the family, worrying about them, but I don't feel they worry about me, but then why should they really, do you know what I mean? ... But I don't think they probably realise, they think, oh, my mum's fine, she copes fine, (Interview 4, male aged 74)

Services for loneliness were not considered appropriate by those who were distressed and grieving the loss of a partner; their grief was a personal matter. Some had considered bereavement counselling and tried it briefly but none had persisted with the counselling or found it particularly beneficial:

I don't know, it [bereavement counselling] might have helped, but sometimes you feel the loss is so great that the only way through it is ... I guess I suppose I'm a bit too independent in some ways and feel that I have to sort of work things out for myself...(pause) I don't know. I started keeping a diary and I used to write to my wife; I just used to write down thoughts and writing it down helped. ... it helped me to work out what I was feeling and what the issues were (Interview 16, male aged 65)

Many participants felt that emotional problems including loneliness were feelings that one dealt with oneself:

Well, I always cope with my feelings and I don't really need to pass them onto somebody else to handle. I'm sorry, that's me (Interview 26, female aged 78)

...you can't hire somebody as a friend. It's not something you can do, (Interview 3, female aged 71)

Participants' views on engaging with community based services and support for loneliness were more favourable towards shared interest or hobby based groups compared to one-to-one services or groups that were purely social.

Primary care was perceived to have a limited role in supporting lonely older people. Many participants preferred to deal with their loneliness privately without external support. A summary of participants' views of involving others in their loneliness, including primary care and community based services and activities, is presented in the Discussion chapter (Chapter 8 Section 8.1.2.3).

CHAPTER 7. FINDINGS 3: OLDER PEOPLE'S ACCOUNTS OF MANAGING LONELINESS

In this chapter I will describe the themes that emerged from participants' accounts of managing their experiences of loneliness. A manuscript based on this chapter has been submitted to a journal and I am currently responding to reviewers' comments.

An overarching theme of an 'outside' and 'inside' world emerged within which they coped. Participants described a range of behavioural and cognitive strategies they employed in response to the distressing feelings they had recounted, as well as the challenges of coping.

Engagement with an 'outside world' described a sense of belonging and connection to people and place. Strategies included physically engaging with the outside world by leaving their home, though not necessarily to have contact with others, being engaged with others or the community in a way that felt meaningful. Some strategies were shaped by earlier life experiences such as work. The 'inside world' was one in which loneliness is managed privately, kept hidden or re-framed to make the feelings more manageable. This included those who lived with others yet dealt with their feelings of loneliness alone. Some strategies, such as comparative thinking, interests and hobbies, the role of religion or spirituality, and using alcohol straddled both the 'inside' and 'outside' world in participant accounts.

Strategies were determined by coping styles, their health and wellbeing, and their living arrangements, relationships and social networks. Those who had experienced loneliness over a long time reported ways of alleviating loneliness that had been employed over the life course as well as specifically in later life. The findings are presented under the broad themes 'outside world' and 'inside world' and are expanded below with illustrative quotations.

7.1 Outside world

7.1.1 *Physical engagement with the world beyond their home*

All participants were able to leave their homes independently and going outdoors regularly was described as an important means of coping with loneliness. Being outdoors, even for short periods of time, allowed them to experience and enjoy the natural world. For some, leaving the home required effort and the use of walking aids; but these participants felt fortunate that they were still able to go outdoors by themselves:

I think really my saviour is my walking; I wish I could walk more, but I walk as much as I can, as I'm comfortable with. I think even if you only go around the block, just go out. The birds are singing and I think it's so wonderful; so much to be thankful for. (Interview 13 female, aged 84)

Being outdoors promoted a sense of connection with the outside world despite not always involving any contact or communication with other people. Participants appreciated simple pleasures of the physical environment and natural world and the beneficial effect of that on mental wellbeing more generally; this included stepping out into their back garden, as described by this participant:

You feel like you're drawing breath, somehow. I mean, it's a lovely house, isn't it,and I'm very comfortable in it, but actually opening the door I feel, oh, I'm out in the world again (Interview 15 female, aged 65)

Some declared needing a purpose to go out and they planned outdoor activities and pastimes. For others walking outdoors was, in itself, sufficient, and had become part of the routine of most days. This was particularly so for those who lived alone, who were also more likely to describe this as increasing the opportunities for chance social encounters and contact with others:

But it's just a fact that I nearly always do speak to somebody when I go to the park, even if it's only somebody saying that the car park has been vandalised, so you should not leave your car there. (Interview 1, female aged 89)

7.1.2 Using technology

Telephones and computers were described as being used for communication, information and social contact. A landline telephone was an important means of contact and communication for the majority of participants, especially those living alone. Many had established a pattern of contact on the telephone; frequent, often daily, contact with those that had children and less frequent but regular contact with other family and friends:

Oh, we phone each other every day. And my daughter phones me every day. And I phone my son in [other region] every day. So [local friend] and I will take it in turns, but we do talk every day. (Interview 13, female aged 84)

Participants described how the telephone helped them stay in touch with friends and family who had moved away. As well as the frequent 'checking in' contacts described of children, the telephone was used for more in-depth conversations by some:

I've got lots of friends, I mean, who spend time on the phone, who live a long way away. I've got one friend who regularly spends an hour on the phone once a week, you know? (Interview 18, female aged 78)

Those living alone and with smaller networks of friends or family used the telephone as their main means of contact with others. One female participant who was lonely much of the time, lived alone, had a very small social network and had some difficulty with her mobility, reported:

Occasionally she'll [friend] come and see me, but almost every day I speak to her on the phone.

[Oh, right, OK, that's very regular.]

Which makes a lot of difference. (Interview 1, female aged 89)

For those living alone, the knowledge that they could have some contact with others over the telephone was reassuring but not everyone was content with this form of communication:

And then sometimes you think you haven't spoken to anybody today, but obviously the phone, you could speak to somebody if you wanted to. (Interview 24, female aged 70)

I'm not very comfortable on the phone. (Interview 23, female aged 85)

The telephone also helped with making arrangements, both planning ahead or in response to times when feelings of loneliness were difficult to bear:

I have to get out and do something, maybe ring up a friend and go out and have a beer. (Interview 16, male aged 65)

Most participants used landlines but mobile phones were also used by several. Mobile phones had been mostly acquired so that the owner could be phoned by others or in case of an emergency, rather than for talking to others, social media or texting:

I need to be taught how to text; if I could do that, then I might use it. (Interview 21, female aged 65)

Computers were used by a smaller proportion of participants and included those that had gained some familiarity with them during their working life or some support from friends or family to set them up at home. They were

mainly used to browse the internet or play games as a pastime or interest, although a few were keen on the use of email as a means of contact:

Well, I don't use it for much. I read the papers from [home region]. I do games on it. Anything I want to find out. I do emails, and if I have any queries about something. (Interview 6, female aged 90)

None of the participants said they used the internet or social media to forge friendships or relationships with others.

7.1.3 Planning

The effort involved in actively planning to fill the time was recounted in detail by all participants. The plans and time frames they referred to were most often in relation to daily and weekly routines, but longer term events were described as well as times that were harder to plan and fill.

Planning with the aim of forging connections with people and place was evident in many accounts; participants described a conscious effort to make social contact with others and to have commitments to look forward to, and they could not rely on others to do this for them. Weekly patterns were recounted both from those who filled every day of the week to those who could describe at least one thing to look forward to in their week. This female participant who lived alone and reported being lonely much of the time described how she filled her week:

'I've got on Monday my class. Tuesday, every second Tuesday I'm at my club in the library. Wednesday, my [cleaner] comes. Thursdays are Dial-a-Ride [community transport service to specific locations]. Fridays [I go to] the hairdresser and I go and visit a friend over there. Saturday I play Scrabble and drink gin! ...And Sunday I very often go to church. And then we're at Monday again,' (Interview 6, female aged 90)

Looking further ahead usually involved plans with family members; get-togethers for specific occasions and the meals involved, and outings or holidays, usually with others:

*We [with sister who is divorced] have been going on holiday for the last five years I think, which is something to look forward to. And I always go away at Easter with my daughter, we go up north.
(Interview 4, female aged 74)*

... it was quite busy for about six weeks and, yeah, that made me feel quite good. I thought, oh, great, I've got that to do and that to do, and I'm going there, and then I went to the [coastal area] with my family about a month ago and it's little events that I look forward to ... so I think that's part of the loneliness and the isolation, you know, that helps me when I've got events to look forward to. (Interview 3, female aged 71)

As well as the evenings, which were considered often harder to plan and fill, participants described periods of the year or days as having limited opportunities to make contacts. These included weekends and winter time, due to the shorter days, but also summer times when others were away or classes/activities had different timetables or ceased:

If I haven't had contact all day ... well, it's more difficult in the holidays, you see, once the painting classes stop (Interview 1, female aged 89)

Considerations in planning the structure of the day often drew upon experiences from their working life and participants compared their present life to previous times:

Well, like today as an example, I've got to go and get petrol, go to the chemist; you think after you've retired, how did you work! And

*everybody says this and every day there's one thing or another
(Interview 24, female aged 70)*

This was perhaps more pertinent to this study's participant group as the majority were aged 65-74 years (see Table 2) and were relatively recently retired or approaching this; three were in regular paid employment and one worked a few hours a week on an 'as-and-when needed' basis. Reflections on working life applied to those who had planned their retirement, those who had an early/unplanned end to their employment and those who continued to work in a paid or unpaid capacity, and promoted a sense of belonging to an 'outside world'. One female participant, who was planning to stop work in the very near future and who had explored many options to fill her time, described her thoughts and concerns about maintaining a daily routine:

Whereas if you're working, you've got to, because I've got to be out the door by 8.30, whereas if you're at home, you're getting up, showering, having your breakfast but it's a different kind of drive, isn't it?

[Mmn. Does that matter?]

If feels so strange at the moment, because I have worked for so many years; for 37 years and the children and everything, to replace it with something, because it really does feel strange at the moment. I'll get my head around it, but it just feels very strange. (Interview 27, female aged 66)

A few had explored options and even started going to clubs or activities aimed at older people (U3A, Women's Guild) before they stopped working altogether:

I didn't have time really to go to the Women's Guild (slight laugh). So I'd been thinking about it, and then when I did retire, I joined the Women's Guild. (Interview 23, female aged 85)

Well, before when I was still working, I joined U3A, because I used to have Thursdays off so I could go to the meetings, and I didn't do anything with them, but I did go to their monthly meeting. (Interview 19, female aged 69)

Some participants discussed interests, habits and skills which had been informed by their working life. This former nurse, for example, described how she continued her approach to organising her life, established from her professional role, which helped her plan:

...and the organising, because you have to learn to; you know, if you're in charge, as I was, of an operating theatre, for instance, you have to be organised, and it's what you're trained to do, and I think, yes, it's stuck. (Interview 18, female aged 78)

Others talked about the structure that employment had provided earlier in their lives, and although they were glad to no longer be working, adjustment to a different pattern to the day and week was difficult, as was filling the time with something they enjoyed:

Yeah, it's about having to have something to do I think, because you could so easily get into the trap of, oh, it's Monday, I'll do the washing today; it's Tuesday, I'll do the shopping today, it's so easy to get into that and I didn't want to do that. Because I think when you're working, your life is very regimented, isn't it? (Interview 19, female aged 69)

I mean, for work I had to go, but I didn't mind. I'm a morning person and I get up at 5, and then go to work and then finish. And then I could come home quite early, so I had the day to myself really. But I know I have done the right thing giving up but it's just that I wish I could chivvy myself to get out a bit more and do things. (Interview 4, female aged 74)

Some plans relied on social connections relating to their working life, acknowledging it was difficult to establish new friends:

Sometimes you make friends, often you don't, you know? So I would do that sort of thing. There is [local resident who worked in same profession] and he loves music, and he has lots and lots of music. Some are in a lovely little church, and I go there and sometimes I meet people I know and sometimes I don't, and that's nice. They have a concert on a Friday from 1-2pm. (Interview 20, female aged 78)

7.1.4 Being engaged in meaningful activity

Within the activities and plans described, some participants gave particular focus to activities that they felt more engaged in or that they felt were more meaningful than those that just filled the time. These tended to be related to voluntary work either formal or informal, and included views on continued learning. Several participants were engaged in voluntary work that they described with some pride. This often required a particular skill or experience linked to their earlier working life, for example, giving advice on filling out benefits forms, being involved in running clubs or interest based groups, speaking another language, and even helping with employment, as described here by this former healthcare practitioner:

... working on a voluntary basis in the [local] libraries, which I love doing because I help people write their CVs, and of course it's a bit like interviewing a patient; they're supposed to write a person spec... And that's interesting.....Well, I missed my patients, I still do. I suppose my library is a sort of substitute. I enjoy talking to people and I always learnt. (Interview 20, female aged 78)

Another former healthcare practitioner volunteered at the hospice where her husband had been cared for her and described the sense of satisfaction she felt from this:

Yes, because you feel you go alongside somebody who is in a pretty grim emotional state, usually quite often we find with other problems as well; you know, it's not just the bereavement... It's lovely when you've perhaps been with them for two or three months perhaps, or even longer, at the end of the time to see them going back into their life again and picking up the threads and being able to move on, and to feel you've been part of that procedure for them. Yes, it is rewarding work. (Interview 18, female aged 78)

Others described an attitude to continued learning which they engaged with in a way that did more than just fill the time. Topics were broad and included learning more formally such as distance courses in psychology and philosophy that had been followed for several years and recent courses on local history and photography, to learning and spirituality in reference to the practice of faith as described by this participant:

... but you know I'm learning all the time. You never stop learning. [You've been practising a long time, so you must have ... you know?] Well, that is kind of what is wonderful about it, it doesn't matter how long you've been practising, what matters is what you're doing right now, this minute (Interview 22, female aged 70)

Again, there were reflections to the contrary from those who regretted the lack of education earlier in their lives, both for the sense of accomplishment as well as contact with others it could provide:

But what I would like, but you can't get it [adult education courses] down our way, because I've never accomplished nothing in my life and I tried to sign up for school so I could learn maths.... Yeah, I'd

just like to accomplish something, you know? I think you can meet people and all when you're in there and all, know what I mean? (Interview 7, male aged 68)

7.1.5 Having a sense of purpose

Engagement in activities that promoted a sense of purpose was described by many. The context was usually family relationships which played a central role in the social networks of many participants. Those who saw children and grandchildren described the pleasure they felt from sharing time with them, and a sense of purpose from being involved in their lives, and helping with immediate practical tasks such as DIY or childcare:

So that's helped a lot, and things to take you out of yourself really, and helping them and picking them up from school. (Interview 24, female aged 70)

But it [daughter's flat] needed a lot doing and of course it's mum and dad who are down there decorating and all the rest of it. But I do that because I want to do it, because I don't want her to struggle. She's too young to be struggling; she should be enjoying her life. (Interview 9, female aged 66)

Other examples included future planning, such as for family finances:

My granddaughter, she's 3, and my son's partner is now pregnant again, so they'll have a second one so I spend a lot of time thinking about ... I do some financial planning for her, so I've invested quite a lot of money, because I get a lot of satisfaction out of thinking if I'm still around when she's 18, I'll have a lot of pleasure out of giving her a cheque to do something; she'll go off around the world, or pay for her university fees, or whatever she wants to do with it. (Interview 16, male aged 65)

Others whose involvement had changed, for example, as grandchildren became older and needed them less or those that were not able to be involved as they would have liked, perhaps reflecting long-standing tensions within the family, expressed sadness at this loss:

Because there are lots of things that one can be helpful with, but I think it's mainly that, a sense of not being able to contribute as I would like, you know, just helping with the children or whatever. But anyway, it doesn't happen, and I find that hurtful.

[Yes. Is it more than the geographical distance, I take it? Is it some ...?]

I don't know what it is. I don't know what it is, I really don't know. I do find that a pity and I have to deal with it in my own way. (Interview 22, female aged 70)

Employment had given many a sense of purpose in their lives. As noted above, the majority of participants no longer worked and some talked about the idea of working again as they felt they did not have enough to do:

I was even looking at a job advert the other day, well a few months back, thinking, a part-time job? Oh, shall I get a part-time job? I feel under-used sometimes, because I'm a busy person. (Interview 9, female aged 66)

7.2 Inside world

7.2.1 Acceptance

Acceptance describes how participants had acknowledged that their loneliness may not be resolvable and that, by focusing on making the best of their situation and recognising they were not the only person who experienced difficult feelings of loneliness, they were able to manage. Statements about loneliness being something that was widely experienced were expressed by most participants:

... but I think everybody experiences loneliness pretty much to the same extent, I think just different people deal with it or fail to deal with it differently. (Interview 15, female aged 65)

Loneliness was seen as unresolvable if it involved loss of a partner or prolonged duration, especially among the oldest old. Despite this, these participants described how they coped and had found a way to accept their situation. These participants experiencing emotional loneliness stemming from the loss of their partner described how they felt they wanted to work through their grief alone (without the support of services such as counselling):

And in all honesty, I'm not sure counselling or whatever, I couldn't feel different to what I do, you know, because of how we were. And, yes, you can always try to take your mind off of things and whatever, but it's something which is always there. (slight pause) Yeah, whatever counselling, whatever people say, you can't change the way you feel and the way you are. (Interview 11, male aged 71)

They described the loneliness they felt as a result of their loss as being a situation they had learned to accept:

There is an emptiness there, because there's a gap that they've got and I haven't got. I can't do anything about it, so I've got to accept it. (Interview 18, female aged 78)

Others coped by adopting a more philosophical stance to their situation, in particular those who had felt lonely for a long time or those who were older:

Oh, well, like I say, I look at it one way: we're all going to pop our socks sooner or later, so don't worry about it. (Interview 7, male aged 68)

I get a bit philosophical and just think, well, I'm not going to live forever. I never thought so, but as you get older, you accept the fact that we're all mortal. (Interview 8, male aged 85)

Others in long-term but unsatisfactory relationships described a sense of resignation with the emotional loneliness they experienced:

I like to know that people are there, but I don't necessarily want a heavy relationship. Mmn. I suppose I'd like to find a way to break out of it, but at this advanced stage in my life, what does one do? (Interview 21, female aged 65)

Participants had chosen to stay in these relationships and coped with their loneliness alone:

...but I do know that I'd live my life very differently if I were on my own. At least I'd have an open door for people to come here. (Interview 26 female aged 78)

7.2.2 Endurance

Participants described very difficult life experiences and situations which they felt had contributed to their loneliness. These included difficult childhoods and early adult life, very difficult relationships with partners, long-term depression and anxiety, and extreme isolation. Participants appeared skilled at managing such situations which had often endured over time. As

well as dealing with these feelings privately, some described how they had to 'lay low' for a time to get through times of acute distress, but with the confidence that they would be able to come through this, as they had previously. This participant described how he had coped over time with several traumatic events in his early life:

Well, I've told you about my early life and because of that I've learnt, you know, the hard conditions, is perhaps a better expression, to suppress the feelings and push them to one side and just get on with it. (Interview 2, male aged 68)

These accounts illustrated a tension between their inside and outside worlds and some participants, including one who did not live alone, described how they retreated for a period of a few days, away from others until they felt able to face anyone:

It is a feeling of isolation, but usually I can work my way through it in two or three days, and then it will pass. (Interview 18, female aged 78)

A few participants reported long-term depression and anxiety for which they had sought help, including both pharmacological and talking therapies. They were able to distinguish their loneliness from their depression/anxiety but there was also overlap in how this was experienced and managed. During particularly difficult episodes, those that took medication had learnt how to respond and the likely pattern of their 'recovery':

Oh, quite short. I expect to feel better within a couple of weeks, because during that time, I don't feel well, I don't really want to go out, I don't really want to face people, I don't want to talk to people, but it does pass. (Interview 3, female aged 71)

As I say, it's only when I'm really at the bottom, which is to be expected when I'm really at the bottom, that I find it difficult to actually get myself going. But you see that doesn't last for very long; as I say, I get back on the tablets or up [increase] the tablets or whatever, at the appropriate time; I mean, it doesn't happen very often. (Interview 9, female aged 66)

The accounts of loneliness that informed this theme were of severe loneliness that was particularly challenging to manage. Loneliness was but one of a mixture of emotions expressed, and at times it was difficult to disentangle it from other distress. Participants were, however, able to describe how they managed, as this was a coping strategy in itself:

If I didn't see it as managing, then it would be very hard to accept. (Interview 25, female aged 68)

7.2.3 Revealing and hiding

The context of participants' experiences of loneliness was broad and varied; many disclosed traumatic events and times which they felt had contributed to their loneliness, whilst others described an 'inevitability' to loneliness, as the experience was considered commonplace. Although most were able to describe the circumstances that had led to their loneliness, most found it harder to articulate how being lonely made them feel in the moment. Most interviews were emotive, several participants became tearful and upset, and the interview was paused. One participant asked me to turn the tape recorder off towards the end of the interview before disclosing more sensitive issues about his ability to cope. Another who had reported being lonely much of the time and referred to earlier periods of life where loneliness had been more acutely felt, found the discussion difficult:

Yes, well, now we're getting down to, erm ... I don't want to say it, actually; I don't want to say things against myself, there's no point.
(pause)

[Are you OK?]

Yes.

[Are you OK? I don't want to upset you.]

