The role of carer stress in acute and long-term care utilisation by community-dwelling older people

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The role of carer stress in acute and long-term care utilisation by community-dwelling older people

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A thesis submitted to the Royal College of Surgeons in Ireland,
in fulfilment of the degree of Doctor of Philosophy,
in the Department of Psychology, Division of Population Health Sciences,
Faculty of Medicine and Health Sciences

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January 2017
Candidate Thesis Declaration

I declare that this thesis, which I submit to RCSI for examination in consideration of the award of a higher degree of Doctor of Philosophy, is my own personal effort. Where any of the content presented is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<tr>
<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
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<tr>
<td>CAPI</td>
<td>Computer Assisted Personal Interview</td>
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<td>CCAT</td>
<td>Crowe Critical Appraisal Tool</td>
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<tr>
<td>CI</td>
<td>Confidence Interval</td>
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<td>CSO</td>
<td>Central Statistics Office</td>
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<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, 4th edition</td>
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<td>ELSA</td>
<td>English Longitudinal Study on Ageing</td>
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<tr>
<td>GP</td>
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<tr>
<td>HCP</td>
<td>Healthcare Professional</td>
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<tr>
<td>HRS</td>
<td>Health and Retirement Study</td>
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<td>HSE</td>
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<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
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<tr>
<td>LTC</td>
<td>Long-term care</td>
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<tr>
<td>MMSE</td>
<td>Mini Mental State Examination</td>
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<tr>
<td>NCPOP</td>
<td>National Centre for the Protection of Older People</td>
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<tr>
<td>NHP</td>
<td>Nursing Home Placement</td>
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<td>NHSS</td>
<td>Nursing Home Support Scheme ('Fair Deal')</td>
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<td>OR</td>
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<td>OT</td>
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<td>PSS</td>
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<td>PWD</td>
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<td>QNHS</td>
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<td>RCT</td>
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<td>SD</td>
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<td>SHARE</td>
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<tr>
<td>SMD</td>
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<tr>
<td>TILDA</td>
<td>The Longitudinal Study of Ageing</td>
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Summary

**Background:** In examining the sustainability of homecare, gerontological researchers have increasingly recognised how stressful caregiving can be. Indeed, several researchers have postulated that carer stress could increase the risk of institutional care utilisation by care recipients. However, this contention has not been critically analysed. Therefore, this thesis asks to what extent, if any, carer stress influences institutional care utilisation by community-dwelling older people.

**Methods:** A mixed methods approach was adopted. Study 1 systematically reviewed and meta-analysed the strength of the effect of carer stress on subsequent institutionalisation of community-dwelling older people. Study 2 qualitatively analysed healthcare professionals’ (n=22) and carers’ (n=16) perceptions of how carer stress and health system factors may influence long-term care (LTC) admissions. Study 3 compared different theoretically-informed models to determine factors that may influence institutional care utilisation by community-dwelling older people (n=205). This was a secondary analysis of The Irish Longitudinal Study of Ageing (TILDA).

**Results:** Study 1 found that while carer stress has a significant effect on subsequent institutionalisation of care recipients, the overall effect size was negligible (N= 54 studies; standardised mean difference =0.05, 95% CI=0.04-0.07). Study 2 found the escalation of care recipients’ needs, to the extent that the carer or community care cannot meet these needs, drove both carer stress and LTC admissions. This suggests that carer stress is an epiphenomenon of the journey to LTC. This was represented in a proposed alternative theoretical model. This model was examined in Study 3, which found the effects of institutional care utilisation on carer stress were as convincing as the effect of carer stress on institutional care utilisation.

**Conclusions:** Carer stress is not a risk factor for care recipient institutionalisation. It appears to co-occur with the need for institutional care utilisation rather than driving this utilisation. The thesis proposed and tested an alternative theoretical model to represent this, which has considerable implications for the caregiving literature. Future research should further test this model in prospective structural analysis with other sufficiently-powered samples.
Acknowledgements

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For Dad

“I call:
And You are already in my voice”

(Pádraig Daily)
Publications and presentations arising from this thesis

Publications


3. Donnelly NA, Humphries N, Hickey A, Doyle F. “We don’t have the infrastructure to support them at home”: How health system inadequacies impact on long-term care admissions of people with dementia. (Under Review) 2016

Presentations


Chapter 1  Introduction

1.1  Ageing population
Population ageing is a phenomenon that is taking place internationally. In the OECD, it is anticipated that share of the population over the age of 80 will grow substantially in the forthcoming decades. For example, OECD projections estimate those aged 80 and over will increase from 4% in 1950 to 9.4% in 2050 (1). Such projections are equally applicable in Ireland, where those aged 80 years and over are expected to increase from 2.8% in 2011 to 3.5% by 2021, an increase of 45% (2). This population ageing is widely recognised in gerontological research.