No, it's just that, well, I don't want to say things against myself, that's all; there's no point in it, is there? (Interview 1, female aged 89)

The private nature of how participants managed their loneliness was evident in these accounts and many managed by keeping their loneliness hidden from others. Again, the tension between outside and inside worlds was evident; these participants described how they kept their true feelings concealed from people they had described as good friends as they didn't want the knowledge of their loneliness to impact on their relationships:

And if you put the act on ... I mean, your friends don't want to see you moping about, do they? (Interview 28, female aged 67)

Bereavement and grief were also considered by many to be private matters. The emotional loneliness experienced after such loss was to be worked through alone, as described by this participant who had been very upset during the interview:

I can talk about it, I think I've just been more emotional this morning than I have been for a little while. But I don't feel as though I want to talk to people about it anyway, really (Interview 11, male aged 71)

7.2.4 Comfortable in solitude

Within the different experiences of loneliness, in terms of severity, recurrence and cause, a narrative emerged about how people had found ways of being more comfortable and in control of their situation. This applied to both those who had lived alone for most of their adult lives as well as in

reference to past relationships. Two female participants had been widowed many years ago and barely mentioned their husbands throughout the interview. Although they reported many challenges of living alone and being lonely, they described being comfortable with times of solitude:

And also when he [husband] was alive, he mostly worked nights, so I had most evenings on my own, mostly. I mean, I know my son was here, but most evenings I sat here on my own. I didn't sit here on my own, but I was in the place on my own, so I was used to my own company. (Interview 23, female aged 85)

Oh, yes, I'm all right going out. I mean, as I say I was in [name of place] all day yesterday shopping, and I can go and have my lunch out, I can go and have a coffee; that doesn't bother us.

[And you'll go and do that on your own, will you?]

Oh, yes, I don't mind doing that on my own. Now my sister, who I go away with, she doesn't like going and having her lunch on her own. So, no, that doesn't bother us, and I mean, there and back, I get seven buses. (Interview 4, female aged 74)

One male participant, whose wife had died suddenly and was one of the youngest participants, attributed this to personality type and compared himself with a friend of his who was also widowed:

But this friend, she really does find it difficult, being on her own and within a very short space of time, she'd actually met another man and he's moved in with her and they live together. She's very happy, but something drove her to find company ... she can't replace her husband, that's not possible, but she needed someone there, some companion. And some people are like that, and I guess I'm not, you know? (Interview 16, male aged 65)

7.2.5 Having a positive attitude or focus

Participants described how, within the varying complexities of their lives, they coped by actively focusing on the positive, both in dealing with the present and also when thinking back to the past by remembering the ‘good times’ rather than ‘bad’:

I am blessed. There are a lot of things that are not so good in my life, but I try and think positively – you have to (Interview 28, female aged 67)

I always try in the past to remember the good things, not any of the bad things. (Interview 8, male aged 85)

One participant who had moved to be closer to family members described this as being an upheaval following which he and his wife had struggled to re-establish a network of friends. Nonetheless he would advise others to do the same and was hopeful that their social networks would improve:

... they would have to learn to cope with fewer comforts than you had, fewer friends. Which we were exactly the same there too when we first went there, but it gradually went up. We hopefully will build that here too. (Interview 5, male aged 71)

When asked what enabled them to adopt a positive focus several participants commented on having a particular personality type and/or having been shaped by their upbringing:

I think I get a lot of that from my mum. She was very, very positive in her attitude, even in her older life as she was 93 when she died. (Interview 19, female aged 69)

A personality type was referred to by some in the way they considered their wellbeing and health more broadly:

Oh, it's a wellbeing in your own mind issue, whether you feel positive about being healthy and you're fairly optimistic that you can stay healthy if you try and struggle. (Interview 14, male aged 67)

7.2.6 Motivation

Participants described how they had to 'talk themselves' into doing things and be motivated to engage with either behavioural or cognitive strategies to address their loneliness. This included overcoming initial reservations and difficulties:

So I live within a very limited regime which initially was devastating, but I was either going to bore myself the rest of my life or I had to learn to manage it. (Interview 25, female aged 68)

The underlying effort that this required was evident in some participant accounts:

... but you also have to force yourself to go out and do things. Because if you didn't you really would become very insular, wouldn't you and never do anything. And sometimes you have to do it; it's almost like I'm going to do this, because what is the alternative? (Interview 27, female aged 66)

Not all participants were able to do this; this male participant was aware of support and interest groups around him but had found it difficult to take the first step to re-engage since being widowed:

... and a lot of it is down to the individual I think because if I made more effort, through the U3A and the like, I could get that contact. (Interview 11, male aged 71)

Meal times were a focal point; the daily preparation of food and mealtimes was broken down into component parts with an awareness of how they could be used to pass the time:

But it's the evenings, often that's why I'll cook, it fills up part of the evening. So if I have to walk to the supermarket, which is down in the town, buy whatever I need and walk back, then that's an hour gone and then start cooking. Then by the time I've cooked and had the meal, it's maybe 8.30pm; sit down, read a book, time for bed. So that cooking part of it is quite important for me. (Interview 16, male aged 65)

7.2.7 Distraction and 'keeping busy'

Simple activities to keep busy usually around the house also filled the time and provided temporary distraction from their loneliness; they were often difficult to pinpoint other than by phrases like 'doing something' or 'keeping busy':

I have a wander around here [home], out there [garden], that's all really (Interview 23, female aged 85)

Well, basically I mean try and busy yourself really. I mean the worse thing in the world is to just sit down and do nothing. (Interview 13, female aged 84)

Housework was also something to do although several, especially those who lived alone, questioned the purpose of it. Participants talked of others who were 'house proud' but not feeling bothered themselves, but also recognised it as something to pass the time:

I suppose I try to keep myself active inside the house if I'm here; I try to keep it relatively tidy. There are bundles of things all over the

place.....hopefully those are the things which keep me kind of occupied at the moment. (Interview 11, male aged 71)

Within these descriptions of how they kept busy was awareness among some of the purpose of these ways of passing the time:

I suppose all of the activity is just trying to fill that in, but it never does; it can't do because it's always there. But, I don't know, it's a distraction; it's trying to distract from actually thinking about that, because if you think about it all the time, well, goodness knows what would happen (Interview 16, male aged 65)

7.3 Both inside and outside world

The themes of comparative thinking, interests and hobbies, religion and spirituality, and using alcohol, straddled both the inside and outside world of participants

7.3.1 Comparative thinking

Comparative or relative thinking was used as a coping strategy in several ways. Participants drew comparisons with other people or other times of their lives when they had been lonelier. They talked both specifically about people they knew or more generally about 'others' to compare how things could be worse for themselves, and to help alleviate the negative feelings of the present:

I think of my friend in [Scottish city] who never has anybody who comes to see her, gets out twice a week to a thing the council run, but doesn't seem to have ... she has only one nephew and he's down in England, but yet she keeps going. I think well if she can do it, I can, you see? (Interview 6, female aged 90)

Then I think, well, there's always somebody worse off than me, that's the way I look at it (Interview 7, male aged 68)

Many examples of times that had been harder to bear were shared. Relationships were again mentioned by both those who had felt lonelier earlier in life when they had hoped to form a significant relationship but had not, and those participants, both men, whose relationships had ended acrimoniously after which they had experienced hardships as single parents and not re-partnered. One female participant described the camaraderie and travel that she had enjoyed as part of her working life, which had meant that when she returned to her home and life alone, she had felt particularly lonely and lonelier than she did in her present retirement:

It may be that I have ... yes, I think things would be much more difficult for me from the point of view of being on my own in other periods of my life than they are at the moment.

[Ah, OK.]

I think, yes, I'm getting awfully used to it, to finding ways and means of coping. (Interview 1, female aged 89)

Other times that were described as being lonelier than others included periods of mental or physical health problems, acute grief, difficult caring responsibilities and looking after a new born child:

I think when you've got a new baby you can feel quite lonely, and your husband is out at work all day and you're left with this little thing that doesn't really do anything much (Interview 19, female aged 69)

This relative thinking helped some participants find a positive feature to focus on within their experiences of loneliness in later life. A few reflected on periods of loneliness in their very early childhood, from being an only child or growing up in a household which had been very stressful, that had left them with unresolved feelings in adulthood. One participant who had been an only

child asserted how this had influenced his own subsequent family size and relationships with his children:

I made every effort to make sure that [his experience from his childhood household] didn't prove to be limiting, just having a little tiny, nuclear family that were locked away out of sight. (Interview 14, male aged 67)

Relative thinking also applied to time spans. Several participants described how they tended to focus on their short term future which felt more manageable than looking too far ahead. Thoughts of managing loneliness in the distant future were mixed in with their thoughts on ageing more broadly and the likely decline of their health and independence. These views were expressed by both the 'young old' and 'older old':

I tend to take each day, day by day (Interview 16, male aged 65)

And try not to look too far ahead because you can look at all the things that could go wrong about it, and then that would probably outweigh it. (Interview 27, female aged 66)

Well, I hope it will be as few years as possible. I certainly don't want to live to be 100, unless it's going to be like this all the time, which it won't be. (Interview 6, female aged 90)

7.3.2 Interests and hobbies

Part of planning to fill the time and manage loneliness included engaging in interests and hobbies and most participants could describe a pastime they partook in. A varied list of interests and hobbies was described that were followed either inside or outside their home, both solitary and with others:

I think the main thing is to have something of interest; you don't have to be an expert at it. I'm not an expert at calligraphy by any means, but I get some enjoyment out of it. (Interview 8, male aged 85)

I try and make sure I keep myself about the house doing my food, making sure I get up. I try to keep it tidy and whatever, and as I say, I do very much enjoy doing my tennis and my walking....Anyway, hopefully those are the things which keep me kind of occupied at the moment (Interview 11, male aged 71)

Many were able to continue with interests and activities they had engaged in earlier in life, fewer described taking up age specific or new interests, although some described taking up new opportunities having more time or resources in later life. Some mentioned exercise-related interests becoming more difficult with poorer health and the motivation required to keep doing them. Others referred to the social contact that attending group classes could bring, as reported in Chapter 6 (Section 6.2).

The availability of local and accessible pastimes was raised in different ways. Transport considerations were a feature of descriptions, both as help and a hindrance, from availability of free public transport, efforts needed to arrange lifts with friends or acquaintances without being a burden, ability to drive and cost of keeping a car, and being mindful of stairs and steps on public transport:

That's my one saving grace that I'm fit and I'm able to get out and visit places, use the Freedom Pass; that's a wonderful thing, being able to use the buses and trains, and go off to London. (Interview 21, female aged 65)

I don't walk for pleasure; I walk to get from A to B, but not for pleasure. It's too painful... I get the home library, and once a week I get Dial-a-Ride to shopping, to [supermarket]. And I've got Computer

Cab twice a month, so that takes me to [local area] to my club one day, and another day to the library, and that's what keeps me going. [And how do you get to your balance class?]
My carer [long-term cleaner who helps with other tasks as needed] takes me in her car. I've got it all organised. (Interview 6, female aged 90)

Relocation, usually to be closer to family members, was discussed by a few participants. One male participant described the availability of local pastimes and acquaintances in considering whether to move closer to his daughter who lived in a different area:

I thought it over and I decided to stay here, because although I haven't got the same clubs and things to go to, and things I belong to, at least I do know a lot of people. There is a club I go to, just a drinking club, and I know lots of people there; I don't know them really well, but I've known them for several years, quite a few years now, you know? (Interview 8, male aged 85)

The challenge of continuing with interests by oneself was raised. Two participants described the efforts involved; the first managed to focus on the positive aspects of being alone, but the second, who found social situations awkward, described the difficulty of forging friendships within a hobby-based group:

Well, I think one of the things that I'm getting better is going to the theatre at night as a single person. It's the sort of thing you wouldn't have done before when you've got a family and a partner. I now do that, and I think it takes time to adapt to a single existence, you can't do that all in one go. And it's a different kind of lifestyle, and there are lots of nice things about it, because you can do things when you want to do it and you don't have to think about anybody else, so that has a certain pleasure. (Interview 20, female aged 78)

...I don't know why, but just going alone to a group and you've got a sort of fear of the unknown. Well, not fear, but, you know, what are you going to do? But I think I can go and sit and listen, I could do that. (Interview 5, male aged 71)

This was also expressed by some of those living with others who described having to forge their own interests and pastimes as their preferences were different to their partner's, as depicted by this woman:

I know I've still got a husband, but he doesn't need me to be his friend, because he doesn't want to go anywhere, he's quite happy to just be; he likes pottering around here, he likes decorating, he likes doing the garden. I need to go out and socialise with people, probably because I always worked with lots of people, but he always worked on his own, so he doesn't feel the same need. (Interview 19, female aged 69)

Watching television helped pass the time with watching the news and following current events perceived as a more 'positive' distraction, providing a connection to the 'outside' world. However participants acknowledged that they generally did this when there was little else to do:

But still there are days when there's a vacuum, there's a blank, so we just flick the channels, look at emails and I do that because I like to see the news always. I take the news in the morning, which is good, that takes my time. Sometimes if they repeat every half an hour, I change the channel, hoping for some different news, but it's the same news again. (Interview 5, male aged 71)

7.3.3 Religion and spirituality

Less than half of the participants described religious beliefs or practices as a way of managing difficult times including their loneliness. This theme

straddles both the 'inside' and 'outside worlds'. Participants talked about religion or faith in terms of its potential to promote reflection and as a set of beliefs from which they drew strength and practised privately. A few attended regular services at religious venues and described the benefits of belonging to a community of people with shared beliefs:

I think faith comes into it a little bit; if you've got a reasonably strong faith ... now, I'm not a church-goer, I was brought up very much as a church-goer, church every Sunday and that's it. But I have retained my faith, and I think that has helped quite a bit to help; you know, you draw strength from what you believe and that does help quite a lot.
(Interview 18 female aged 78)

In contrast, others described mixed feelings about how religion had made them feel excluded or how religious practices in their childhood had shaped their later lives less positively:

... the feeling of not really belonging, from the wrong side of the tracks; ...I'm sure that was not being Christened; you're not part of ... it's not something that's really been discussed. (10)

One female participant had changed her religion and practiced regularly, drawing comparisons with the faith in which she was raised:

Well, my practice helps, it really does. When my practice is strong, it's fine. So when I kind of get one of these gloomy things, I practice and make sure, when I have the energy to do that. Because I think what the practice does is give you an understanding of life. It's not like [name of religion], where there's some external god or some far off heaven or hell, it's kind of like now in the moment really. So I mean in that, it's very good at grounding one. It's very helpful there.
(Interview 22, female aged 70)

7.3.4 Using Alcohol

A few participants mentioned drinking alcohol to help them manage times of loneliness and distress, both alone and with others. Most of these participants drank at home, usually later in the day when perhaps it was more 'acceptable' and/or because the evenings were harder to fill. One man described the variations in what he did to manage his loneliness at different times of the day:

Something around the house normally, unless it's after 6pm, and then I'll have a drink. (Interview 17, male aged 70)

Going to the pub or inviting someone out for a drink was also perceived as socially acceptable:

I don't go to this club every night, but if I feel depressed I think, oh, well, I'll go down the club and get cheered up. (Interview 8, male aged 85)

One participant was keen to assert how one should not be judgemental about older people drinking alcohol:

... or I have a glass of whisky! (slight laugh) I know you're always asking older people how much you drink, but I don't see how you can get through this without, I really don't. ... (Interview 6, female aged 90)

For others, drinking as a coping strategy was described in relation to specific times or situations including their earlier life:

But at one time, when I was under stress and in my late forties to mid-fifties, I was drinking fairly heavily and again, as a prop, as I saw it, for

this 'I'm on my own with this problem' thing'. (Interview 15, female aged 65)

One male participant who found his caring role stressful and whose loneliness stemmed from the impact it had on his life described drinking more alcohol currently than previously, to help him cope:

Of a night, I'll probably have a couple of large gin and tonics. See, I am drinking more now than I ever used to and I drink a half a bottle of wine as well. But, sod it! (Interview 17, male aged 70)

7.4 Summary

Within the discourses of lonely older people, an overarching theme emerged of coping within 'inside and outside worlds'. Older people described multiple strategies they used to deal with their situation which included behaviours, thoughts and feelings, and which they carried out privately within an inside world, or through which they engaged with other people or places, that is the outside world.

The relationship of this overarching theme to the sub-themes or strategies for managing loneliness is described in this chapter and serves to emphasise the difference between social isolation and loneliness, particularly in this group of participants many of whom lived with others. Examples include those who live or cope alone by finding connection or engagement with an outside world that does not necessary include direct contact with others, as well as whose living with others who keep loneliness hidden from their partners, as well as close friends and potential confidantes, due to the stigma of admitting loneliness.

The range of strategies used by participants to manage their feelings of loneliness reflects the subjective nature of loneliness, characteristics of

loneliness such as duration and intensity of distress, the stigma of disclosing loneliness to others, and individual coping styles and preferences. For some the experience of loneliness and managing it overlapped with other distress or difficulties that they were managing.

Loneliness that participants were not managing may have been underplayed or hidden. This is illustrated by this participant for whom a feeling of control was important given the challenges of her health, relationship with partner and financial difficulties:

*If I didn't see it as managing, then it would be very hard to accept.
(Interview 25, female ages 68)*

In the following chapter, (Chapter 8 Discussion) the findings from the qualitative study and the systematic review are summarised, interpreted further and discussed in the context of other research.

CHAPTER 8: DISCUSSION

This chapter firstly summarises the main findings of the systematic review and the qualitative study exploring older people's experiences and responses to loneliness. It then considers these findings alongside published literature. The strengths and limitations of the methodology are discussed. Finally the implications for future research, policy and practice are outlined.

The main research questions of this thesis are:

4. How do lonely community dwelling older people understand their loneliness and its causes and consequences?
5. What are the views of this group towards involving others in their loneliness, including community-based services and activities?
6. How do older people respond to and manage loneliness themselves?

Greatest emphasis was placed on the third research question as less research has been carried out on responses to and self-management of loneliness in later life compared to the causes and experiences of loneliness.

8.1 Summary of findings

8.1.1 *Systematic review of self-management of loneliness*

The systematic review reported in Chapter 3 found only 11 eligible qualitative studies that had explored the strategies older people use to manage loneliness themselves. These studies were limited by largely recruiting people through services, or on the basis of certain characteristics such as living alone. From the thematic analysis, two main dimensions were identified. The first was the context of coping, either alone or with others, the latter referring to either direct involvement with others or with others in mind. The second dimension describes a spectrum of strategies used in response to loneliness, ranging from preventative approaches, taking action, acceptance of loneliness and endurance in which distressing feelings are lived with. The two main dimensions overlapped as the strategies for managing loneliness could be practised either alone or with/in reference to

others; this relationship can be represented as a model which conceptualises coping styles for loneliness along these two dimensions. The model is presented in Chapter 3 and the associated paper (Kharicha *et al.*, 2018); see Appendix 5. I further explore the ‘fit’ of this model to my own findings below (Section 8.2.4.1).

8.1.2 Qualitative study

8.1.2.1 Sample

The experiences and responses to loneliness presented in this thesis are from a sample of 28 community-dwelling older people from a range of settings who had identified themselves as lonely or screened positive for loneliness. The sample was diverse in terms of age, gender, living circumstances, education and socio-economic status. However there were few from ethnic minority groups, all participants had capacity to consent to be interviewed (excluding those with severe dementia) and while a number had difficulty leaving their homes, none were unable to do so completely.

8.1.2.2 *How do lonely community dwelling older people understand their loneliness and its causes and consequences?*

Participants’ accounts of their experiences and understanding of loneliness are described in some detail in Chapter 5 and summarised below. The subjectivity of loneliness was a key feature of participants’ accounts. Loneliness was used to describe a wide range of negative emotions including, loss, dissatisfaction, despair, grief, sadness, emptiness, feeling alone, disappointment, regret, unresolved emotional problems, and anxiety about the future. There was a high level of disclosure as participants shared difficult and distressing times of their lives with me; several participants were upset during the interviews and most seemed to find it challenging to talk about the circumstances and feelings associated with their loneliness.

The context of the loneliness experienced by participants was wide-ranging.

Those who ascribed a severity to their feelings of loneliness included those who were grieving the loss of a partner, those who described past traumatic events that had shaped their lives or left them with feelings of 'never having fitted in' or having unfulfilled lives, and those with mental health problems such as depression or anxiety.

For others loneliness was triggered by a variety of losses. These included bereavement following the death of wider family members (including children) and friends, the loss of role, structure and 'meaningful engagement' following planned retirement and the frustration and financial difficulties following unplanned retirement. Others losses included unsatisfactory or stressful relationships with partners and other family, decreasing or inadequate networks and support which were exacerbated in those who had moved to a new area, and an 'empty nest' associated with the loss of parenting role and/or unsatisfactory relationships with adult children. Declining function and health-related problems (both physical and mental health), difficult caring roles, and an increasing amount of time spent alone and/or without any interaction with others were also described.

Most described more than one of these feelings or circumstances; the complexity and interplay of emotions related to life events and responses to them over time were evident in accounts. Loneliness embedded within such a breadth of contexts and circumstances was often difficult to disentangle from other negative emotions; the interplay between loneliness, other affective symptoms and mental health problems is discussed later in this chapter (see Section 8.2.2.3).

The heterogeneity of loneliness documented in these accounts does resonate with the widely used definition of loneliness as a subjective experience and an emotional and unpleasant response to a lack of satisfactory companionship (Weiss, 1973). However, given the breadth of accounts, this definition may not be helpful in understanding all individual experiences of loneliness and the responses to it that may be meaningful.

Participants reflected on their lives and compared recent experiences to earlier episodes of loneliness. There were mixed views on loneliness in later life; some placed more emphasis on past events causing their loneliness than on their current situation, whereas others felt lonelier as they had aged. None of the experiences could be described as linear but were episodic and circumstantial in nature. The transient nature of loneliness was illustrated by episodes of different lengths of time, frequency and severity over periods of life.

As well as acute events such as bereavement, others described an accumulation of occurrences that had led to their current situation being difficult to deal with. For some this also exacerbated their loneliness; for example, the three participants who alluded to increasing difficulty in maintaining their homes for a variety of reasons which meant they no longer allowed others to visit. Other cumulative factors were those common in later life such as bereavement, reduced social networks and declining health; these experiences of loneliness were described alongside their experiences of ageing more broadly.

Stigma of loneliness

Some found loneliness difficult to describe and talked of other people who they considered lonely. A few reported they were not lonely when interviewed despite having given responses to the earlier questionnaire that indicated they were lonely. This may be due to the dynamic nature of loneliness, which meant they no longer felt lonely as they had done when they had completed the questionnaires. Or it may also be due to the social stigma of loneliness, which was evident in accounts of those who said they were lonely at interview and those who denied it. It is possible that those who found loneliness difficult to discuss directly may have found it easier to describe loneliness in terms of other negative emotions or life events that were associated to their feelings of loneliness.

Relationships and loneliness

Perhaps unsurprisingly, relationships formed a significant part of the narrative in this exploration of loneliness. This thesis adds the experiences of those who continued to live with partners as well as those living alone. Social and emotional loneliness could be identified in the accounts of those in difficult long-term relationships, due to both the poor quality of the relationships themselves as well as the way in which partners influenced their ability to maintain wider networks. Similarly those living alone after the loss of a partner described the loss of a confidante as well as no longer feeling comfortable within social groups comprising couples. Negotiating a balance in relationships with wider family and friends was also expressed; differences in expectations of the relationships, both in terms of quality and quantity, led to feelings of loneliness, which were often long-lasting.

8.1.2.3 Perceptions of services to alleviate loneliness

Older people's perceptions and experiences of community based services and activities to alleviate loneliness are reported in Chapter 6 and in the associated publication (Kharicha *et al.*, 2017), see Appendix 5. This study is one of the first to explore perceptions of these resources from a sample that was not recruited from services supporting older people, which are the source of participants for the majority of studies of managing loneliness (Kharicha *et al.*, 2018).

Participants were generally knowledgeable about local resources but did not consider services which they perceived as being for 'lonely older people' as desirable or helpful. The sample included both those who had and had not tried these services, including those with very limited networks and those who described the severity of their feelings of loneliness. Most held the view that the services were for individuals whose needs were much greater than their own, which may reflect the fact that all participants in this study were able to leave their homes independently, albeit with some difficulty and that

the majority were aged between 65-74 years. Some said they would consider these services in the future, but that they were not that 'desperate' yet.

Four main avenues of potential support were considered: one-to-one support such as befriending services, group support with a social focus such as day centres and lunch clubs, group support that was interest based, and the primary care team. Specific features of each were given as reasons why they would engage or not with these services. Overall, group based activities with a shared interest were preferred to one-to-one support or social groups. Group based activities that were interest based usually covered interests that had been established in earlier life and were not later life specific. Participants were aware of the secondary role these groups served in that they provided an opportunity to socialise, but some were uncomfortable about attending these groups primarily to make friends, particularly if this required attending alone or amongst those with mental health problems. Views on one-to-one support and groups that come together for social reasons alone were similar and were perceived to be for those who were much more dependent than themselves and also those with minimal networks or support. Concerns about one-to-one support such as befriending also included the personality and compatibility of the individual delivering the service and having a stranger coming to their home.

Important features of the delivery of group based services were raised by those who had attended them. They included how new members were welcomed and supported, knowing others in the group which made local groups more appealing, and basic hospitality in terms of attitude as well as refreshments.

Participants did not consider that primary care has a role in alleviating loneliness. As well as practical considerations such as inadequate appointment length and difficulty accessing their practitioner of choice, participants felt that talking to their GP or nurse about loneliness was

inappropriate. Discussing emotional issues was perceived as low priority compared to other concerns and wasting practitioner time, and might result in loneliness being 'medicalised'. A few exceptions included some of those with long-standing depression or anxiety and those who had established a trusting relationship with members of the primary care team over time.

Involving 'others' in their loneliness

As well as contributing their views about seeking support from services, participants talked more generally about involving 'others' in their experience of loneliness. The stigma of admitting to being lonely, not wanting to appear unable to cope or being a burden on others, meant that many preferred to keep their feelings of loneliness private. Loneliness, like other distress or emotional problems, was considered by many to be a private matter and something to be dealt with by one's self.

8.1.2.4 *Responding to and managing loneliness*

Responses to loneliness have been described in Chapter 7 and the associated paper (Kharicha *et al.*, currently under review). Within the discourses of lonely older people, an overarching theme emerged of inside and outside worlds within which they coped. Multiple strategies were used to manage their distress including behaviours, thoughts and feelings which they carried out privately within an inside world, or through which they engaged with other people or places, in the outside world. Participants recounted their responses to the distressing feelings as well as the challenges of coping with loneliness.

Engagement with an 'outside world' described a sense of belonging and connection to people and place. Strategies included physical engagement with the world beyond their home, not necessarily to have contact with other people but to experience simple pleasures or moments such as listening to birds sing. Other strategies included connecting with others or the community in a way that felt meaningful and strategies that were shaped by

earlier life experiences in which they had felt part of an 'outside world', such as their working life. Planning as a strategy described the effort that was made to actively make connections and fill the time. Other modes of connection with the outside world included landline telephones and computers, but none of the participants used these to seek new friendships.

The 'inside world' described how participants managed their loneliness privately, kept it hidden or 're-framed' the feelings to make them more manageable, again often drawing on earlier experiences. This included those who lived with others but chose to deal with their feelings of loneliness alone. Cognitive strategies to re-frame loneliness included acceptance and endurance. Acceptance described a sense of resignation to a situation that they felt they could not change, for example the loss of a partner or having decided to stay in an unsatisfactory relationship. Feelings were re-framed by many to consider loneliness as commonplace, or by adopting a more philosophical stance to situations and describing a comfort in solitude.

Endurance of loneliness described the patterns participants had developed over time to manage very difficult life experiences and situations. This included 'lying low' to get through times of acute distress with the knowledge that they would be able to come through this time, as they had previously. An extension of endurance was keeping loneliness hidden and illustrated a tension between their inside and outside worlds, and was described by those who lived with others and managed alone as well as those who lived alone.

Other cognitive strategies were attributed to personality and coping styles and included the ability to maintain a positive focus and motivation despite the challenges they faced, as well as being able to find distraction in simple activities to pass the time.

Some themes such as comparative thinking, interests and hobbies, the role of religion and using alcohol straddled both the 'inside' and 'outside' world and have been described in Chapter 7 (Section 7.3). Comparative thinking

included making assessments of other times of their own lives as well as of other people. Interests and hobbies, religion and consuming alcohol could be solitary pastimes practised privately, as well as with others.

Multiple strategies were used, some simultaneously and variably over time. Mirroring the subjectivity of loneliness evident in participants' accounts and the different contexts of their loneliness experience, participants' responses to loneliness were wide-ranging. They were shaped by many factors including life experiences, individual coping styles, health and wellbeing, their living arrangements, relationships and availability of social networks.

This study describes how lonely older people managed their loneliness at an individual level, within relationships and wider social networks, as well as at a broader community, societal and environmental level. Older people were able to articulate strategies they used to cope with distressing feelings, and can be regarded as active agents in managing their loneliness.

8.2 Discussion of these findings in relation to other research

In this thesis on loneliness in later life, narratives of loneliness and responses to the distress were shaped by cumulative life events experienced within dynamic social and structural contexts over participants' lives. These findings support a life course approach (Elder, 1994) to understanding the causes, consequences and potential responses to loneliness in later life. Within this sample of older people who ranged in age from 65-90 years it serves to further emphasise the different experiences and responses to loneliness over the course of 'older age' not necessarily defined by chronological older age but by life events and contexts that are meaningful to the individual.

A focus on loneliness restricted to later life and without context would be reductionist, deficit based and perpetuate ageist stereotypes of passivity, vulnerability and dependency. Ageism is a process of discriminating and stereotyping people due to their age (Butler, 1975) both explicitly through

behaviours and actions and implicitly through attitudes, beliefs and values (Nelson, 2004). Ageism can lead to older people being marginalised and less visible in society. Despite ageism being included as one of several 'protected characteristics' in the Equality Act (2010), it has been suggested that ageism is the most socially accepted form of prejudice (Nelson, 2004), particularly in Western societies that are oriented to younger people, venerate youth and devalue ageing and old age (Gullette, 2004). Theories of life course and ageism underpin this thesis on later life loneliness and the contribution of these findings to these positions is discussed in this chapter.

Four key themes are described as being central to the life course paradigm which have relevance to the cohort in this study (Elder, 1994). Firstly, the interplay between *lives and historical times* and the dominant discourses of the time; the cohort of participants born between the two World Wars or just after World War II who had lived through the hardships of these years which may have shaped their coping styles and inclination to deal with emotion privately. The *timing of lives* refers to the social meanings of age and the expectations and beliefs of particular times of life; for example times of life when being in a relationship was deemed more desirable than others. The principle of *linked lives* is key to a study on loneliness as it describes how lives are embedded in social relationships with family, friends and co-workers across the lifespan as well as the influence of wider societal norms and historical events. The loneliness experienced within long-term relationships as well as the changing roles of women within society featured in the discourse of participants. And finally the concept of *agency* which describes how people plan and make choices to construct their life course within the constraints of their world. This relates to the strategies participants described to respond to and manage their distress and feelings of loneliness over time.

8.2.1 Sample characteristics

8.2.1.1 Age

Accounts of loneliness were not limited to later life; participants recounted episodes from childhood and earlier adult life, as well as early later life in the oldest participants. Episodes were compared and contrasted alongside detailed descriptions of context and perceived causes to loneliness.

Participants reflected on how earlier episodes had shaped their responses to later life loneliness. In this study there was no evidence to suggest a difference in severity or experience of loneliness across the different age bands, though my sample included few older people (>85years) and few people with frailty. The relationship between increasing age and loneliness is mixed; evidence of both increasing and decreasing loneliness has been reported (Tijhuis *et al.*, 1999; Dykstra *et al.*, 2005; Victor *et al.*, 2005; Wilson and Moulton, 2010; Beaumont, 2013).

Among my sample the oldest had all been living alone for many years and described an acceptance of the loneliness they experienced, or earlier episodes that had been more distressing. They articulated a sense of 'not long to go now', and a philosophical stance to their situation, mixed in with their feelings about ageing and coming towards the end of their lives. They described a change in expectations of the relationships they with had with others and their networks, which helped them cope. These descriptions align with the disengagement theory of ageing (Cumming and Henry, 1961) and the change (reduction) in expectations of relationships with age that may reduce the subjective experience of loneliness (Perlman, 1988). The latter corroborates evidence from Victor *et al.*, (Victor *et al.*, 2009) who found that the oldest old (85+ years) were not the loneliest and contrary to other research, the oldest old seemed to be 'overcoming loneliness'.

In this study, the ability of participants, including the oldest, to manage their loneliness is likely to have been helped by the fact that they all remained relatively mobile and could live independently. Maintaining independence in

later life has been reported as a key feature of models of successful ageing (Rowe and Kahn, 1997). However, psychosocial elements of successful ageing, including social engagement and personal resources such as attitude, have been found to be central components of successful ageing and more important than 'physiological' components, such as longevity or physical functioning (Cosco *et al.*, 2013). Given the importance of lay models of successful ageing in determining perceived quality of life (Bowling and Iliffe, 2006) and the subjectivity of successful ageing, it would have been interesting to explore participants' views of the relative importance of loneliness amongst their other experiences of ageing.

8.2.1.2 *Gender*

Almost two thirds of the overall sample were female and among those aged 85 and over three of the four participants were female. Similar proportions across both genders lived alone. Gender appeared to have a limited influence on the experiences of loneliness in these participants. The exceptions were themes related to the principle of 'linked lives' (Elder, 1994) such as the role of parenting and traditional gender roles within relationships in this cohort of participants which were more commonly raised by women rather than men among those that had children and are discussed later in Section 8.2.2.2. Research has suggested that women are more likely to be lonely than men (Beal, 2006) but the relationship between loneliness in later life and gender is likely to be influenced by risk factors for loneliness including age related health decline, and increased likelihood of being widowed and living alone than men (Pinquart and Sorensen, 2001a; Pinquart and Sørensen, 2001b; Dahlberg *et al.*, 2015).

8.2.1.3 *Other socio-demographic characteristics*

Twenty five of the 28 participants identified as White UK. There was insufficient diversity in ethnicity in the sample to explore potential variation in meaning, experience or response to loneliness based on cultural background, migration status, beliefs and expectations. Research has

reported differences in loneliness prevalence between older minority ethnic groups in the UK; for almost all groups, the rates were higher than the general older population but comparable with rates of loneliness in older people in their countries of origin (Victor *et al.*, 2012).

Socio-economic status was based on years of education; the majority (17 out of 28 participants) had post-basic education, that is, they ended their education at the age of 17 or later. The relationship between socio-economic status, in particular reduced income, in later life and increased loneliness has been reported (Luhmann and Hawkey, 2016), as well as post-basic education being protective of loneliness in later life (Victor *et al.*, 2005). Within the interviews, many participants described their experience of education, including the opportunities it afforded or denied them, as well as skills developed in later adult life related to their working life and interests. The experiences across the life course are reflected in the findings related to retirement and skills used post-retirement, discussed later in this chapter (see Section 8.2.3.2). Data on sexual orientation were not collected in the WISH study or discussed within the interviews.

8.2.1.4 *Living alone, social isolation and loneliness*

Much research on loneliness in later life has focussed on those living alone (as reported in Chapter 1 Introduction). In this study, just under half of the participants lived with others, with the rest living alone. The proportion living alone is considerably higher than reported in the 65 and over population in England and Wales in the 2011 Census, in which just under a third (31%) were living in one person households (Office for National Statistics, 2011). This reflects the relationship between living alone and loneliness (Bond and Carstairs, 1982; Tomstad *et al.*, 2017). The experiences of those living with others affirm that loneliness and social isolation are overlapping but different concepts. In this study the experience of loneliness in those living with others was limited to those living with partners; loneliness in older people cohabiting with others such as their children has also been reported

(Ojembe and Kalu, 2018).

Participants' descriptions of changes in loneliness and network over time tally with the longitudinal data on social isolation and loneliness which have shown that very few people are consistently lonely or socially isolated. Patterns of increasing and decreasing social isolation and loneliness are dependent on both a mixture of factors that are both beyond the control of individuals, such as widowhood and declining health, and others over which they may have some choice, such as geographical relocation in later life, living with children and being able to ask for help (Wenger and Burholt, 2004). The rich and detailed descriptions of experiences, contexts and responses to loneliness in this qualitative thesis based within a life course paradigm augment the longitudinal survey data on social isolation and loneliness. There were examples of increased social isolation and loneliness following re-location to live closer to children, after which participants had struggled to re-establish their networks. Although none of the participants were confined to the home, three of the oldest participants (all 85+ years) described how their environment was becoming increasingly constrained; two discussed not renewing their car insurance and stopping driving in the very near future and the other who could not drive or use public transport unaided and was therefore dependent on friends or low-cost options. These experiences resonate with isolation resulting from a 'geographical separateness' (Victor *et al.*, 2009) and 'spatial isolation' (Sinclair *et al.*, 2007).

8.2.2 Experiences of loneliness

Participants' experiences were largely aligned to the psychosocial theories of loneliness as described in Chapter 2 (Section 2.3). At a personal level loneliness was defined by unmet expectations of interpersonal relationships drawing on the cognitive discrepancy model of loneliness (Perlman and Peplau, 1982). In addition, loneliness was connected to age-related changes and losses at an individual level and socio-economic and structural factors that influenced the ability to engage with wider society as well as

participants' perceived value within it, which aligns with the stance of social gerontology, (for example, Victor *et al.*, 2009). The experiences of later life loneliness among a minority within the sample may have stemmed from early life experiences which continued to influence them negatively. These experiences draw on attachment theory (Bowlby, 1969) and challenge the existential theories of loneliness (for example, Mijuskovic 1977).

Prominent themes of loneliness as loss, loneliness as unfulfilled expectation and the interplay of loneliness, other negative emotions and mental health recurred through the interviews. These themes occurred individually as well as overlapped and will be discussed in the following section.

8.2.2.1 *Loneliness as loss*

Loss was a key theme in the discourse of loneliness in this study. Within this, the loss associated with bereavement, particularly widowhood, and the loss of role were particularly strong themes.

Ten participants were widowed; many of these participants were the most distressed of the sample and still grieving the loss of their partner. These experiences resonate with the well documented relationship between widowhood and loneliness (Tijhuis *et al.*, 1999; Jylhä, 2004; Dykstra *et al.*, 2005; Golden *et al.*, 2009; Victor *et al.*, 2009; Nicolaisen and Thorsen, 2014). Grief following the death of a partner was not a homogenous experience; when the death was not unexpected (for example, following a period of ill-health) or those who had been widowed for longer seemed to be coping better with their grief. Given these findings are well documented, the rest of this section will focus on loneliness associated with a loss of role.

Loss of role related to retirement

Reflections on retirement were common in this sample. Participants' experiences of retirement included those who had retired at state pension age, and both voluntary and involuntary retirement that was planned or unplanned/early. Apart from those who had been made redundant and found

it difficult to find other employment, or had to take early retirement due to ill-health or caring responsibilities, most participants had planned the timing of their retirement or were doing so at the time of interview. Participants had worked in a range of skilled and unskilled/manual employment. All except two participants were retired and as the majority of the sample was aged 65-74 years (n=19/28) the time since most had stopped working was relatively short.

The loss of role related to retirement was described at personal, community and societal levels. Participants' experiences of retirement resonated with the research evidence on this transition and were interwoven into their accounts of loneliness. For example, the loss of role following retirement was discussed along with the change of daily and weekly structure, interaction with others and reduced income. These themes were also mentioned in relation to the experiences and responses to loneliness such as the desire to have a meaningful role, efforts to fill the time, maintaining social networks or encounters with others and the cost of this. Comparisons can be made with the typology for the meaning of work developed some time ago which describes work as i) a source of income, ii) a life routine structuring the use of time, iii) source of personal status and identity, iv) a context for social interaction and v) a meaningful experience that can provide a sense of accomplishment (Friedman and Havighurst, 1954). Although retirement may be welcomed and planned for, it can reduce social connections, opportunities and meaning. Mandatory retirement is considered a form of social exclusion; at a certain age people are expected to retire regardless of their personal preference on whether or not they wish to continue working and enjoy the range of rewards described above. It can be considered an example of how ageist norms and practices in society can become barriers to older people's active participation in social activities and increase risk of loneliness in later life (Shiovitz-Ezra *et al.*, 2018).

There is mixed evidence on the impact on health and wellbeing of retirement unless retirement has been due to ill health which has continued into

retirement (Hyde *et al.*, 2004). In the absence of the latter, the relationship is dependent on timing of retirement, the circumstances surrounding the retirement transition including previous health and whether it was voluntary or involuntary and the quality of the employment experience. Moen (1996) argues that there are two perspectives to consider: retirement can offer the freedom to structure time, social networks and identities, or retirement may be experienced as a loss of structure of goals and 'situational imperatives' related to working life. The latter are socially constructed options and expectations, without which older people may feel limited in terms of position or status in society (Moen, 1996) and was evident, particularly within the skilled professional groups, in this sample. The loss of community associated with retirement was described by those who lived alone, in particular those who had never married or had been divorced, separated or widowed many years earlier.

8.2.2.2 *Loneliness as unmet expectation*

Unmet expectation describes both the loneliness resulting from the unsatisfactory relationships at a personal level as well as the influence on individuals of wider societal norms and structures.

Loneliness within relationships with partners

Most of the research on loneliness in later life focuses on those living alone. This study adds the experiences of those living in long-term relationships with partners which had lasted most of their adult lives and who described themselves as lonely. These relationships were described as both a cause of loneliness as well as source of support. Descriptions of social and emotional loneliness could be identified in these accounts, attributable to both the poor quality of the relationship in which participants reported not being understood or respected, as well as the way in which partners influenced their ability to maintain wider networks, for example, partners who would make it difficult to invite anyone into their home. Participants described how they had to accept the difficulties of their relationship to be

able to stay within it, implying that it was possibly better than their perception of being alone.

There is evidence that married adults are less lonely than unmarried adults (Stack and Eshleman, 1998; Scanlan *et al.*, 2001). Previous evidence has suggested that marriage protects individuals from emotional and social loneliness due to the presence a potential confidante and access to a wider circle of family and friends from social activity which can often be 'couple-based' (Weiss, 1973; Dykstra and de Jong Gierveld, 2004). My study suggests that this does not apply to all. Instead, my findings tally with a US study of older women which reported that relationships were found to be a major source of loneliness and that if the relationship was stressful, other relationships did not adequately substitute for it. For women that had never married, health status contributed to feelings of loneliness more than their relationships with others (Essex and Nam, 1987). None of my participants raised the subject of their sexual orientation and I did not probe. There is evidence that the prevalence of loneliness in older people who identify as lesbian, gay, bisexual, transgender or queer/questioning (LGBTQ) is higher than those who are heterosexual. Compared to their heterosexual peers, older LGBTQ adults are more likely to be single and live alone and less likely to see family members regularly (Fokkema and Kuyper, 2009; Campaign to End Loneliness, 2014).

Single older adults are not a homogenous group; the experiences of those who have never married/had a long-term relationship are likely to differ from those who are divorced, separated or widowed (Wister and Dykstra, 2000). Also as well as these characteristics of relationships it is important to consider relationship preferences of being single or not, which may also be influenced by previous experiences (Dykstra, 1995; Dykstra and Fokkema, 2007). Expectations of being in a relationship may also be different at different times of life given the social meanings of age (Elder, 1994); accounts of a stronger desire to be in relationships in earlier adult life compared to later life were shared by participants in my study who had

always lived alone or who had divorced a long time ago.