Despite recognition of population ageing, it should be noted that there is no current United Nations standard definition for the age threshold at which an individual is considered ‘old’ (3). Ryan discusses the different approaches that may be adopted in defining ‘old age’, be this in chronological, functional or social terms (4). Traditionally, the age of 65 has been adopted as a somewhat arbitrary threshold. This is because this age is associated with a transition out of the labour market and an alteration of social roles (3, 5, 6). There is huge variation in the characteristics and health service utilisation patterns of those aged over 65 (4). However, while the threshold of the age of 65 may seem arbitrary, it is a commonly accepted definition amongst gerontological researchers. Therefore, it will be adopted as the age at which an individual is considered an older person for the purpose of the first two studies of this thesis. The final study concerns health service utilisation patterns. The study sample is aged 50 plus as this is a time in life when many people begin to experience chronic conditions (7, 8). As such, it is an interesting time to examine health service utilisation.

This ageing population is expected to result in an increased demand for long-term care services (9). In tandem with this, it is widely recognised that many older adults would rather continue to live in their own homes for as long as possible (10). Both of these factors have meant that a key policy objective for older people in Ireland,
as in many OECD countries, is to support older people to live independently in their own homes for as long as possible (11). In light of this, there has been a great deal of research on what factors predict entry to Long-Term Care (LTC).

Long-term care facilities are referred to differently in different jurisdictions. Most commonly, these facilities are referred to as nursing homes, but are also known as residential care homes and assisted living facilities in different countries (12). The terms for these facilities may be different, but their essential principle purpose is the same. They are communal living environments for those who do not require acute care (hospital care), but whose care needs are such that it is no longer possible to live independently in the community. For this thesis, long-term care (LTC) and nursing home care are referred to synonymously.

1.2 Long term care research

For many researchers, understanding the risk factors associated with LTC admissions could enable the development of prognostic tools to identify those at risk of admission. This may support the design and targeting of services so as to delay such admissions (13-15).

Conventionally, this research has focused on the characteristics of the older person that increase their risk of transitioning from the community to LTC. The risk factors identified appear to stem from the socio-demographic and clinical characteristics of the individual, as well as their health service utilisation history. These risk factors include the individual’s age, marital status and prior nursing home use (13, 16-20). The clinical characteristics largely emanate from what has been termed the ‘geriatric giants’ of ageing (21). These are the major categories of disability associated with old age. They include immobility, falls, incontinence and dementia (16, 17, 21). However, their importance in the transition to LTC is largely based on the underlying cognitive and functional impairments with which they are associated (13, 16-18, 22-25). Functional impairment is often measured through an individual’s capacity to undertake Activities of Daily Living (ADLs). These are basic tasks of self-care: eating, toileting, bathing, dressing and moving about (26).
The research on an individual’s risk of LTC admissions is extensive. However, it includes many contradictory and inconclusive findings. Meta-analyses in the area have acknowledged that this research contains a considerable amount of unexplained variance in the prediction of LTC admissions (ranging from 50-60%) (16, 24, 25). This has led researchers to look beyond solely the characteristics of the older person, to instead take a more holistic view of the factors which are critical to sustainable homecare. As a result, there has been an increased recognition of the role of carers in the provision of homecare.

1.3 Carers and caregiving
This thesis concerns older people whose physical and/or mental health may have compromised their capacity to live independently in the community. Consequently, they require support to continue living at home. The activities undertaken in the provision of homecare to support these older people are referred to as ‘caregiving’ in this thesis (27). The older people who require this support are referred to as ‘care recipients’. Carers are those who take primary responsibility for the provision of homecare to an older person on an on-going basis (11, 28, 29). The caregiving role is often described as informal and voluntary to distinguish the role of carers from healthcare professionals who are also involved in the provision of homecare (30). Chapter 2 expands upon these definitions.

Carers are largely close relatives, such as a spouse or adult child of the care recipient. However, they are not a homogenous group. The role and its degree of intensity will vary hugely depending on the care needs of the care recipient. The profile of spousal carers, adult child carers and dementia carers and the challenges they face can vary considerably. This is discussed in further detail in Chapter 2.