Based on the hierarchical compensatory model of support (Cantor, 1979) in which the importance of the relationship determines the use of the support, spouses are considered the primary source of support, followed by adult children, other close relatives, friends and others (Pinquart, 2003).

Attributing loneliness to a mismatch in experienced and desired relationships (Perlman and Peplau, 1982) simplifies and groups together the different relationships within an individual's network; one may have unfilled expectations of one relationship but be satisfied with another. Being discontented with relationships may lead simply to dissatisfaction rather than loneliness (Stein and Tuval-Mashiach, 2015). This is pertinent to this group as, despite self-identifying as lonely, all except one participant could identify someone they could call on if they really needed. Their views are likely to be different from those who cannot identify anyone.

Unmet expectations in retirement

Historically, retirement was considered a time of physical decline and the end of social life (Cummings and Henry, 1961; Townsend, 1981). More recently, given that people are living longer and healthier lives with more disposable income, those who are able to enjoy the greater opportunities for leisure and personal activities that these changes can foster have been described as being in the 'Third Age' (Laslett, 1996; Gilleard and Higgs, 2000). Given the age and health profile of this sample, this description is more fitting of many of the participants in this study than are earlier descriptions of retirement.

The privilege of greater choice in later life was not, however, uniform among those in the younger age band (65-74 years); limitations were related to finances (influenced by lack of education opportunities and subsequent employment, redundancy or early retirement due to ill-health, and divorce), mental and physical health problems and caring responsibilities. Cumulative

disadvantage describes how birth cohorts can become more unequal over time and lead to social exclusion in later life (Phillipson and Scharf, 2004). A life course perspective on retirement (Moen, 1996) may more accurately reflect the cumulative effects of these life events and the influence of wider societal constraints.

Overlapping loss of role and unmet expectation related to parenting and grand parenting

Participants with children/step-children or grandchildren/step-grandchildren described the role these family members currently played in their networks and whether their expectations of these relationships were met. The majority (n= 22/28) of participants had children or step-children. They differed in terms of proximity and frequency of contact, including co-resident adult children and those living next door, those living locally, those living in different parts of the country and those who travelled with work so were regularly abroad. Two daughters were described as the key confidante in two participants' lives.

When expectations were not met, the loss of role related to parenting/grand parenting was a dominant feature in these narratives. The range of circumstances was broad and, for some, long-standing. The 'empty nest' when children needed less support or left home, or when grandchildren became older, needed less looking after and were seen less often, was described. Feelings of no longer being needed by family and community have been described as a threat to the concept of self and contributing to a loss of meaning and life purpose (Kitzmüller *et al.*, 2018).

This loss was also described by participants who had not had children and grandchildren or were denied access to them, who said they felt excluded from conversations with their peers about their role as grandparents. Other very difficult times of life related to children/parenting were recounted including having to give up a child born outside of marriage for adoption, and

the parenting experiences related to severe mental health problems in an adult child. These losses were examples which were largely recounted by female participants. Intergenerational exchanges have been suggested as being protective of depression and loneliness in older people, particularly those living alone. The relationship between being involved in the care of grandchildren, living circumstances and mental health (depression and loneliness) of older community dwelling Taiwanese people was explored in cohorts over 14 years (1993–2007). Over this time the prevalence of older people living with partners or with their children decreased and the percentage providing care for grandchildren increased. After adjusting for confounders, those living without a partner or children and providing no grandchild care, had a greater risk of feeling lonely and being depressed (Tsai *et al.*, 2013).

Loneliness in mothers has been described as a discrepancy between what is expected and what is experienced in terms of support and companionship from children; older women who saw their children at least weekly were less socially and less emotionally lonely than those who interacted less often. In addition, older women without children were less socially and less emotionally lonely than women who saw their children less than once a week (Dykstra and de Jong Gierveld, 2004).

The participants that did not have children in my sample (n=6) were mostly women and lived alone (n=5). Without prompting, experiences were shared of decisions not to have children, difficulty conceiving and recurrent miscarriages. Their experiences and responses to loneliness were mixed and resonate with other research on older women without a partner or children termed “solo-dom”. This has been described as a range of experiences from happy, successful and learned over time, to feeling the weight of their ‘ascribed identity’ so acutely that socialising was limited accordingly (Hafford-Letchfield *et al.*, 2017).

8.2.2.3 *Loneliness, negative emotions and mental health*

Participants articulated a range of affective symptoms and clinical/medical terms such as depression and anxiety to describe their mental health. The manifestation of loneliness as sadness, despair, fear or uncertainty was evident in the participant discourses of both those who did and did not have diagnosed mental health problems such as depression or anxiety. Anxiety and fear have been described as common ‘companions’ to loneliness in later life (Kitzmüller *et al.*, 2018). The losses and unmet expectations summarised earlier in this chapter as well as the efforts of dealing with struggles over time contributed to these feelings in many. At times, it was difficult to separate loneliness from other negative emotions and experiences within participant narratives which may be explained by the subjectivity of loneliness. Probing participants for clarification needed to be balanced with an understanding of the difficulty of talking about distress and loneliness. Two theoretical perspectives have been suggested for how negative age perceptions and age discrimination can lead to loneliness. Firstly ‘social rejection’ which proposes that negative feelings of being unwanted and rejected socially can lead to withdrawal. And secondly the ‘stereotype embodiment’ theory which described how age-related negative stereotypes are internalised, for example when loneliness is expected in later life, it is more likely to become a reality (Shiovitv-Ezra *et al* 2018).

It was commonly considered by participants that loneliness could lead to depression and that it was the individual’s responsibility to do something to prevent the situation worsening. Qualitative studies have reported that older people consider loneliness and depression to be a normal part of ageing but more severe loneliness is connected to mental ill health (Barg *et al.*, 2006; Corcoran *et al.*, 2013). It was more common for those with diagnosed depression or anxiety to describe these as being long-term rather than later-life specific, with some describing familial patterns of mental ill-health, especially in parents and siblings. It was difficult to separate accounts of long-term mental health problems from possible trait loneliness. Participants’ accounts corroborate with the evidence that loneliness and depression are

distinct but overlapping constructs (Tiikkainen and Heikkinen, 2005; Cacioppo *et al.*, 2006b; O'Luanaigh and Lawlor, 2008) and that loneliness is considered both a cause and effect of depression (Barg *et al.*, 2006).

Most described patterns of coping and help-seeking that included managing alone and both talking and pharmaceutical therapies. Participant and practitioner views on the role of primary care services for loneliness and mental health problems are discussed further in Section 8.2.5.3 below.

8.2.3 Community based services and activities for loneliness

The second research question explored participants' views towards involving others in their loneliness, including community-based services and activities. The majority of participants in this study were not engaging with services designed to support older people experiencing loneliness, such as befriending or groups that met for purely social reasons, and held negative views about them. Their views are likely to differ from those using these services (Windle *et al.*, 2011).

A fundamental deterrent to engaging with services and activities for loneliness was the language used to describe them. Labelling of services for 'old people', the 'lonely' and 'isolated' is negatively perceived and deficit based (Big Lottery Fund, 2018), and was reported in my study. The language perpetuates ageist stereotypes of vulnerable and neglected older people and such deprecatory language has been described as a linguistic mirror of the pervasive individual and institutional ageism in our society (Nuessel, 1982). An analysis of a range of printed sources from 1810 to 2009 found that stereotypes of older people have become increasingly negative over the last two centuries, possibly due to the medicalisation of ageing and the growing proportion of the population over the age of 65 (Ng *et al.*, 2015).

Research reporting the views of older people engaged with befriending services have reported the characteristics of the service they had found to be helpful were: good conversational skills and empathy in the befrienders, and opportunities for emotional support and reciprocal social exchange through safe, confiding relationships (Lester *et al.*, 2012). These experiences address some of the concerns expressed by the sample in this study about the type of people delivering the service and the service remit. Participants' views on befriending schemes including an attitude of 'not now, maybe later' may also have been influenced by the fact that two thirds of participants in this study were 'younger old' (65-74 years), and all participants were able to leave their homes independently (although some had difficulty in this), in comparison to the largely housebound and very old population engaged with befriending schemes (Lester *et al.*, 2012).

Themes related to groups that met for social reasons alone, such as lunch clubs and day centres, overlapped to some extent with those of befriending services in that they were perceived to be for those who were more dependent and with smaller or no support network than themselves. This view tallies with findings from a recent systematic scoping review on the benefits, purposes and perceptions of day centres for people without dementia (Orellana *et al.*, 2018). This review showed day centres were perceived by some professionals and older people as undesirable welfare services for people who are old, isolated, ill or miserable. However, amongst the older people, attitudes became more positive once attending. In this review (*ibid*), within the caveats of a diversity of research methods, day centre types and countries of origin with distinct systems of day services (only 11 of 77 included papers were UK based studies), and data on attenders being based on less than half of the included studies, attenders were primarily women who lived alone or were widowed, divorced or single and older. Most were without further education, with low income, multiple comorbidities and who took multiple medications. There are similarities in characteristics with the three participants (of 28) in my study who attended social groups fairly regularly; all were widowed women in their 80s or 90s,

living alone and who reported benefits of attending these groups. The findings of the review (Orellana *et al.* 2018) included that attending day centres and participating in interventions within them may have a positive impact on the mental health, social life, physical function and quality of life of older attenders. The desire not to be seen as dependent and 'burdensome' in the oldest old has been described as 'ageist distancing of the third from the fourth age' and which can have negative impact on health and wellbeing (Kydd *et al.*, 2018 p122).

In contrast, activities and groups that were interest or hobby based were more popular. Participants described both the direct positive impact of attending, based on the interest or hobby itself, as well as indirect benefits of having something to look forward to, getting outdoors, being with others and filling the time. Preference for interest groups corresponds to evidence that suggests these might be more effective at addressing loneliness, perhaps due to the fact that people may engage better (Cattan *et al.*, 2005; Dickens *et al.*, 2011; Cohen-Mansfield and Perach, 2015; Gardiner *et al.*, 2018). Activities and groups ranged from interests established earlier in adult life as well as after retirement, and several examples were given to support the activity theory of ageing (Havighurst, 1963). Most of these participants resembled those in the 'Third Age' who were in good health and engaging in various leisure and personal activities (Laslett, 1996; Gilleard and Higgs, 2000).

This did not however reflect the whole of my sample. Inequalities in accessing the opportunities of the 'Third Age' have been associated with the continuation of structural inequalities from working life into the activities and interests during retirement. These include time, resources (financial and access) and opportunities available to develop and continue interests (Hyde *et al.*, 2004). Some participants who had worked in professional roles referred to the skills they could continue to use in retirement as volunteers, such as assistance with completing benefits forms, writing CVs, bereavement support in a hospice, and running local interest clubs. In this

small sample, those who had been in less skilled employment and/or having taken involuntary or early retirement on health grounds described fewer work related characteristics in the activities or pastimes they chose to continue with.

8.2.3.1 *Social productivity*

Post-retirement activities have been discussed in terms of social productivity. This is described as a form of inter-personal exchange and typically includes paid work, volunteer work, caring for family and informal help to friends (Siegrist *et al.*, 2004). Socially productive activities are underpinned by values of reciprocity (Gouldner, 1960), that is, efforts to engage are made in return for rewards that are perceived as socially valued.

These activities were described by the participants in this study and the reciprocal nature of the arrangements was important to some of them. Although not described directly as a means to manage feelings of loneliness, they helped to address many of the indirect / contemporaneous experiences of loss of meaningful role, difficulty filling the time and maintaining social networks or encounters with others. For some, these features were addressed by the role of work. Volunteering has been suggested as easing the transition of retirement from paid-work (Smith and Gay, 2005).

The activities included within social productivity as described above have been explored separately to understand their impact on health and well-being, in particular, volunteering and caring. The benefits of volunteering for older adults compared to those who do not volunteer include less depression, better cognitive functioning and improved mental wellbeing (Mundle *et al.*, 2012), lower cumulative odds of frailty (Jung *et al.*, 2009), a lower risk of cognitive impairment (Infurna *et al.*, 2016) as well as a 'dose effect' in improvement but only for those who felt rewarded for the efforts they put in (Nazroo and Matthews, 2012). Volunteering is a socially valued role and which is likely to enhance identity, provide a sense of worth and

status. When there is reciprocity in volunteering, improved self-esteem, wellbeing and social engagement have been reported for both recipient and the volunteer (Mundle *et al.*, 2012).

Theoretical frameworks to explain why people volunteer include role theory to maintain a productive role in society, and social integration theory owing to the additional role provided by volunteering. Having multiple social roles provides meaning and purpose in life, promotes social support and interactions and so contributes to feelings of wellbeing (Casiday *et al.*, 2008). It also draws on activity theory; volunteering as an activity provides a sense of purpose and control, increases personal energy and an active stance in society (Ayalon, 2008). However a lack of reciprocity in socially productive activities can lead to strong negative emotions (for example, injustice) which influence self-esteem, such as, when caring becomes stressful (McMunn *et al.*, 2009). Examples of difficult caring roles shared in this study included caring for a spouse and the challenges of caring for very young children (see Chapter 7 Section 7.3.4 and Chapter 5 Section 5.4, respectively).

Volunteering may fulfil some the challenges reported by this sample experiencing loneliness especially in relation to the narrative of loss of role in retirement; only a minority of them described any current or previous volunteering. Given the age and health of the majority of the participants, it may have been more appropriate to further explore their views on being providers of 'socially productive' activities rather than recipients of interventions for loneliness. Volunteering as a means to address social isolation and loneliness has been promoted by the third sector, for example the Ageing Better Programme in England (Big Lottery Fund, 2018). Support to ease the transition at the end of the volunteering role may be needed in a comparable way to that at retirement.

8.2.3.2 *Loneliness, mental health and primary care*

In this study, most participants experiencing or at risk of loneliness did not consider that primary care has a role in alleviating it. Over and above the constraints of time and access, some participants were cautious about the possible medicalisation of and pharmaceutical response to loneliness. The evidence base that has reported associations between loneliness and poor health and wellbeing (see Introduction Section 1.4) as well as comparisons with loneliness being as bad for your health as smoking (Holt-Lunstad *et al.*, 2010; Holt-Lunstad *et al.*, 2015) has contributed to the construction of loneliness as a health concern. This is counter to the resistance to medicalise loneliness articulated in this study.

An exception was some of those with mental health problems who had established a relationship with a member of the primary care team, some of whom were taking medication for their depression or anxiety. The perceived cause of their low mood/depression or anxiety determined their choice of response which was also influenced by the stigma of both loneliness and mental health problems.

These views correspond with the wider literature on the views of older people with depression seeking support from primary care. Older people are similarly reluctant to recognise and name 'depression' as a set of symptoms that warrants seeking support from primary care. Depression is perceived to have a social cause and hence not considered to be a medical problem; older people have limited expectations of treatment, which are assumed to be predominantly pharmaceutical. This is partly due to perceptions of the role of the GP but also to previous negative experiences of help seeking (Burroughs *et al.*, 2006; Chew-Graham *et al.*, 2012).

A good relationship was deemed necessary to discuss sensitive matters like loneliness. This is similar to the 'active listening' by healthcare providers proposed by Smith (2012) in her exploration of meaning and coping mechanisms for loneliness in community dwelling older adults. Given the

reluctance to discussing loneliness with primary care professionals within this study, initiatives such as social prescribing (Department of Health and Social Care, 2018) and the Community Action Plan to Tackle Loneliness (Royal College of General Practitioners, 2018) are likely to face challenges in addressing loneliness in this setting.

From a primary care perspective, a recent systematic review on management of later life depression and referral to psychological therapies reported similar views from professionals, contrary to the expectations of many of the lonely older people in this study. Practitioners attributed depression in later life to social isolation and functional decline, for which appropriate treatments were limited. They were restricted by the time they had available for consultations and prioritised physical health problems over mental health particularly in frail older adults, and good management of depression was driven by the skills and interests of individuals rather than a structured approach (Frost *et al.*, 2018).

8.2.4 Responses to loneliness

The third research question explored in this thesis was how older people respond to and manage loneliness themselves. A range of strategies has been identified from participant accounts reflecting the subjectivity of loneliness, which is shaped by contextual factors, expectations and previous experiences. When the idea for this PhD was conceived the research evidence focused on experiences of loneliness and characteristics of interventions to alleviate loneliness and the views of how lonely older people wished to respond were sparse.

Responses to loneliness fall into three broad areas: (i) ways of engaging and contributing, both with others and to society, which are meaningful to the individual, (ii) cognitive strategies to re-frame the negative feelings, and (iii) respecting the wish of those who prefer to manage their loneliness privately. The latter strategy, the preference to manage privately resonates with the view that loneliness can be a range of feelings which people live with and

experience and manage differently (Hauge and Kirkevold, 2012) and challenges assumptions about older people being recipients of support in later life (Allen and Wiles, 2013). These findings contest the ageist premise that older people are passive in their experience of loneliness and that intervention for loneliness should focus on increasing contact with others. It also emphasises the need for responses to loneliness to be personalised and assets based. These findings are counter to the portrayal of vulnerable and neglected older adults who require intervention, as described in Chapter 1 (Section 1.9).

A range of responses developed over their lives and shaped by individual coping styles and contexts was drawn on to ameliorate their distress related to feelings of loneliness as well as other challenges they had faced over the life course. The ability to manage loneliness over time draws on principles of resilience theory which has been defined as ‘flourishing despite adversity’ (Hildon *et al.*, 2009). It is used in debates about ageing in which adversity is understood as the increased likelihood of personal loss, exacerbated inequalities, age-related health challenges and disability (Stephens *et al.*, 2015). These common life experiences were contextual triggers for loneliness in this study; participants reported different abilities to remain resilient when faced with these cumulative challenges over time. However, challenges to an individual’s resilience need to take the social and physical environment into account and avoid blaming individuals for a lack of resilience (Wiles *et al.*, 2012).

In this thesis, experiences and responses to loneliness were described at individual, interpersonal, community and societal levels, however participants’ responses to societal or structural drivers of loneliness were limited. This has been described as ‘alienation’ between older people and society and due to the lack of perceived value of as members of society and wider ageism (Wong *et al.*, 2017; Royal Society for Public Health, 2018).

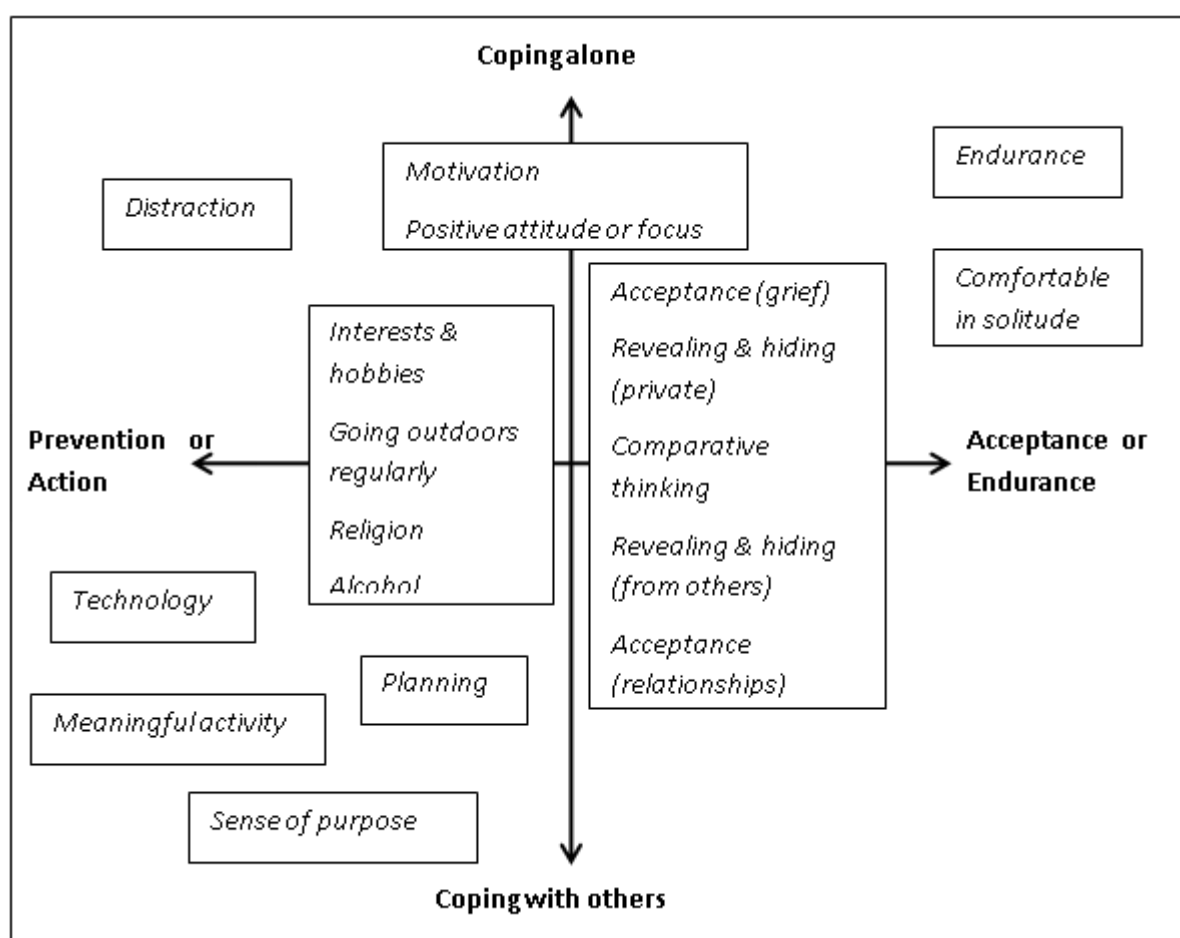
8.2.4.1 *How do these findings fit within the model for managing loneliness?*

My model for managing loneliness developed from the findings of the narrative synthesis review undertaken for this thesis is presented in Chapter 3, associated paper (Kharicha *et al.*, 2018), and Appendix 5. It represents the two overarching dimensions that illustrate the strategies used to manage loneliness that were identified from the 11 eligible qualitative studies. This section describes how the findings from the 28 interviews in my research fit with this model for managing loneliness.

The individual strategies identified from the interviews (as described in Chapter 7) have been added to the model in Figure 3. Some examples are given below to illustrate how my data fit the model developed from the review, including strategies that fit in more than one quadrant of the model.

In relation to theories of ageing, the strategies of prevention and action draw on activity theory (Havighurst, 1963) and the cognitive strategies of acceptance and endurance align with disengagement theory (Cumming and Henry, 1961) in the preference to manage alone.

Figure 3: Themes mapped to model for managing loneliness



Context of coping: alone or with/in reference to others

My findings of an 'inside' and 'outside' world within which people manage their loneliness are comparable to the dimension related to the context of coping in the model, that is, whether people cope alone or cope with/in reference to others.

As well as referring to coping with other people or with others in mind, my 'outside' world referred to a connection with both people and place. For example, the solitary activity of going outdoors regularly, which was mentioned by many, was to feel connected to the outside world, not necessarily to have contact with others, and included, for example, stepping into the garden. For others it was to increase the chance encounters or small

exchanges with others in their local area. The strategies using technology, planning, being engaged in meaningful activities and having a sense of purpose all referred to efforts to engage or connect with other people.

The 'inside' world described many strategies that meant being physically alone but also described the private nature of coping with loneliness that participants described. This tension between the private coping of loneliness in an 'inside' world and keeping loneliness hidden from the 'outside' world mean that several cognitive strategies straddle both coping alone and with others. This may have been because almost half of my sample lived with others whereas almost all participants in the studies in the systematic review lived alone (often as this was a selection criterion in their sampling). For example, whilst most examples of using acceptance as a strategy referred to the loss of partners or re-framing loneliness to consider it as commonplace, this differed for those living with others. Acceptance of loneliness within on-going relationships meant that although this was a private way of dealing with loneliness, the context was very much with others (partners) in mind. There are similarities with the theme of 'revealing and hiding' in which loneliness is both managed alone and concealed from others so not to impact on the relationship.

Based on my findings, four strategies straddled both the 'inside' and 'outside' worlds, and have as such been placed on the model across the dimension of coping alone and with/in reference to others. Interests and hobbies, religion, and consuming alcohol were preventative strategies or ways in which participants actively managed their loneliness and could be carried out to fill the time alone, or in an effort to engage with others. Similarly, comparative thinking was a cognitive strategy used to compare both other personal episodes of loneliness or other people who were considered worse off than themselves.

Strategies that were practiced alone as solitary ways of dealing with loneliness were distraction, endurance, and being comfortable in solitude.

Strategy type: prevention, action, acceptance and endurance

The second dimension of the model describes strategy type. The examples of behaviours, thoughts and feelings used to actively manage loneliness from my interviews resonate with the four main approaches in the model: behaviours being described mainly as prevention / action, and thoughts and feelings being most comparable to acceptance / endurance.

Examples of prevention of loneliness were given by participants who were aware of their own personal triggers for loneliness and who described strategies they put in place to deter these feelings as well as actions in response to their feelings of loneliness.

The strategies of acceptance and endurance were clearly identified in my interviews and fit with the model. Examples of how they fitted within participants' 'inside' and 'outside' worlds have been described earlier. 'Having a positive attitude or focus' is a cognitive strategy and a way of accepting an undesirable situation but also has a preventative angle in that it may be practised to help deter feelings of loneliness. As such, it has been placed across the strategy type dimension. Motivation as a theme was harder to place within the model due to its contextual nature. It could be applied to both behavioural and cognitive strategies to initiate engagement with others or to manage alone. 'Having a positive attitude/focus' and 'motivation' were identified in the review but described as 'personality related strategies'.

Summary of findings and methodological considerations

The strategies identified to manage loneliness by the community dwelling older people in this research can be meaningfully fitted within the model for managing loneliness developed from the systematic review. In particular distinguishing strategies by a preference to managing alone or within an 'inside' world and with/in reference to others or within the 'outside' world was a clear theme of both. The description of an 'inside' world puts greater

emphasis on the private nature of coping with loneliness and keeping loneliness hidden from others as well as being physically alone. Coping with/in reference to others encompassed both a connection with place as well as people. In terms of strategy, the spectrum ranging from prevention, action, endurance and acceptance can all be found as responses to loneliness in my data.

The strategies identified in the review and my data present a broader response to loneliness than intervention to increasing social interaction which has been the primary focus of approaches to reduce loneliness to date. The strategies promote an assets-based and personalised approach to loneliness which is driven by older people themselves and how they wish to respond. Mapping my themes onto the model, however, emphasises the simplicity of the model and the importance to take the complexity of past and present circumstances and contexts as well as thoughts and expectations of the future into account.

The model was developed from secondary analysis of primary research based on verbatim quotes and author interpretations, as well as papers reporting secondary analysis. My analysis of these papers builds on previous interpretations from the authors and increasing distance from the views of the older people themselves; I did not have access to the primary data in the eligible studies. In addition, the word counts of the journals in which the papers are published limit the level of detail that can be reported. In contrast, the strategies identified in my findings draw on rich in-depth interviews which I collected and analysed myself. This may have facilitated a greater awareness of the sensitivities and detail of experiencing and managing loneliness.

Furthermore, although the papers included community dwelling older people aged over 65 (the same as my sample), some papers also included participants who were recruited from other housing arrangements and via groups, as well as those who were identified as lonely by other people rather

than self-identifying, so may differ from my sample in those characteristics.

It is also important to highlight caution in the following areas. Positive coping strategies for loneliness may be over-emphasised as those who were not coping are less likely to come forward to participate in research. The model can appear to present loneliness as a static state and does not take into account that responses to loneliness are likely to differ according to the length, recurrence, intensity, perceived causes and contexts of loneliness experienced over the life course, as described in my interviews. For example, a theme from my interviews included 'distraction and keeping busy' which described a temporary relief or escape to loneliness; strategies in response to chronic loneliness are likely to differ. The model focuses on individual responses to loneliness; when using the model, a wider discussion to explore how the socio-economic and physical environment of the older person impacts on their ability to respond is necessary.

8.2.4.2 *Recent qualitative research on responses to loneliness*

A recent meta-synthesis of qualitative studies published between 2001 to 2016 (Kitzmüller *et al.*, 2018) using a meta-ethnographic approach (Noblit and Hare, 1988) explored how older adults experience loneliness and how they deal with loneliness. Eleven eligible studies were identified. Given that the data parameter used in this review was included within the date range of my systematic review for this thesis (1990 – January 2017), no further recent papers were identified. The two reviews searched on overlapping but different databases. The eligible papers in both reviews are overlapping but include papers that differ, as described below.

Six of the 11 studies in the meta-synthesis were in my systematic review, either directly (Graneheim and Lundman, 2010; Roos and Klopper, 2010; Stanley *et al.*, 2010; Smith, 2012; Taube *et al.*, 2016); or within the paper reporting secondary analysis (Hauge and Kirkevold, 2012; Kirkevold *et al.*, 2013)).

Of the remaining five studies, four were not eligible for my review as they focussed on experiences of loneliness rather than responses and two of the four recruited participants from secondary health care or nursing homes. One paper was not included in my review (Theeke *et al.*, 2015); it explored the experience of living with loneliness and multiple chronic conditions for rural older women in Appalachia, in Northern West Virginia, US. The paper predominantly reports experiences of loneliness, but includes one theme on 'endeavours to deal with loneliness' which included remembering holidays and happier moments, staying busy, and getting out. Although the journal (Journal of Rural Mental Health) is covered by a limited number of databases, it is indexed in PsycINFO, a database included in both reviews. Although a systematic approach was taken in the systematic review for this thesis, this is one paper that was missed. Theeke *et al.*, (2015) used thematic content analysis was used to identify themes based on the number of times topics were raised. The themes are reported descriptively with little interpretation; the examples within the theme of 'endeavours to deal with loneliness' are included within the findings of my review.

Six studies identified in the systematic review for this thesis (Cattan and *et al.*, 2003; Pettigrew and Roberts, 2008; Lou and Ng, 2012; Kirkevold *et al.*, 2013; Davies *et al.*, 2016; Sullivan *et al.*, 2016) were not included in the Kitzmuller *et al.* (2018) review. The secondary analysis by Kirkevold *et al.*, (2013) includes findings from two further primary studies. The six studies listed above were all within the date parameters of the Kitzmuller *et al* (2018) review and indexed in databases included in both reviews.

Responses to loneliness reported in the meta-synthesis (Kitzmüller *et al.*, 2018) include: the importance of continuing to actively engage in life, both mentally and physically, by maintaining enjoyable activities, initiating contact with others by using the telephone, volunteering or going out, having a structure to the day, and enjoying memories from happier times together with others. Being active was considered a conscious decision and

individual's own responsibility. Other ways of dealing with loneliness include religious practise. Some positive features and acceptance of loneliness were identified in the oldest old.

These themes are a subset of those from my review and data from the empirical work for this thesis. In terms of the model developed from my systematic review, the strategies identified are mainly actions taken to address loneliness, with some mention of prevention (taking responsibility to prepare for future loneliness) and acceptance of loneliness in the oldest participants. Endurance was not reported as a means of managing loneliness although it was an important finding in my own systematic review and empirical study. However, within descriptions of loneliness Kitzmuller *et al.*, (2018) mention the challenges of enduring loneliness, how some were not able to disclose their loneliness and some kept it hidden. Similar to findings from my review and qualitative study, strategies to manage loneliness were carried out both alone and with others.

Their findings are described within an over-riding theme, expressed as a metaphor "trapped in an empty waiting room" (Kitzmuller *et al.*, 2018 p221) which refers to how older people's lives were put on hold, being trapped in an anxious state without meaningful relationships and imprisoned in feelings of being useless and unconnected. These descriptions focus on older people's feelings and experiences of loneliness rather than their response. Although the authors state that the lonely older person may "open the door" themselves, the emphasis appears to be on the door being opened by someone else. A broader range of strategies were identified from the papers included in my systematic review including older people's desire for privacy in managing their feelings and their agency in responding to their feelings.

Another recent paper has reported coping strategies for loneliness in older people in urban Nigeria (Ojembe and Kalu, 2018). Strategies included interacting with others, using technology, acquiring new skills (as hobbies and interests) and being involved in religious, social or recreational activities

and have been widely reported in other research. The findings are reported with little consideration to what might help or hinder older people to implement the strategies suggested.

8.3 Methodological strengths and limitations

8.3.1 *Systematic review*

The findings of the review highlighted the challenges of identifying older people who are lonely and recruiting them into research to seek their views and experiences. Only three of the 11 studies recruited older people who self-identified as lonely; one asked directly about loneliness or purposive sampled from a prior quantitative study in which data on loneliness was collected. The remaining eight papers employed one of the following three approaches: (i) inviting older people to talk about loneliness but not enquiring whether the participants were lonely themselves, (ii) asking practitioners/managers to identify those they thought might be lonely, or (iii), using risk factors for loneliness such as living alone or being widowed as a basis for recruitment. These approaches may have sought to overcome the potential stigma of admitting to be lonely during recruitment. However, they also risk recruiting those who are not lonely to give their views, or seeking the views of a particular sub-group and not capturing the heterogeneity of experience and context.

For pragmatic reasons, the systematic review for this thesis was conducted after data collection was complete and during data analysis. The findings of the narrative synthesis will have influenced the analysis of qualitative interview data.

8.3.2 *Qualitative study design*

The use of qualitative research methods and in-depth interviews in particular is strength of this study. Qualitative research methods allows for more detailed exploration and discussion of participant experiences, than quantitative research methods, as discussed in Chapter 3. In-depth

interviews are more participant-led and are useful for the study of subjective topics like loneliness, to enable participants to focus on areas that were important to them and to limit the influence of my assumptions about their situation or experience of loneliness.

Lewis and McNaughton Nicholls (2014) describe a continuum of qualitative data collection methods ranging from 'naturally occurring' to 'researcher generated'. Examples of the former which may be used to capture the experience of loneliness include recorded conversations, media coverage, blogs, diaries, public archives and the Internet, amongst others. Researcher generated data are created specifically by the interaction of researcher and participant and include interviews and group discussions; observational data, such as video recordings, fall in-between the two. A key difference between naturally occurring and researcher generated data is how the data can then be interpreted; naturally occurring data rely on interpretation by the researcher alone whereas researcher generated methods (such as interviews) allow participants the opportunity to articulate their own meanings and interpretations, both spontaneously and in response to specific questions. Although the researcher interprets the data during analysis, the participant has the opportunity to give their own interpretation in their account – a feature implicit in data collection methods that aim to capture a subjective experience such as loneliness.

Face-to-face interviews with participants were favoured above interviews using the telephone or other technologies such as Skype. Qualitative methods using Skype or telephone can facilitate disclosure of sensitive subjects but are limited in their capacity to build rapport with participants and put them at ease; both these skills were essential in the interviews I carried out. Using technology also limits the ability to detect non-verbal communication and may be further curtailed with participants with sensory impairment (Gothberg *et al.*, 2013).

As noted, participants were given the option of being interviewed in their home, at the research department or a local community venue of their choice. This helped to recruit both those that did not allow others into their home and those who preferred to discuss the topic of loneliness as part of a research study within their home.

Despite volunteering to take part, it may have been difficult for participants to say that they were not coping with their distress. Loneliness that participants were not managing may have been underplayed or hidden. Interviews may favour accounts which are believed to be acceptable to disclose and may not be a true reflection of what people do (de Vaus, 2001). This social desirability bias was addressed by reassuring participants at the outset that having fewer people to call on for support and feelings of loneliness can be common in later life. Continuity of research team in this study (as listed in the information sheet) from the earlier WISH study (Walters *et al.*, 2017) may have helped to put participants at ease. However, positive coping strategies may have been exaggerated given the social stigma of loneliness meaning that only those who were able to articulate their distress are likely to have volunteered.

For pragmatic reasons in this PhD data collection was carried out before the systematic review was completed. This limited how much I was influenced by the literature and allowed me to be inductive in my approach; within the broad lines of enquiry of my research questions, I was able to be participant led within the interviews.

8.3.3 Sample and recruitment

8.3.3.1 Advantages of sampling from the WISH study

Sampling and recruiting participants from the WISH study to this follow-up study on loneliness enabled access to a group of community dwelling older people who reported being lonely using two different measures of loneliness. To date, most studies exploring the experience of loneliness in comparable

population of older adults have relied on recruitment via services for older people who may be lonely or socially isolated and/or by practitioners/managers of services or housing facilities (Kharicha *et al.*, 2018) which may yield a different perspective.

Almost all older people in the UK are registered with a GP; the sampling frame for the WISH study was a primary care registered population aged 65 or over with few exclusions (see chapter 4 Section 4.1.2). Recruitment from this wider study enabled sampling and recruitment to take place without the involvement of services for older people such as day centres and clubs; the views of those not recruited from these services may be different in terms of how older people manage their loneliness.

8.3.3.2 *Disadvantages of sampling and recruiting from the WISH study*

Recruitment to this study was limited to a sub-sample of those who responded positively to an invitation to take part in research on health and well-being promotion in later life from their GP. The response rate to initial invitations to participate in the WISH study was low (34%) and compared to local UK 2011 Census data (Office for National Statistics, 2011), participants were younger, more were owner occupiers and fewer were from ethnic minority groups than expected (Walters *et al.*, 2017). Furthermore based on the exclusion criteria for the WISH study, older people who lacked capacity to give informed consent were not included, and therefore my findings do not reflect the experiences of those with more advanced dementia. Those living in nursing or residential care were also excluded so the views of lonely older people reported here are limited to a community sample of older people and do not reflect the views of people living in supported or residential environments where the lived experience of loneliness may be different to those living in their own homes.

8.3.3.3 *Loneliness measures*

Participants self-identified on the basis of their response to two different measures of loneliness. Using the direct question 'Are you lonely much of the time?' with a response option of yes or no, ensured that the topic of enquiry was clear and unambiguous, that is, it had face validity. From the de Jong Gierveld 6-item loneliness scale (de Jong Gierveld and van Tilburg, 2006), those who scored 2 or above (out of 6) were invited to take part representing those who were moderately (score of 2-4) and severely (score of 5-6) lonely.

As described in Findings Chapter 5, some participants said during the interview that they were not lonely; these participants were more likely to have been invited due to their response on the de Jong Gierveld scale (de Jong Gierveld and van Tilburg, 2006). There are several methodological explanations why those who reported being lonely in the questionnaire denied loneliness at interview. Firstly the de Jong Gierveld loneliness scale (de Jong Gierveld and van Tilburg, 2006) may have identified those experiencing distress other than loneliness; the scale does not use the word lonely or loneliness in any of its items but enquires about lack of trust, emptiness and rejection, which participants may have identified with but which may not have resulted in or been related to feelings of loneliness. Secondly, it may have been easier to admit to being lonely in a questionnaire than in a face-to-face interview. Thirdly, their feelings of loneliness may have changed in the time between questionnaire completion and interview, reflecting the temporal nature as well as regenerative trajectory of loneliness (Wenger and Burholt, 2004; Victor *et al.*, 2009). Recruitment was continued beyond saturation of major themes related to loneliness but not the individual context of loneliness experience, which was very varied. All those who volunteered to participate were interviewed; I oversampled to maximise diversity in participant characteristics.

8.3.4 Data collection and analysis

The data collected from the in-depth interviews was rich, reflecting a high level of disclosure; participants recounted very difficult and traumatic times of their lives. Many were reflective in their narratives and described a range of perceived causes of and responses to their experiences of loneliness over their lives.

I was aware of the potential bias on positive responses to loneliness, both by participants and myself. Participants' accounts may have been influenced by having been involved in the previous study (WISH study) on health and well-being promotion in older people (see Chapter 4 Section 4.1). The difficulty of both talking about feelings of distress and listening to these accounts may have led both participants and me to focus on responses to rather than experiences of loneliness. In addition, I was aware of a greater literature on experiences of loneliness, relative to how older people manage themselves, which may have increased the likelihood of focussing on the latter and minimising discussions of distress; these negative experiences could be described as loneliness that had not been dealt with very well. These concerns were raised during supervision and wider team meetings when transcripts were read to address the balance of the discussion and to make any necessary adaptations needed to the topic guide.

Different accounts contributed to a greater or lesser extent to the themes; there were some outliers, in particular one participant who had been recruited based on a score indicating moderate loneliness in the de Jong Gierveld scale. There was no mention of loneliness in the narrative, although feelings of a lack of trust in friends and family were described. The interview was difficult to conduct as the participant was keen to recount life stories in detail which were underpinned by conspiracy theories, and was repetitive. There was a long history of heavy drug and alcohol use and, following discussion with clinical supervisors, an indication of possible mental health problems. Data from this interview were largely coded into contextual factors.

Another participant who said they had Asperger's syndrome was difficult to engage with and probe in any detail, and gave very short clipped responses to my questions. A third participant (as mentioned earlier) asked for the audio-recorder to be turned off before disclosing traumatic and distressing life experiences; again the data from this interview were limited.

8.3.4.1 *Thematic analysis*

The reasoning and decision to use thematic analysis to analyse the interviews in this study are outlined in Chapter 4 Methods. One limitation of thematic analysis is the ability to capture the emotion in participant responses. As described earlier, most participants displayed a range of emotions whilst recounting their experiences of loneliness. Those that were audible were written into the transcripts and my field notes were helpful in augmenting the data. However, within a thematic analysis these emotions may have been underplayed. By focussing on the content of the data (for example, what participants have said), the nuances within the data, for example the type of language participants used or how it was expressed may have been reduced. However, I have tried to allude to this during the discussion within the findings chapter.

8.3.5 *Trustworthiness and rigour*

In qualitative research, four areas of concern for thinking about the trustworthiness and rigour of findings have been proposed: truth value, applicability, consistency, and neutrality (Guba and Lincoln, 1981).

Truth value refers to the credibility of findings. In this study, given the subjective nature of loneliness, a key concern was to engage with those who considered themselves to be lonely rather than relying on other means of identifying lonely older people (as outlined earlier). Participants were also asked to reflect on their earlier (questionnaire) responses indicating loneliness. A breadth of loneliness experiences was captured in this study to

reflect the subjectivity of the feeling. However, a minority said they were not lonely which highlights the challenges of researching this topic.

Public and patient involvement (PPI) throughout the study process (See Chapter 4 Section 4.3), including interpretation of findings, further helped to ensure credibility as PPI members were older people with personal and professional experiences of loneliness, who also drew on the experiences of their peers. Finally the results of the study have been presented at conferences with academic and third sector organisations focussing on loneliness; this allowed for a form of member checking to further constructively challenge the credibility of the results (as recommended by Barbour, 2001; Mays and Pope, 2000).

Applicability refers to the extent to which findings can be applied to other contexts, settings or groups of people. Unlike quantitative research which aims to produce findings which are generalisable and which have external validity, qualitative research aims to reflect the diversity within populations; the findings from this study have high internal validity and may be transferable to other similar populations, contexts or experiences (Barbour, 2001). Purposive sampling was continued beyond data saturation to try and achieve maximum diversity within the sample.

Consistency has been defined as the dependability of findings and in quantitative research is referred to as reliability and repeatability. Several steps were taken in this study to ensure rigour within the methodology and approach to analysis which was conducted within a multi-disciplinary team as described in detail in Chapter 4 Methodology (Mays and Pope, 1995). One limitation is that I coded all the transcripts myself; pragmatically it was not possible for other team members to help with this. However, all transcripts had been read by multiple team members who developed a coding framework independently which was then discussed and agreed as a team.