The role will also change over time as the care recipient’s health deteriorates and their care needs increase. This is commonly referred to as the ‘caregiving career’ (30-33). As the older person’s health deteriorates, carers are required to provide assistance with ADLs. It is estimated that across the OECD, more than one in ten adults aged over 50 years provide unpaid help with ADLs (1). These carers provide
help with functional mobility, which includes moving between or within rooms at home. They also may provide help with personal care, such as toileting, bathing and dressing as well as eating. When a care recipient requires this level of care, the role can be intense and physically demanding. It can often mean responding to a care recipient’s needs during the night and consequently sleep deprivation. The intensity of the role limits carers’ time for activities outside of the provision of care. This includes employment and social activities (34, 35).

Assistance with ADLs is often accompanied with support through interactions with the health system. This includes visits to the General Practitioner (GP) and hospital visits. At the same time, carers providing support with ADLs may also be providing support with medication management and nursing care such as injections and incontinence management. Incontinence management can be challenging. It is physically demanding, time-consuming and often unpleasant for both the care recipient and carer (30, 36, 37).

The caregiving role can be a significant change in a carer’s way of life (38). Traditionally, the caregiving literature has concentrated on the negative impact caregiving can have on a carer. The positive impacts of caregiving have been recognised more recently. These include the positive impact on the carer, including increased self-esteem and satisfaction in being able to keep the care recipient at home (39-41). They also include the positive impact on the carer and care recipient’s relationship (39, 41).

As this thesis is concerned with the role of carer stress in the transition to LTC, the detrimental impact caregiving can have on carers is explored in detail in Chapter 2. This includes an impact on carers’ physical health. A number of meta-analyses and systematic reviews have concluded that carers are more likely to have poor physical health outcomes when compared to non-carers (42, 43). This includes weakened immunity and wound healing, cardiovascular disease and hypertension (44-47).
Caregiving can also have a financial impact. This is largely associated with the change in the carer’s employment status as a result of providing care (48). This may be a move to part-time employment or exiting the labour market in order to provide care (1). The provision of care can also negatively impact a carer’s personal relationships and restrict their social life (49).

The greatest impact from caregiving is regarded to be psychological morbidity in carers (1, 50). The OECD estimate that “the prevalence of mental health problems among carers is 20% higher than among non-carers” (1 p.98). The most commonly analysed aspects of psychological morbidity associated with caregiving are stress and burden. However, as explored in Chapter 2, there is a lack of clarity on their distinction and how they interact in the caregiving process. To overcome this lack of clarity a number of researchers analyse carer psychological morbidity within the context of the Pearlin et al. Stress Process Model (27). Within this model, burden is not understood as a separate concept from stress, rather it is a carer’s subjective appraisal of his or her situation (27, 51, 52). This interpretation of carer burden and stress has been adopted for the purposes of this thesis, as explored in Chapter 2.

1.4  Carer stress as risk factor for institutionalisation

The literature on carers’ psychological morbidity has led to a contention that the level of stress carers’ experience could undermine the sustainability of homecare and lead to the institutionalisation of care recipients (53-57). This has been analysed widely through the Pearlin et al. Stress Process Model (27). According to this model, the components of stress interact to drive a process that results in LTC admissions of care recipients. This hypothesis is the primary focus of this thesis.

Higher levels of carer stress have been found to be associated with subsequent utilisation of LTC by the care recipient in a range of studies (14, 28, 53-55, 58-75). Consequently, it is believed that there is a “strong link between caregiver stress and nursing home entry” (54 p.155). However, the findings between studies are not consistent. Estimated effect sizes vary and insignificant effects have been found in other studies (76-83).
The association between carer stress and institutional care utilisation has been examined as part of a number of systematic reviews (22, 57, 84). However, these reviews have not included a meta-analysis. Prior to commencing this thesis, the actual size of the pooled effect between studies of carer stress on LTC admissions had yet to be established. This suggested a need for a systematic review and meta-analysis.

The analysis of carer stress on LTC admissions has conventionally focused on the transition from community to LTC. The potential influence of acute care in the interaction between carer stress and LTC is often overlooked in the literature. However, LTC admissions are often arranged when the care recipient is admitted to acute care (85, 86). This suggests acute care may play an important role in the transition to LTC. Therefore, the scope of analysis may need to be expanded – does acute care affect the relationship between carer stress and the transition to LTC? To do this, it is first necessary to examine the association between carer stress and acute care admissions.

A number of studies have also found carer stress to be a risk factor for subsequent acute care admissions (87-94). As a result, carer stress has been reported to be “a considerable risk factor” for acute admissions (89 p.426). However, as with the studies concerning LTC discussed above, the findings are inconsistent in the studies of acute admissions. Some studies did not find carer stress to have a significant effect, for those which did the size of this effect varies (95-97).

Despite the inconsistency in the findings of these studies, the importance of carer stress as a risk factor for subsequent acute and LTC admissions is a common theme in the literature (53-57). Authors frequently claim that carer stress “jeopardizes the feasibility of continued home care” (22 p.66). The assertion has led to investment in large randomised controlled trials (RCTs). For example, a number of research teams are currently conducting RCTs designed to reduce carer stress, with a secondary outcome being reduction in LTC admissions (56, 98, 99).
While carer stress has been added to the set of variables analysed in the prediction of LTC admissions, the role of carer stress in LTC placement has not been critically examined. There is a lack of clarity on the basis in which researchers claim that carer stress is a risk factor for such institutional care utilisation. There also is inconsistency in the literature between findings presented in articles and the discussion of results. Thirdly, studies which make this claim often fail to adjust for key confounders, particularly health system factors such as community care. The combination of these limitations of studies in this area creates difficulties in drawing firm conclusions about the role of carer stress in the transition of care recipients to LTC. These issues are explored further in Chapter 2.

The inconsistency between study findings and the questionable degree of rigour in the literature suggests a need to critically review if carer stress can be regarded as a critical risk factor in admission to institutional care (acute and subsequently LTC). It should be noted that this thesis is concerned with carer stress as just one factor of the broader set of factors which interact to influence the admission of the older person to LTC. Thus, the hypothesis is not that carer stress alone predicts admission to LTC, but to examine to what extent carer stress influences institutional care utilisation by older care recipients, particularly admission to LTC? This has been addressed through a mixed methods approach.

In doing so the thesis asks a series of related questions: How strong is the effect of carer stress on acute and LTC admissions? What do healthcare professionals and carers perceive as the key risk factors in LTC admissions? How do healthcare professionals and carers compare the influence of carer stress to other factors influential in the transition to LTC? How do health system factors affect the relationship between carer stress and the transition to LTC? How does the effect of carer stress on institutional care use compare to other potential risk factors?
1.5 Thesis aims

To answer these questions the thesis aimed to explore the role of carer stress on institutional care utilisation, particularly LTC utilisation, by older care recipients. This overall aim incorporated four specific aims, these were:

1. To systematically review and meta-analyse the prospective association between carer stress and institutional care utilisation by community-dwelling older people (Study 1).

2. To explore healthcare professionals’ and carers’ perceptions of the main factors influencing long-term care admissions of people with dementia and how carer stress influences these factors, if at all (Study 2, part 1).

3. To explore healthcare system factors which influence long-term care admissions of people with dementia (Study 2, part 2).

4. To quantitatively examine hypothesised factors that may influence carer stress and institutional care utilisation in community-dwelling older people (Study 3).

1.6 Thesis outline

The following chapter reviews the literature in which the thesis is based. This includes the definitions for carers and carer stress adopted for the thesis. The literature on carer stress as a risk factor for institutional care use (that is both long-term and acute care utilisation), is also reviewed. The theoretical models adopted in this thesis are discussed. The chapter concludes by setting out the context of caregiving in Ireland.

Chapter 3 presents the aims and objectives of the thesis. The un-answered questions in international literature which are addressed in the thesis are described in detail. The specific chapters of the thesis which address these questions are provided.
The methodology for the thesis is discussed in Chapter 4. This includes the rationale for adopting a mixed methods approach to the thesis. The research design for the thesis is discussed. This is a multi-phase mixed method approach with three studies to address each aim of the thesis.

The results of Study 1 are presented in Chapter 5. This was a systematic review and meta-analysis of the impact of carer stress on subsequent institutional care utilisation by community-dwelling older people. Study 2 formed the qualitative component to the thesis which built on the findings of the meta-analysis. There were two parts to Study 2. The results of each of part are presented in separate chapters. Chapter 6 presents the results of the first part of Study 2. This was a qualitative analysis of healthcare professionals’ and carers’ perceptions of the influence of carer stress in LTC admissions of people with dementia. The results of the second part of Study 2 are presented in Chapter 7. This was a qualitative analysis which examined how health system factors impact on LTC admissions of people with dementia in Ireland. Chapter 8 presents the results of Study 3. This was a structural analysis which quantitatively examined hypothesised factors that may influence carer stress and institutional care utilisation by community-dwelling older people. The study was based on quantitative analysis of data from the Irish Longitudinal Study of Ageing (TILDA). This study attempted to incorporate the findings from the qualitative analysis in a quantitative model. Finally, Chapter 9 provides the overall discussion of the thesis findings and implications for future Health Services Research and for planning of future health service provision.
Chapter 2   Literature review