Neutrality refers to the bias of the researcher on the data. Reflexivity and transparency in acknowledging how my preconceptions and interaction with participants may have influenced the data collection, analysis and hence the findings (Ormston *et al.*, 2014) have been reported in the Chapter 4 Methodology and earlier in this present chapter. In addition, analysis was conducted within a multi-disciplinary supervisory team to minimise researcher bias.

8.3.6 Ethical considerations

The experience of researching later life loneliness raises ethical issues to reflect on. Although 158 older people identified as lonely in the WISH study, only 28 volunteered to participate in an interview. The challenges of discussing loneliness were evident in interviews and may have been a deterrent to those who chose not to participate. Participants could identify the cause of their loneliness and for many these were circumstances or events that were difficult to recount. It had been anticipated that loneliness could be potentially distressing for participants and steps were taken to minimise this as described in Chapter 4 (Section 4.6). Many participants said they had not spoken about their feelings of loneliness before and recounted very difficult and traumatic times of their lives; reassurances of confidentiality and anonymity were important and had to be repeated. For others the stigma of disclosing feelings of loneliness was evident. Several participants felt there was little they could change about the circumstances of their loneliness and it was something they had to live with. These descriptions may explain why participants described how they coped privately or used cognitive strategies to re-frame their feelings. Loneliness was at times difficult to disentangle from other negative emotions. Interviews allowed participants to use their own language to describe their experiences and definitions of loneliness. As a researcher it was essential to be sensitive and empathic during interviews; I had to balance probing with potentially upsetting participants and it was important to ensure that the time with participants ended on a positive note. Despite having many years of

experience interviewing older people about sensitive topics, the interviews for this thesis were some of the most challenging interviews I have done. After an early difficult interview with a participant who was very frustrated and angry at his situation, routine de-briefing with supervisors was made available; I contacted my primary supervisor as needed. A follow-up letter of thanks to participants which was personalised to include any specific information requested (for example on local services), felt appropriate given the level of disclosure in these interviews

8.4 Recommendations for future research

This study successfully identified lonely older people's experiences and responses to loneliness. Based on this experience the following areas may warrant further investigation:

- Participants articulated strategies used over their lives to deal with loneliness as well as other distress related to difficult life events and circumstances. These accounts draw on theories of resilience and the life course. They challenge ageist stereotypes of passive and dependent older people. Given the subjectivity of loneliness, older people's views should be central to future research on what responses are acceptable, meaningful or desired.
- The subjectivity of loneliness which is influenced by social and structural contexts and individual coping mechanisms means that these findings may not be applicable to older people who were under-represented. This includes those who are more disabled and unable to leave their homes unaided and those with cognitive impairment who may be described as being in the Fourth Age. Also, there was insufficient diversity in ethnicity and none of sexuality in the sample to explore potential variation in meaning, experience or response to loneliness. Within ethnicity, different experiences of migration and intergenerational factors should be included to account for variations

in experience and expectation.

- A focus on the persistently lonely to explore how they experience and respond to loneliness as evidence suggests this is a different group compared to those who report fluctuating / less severe loneliness. Also exploring the views of those who consider they have no one to call on for support; almost all participants in this study could identify someone and their views may be different.
- A tentative model was proposed from the findings of the review which may be used to engage lonely older people to consider ways in which they may want to manage their loneliness, taking into account their coping styles and preferences. Further research is needed to explore whether lonely older people consider this an acceptable approach, and whether it is applicable to different groups of older people, in different settings and contexts.
- Cognitive strategies of acceptance and endurance to manage loneliness were identified from both the systematic review as well as the qualitative study. Further research to explore whether acceptance commitment therapy (Hayes *et al.*, 2002) or the principles of it may be useful to help older people deal with their loneliness. This would reflect a shift from 'ending' loneliness to acknowledging and accepting elements of the cause or ability to respond to loneliness which may not be remediable.
- Given the recent evidence on rising rates of loneliness in younger adults aged 16-24 years (Office for National Statistics, 2018), as well as depression and anxiety, particularly in young women (NHS Digital, 2016), the approach used in this study to engage with those who identify as lonely to explore how they respond and wish to manage their feelings may be useful to identify strategies to help younger

people cope and build resilience. Their use of technology and social media as a mechanism to alleviate loneliness is likely to be different than in older adults.

8.5 Implications for policy, practice and older people

- The agency of the older people in this study who articulated their experiences and responses to loneliness is counter to the passive and ageist stereotypes of lonely older people prevalent in society. Anti-ageist policies can challenge current narratives and representations of ageing and older people which emphasise decline and dependency.
- Engaging with those who are lonely is essential to understanding what loneliness means to individuals, what triggers it, how it affects them, to what extent they manage themselves and what support they may consider helpful or acceptable; within this the preference to manage loneliness privately needs to be acknowledged. The recent government loneliness strategy for England (Department for Digital Culture Media and Sport, 2018b) was based on a consultation with organisations with expertise and experience in tackling loneliness. The views of organisations may differ from personal experiences of those who are lonely and the perspectives of older people not accessing organisations for support are likely to be under-represented.
- An important way to manage loneliness in participant accounts was to identify ways of engaging and contributing, both with others and to society, which was meaningful to the individual. Rather than being recipients of intervention, older people wanted to be meaningful social contributors; this emphasis is lacking in the recent loneliness strategy.

- Services for older people such as befriending and social groups are perceived by some as being a 'last resort' and for those without other options to engage. As well as challenges to attending alone, older people may be easily deterred if the initial contacts are not successful; in particular those struggling with grief or mental health problems. Staff or volunteers providing services may wish to make additional efforts to engage and introduce new members to existing members as well as following-up those who stop attending to encourage them back/explore their reasons for not attending. Such efforts may need to be resourced by initiatives that are focussing on asset-based or place-based community developments (Social Care Institute for Excellence, 2017).
- My findings support the view that 'shared interest' groups have more appeal to older people (and may be more successful) than purely social groups. Options for groups need to cover a broad range of interests (and be accessible to all); older people appeared more likely to take up such groups if they related to a long-held interest or hobby from earlier in their life. In addition, fostering opportunities and addressing barriers to life-long learning would help both those who missed or were excluded from opportunities in earlier life as well as those who want to continue in later life.
- Participants did not consider primary care as a place to discuss their loneliness which may be problematic for social prescribing schemes currently being widely promoted that rely on primary care as a place to identify the problem and refer on to, for example a community navigator or similar. Primary care practitioners and other professionals should also avoid assumptions about how older people might want to respond to their feelings of loneliness as many wish to cope alone and privately.

- Support for those who are lonely should not be exclusive to those living alone; older people in long-term relationships in this study also described feelings of loneliness. Those in relationships may have specific barriers to overcome that prevent them engaging in an outside world; they may also benefit from a different approach to support which considers the quality of their relationships.
- The retirement transition may need additional support to address a potential loss of role and structure and to help fill the time. Recent research has identified necessary elements to support the retirement transition (Calouste Gulbenkian Foundation and the Centre for Ageing Better, 2017). This study suggests that, for some, identifying how skills developed during working life might be used in retirement may also be useful. Further promotion of the benefits of volunteering, both to the individual and society, as well as the different options of volunteering available, may contribute to ease the transition. Barriers to volunteering, tailored to sub-groups of older people, need to be considered to support and futureproof contributions (Centre for Ageing Better, 2018).

8.6 Conclusion

This thesis exploring later life loneliness has highlighted the importance of engaging with those who identify themselves as lonely to understand what loneliness means to them, how it affects them and what responses to it they consider appropriate. A range of cumulative experiences over the life course underpinned definitions and experiences of loneliness in later life. Feelings of loneliness were episodic, varied in severity and for some were worse in earlier life, confirming the subjectivity of the experience.

In this sample participants were able to live and leave their homes independently, albeit with difficulty for some, and half lived with partners. Loss and unmet expectations were prominent themes in their narratives. Loss was associated with both bereavement and the loss of role following retirement. Unmet expectations were described by those who remained in unsatisfactory relationships with partners rather than live alone and those whose lives in their retirement were challenging and unfulfilled reflecting a lack of choice over the end of their working lives and subsequent opportunities. Unsatisfactory relationships with children/step children and those who had not had children were described as both loss of role and unmet expectation. Loneliness was difficult to separate from other negative emotions in participant narratives. In addition to those with diagnosed depression or anxiety, participants described anxiety, sadness, despair, fear and uncertainty alongside their feelings of loneliness. This further emphasises the need to understand individual meanings of loneliness, in particular when considering responses.

In terms of attitudes towards involving others in their loneliness and participating in community based activities and groups, participants appeared largely ambivalent about services with a primary social purpose, either those delivered on a one-to-one or group basis. They were perceived as being targeted for those who were more dependent and without any social network. More positive views were expressed of interest and hobby based groups. Participants perceived a very limited role for primary care as

a place to take their loneliness. For many, it was a private matter that they wished to manage without external support.

A tentative model for managing loneliness in later life has been developed from the findings of the systematic review of qualitative studies of strategies used by older people to manage loneliness themselves. The model conceptualises coping styles for loneliness as being on two key dimensions representing a spectrum of strategies from prevention or action through to acceptance or endurance, and coping alone or coping with/in reference to others. This taxonomy of coping with loneliness could have implications for interventions to reduce loneliness, if validated by other studies.

Older people articulated strategies they used to deal with their feelings of loneliness at an individual level, within relationships and wider social networks, as well as at a broader community and societal level. Within these discourses, an overarching theme emerged of inside and outside worlds within which they coped. Multiple strategies were used to manage their distress including behaviours, thoughts and feelings which they carried out privately within an inside world, or through which they engaged with other people or places, in the outside world. The agency of participants in this study who articulated their experiences and responses to loneliness challenges the prevalent ageist stereotypes of passive lonely older people. It suggests the need to reframe discussions of loneliness from simplistic solutions of offering advice or intervention to more person-centred discussions to understand individual meaning, coping styles and contexts, to identify responses that are acceptable and meaningful. It also emphasises the need for older people to be more 'visible', and that loneliness be normalised and discussed without stigma.

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APPENDICES

APPENDIX 1: SYSTEMATIC REVIEW SEARCH

- 1 exp geriatrics/
- 2 elder*.mp. [mp=title, abstract, heading word, original title, keyword, floating
subheading]
- 3 exp "Aged"/
- 4 geriatric.mp.
- 5 old* person.mp.
- 6 old* people.mp.
- 7 exp aging/ or ag?ing.mp.
- 8 exp very elderly/
- 9 senior*.mp.
- 10 old* age*.mp.
- 11 exp loneliness/
- 12 exp social isolation/
- 13 lonel*.mp.
- 14 solitude.mp.
- 15 solitary.mp.
- 16 liv* alone.mp.
- 17 exp self care/
- 18 self manag*.mp. or exp self-management/
- 19 exp adaptive behavior/
- 20 exp coping behavior/
- 21 (emotion* adj3 manag*).mp.
- 22 (feeling* adj3 manag*).mp.
- 23 (psycholog* adj3 manag*).mp.
- 24 (coping adj3 mechanism*).mp.
- 25 (psychological* adj3 adjust*).mp.
- 26 (emotion* adj3 adjust*).mp.
- 27 (behavio?ral* adj3 adjust*).mp.
- 28 (psychological* adj3 adapt*).mp.
- 29 (behavio?ral* adj3 adapt*).mp.
- 30 (psychological adj3 strat*).mp.
- 31 (emotion* adj3 strat*).mp.
- 32 (coping adj3 strat*).mp.
- 33 self efficacy.mp.
- 34 resilience.mp.
- 35 self reliance.mp.
- 36 (cop* adj3 lonel*).mp.
- 37 (manag* adj3 lonel*).mp.
- 38 (coping adj3 skills).mp.
- 39 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
- 40 11 or 12 or 13 or 14 or 15 or 16
- 41 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or
30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38
- 42 39 and 40 and 41
- 43 limit 42 to yr="1990 -Current"

APPENDIX 2: 6-ITEM DE JONG GIERVELD LONELINESS SCALE

Please indicate for each of the statements, the extent to which they apply to your situation, the way you feel now. Please tick the appropriate answer.

	Yes, definitely	Yes	More or less	No	No, never
I experience a general sense of emptiness					
I miss having people around					
I often feel rejected					
There are plenty of people I can rely on when I have problems					
There are many people I can trust completely					
There are enough people I feel close to					

**APPENDIX 3: PARTICIPANT INFORMATION SHEET, COVERING
LETTER AND CONSENT FORM**



School for Primary Care Research

The WISH study: Well-being Interventions for Social and Health needs

Participant Information Sheet – Interviews

Thank you again for taking part in the WISH study. You may remember that as part of this study we are approaching some of the people who have completed the Health and Well-being Questionnaire to talk to them in person and find out about their experiences.

We would like to invite you to take part in this. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if anything is unclear or if you would like more information.

What is the purpose of the study?

The WISH study is about promoting health and well-being in older people. You have kindly completed the questionnaires and received a feedback report. We want to know how we can support people who feel they have few others they can turn to for help, who might feel lonely at times or have little contact with others. This feeling may affect health, well-being and quality of life.

Why have I been invited?

As part of the study, we are following up a smaller group of people and inviting them to take part in an interview.

Do I have to take part?

As before, it is up to you whether or not to take part in an interview. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw or not to take part, will not affect the usual care you receive. If you decide to withdraw midway through the study, we will use any information you have given us up until that point, unless you ask us to destroy it.

What will happen to me if I take part?

If you are interested in taking part, our researcher, Ms Kalpa Kharicha, will come and talk to you about your experiences. She will gather a more detailed picture of what this feeling means to you, how it affects you and what you can do about it. We are also interested in your views on 'healthy aging' – how older people can stay feeling well in themselves.

The interview would be at a time and a place convenient to you and would last about one hour. We will pay back any travel costs for taking part in the interview. With your consent, interviews will be audio-recorded and transcribed so we can analyse the results. This information will be kept completely confidential.

What are the possible disadvantages and risks of taking part?

The interviews will involve discussion about your experiences and some people may find this difficult. Interviews will be carried out by an experienced researcher and participation in this study is entirely voluntary.

What are the possible benefits of taking part?

The information we gather will help us to understand your experiences in more detail. It is hoped that the results of this study can help to design new ways to support people which we can test in larger studies.

Will my taking part in this study be kept confidential?

All the information you give us will be treated in the strictest confidence and will only be used for research purposes. Paper copies of your consent form will be stored in a locked filing cabinet, at the Research Department of Primary Care at UCL.

The audio-recording from the interview will be written out by an external typist who listens to the tapes and writes down what is said. The typist will be observing strict confidentiality, as will all the researchers. The original recordings will be destroyed and the transcripts (paper copies) will have no identifying data on them. They will be stored securely in accordance with the Data Protection Act 1988. Parts of the transcripts may be published, but in a form whereby the person making the comments cannot be identified.

What if there is a problem?

We do not expect you to suffer any adverse effects from this study since we are not testing any medicines or procedures and it will not affect your usual care. There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action, at your expense. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you. You will be able to contact the research team in the first instance.

What will happen to the results of the research study?

We will analyse the results and produce a report for the National School for Primary Care Research and the Medical Research Council who have funded this research. The findings will be shared with a variety of audiences including practitioners and academics in newsletters and well regarded scientific journals, as well as presentations at local and national conferences. You will not be identified in any publication or presentation.

Who has reviewed the study?

Research ethics committees make sure the rights, safety, dignity and well-being of research participants are protected. The South-East Coast and Surrey research ethics committee has reviewed the study and given a favourable ethical opinion.

I have trouble reading in English, can I still take part?

We can provide copies of this leaflet and the consent form in different languages and can supply copies in larger font size. You can ask someone else such as a friend, family member or carer to help you complete the form. A researcher would be happy to help over the telephone. Please contact Kalpa Kharicha, the project manager, for further information.

If I would like to take part, what should I do next?

If you would like to take part in this final stage of the study, please complete and return the enclosed reply slip in the pre-paid envelope provided. We will then contact you to arrange a convenient time and place to meet to be interviewed. Please keep this information sheet to refer to.

Who is organising and funding this research?

This study has been funded by the Medical Research Council's Life-long Health and Well-being Programme and the National School for Primary Care Research. It is being carried out by a team of researchers:

- Dr Kate Walters (the Lead Researcher), Professor Steve Iliffe and Ms Kalpa Kharicha, University College London
- Professor Mima Cattan, University of Northumbria
- Professor Carolyn Chew-Graham, University of Manchester
- Professor Claire Goodman, University of Hertfordshire
- Professor Jill Manthorpe, King's College London
- Philip Hurst, Age UK
- Janet Whitehouse from the University of the Third Age (U3A).

Contact for Further Information

If you would like any further information on the project, please contact the project manager, Kalpa Kharicha:

Tel: 020 7830 2392 Email: k.kharicha@ucl.ac.uk

Post: Research Department of Primary Care and Population Health, University College London, Royal Free Campus, Rowland Hill Street, London NW3 2PF

Or Project Lead, Kate Walters

Tel: 020 7830 2239 ex 36755 Email: k.walters@ucl.ac.uk

Post: Research Department of Primary Care and Population Health, University College London, Royal Free Campus, Rowland Hill Street, London NW3 2PF

Thank you for taking the time to read this, and for considering taking part.



School for Primary Care Research

Participant address

Date

Dear

Thank you very much for taking part in the WISH study and completing the questionnaires we sent you. As part of the study, I am inviting a smaller group of people to take part in an interview with me, so that we can gather a more detailed picture of people's experiences.

One of the areas we are particularly interested in following up is how to help older people who may have few people they can turn to for support, who may feel lonely at times or have little social contact with others. This is important as we know that this can affect health, well-being and quality of life. We are very interested in your views on this.

An information sheet is enclosed which tells you more about the interview. If you are interested in taking part, please complete the enclosed reply slip and return it to me in the pre-paid envelope by [date 3 weeks after receipt of letter]. If you have any questions about the study, you can contact me by telephone on 020 7830 2392 or by email k.kharicha@ucl.ac.uk. It is up to you whether or not you decide to join the study and your decision will not affect the usual care you receive in any way.

Yours sincerely

Kalpa Kharicha
Project manager
Well-being Interventions for Social and Health (WISH) needs study

Participant Identification Number:



School for Primary Care Research

The WISH study: Well-being Interventions for Social and Health needs

Participant Consent Form for Interviews

- | | Please
initial
box |
|--|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated 22.04.12 (version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="text"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. | <input type="text"/> |
| 3. I understand that the interview will be audio-recorded, and transcribed (written out), then the audio-recordings will be destroyed. All data will be kept confidential and made anonymous. | <input type="text"/> |
| 4. I agree to take part in an interview | <input type="text"/> |
| 5. I agree to anonymous excerpts from my interview being used in publications related to the study. | <input type="text"/> |

Name of participant

Date

Signature

Name of researcher

Date

Signature

When completed: 1 for participant; 1 (original) for researcher site file.

APPENDIX 4: FINAL INTERVIEW TOPIC GUIDE

Loneliness in later life: topic guide for interviews with older people

Check Information Sheet has been read, reiterate confidentiality and anonymity and ask participant to complete the Consent Form. This interview should take about an hour. Do you have any questions before we start?

1. How did you find taking part in the WISH study?
2. Thank you for filling out the questionnaires we sent you. The questions aimed to gather a full picture of your health and well-being. Do you think they achieved that? Why?
3. In general, what things do you do that help you feel well in yourself?
4. What makes the biggest difference to you to feeling well?
5. At the time of the questionnaires, you said you: [sometimes felt lonely] / [de Jong Gierveld responses]
[Above prompts will be based on baseline & 6 months responses and tailored accordingly]

	0	6
Experience general sense of emptiness		
Miss having people around		
Often feel rejected		
Plenty of people can rely on when have problems		
Many people I can trust completely		
Enough people I feel close to		

Probe: Can you tell me more about that? Was there anything going on at that time that made you feel that way?

6. How does that compare to how you feel now?
7. Have there been other times in your life you have felt this way?
8. When you feel lonely *[or other word(s) used to describe the experience]*, how does it affect you? (Prompt: Feelings. Ability to get things done, get out and about, including transport and environmental factors)
9. How do you maintain your moral? How do you manage?
10. Do you think some people are more likely to experience loneliness than others?
11. Now, I'd like to ask you about the feedback report you received based on your answers to the questionnaires. There were some suggestions for local activities. What did you think of those?

12. [Describe services for older people at risk of loneliness]

Which, if any, of these services, would you be interested in?

(Prompt: group vs one-to-one, face-to-face vs tel, social vs specific interest.

Likes and dislikes, Why?)

13. Is this something you feel you could talk to your doctor or nurse about? Why?

14. Lastly, thinking of your experiences and how you have managed, what advice would you give to others, to help them?

That's everything I wanted to ask you. Is there anything else you would like to add or think I should have asked? Is there anything you would like to ask me?

Thank you very much for taking the time to give us your views. Your contribution to this research will help us to think about how best to help keep people well in later life.

APPENDIX 5: ANNOTATED TRANSCRIPT

K: No, you certainly haven't. I'm quite interested if you could tell me a little bit more about your contacts and things. You were saying you try and have some contact with somebody most days, and if you don't manage it, I mean, how do you manage on the days that you don't really get to speak to people?

negative feelings when no regular contact **OP1:** It's not very good, I have to say. But I say to myself, well, after all these years, you ought to be able to manage!

K: Yes. (pause) Is that enough to ...? Is that because you've been ...?

Living alone for long-term **OP1:** On my own all these years?

K: Yeah?

OP1: Well, in a way, but I mean, when you're working of course it's completely different. So, yes, I would say sometimes it's difficult, it's not easy, but then as I say, I have this good friend who I can speak to at any time really, almost. Well, she's got her problems, dreadful problems actually. Have you heard of scoliosis; that's what she's got.

key friendship - safety net **K:** Uh huh. That can be painful, can't it?

OP1: Horrible, yes.

K: How do you feel then when you don't manage to speak to somebody and you feel alone?

OP1: I don't feel good. I don't feel good.

K: In what way?

Loneliness not as bad as depression. Talks herself out of it - short term feelings that will pass, infrequent **OP1:** Well (slight sigh) I don't suffer from depression; I never have suffered very much from depression, so I'm lucky in that way. So I don't get depressed; I suppose I say to myself, well, this is just one day and it doesn't happen all the time. In fact it doesn't happen a lot, and as I say I have got this good friend I can phone and speak to on the phone. And there aren't many people that I can ring up and speak to actually, although my Alexander teacher said that I can if I want to, talk to him, ring him up and have a chat. But you don't really like to ... well, I feel like I'm sort of, you know, making use of people in a way if I do that.

Coping strategies - long term, familiar with Simone's ways of self-motivating talks herself out of it. Resigned to Simone's comparison w working with comparison w other people & challenge Simone's

Difficult to describe negative feelings

Phone contact important key friend v. limited network

Boundaries - appropriate of social contact with non-family friend

K: Well, they've offered. If they've offered that to you, haven't they?

OP1: Yes, that's true. Silly to be so sensitive.

K: So it's not so much your mood, it's not a depression that you feel. Can you describe how you do feel?

OP1: Is this really helpful to anybody?

K: Well, I think people have different experiences of it and it's quite useful for us to understand the differences in people's own experiences of this, because by getting that understanding, you might be able to find ways of being able to support it; that's the idea behind it really.

OP1: Well, contact with people. It's quite simple.

K: OK.

OP1: It's no contact with people that makes me feel not good, if I have no contact at all.

K: And what type of contact do you mean? Does it matter what the type of contact is that you have?

OP1: Not really, even on the phone is a lot better than nothing.

K: Yeah.

OP1: (pause) And, well, I went to this painting class for 19 years or so I think, and that was wonderful contact with people, you see.

K: Yes, I'm sure.

OP1: Every week, once a week, I knew I was going to have that contact. And it was something to work at; I worked at my painting quite hard, you see.

K: Mm. Have you felt this way in any other period of your life? Have you felt what you've just described at earlier stages of your life, or is this something more recent do you think?

OP1: No, it has been an on-going thing, because with an [REDACTED] you see, there's an awful lot of people around, (slight laugh) but when they're not there, then there isn't anyone.

Difficulty in
initiating contact

Contact with
other people
is key
(lives alone +
no family
nearby)

Phone contact
important when
can't meet face-
to-face.

Group-based
hobby / interest
long-term +
provided
contact w.
others.

Regular, reliable
contact
planned.
Endeavour
engaging

Loneliness in
a crowd?

Long term
relationships,
[REDACTED] *
(work) as
'family', esp.
when living
alone + no
family nearby.

(* deleted for anonymity)

APPENDIX 6: SAMPLE OF TEXT THAT INFORMED THE THEME 'RECIPROCITY AND BOUNDARIES'

Int 1: Because when you get to know your neighbours, you know, if you've both got cars ... I'm still driving but not for much longer, so I think that's when I met him out at the garage. Yeah it was.

K: OK. It's very useful to have somebody around that can fix things. It's very useful to know someone.

Int 1: Yes, well, fortunately he likes going to concerts and I get tickets, you see, so I can repay him in a way, which is a good thing.

K: Mmn. Do you get to go to concerts much yourself?

Int 1: No. No, I don't. I give them to him, the complementary tickets that I get quite a lot, and he really appreciates it, because he's getting to know a lot of things he didn't know before.

.....

Int 13: And my friend I do the walking with, she's a very private person; I might see her and I might not see her for another two or three weeks. I might meet her down the road going shopping, and just stop and have a chat. She obviously is the same as me, she doesn't want to get too close to anyone.

K: Why do you think people feel like that? Why do you feel like that?

Int 13: I don't know. I really feel that I can't be responsible for anyone probably,

.....

Int 15: I think it's beginning to. In some ways it's not enough, a bit more of a kick from somebody else would be useful. As I say, that's where my friends come into it, you know, my friend who says, "Oh, there's an art exhibition. Shall we go?" you know? But I mean, it's very unfair, isn't it, to rely on other people to pull you out of the hole.

K: Do you initiate these things ever?

Int 15: Not as much as I should, no; occasionally, yes. And the trouble is if the person in question can't do it, that's a knock-back. So that's a slight problem.

.....

Int 16: One of the nice things about it is it encourages people to come and stay with me and to sail, and because it's not something I particularly want to do on my own, it's nice to have company. And when you say to people, "Oh, I've got a boat in Greece, would you like to come with me?" it's great, it encourages people to come out for a week or two at a time, or whatever it is; lots of new challenges and new places to go and visit and explore, yeah.

.....

Int 16: The guy I know in (*another local town*) is an interesting character; his wife died, but he's since met another woman and they're very happy together. But his wife was an alcoholic and drank herself to death.

K: Oh, that must have been hard.

Int 16: He's got two grown up kids, and we talk about things like that because he's been through that experience. Yeah. Anyway, he's sometimes quite hard on his son, and his son was 18 when his mother died which is a fairly key age really for a young lad, and I always talk to (*his friend*) about how you've got to give a little bit, because he's very hard on him; we do talk about stuff like that, simply because he's been through that awful experience.

K: And do you tell him how you're feeling?

Int 16: Oh, yeah.

.....

Int 18: but I want to keep all my other things going, like the choir and the work I do for the hospice ...

K: Yes, you mentioned that.

Int 18: ... which is important to me because I feel I'm still able to do something to help and give back a bit what I received on the other end of the line.

.....

K: but can I ask you how you manage in terms of concern, you know, in terms of the emotional concerns of worries that you have?

Int 18: I think that is something else that I hold back a bit on sharing with friends, because I don't want to burden them with my worries. If you've got somebody you're really close to then it is a slightly different relationship. I mean my husband had cancer and we faced it together, but with friends they are sorry for you, they do all they can to support you, but the emotional support is not there; I think that perhaps is one way of saying it.

.....

Int 2: But then when I needed people, the only person I had was a cousin, I had only seen twice in about 50 years. The last time I tracked him down was when my mother died just before Christmas 1990; I got a message from my brother on the answer machine saying, "Our mother is dead. Make the funeral arrangements!" which I did, because I can organise. I tracked my cousin down and he came to the funeral. I hadn't seen him from then in January 2000 until November 2012, when he had a stroke and I went to see him in hospital. He had another stroke, which was successfully treated, he has a loving wife and family and I just feel that I cannot now bother him. A couple of good friends, one I've known for 33 years, but I just think that I'm only contacting them when there's something wrong with me. And up until that I'd actually done nothing for them, I just thought I really can't do it, I just can't.

.....

Int 20: Hmn, concerns. I discuss the local politics or not so local politics, or whatever it is, the art, or somebody else's illness or something, yeah. But not ... I mean friendship is sort of odd ... it's very variable, depending on who you're friends with, and it's really a question of exchange, and you learning about them and they learning about you. I mean, I have a friend, we go to (*local stately home*) for a Sunday morning conference, and we have a meal afterwards and that's great, and we do that about four or five times a year, and in-between, we don't meet at all, right? And that sort of friendship I like very much because it doesn't commit me to anything except on that particular thing.

.....

K: what is it about the making contact that you find difficult?

Int 21: I think, what is it I'm going to talk about really (*slight laugh*)

K: It's not the effort of doing it, it's about the actual what it will be like when you get together or ...?

Int 21: Yes, we ought to have a bit of news to swap and I always find it difficult to dive in and just have general chat with someone; if I meet a stranger, what will I talk to them about? My mother was exactly the same, yeah, she found it very difficult meeting strangers.

K: Uh huh, OK. But you must come across all sorts of people with your quite full life: you work, you're active, you're social with your sports.

Int 21: Yes, well, just casual acquaintances, that's fine; I'm happy in that situation, but I know I ought to develop it further.

.....

Int 22: I see them very, very little. My stepson is the one I see most of, maybe two or three times a year and Christmas, but I feel like the charity case at Christmas, you know? (*slight laugh*)

....

Int 22: I just try and get out every day and if I'm down in E***, I have a friend down there, an artist, who I kind of ring up if she's down and I'll sort of say, "Are you about?" and we can have a coffee and a chat. She'll do the same if she's up here, but it's kind of random, you know?

.....

Int 23: I mean, there have been a couple of times lately that I haven't been able to go out, and everybody has been very good to me. But I wouldn't like to live with my son all the time, because I don't want to be a burden to them for a start. But it's not just that, they've got their life and I don't want to interfere with it.

.....

Int 25: Because there was one floor in the house where people could actually get in, and we went to other people's houses. The trouble with not being able to invite anyone-to-one's own house is because one can never reciprocate, it's very difficult to accept, or one can't, one simply cannot accept other invitations.

....

Int 28: Plus the fact, I mean, my classes, the support that I've had from what I call my ladies, my girls, has been amazing, you know? They've got me through prison with (*her son*), with him disappearing, with him being in mental institutes, with my hips when I had to go and have a new hip, which all went wrong! They have just been so supportive. It's a two-way thing, it is a two-way thing.

....

Int 28: Probably (*her Essex friend*), when we go on holiday, we might have a few heart to hearts, because the girls are out without the fellows, having a coffee. But then I don't want to go there and tell them all my woes and worries.

.....

Int 3: I do tend to wait for people to phone me and say, "Would you like to do this or would you like to do that?" rather than initiating it. I think that's because I'm very aware that all my friends are married and have got children, grandchildren and that, so I don't initiate a lot of the stuff; I feel that if they want to see me or go out somewhere they will phone me, which

maybe I shouldn't do. Because they can easily say 'no' can't they? But I wait for people to invite me really.

.....

Int 9: I know this sounds absolutely crazy, but there are times when I feel as though I am not really here.

K: Uh huh, what do you mean?

Int 9: Surplus to requirements. I do an awful lot for my daughters, and I don't begrudge what I do, I do it very, very willingly, but there are times when I think, well, why can't you put yourself out for me? You know, especially the eldest one; frequently she phones up. Yeah, I do, I just feel as though everybody is using me, but it doesn't turn round the other way.

APPENDIX 7: THEMATIC FRAMEWORK

1. Definitions and characteristics of loneliness experience

- A. Individual definitions of loneliness and the subjective nature of loneliness
- B. 'Types' of people who are likely to be lonely
- C. Loneliness typologies - social and emotional
- D. Loneliness typologies - state and trait
- E. Severity of loneliness experience
- F. Duration, frequency, recurrence of loneliness experience
- G. Life-long loneliness or loneliness not specific to later life
- H. Loneliness in later life
- I. Where loneliness fits in amongst other factors and issues in their life
- J. Prompts from de Jong Gierveld scale

2. Context

- A. Work (employment, retirement, voluntary work)
- B. Neighbourhood (length of time in neighbourhood and level of integration or support)
- C. Background circumstances or the broader context
- D. Generational factors eg more traditional gender roles
- E. Family
- F. Home – descriptions of where they live
- G. Health, illness including health service - not primary care

3. 'Causes' or circumstances that have led to loneliness or that perpetuate or exacerbate loneliness

- A. Life experiences - bereavement
- B. Life experiences – transitions (retirement, moving geographically)
- C. Life experiences - early life experiences
- D. Life experiences - caring responsibilities
- E. Life experiences - poor relationship with partner
- F. Life experiences - socio-economic circumstances
- G. Personality type
- H. Physical and mental health factors associated with loneliness, both directly and indirectly
- I. Living alone
- J. Cumulative effects of 'risk factors' including over time and 'tipping-points'
- K. Seasonal impact on loneliness
- L. Geographical distance

4. Role of friends and family in loneliness experience

- A. Relationship with partner
- B. Having a key, meaningful relationship
- C. Expectations and relationships with different family members
- D. Hierarchy of network within family and friends
- E. Other groups and structures that provide the role of 'family'
- F. Impact of not having children and grandchildren
- G. How not having a family affects how you plan and cope
- H. Reciprocity of relationship and boundaries

- I. Friendships maintained over time, lifecourse.
- J. Impact on relationships (with friends or family) of key transitions
- K. Decreased contact with family, friends
- L. Difficult family relationships

5. Managing loneliness

- A. Going outside regularly
- B. Planning
- C. Having interests and hobbies
- D. Being engaged in meaningful activity and having a sense of purpose
- E. Other coping strategies including distraction to pass the time and keeping busy
- F. Cognitive coping strategies
 - F. i. Endurance of your situation
 - F. ii. Acceptance of your situation
 - F. iii. Having a particular self-defined personality type
 - F. iv. Adopting a positive attitude or focus
 - F. v. Being motivated including doing things you may not want to do
 - F. vi. Thinking of the short term future and not too far ahead
 - F. vii. Being comfortable and feeling in control on your own (solitude not loneliness)
 - F. viii. Comparative thinking
- G. Use of technology (phones, internet) for communication, information, social contact
- H. Spirituality and religion
- I. Alcohol
- J. Ability to talk about loneliness and keeping loneliness hidden

6. The role of 'others' (services, formal interventions, religious groups etc and reasons for self-management)

- A. Views of one-to-one loneliness services +ve
- B. Views of one-to-one loneliness services –ve
- C. Views of group-based loneliness services +ve
- D. Views of group-based loneliness services –ve
- E. Views on groups with a shared interest or hobby based
- F. Views on 'social' groups
- G. 'Types' of people who use services for loneliness
- H. Issues about how you are welcomed to groups and how they are run
- I. Tailoring of services to accommodate individual differences – not just for 'old people'
- J. Role of the religious groups
- K. Attitudes towards involving others in your loneliness (including not wanting to involve others)
- L. When services for loneliness might be appropriate
- M. Views on other services

7. Role of primary care for loneliness

- A. 'Appropriateness' of contact with primary care re loneliness
- B. Dr or nurse - patient relationship
- C. Appointments and access

E. Contact with primary care - not loneliness specific

8. Healthy ageing and staying well

A. Self-management strategies for staying well (other than for loneliness)

B. Other strategies for staying well (eg services, clubs), and how these are accessed eg via internet, family member, primary care etc

C. Motivating factors for participation in activities to promote health and well-being

D. Barriers to participation in activities to promote health and well-being

E. What healthy ageing and staying well means for them

F. Their expectations for the future as they age themselves including planning for the future

G. The 'trigger points' of change that would potentially lead or have led to a significant change in their health & well-being

H. Impact of declining health

I. Other age related changes

J. WISH specific

9. Other (text uncoded)

APPENDIX 8: STUDY OUTPUTS

Publications

Kharicha, K., Manthorpe, J., Iliffe, S., Davies, N. & Walters, K. 2018. Strategies employed by older people to manage loneliness: systematic review of qualitative studies and model development. *International Psychogeriatrics*, 1-15.

Kharicha, K., Iliffe, S., Manthorpe, J., Chew-Graham, C. A., Cattan, M., Goodman, C., Kirby-Barr, M., Whitehouse, J. H. & Walters, K. (2017). What do older people experiencing loneliness think about primary care or community based interventions to reduce loneliness? A qualitative study in England. *Health & Social Care in the Community*, 25, 1733-1742.

Conference oral presentations

Kharicha K, Manthorpe J, Iliffe S, Davies N and Walters K (2018) Strategies employed by older people to manage loneliness: systematic review of qualitative studies and model development. British Society of Gerontology 47th Annual Conference, Manchester, UK, 5th July 2018.

Kharicha K, Walters K, Iliffe S, Manthorpe J (2017) on behalf of the NIHR SPCR Loneliness Study group. 'How do older people manage loneliness for themselves? A qualitative study in England', within symposium titled: 'Tackling Loneliness in Later Life: When, How and at What cost? An Interdisciplinary Symposium. International Association of Gerontology and Geriatrics conference, San Francisco, USA, July 2017.

Kharicha K, Iliffe S, Manthorpe J, Goodman C, Cattan M, Chew-Graham C, Kirby-Barr M, Whitehouse J, Walters K (2014) Experiences, Self-management, and Interventions for Loneliness in Later Life. School of Primary Care Showcase, Oxford, 26 September 2014.

Other presentations

Kharicha K (2018) Strategies employed by older people to manage loneliness, Campaign to End Loneliness: Research and Policy hub meeting, London 7th September 2018

REVIEW

Strategies employed by older people to manage loneliness: systematic review of qualitative studies and model development

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What do older people experiencing loneliness think about primary care or community based interventions to reduce loneliness? A qualitative study in England

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What is known about this topic

- Loneliness in later life is a common problem, with poor health outcomes and implications for public health.
- Interventions to prevent or ameliorate loneliness have a weak evidence base.
- We have a limited understanding of how older people experiencing loneliness view services aiming to reduce this concern.

What this paper adds

- Older people with characteristics of loneliness generally know about local resources but do not consider services they perceive as being for 'lonely older people', as desirable or helpful.
- Group-based activities with a shared interest are preferred to one-to-one support or social groups.
- Older people experiencing or at risk of loneliness may not consider that primary care has a role in alleviating this.

Abstract

Loneliness in later life is a common problem with poor health outcomes. However, interventions to prevent or ameliorate loneliness have a weak evidence base. The views of older people experiencing or at risk of loneliness in the community are important in identifying features of potential support, but have been little studied. Twenty-eight community dwelling people, aged 65 and over who reported being 'lonely much of the time' or identified as lonely from the de Jong Gierveld six-item loneliness scale in a larger study, participated in in-depth interviews, between June 2013 and May 2014. Views and experiences on seeking support from primary care and community based one-to-one and group based activities, including social and shared interest groups, were explored. Interviews were recorded and transcribed. Thematic analysis was conducted by a multidisciplinary team, including older people. Using two different measures of loneliness enabled a spectrum of loneliness experience to be explored. Two-thirds of the participants were the 'younger old' and all were able to leave their homes independently. Older people with characteristics of loneliness were generally knowledgeable about local social and community resources but, for the majority, community and primary care based services for their loneliness were not considered desirable or helpful at this point in their lives. However, group based activities with a shared interest were thought preferable to one-to-one support (befriending) or groups with a social focus. Descriptions of support as being for loneliness and specific to older people discouraged engagement. Older people experiencing or at risk of loneliness did not consider that primary care has a role in alleviating loneliness because it is not an illness. They thought primary care practitioners lack understanding of non-physical problems and that a good relationship was necessary to discuss sensitive issues like loneliness. For many, loneliness was a complex and private matter that they wished to manage without external support.

Keywords: community based interventions, loneliness, older people, primary care

Background

Loneliness in later life is increasingly considered a public health problem (WHO 2002; DH 2012). It has a prevalence of 16%–35% in those aged 65 and over, rising to up to half of those over 80 years, with severe loneliness (lonely all or most of the time) occurring in between 5% and 13% of the older community dwelling population in the UK (Savikko *et al.* 2005, Victor *et al.* 2005, Luanaigh & Lawlor 2008, Age UK 2010).

Loneliness is a subjective experience; an emotional and unpleasant response to a lack of satisfactory companionship (Heinrich & Gullone 2006). In later life, loneliness is linked closely to other experiences associated with ageing, such as loss of family and friends and declining health and income, as well as more recent socio-demographic trends such as longevity, living alone for longer, relationship breakdown, and changes to families and communities (Age UK Oxfordshire 2011, Bernard 2013, Nicolaisen & Thorsen 2014). The links between loneliness and its harmful physical and mental health consequences are widely reported (Stuck *et al.* 1999, Savikko *et al.* 2005, Victor *et al.* 2005, Iliffe *et al.* 2007, Luanaigh & Lawlor 2008) and include increased risk of mortality (Lyyra & Heikinen 2006). Depression and loneliness in older people are strongly associated (Green *et al.* 1994, Cacioppo *et al.* 2006, Golden *et al.* 2009), while loneliness seems an independent risk factor for future depression (Heikinen & Kauppinen 2004).

Despite these associations, the role of primary care in reducing loneliness has not been clearly delineated and there is little indication of what it can offer above identifying and treating associated depression. The relevance of loneliness to primary care is clearer. Loneliness has been independently associated with increased primary care consultations (Ellaway *et al.* 1999), emergency (but not planned) hospitalisation among community dwelling older adults (Molloy *et al.* 2010) and early moves to long-term care (Russell *et al.* 1997, Savikko *et al.* 2010).

Given the frequency of consultation with primary care, social prescribing may be a way that primary care practitioners can refer patients to non-clinical community based sources of support. Social prescribing aims to promote integration between health and social care services with the voluntary and community sector (DH 2006) and the range of community options available commonly includes activities aimed at those experiencing or at risk of loneliness, such as befriending schemes. However, evidence of the effectiveness of social prescribing is currently limited to evaluations of pilot projects and little evidence on

cost-effectiveness is available; a rapid appraisal found little evidence on social prescribing programmes to inform commissioning (Centre for Reviews and Dissemination 2015).

For several decades in the developed world, welfare state and voluntary sector groups have sought to alleviate loneliness among older people (Means & Smith 1999). Currently in the UK, three main types of community based services to alleviate loneliness are common. These may be (i) run by local government as part of social services or community resources; (ii) run by local government or other public sector funded voluntary sector organisations; or (iii) offered by self-funding community, self-help and voluntary bodies that receive no/little state support but are linked to neighbourhood, leisure, self-help, educational, occupational or faith groups (Moriarty & Manthorpe 2012). The activities undertaken may be individually or group focused, with one-to-one home-based befriending being at one end of this spectrum and large-scale social or educational groups at the other.

There has been very little high-quality research into the effectiveness of community based interventions specifically designed to reduce loneliness and social isolation in later life (Findlay 2003, Cattan *et al.* 2005, Frost *et al.* 2010, Dickens *et al.* 2011, Masi *et al.* 2011). A systematic review of the effectiveness of health promotion interventions for loneliness and social isolation among older people found that 9 of the 10 potentially effective interventions were group activities with educational or support input, and those that targeted specific groups were more effective, and that six of the eight ineffective interventions provided one-to-one support, advice and information, or health needs assessment (Cattan *et al.* 2005). More recent systematic reviews of the characteristics of effective interventions for social isolation (Dickens *et al.* 2011) and loneliness (Hagan *et al.* 2014) in older people have similarly reported that group based formats were more effective. In addition, interventions developed with a theoretical basis, groups offering social activity and/or support, and those in which older people are active participants were effective for social isolation (Dickens *et al.* 2011), and those involving new technologies, effective for loneliness (Hagan *et al.* 2014). A meta-analysis to assess the strength of evidence of interventions to reduce loneliness found pre-post and non-randomised comparison studies yielded larger mean effect sizes compared to randomised comparison studies and in studies that used the latter design, the most successful interventions addressed maladaptive social cognition (Masi *et al.* 2011).

These systematic reviews are limited to quantitative outcome studies. Despite the range of services and activities with the remit of alleviating loneliness, the prevalence of loneliness in community dwelling older people has remained fairly constant over the last few decades (Victor *et al.* 2002, Honigh-de Vlaming *et al.* 2014). With the limited evidence base for interventions, it is important that services take into account the views of older people experiencing loneliness. Most views on such interventions are from those already engaged with services (e.g. Cattan *et al.* 2003, Lester *et al.* 2012, Silver Line, 2015), or report views that are not service specific (Johnson *et al.* 2007). We therefore know little about what older people with loneliness in the general population actually want, if anything, from services to address loneliness.

This paper describes findings from a study that aimed to explore the perspectives of community dwelling lonely older people about seeking support for loneliness from primary and community based services and the features of these services which informed their views.

Method

Population and setting

This study was nested within the Well-being Interventions for Social and Health (WISH) study (Medical Research Council funded) which explored the feasibility of embedding a health and well-being risk appraisal system into primary care. The 454 participants were community dwelling older people aged 65 and over, registered and recruited from five English NHS primary care practices (three in a London Borough, two in a semi-rural County). Participants completed a multidimensional, comprehensive self-assessment postal questionnaire, including two loneliness measures. Participants were excluded if they lived in a long-term care facility (care home), had a severe incapacitating, life-threatening or terminal illness, were unable to provide informed consent or if an assessment would be considered burdensome.

Sampling

Following the main study, all participants who identified as lonely at baseline or 6 months follow-up, either because of their answer to the single stem question 'Do you feel lonely much of the time?' or because they scored two or above in the six-item de Jong Gierveld Loneliness scale (de Jong Gierveld & van Tilburg 2006), were sent a postal invitation to interview. Unlike the single stem question, the

statements in the de Jong Gierveld Loneliness scale do not include the word 'lonely'. Interview recruitment continued until the main emerging themes were reinforced and to oversample for diversity in age, gender, socioeconomic status, ethnicity and severity of loneliness among participants.

Data collection

An interview topic guide addressing the research questions was developed iteratively using knowledge of the literature and in consultation with the voluntary sector and older people representatives on the study team. Topics included experiences of loneliness, attempts to ameliorate loneliness made by themselves or others, including prompts on views of both one-to-one and group based support (social and hobby-based/educational) if these did not arise naturally in the discussion, barriers and facilitating factors to reduce loneliness, the perceived role of professionals (including primary care) in reducing loneliness, and potential components of interventions designed to reduce loneliness in older people. Data reported in this present paper draw mainly from the responses to questions about primary care and community based services.

Participants were offered interviews in their home, the university or a local community venue of their choice. Interviews were audio-recorded and transcribed verbatim with consent.

Analysis

A thematic analysis was undertaken to identify key emergent themes and their meaning. Transcripts were read independently by nine members of the research team including lay members and analysed using a constant comparative approach including searches for disconfirming evidence (Spencer *et al.* 2014). Transcripts were read thoroughly to ensure familiarity with the data, and significant sections of text were identified, annotated and summarised to describe emerging themes, both *a priori* themes from the topic guide and those emerging from participants' accounts. The themes were organised into higher and lower level themes in a thematic framework, discussed within the study team and the framework further refined. The clusters of themes were then referred back to the original transcripts for validation (Spencer *et al.* 2014). The overall interpretation of meaning and explanations were then developed and their implications considered, with input from the entire research team. NVivo 10 software was used to facilitate data management.

NHS Research Ethics Committee approval for the loneliness interviews was given by NRES Committee South East Coast - Surrey.

Findings

Twenty-eight interviews were completed, lasting between 75 and 135 minutes. Nine participants (32%) reported being lonely much of the time and 19 (68%) were lonely based on their responses to the de Jong Gierveld six-item scale alone. Almost half the sample lived with others. In addition to the socio-demographic details presented in Table 1, it is noteworthy that all participants were able to leave their homes, albeit with some difficulty for a few.

This sample of community dwelling older people who either self-identified or scored as lonely on a validated scale was able to describe their understanding and experience of loneliness in detail. The overarching view expressed was that support from community and primary care based services for their loneliness was not something they desired or considered helpful, at this point in their lives.

The level of current or previous engagement with services and support was variable. Participants who had not sought support were able to share their considerations and perceptions of local resources or described their knowledge of such resources. Those who had previously or were currently engaged in social activities described the factors that facilitated or were a barrier to their involvement. Across the spectrum of community and primary care based

services and activities, the extent to which their focus was explicitly on supporting loneliness, also varied. Within this sample of lonely older people, most had previous or ongoing involvement in shared interest or hobby-based groups, that is, activities without an explicit focus on loneliness. Behind such general impressions lay other understandings; themes emerging from participant narratives are presented below by type of service/resources and are illustrated with quotes.

Could befriending be for me?

Many participants were unaware of one-to-one befriending schemes that were running in their neighbourhood at the time of interviews, either face-to-face or by telephone, led by local voluntary sector groups. A few asked for details about such services, however others expressed uncertainties around the motivation, personality and compatibility of the individual volunteer, the idea of a volunteer/stranger coming to your home and concerns about the content of such conversations. As one woman explained:

The one-to-one I'm not too sure about; it just depends, doesn't it? I presume people who do that are quite extrovert and jolly-jolly, and have a chat with you. It could be that you really took to somebody and found them easy to chat with. I mean, yes, I think they're great ideas but I don't know. (Int 19: Female, 65–74 years, lives with others)

A volunteer? Well, I'd be embarrassed actually. (Int 2: Male, 65–74 years, lives alone)

Barriers to taking part in such schemes were identified including the stigma of being identified as lonely and the associated stereotypes of people who use services for loneliness or isolation, and not wishing to see themselves within this group. Several of the younger participants (65–74 years) reported, 'Not now, maybe later' including those who reported being lonely much of the time:

I'm not that desperate yet! (Int 5: Male, 65–74 years, lives with others)

But what I'm saying is, ten years down the line, I might think that's a really good idea. At the moment, I'm saying it's not for me, but if I was isolated in this house and couldn't get out, yeah, I think that would be a lovely idea, but just not at the moment. I think I have to find my own way at the moment of doing things. (Int 3: Female, 65–74 years, lives alone)

None of the participants expressed a wish to access a telephone befriending service, stating either that they did not particularly like that type of communication or that they would just telephone

Table 1 Socio-demographic characteristics of sample and self-rated loneliness ($n = 28$)

Characteristic	n (%)
Gender	
Female	18 (64)
Male	10 (36)
Age	
65–74	19 (68)
75–84	5 (18)
85+	4 (14)
Ethnicity	
White UK	25 (90)
Other	3 (10)
Living arrangements	
Lives alone	15 (54)
Lives with others	13 (46)
Lonely much of the time	
Yes	9 (32)
No	19 (68)
Lonely on de Jong-Gierveld six-item scale (two or above)	
Yes	27 (96)
Total	28 (100)

someone they knew instead. Some described the usual ways in which they developed acquaintances in the local neighbourhood to indicate that they did not have a problem with social contact:

I feel something like that may grow from somebody I might meet, say when I go up to the market and so on, and then I'll see them the next week and say 'Hello' and then I'll see them the next week 'How are you?' and it may grow into something, but I don't see it being presented to me and my saying welcome. (Int 26: Female, 75–84 years, lives with others)

'Social groups' are for others

Themes related to social groups (groups convened for a primary social purpose) overlapped to some extent with views on befriending schemes. Purely social groups with little or no specific activity (e.g. lunch clubs, coffee mornings) were widely perceived as being for 'lonely old people' and most participants were reluctant to attend, or reported some negative initial experiences when they had previously tried them. Some considered they were in better physical health than those attending groups targeted for the 'elderly' or expressed a preference for the company of younger people. Two men who both lived alone, who described themselves as lonely much of the time and did not mention any meaningful relationships other than their children who lived at some distance, painted a picture of the type of the people they thought went to social groups and why they would not go themselves:

To tell you the truth, I'm not really interested in that. I don't want to sit down there and listen to Mrs Jones and her rheumatism, and old Fred Bloggs talking about his bleedin' lumbago! (Int 7: Male, 65–74 years, lives alone)

Other participants reported similar negative views of such groups, for example as providing 'tea and bingo' for older people:

I just feel they're not for me. I feel that the level at which they work wouldn't satisfy me. You're painting a picture of people really who have gone into old age and accepted it and are not asking anything of life now, except to go and have a cup of tea with somebody in a little group. It wouldn't do. I'd be thinking what could I be doing at home? I'm not coming back here again, I'm sure. (Int 26: Female, 75–84 years, lives with others)

The very idea that a group would meet individual needs was questioned by some:

We're all very different and we've got different needs and so the support mechanisms have got to be completely flexible to take into account every individual, and they are all

individual needs, aren't they really? (Int 16: Male, 65–74 years, lives with others)

As few participants had successfully engaged with groups or activities in which addressing potential or actual loneliness was explicitly part of their remit, limited information can be gleaned on what would facilitate further engagement with such activities. However, basic hospitality and being generous both in attitude and with refreshments were important, as described by one participant as a group member:

They're always coming round, 'Would you like a biscuit? Would you like a sausage roll? Cakes?' and there's always tea and coffee available ... Yes, it is very good, very generous. (Int 23: Female, 85+ years, lives alone)

However, another participant who had volunteered (once and many years ago) said her contrasting experiences had subsequently deterred her from going along as a member:

I just didn't like the atmosphere at all ... I think they were impatient and I think with very elderly people, you've got to be really patient. And I think maybe I saw the impatience of, 'You've had two cups of tea already!' I mean, whose business is that if she wants ten cups of tea! You know, and I just had the feeling, no, you know, it's not for me. (Int 3: Female, 65–74 years, lives alone)

Having a common interest

Most participants had or were currently attending shared interest group activities and views on these groups contrasted to those described above. Having a shared interest (rather than meeting for purely social reasons) seemed to make it easier to become involved, as expressed by participants who regularly attended group-based activities, such as exercise groups. These groups were valued for their expressed content and also the social element that developed. This suggests that people may be sociable, involved with others, indeed nearly half were also living with others, and also feel lonely. One participant in the study, who ran a popular exercise group for older people and who was clearly valued by her members, despite reporting that she herself felt lonely, shared some of the many techniques she employed:

That's why with some of my ladies, I've known them so well for so long, that when they become widowed, I just make sure I ring them up, send them cards, 'We miss you. When are you coming back?' you know? Because it would be so easy for them. I've got one at the moment who is just not coping very well at all. I ring her and say, 'Come along, because I can have a laugh with you'. (Int 28: Female, 65–74 years, lives with others)

Group activities enjoyed in later life were often interests that had often been established earlier. Participants described features that facilitated or presented barriers to their current engagement. Already knowing or recognising others attending the group seemed to reduce feelings of social unease, even if members were not known people but just recognised. Perceptions of how a person is welcomed to groups, in particular on the first occasion and how they are run, for example, in a paternalistic manner, was also important. Two contrasting experiences suggested different reactions to joining a group:

The things that put me off them is that generally to the extent that I've seen them, what's going on in them (and people aren't even conscious of it) is a tiny bit of power-play that in a group of people that have come together to do something, some people feel the need to ever so slightly take charge, and then have around them people who, just maybe in the way the thing is organised and run, if you join, you join on their terms. (Int 14: Male, 65–74 years, lives with others)

In the second example, one person who had been anxious about joining a new group described how she planned ahead to make the first visit easier:

I went on my own, because two people I know were on holiday, but I phoned the lady who runs it and she introduced me to some people. (Int 27: Female, 65–74 years, lives alone)

What can primary care offer?

Overall, the appropriateness of discussing loneliness with primary care practitioners was questioned by participants. There was a strong view that loneliness is not an illness, and a perception that GPs lacked understanding of problems that were not physical health problems. A few exceptions to this were cited, for example, by people with co-existing mental health problems such as depression and anxiety. This small minority who were more likely to consider talking to their GP about loneliness had good relationships with their general practice, were used to discussing their mental health problems and had generally received treatment. A smaller number had managed to develop a relationship with a member of the primary care team having lived in the area for a long time:

Well, for instance, coming up 2 years ago, my doctor put me down for a sort of refresher in CBT [cognitive behavioural therapy] ... Yeah. I mean, he's very good; he's spent a lot of time with me. (Int 10: Male, 65–74 years, lives with others)

Many, however, felt that they did not have the close relationship with their GP that they thought

necessary to talk about problems such as loneliness, although some had identified individual members of the practice team they could talk to or would consider doing so in the future:

Well, that would be the last place I'd want to go, you see; they're not very sympathetic. (Int 4: Female, 65–74 years, lives alone)

The practice nurse I was sort of seeing was very, very sympathetic to me; she was very, very nice and I talked to her about the things that were really bothering me and she was so sympathetic, but it was like really a one-off. (Int 3: Female, 65–74 years, lives alone)

Participants were also aware of the constraints on GPs' time:

There are many times when I would have liked to have had a discussion, but the appointments are just 10 minutes. (Int 25: Female, 65–74 years, lives with others)

Others felt that talking to the GP or nurse about emotional problems would be 'wasting their time' as other problems were considered more pressing or that the likely solutions offered would be pharmaceutical. For example, one participant who reported being depressed and very lonely said:

Well, really, there's nobody to talk to really, is there? You can't talk to your doctor about it, because they'll just turn around and say, 'Here's a tablet!' And I take enough of them now, and that's about all; there's nobody actually to talk to really. (Int 7: Male, 65–74 years, lives alone)

Dealing with loneliness privately

Other themes emerged about the overall idea of involving 'others' in their loneliness. Situations or life events for which services or support for loneliness were deemed inappropriate by many included those in unsatisfactory relationships, those grieving the loss of a partner and/or those who had experienced worse episodes of loneliness at other times. For many, these feelings of loneliness, particularly for those grieving, were seen as a private matter and ones to be worked through alone. Some had considered bereavement counselling and tried it briefly but none of them had persisted with it or found it particularly beneficial. Others had a good understanding of their situation and were able to describe how they managed their feelings. For example, one participant described the stigma she would feel using services that supported older people who were lonely, and ultimately loneliness for her was a private matter that she would not consider talking to anyone about:

I know I've said, you know, I feel alone and isolated, but I'm not sure whether it would help me to talk about it. I think I know why I feel alone and isolated. I think I know, I don't need somebody to tell me if you like. (Int 3: Female, 65–74 years, lives alone)

Discussion

Summary

This is one of the first studies to explore perceptions and experiences of lonely older people on community based avenues of support, in which the sample had not been invited on the basis of their current use of services for loneliness or loneliness risk. Overall, participants held negative views about services and activities they perceived as being badged or targeted at 'lonely older people'. Many had tried a range of activities and services and were able to report reasons why they had stopped engaging. In particular, reservations were expressed about befriending and purely social groups, with most expressing preferences for groups with an activity or purpose that is not primarily social, and ones that are not necessarily specific to older people. Primary care was not seen as a place to share feelings of loneliness, meaning that it is unlikely that all older people with loneliness will volunteer themselves or request 'social prescribing'. For many, loneliness is a complex and private matter that they prefer to manage themselves.

Comparisons with previous literature

Participants in this study were not engaging with services for loneliness such as befriending or many social groups and their views are likely to be different to the sizable number of people who do use these services (Windle *et al.* 2011). Lester *et al.*'s (2012) study of the views of older people engaged with befriending services reported characteristics of the service that people had found to be helpful were: good conversational skills and empathy in the befrienders, and opportunities for emotional support and reciprocal social exchange through safe, confiding relationships. These experiences address some of the concerns expressed by the sample in the current study about the type of people delivering the service and the service remit. Participants' views on befriending schemes including an attitude of 'not now, maybe later' may also have been influenced by the fact that two-thirds of participants in our study were 'younger old' (65–74 years), and all participants were able to leave their homes independently (although some were beginning to have difficulty in this), in

comparison to the largely housebound and very old population engaged with befriending schemes (Lester *et al.* 2012).

Older people experiencing or at risk of loneliness did not consider that primary care has a role in alleviating this. Over and above the constraints of time and access, some participants were cautious about the possible medicalisation of and pharmaceutical response to loneliness. A good relationship was deemed necessary to discuss sensitive matters like loneliness, similar to the 'active listening' by health-care providers proposed by Smith (2012) in her exploration of meaning and coping mechanisms for loneliness in community dwelling older adults. Johnson *et al.* (2007) explored the coping and prevention strategies for loneliness of individuals aged 50 and over recruited primarily from voluntary agencies. A significant number were currently/had previously received some form of health or social care services, but little was reported about the role of these services regarding loneliness and social isolation. The services were described as enabling living in a 'physical sense' rather than 'enhancing the social experience' (p. 44).

Although there is little comparable research in this area, these views resonate with the larger literature on the views of older people with depression seeking support from primary care. Older people are similarly reluctant to recognise and name 'depression' as a set of symptoms that warrants seeking support from primary care and they have limited expectations of treatment, which is assumed to be predominantly biomedical. This is partly due to perceptions of the role of the GP and also to previous negative experiences of help seeking (Burroughs *et al.* 2006, Chew-Graham *et al.* 2012). From a primary care perspective, studies have reported that some GPs have mixed feelings about offering medication to address what they believed to be the consequences of loneliness and social isolation (Murray *et al.* 2006), namely depression, which is contrary to the expectations of many of the lonely older people in this study.

Many expressed views about the private nature of their feelings of loneliness and the desire to manage these without involvement of others. This resonates with the view that loneliness can be a range of feelings which people live with and experience and manage differently (Hauge & Kirkevold 2012) and challenges assumptions about being recipients of support in later life (Allen & Wiles 2014).

Strengths and limitations of the study

Study participants were able to articulate a breadth of experiences of loneliness and their considerations

in seeking support to help manage these negative emotions. One strength of this study is that it includes older people with different degrees or characteristics of loneliness, ranging from those who admitted being lonely to a researcher to those whose prior completion of a survey about health status in private had indicated that they were at risk of loneliness. Furthermore, most people had not engaged with services for loneliness and many said they had not spoken about their loneliness to anyone previously. The sample therefore included those with loneliness whose views may not previously have been heard.

In addition, the older people in the multidisciplinary research team contributed both personal and professional perspectives to the development of the topic guide and analysis and interpretation of the data, a further strength of this study.

In interpreting the views of participants in this study, it should be borne in mind that the sample was recruited from a larger study of health and well-being in later life, and it may not represent the views of those who do not take part in such research. Two-thirds of the sample were in the 'younger old' age group and all were able to leave their homes (with some difficulty in some instances), and so the research does not represent the views of those unable to leave their homes, and under-represents the older, frailer population who are likely to express different views. There was a good spread of gender and socioeconomic status, but a smaller number of older people from black and minority ethnic groups, who may also hold different views.

Implications for research

Further research should explore the views of older people with loneliness who are unable to leave their homes but are not in contact with services, in particular regarding one-to-one approaches such as telephone or face-to-face befriending, or use of the Internet. Loneliness was considered a mostly private matter, and we need to understand more about how older people can be supported to 'self-manage' their loneliness. Research developing new interventions should consider the heterogeneity of views regarding services seen as being targeted for loneliness, and the need to take these into account in the design.

Implications for policy and practice

Participants reflected a population whose needs are important to consider in the commissioning of

services. Avoiding descriptions of services and activities as being for older people experiencing or at risk of loneliness may increase their accessibility and their acceptability. Features to emphasise that may encourage this group of older people to make community connections include: the ability to maintain interests established earlier in life, accessing groups with a shared interest which may allow a reciprocity, purpose and value to the exchange, geographical proximity to increase the likelihood of recognising others attending local groups, and other efforts to acknowledge and minimise the potential social unease particularly felt by some older people who may find groups difficult. This largely mobile and active group of older people with loneliness were mostly ambivalent about using befriending services, which supports targeting of these services on older people who are unable to leave their homes.

Our study also provides important evidence about isolation and loneliness, in that nearly half of the participants lived with other people and so would not necessarily be seen as socially isolated. Targeting social and other resources on older people living alone would likely miss this group. Older people were reluctant to seek help from their GP or practice nurse for loneliness, and social prescribing initiatives in primary care would require a pro-active approach to identify people who may benefit.

Conclusions

Older people with loneliness who are able to leave their homes appeared largely ambivalent about services with a primary social purpose, perceived as being targeted for 'others'. More positive views were expressed of activity based groups. They perceived a very limited role for primary care, and for many their loneliness was a private matter that they wished to manage without external support.

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Conflict of interest

No conflicts of interest have been declared.

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