2.1   Overview
This chapter provides a review of the literature relating to the core issues dealt with in this thesis. As the thesis is concerned with the role of carer stress in the transition to long-term care (LTC), the chapter begins by reviewing the literature on the risk factors for LTC admission. Conventionally, studies in this area concentrate on the individual risk factors for the care recipient and so the findings from these studies have been presented. Over time researchers have recognised the pivotal role carers play in the sustainability of homecare and so research on carers and caregiving has expanded in the last three decades. This research is discussed in detail, including a profile of carers as found in international research, their role in caregiving and the impact caregiving can have on carers. This includes the psychological health effects of caregiving and a discussion of the definition of carer stress adopted for the thesis. Following this, the literature on carer stress as a risk factor for institutional care use (that is to both long-term and acute care), is also reviewed. The theoretical models that underpin this literature are discussed along with the theoretical models adopted in this thesis. As Studies 2 and 3 (Chapters 6-8) are drawn from data collected in Ireland, the chapter concludes by setting out the context of caregiving in Ireland.

2.2   Introduction
As referred to in Chapter 1, it is widely recognised that population ageing is a phenomenon that is taking placing internationally. It is anticipated that public and private healthcare expenditures will have to significantly increase to meet the needs of this ageing population. Balia and Brau believe the required increase in expenditure will be of such an extent that it will be a “cause for concern for the sustainability of national welfare and healthcare systems” (9 p.1185). A substantial component of this expanded healthcare expenditure is expected to come from the increased demand for LTC (9). For example, a recent European Commission report
estimated that, across the EU, public expenditure on LTC will increase by 71% by 2060 (100).

The concern for the growth in demand for LTC has resulted in substantial interest in understanding the risk factors associated with admission to LTC. These risk factors have been studied extensively (13-19, 22, 23, 25, 28, 57, 59, 76, 84, 101-103). For many researchers, understanding the risk factors associated with LTC admissions may enable the development of prognostic tools as well as the design and targeting of services so as to delay such admissions (13-15).

2.3 Risk factors for LTC admissions in the general population
In examining the risk factors for LTC admissions, researchers have conventionally concentrated on the individual care recipient. There are two main approaches to this research. Firstly, to examine the risk factors for LTC admissions in general older age population groups. Secondly, to examine the risk factors for LTC admissions in people with dementia. In both cases, researchers have analysed the socio-demographic and prior healthcare utilisation patterns as well as the clinical characteristics that are associated with LTC admissions. Each of these aspects shall be considered in turn, firstly looking at the general older age population.

2.3.1 Socio-demographic characteristics associated with LTC admissions among general population
LTC placement is commonly associated with older age groups. It is therefore not surprising that a number of studies have found a positive association between advanced age and LTC admissions (13, 16-18). However, the need for LTC does not stem purely from increased age. A number of authors have found that those who were married were less likely to be admitted to LTC (16, 20, 104). As Wren et al. write “a consistent finding across the UK literature has been the lower risk of admission to care homes of currently married people to non-married people” (20 p.10). Luppa et al. also found a protective effect in being married, though regarded the level of evidence to support this as ‘moderate’ (17).
The protective effect of being married may not stem from marital status *per se*, but other characteristics that are associated with those who are married. For example, Jette found the co-residency between the carer and recipient reduced the risk of LTC admissions (18). Similarly, a number of studies have found that living alone is a substantial risk factor (13, 16, 19). For Greiner et al., living alone was found to be the strongest risk factor, while for Gaugler et al. those who lived alone had twice the risk of LTC admission (16, 19).

A number of studies have examined whether the relationship between the carer and the care recipient affects an individual’s risk of LTC admission. That is, if the risk varies depending on whether the carer is a spouse, an adult child of the recipient or another relative. These studies have produced contradictory results. In some cases, the relationship between the carer and recipient was not associated with LTC admission (18). In other cases, a significant though moderate association was found (14). There also appears to be inconsistency in the effect of the recipient’s sex on LTC admission. Some authors regard this as a ‘consistent factor’ (16), with women less likely to experience an admission. Other studies have found no association (18). Consequently, Luppa et al. believe the evidence on the effect of the recipient’s sex is inconclusive (17).

The effect of education and income on the risk of LTC admission has been examined in a number of studies, though this analysis has also produced contradictory findings. Some authors have found a moderate positive association (16), whereas others have found no association (18). Therefore, the evidence to date appears to be ambiguous in relation to sociodemographic predictors of LTC admission (17). The inconsistency in these findings suggests that wider issues may be at play and so further research is needed in this area.

### 2.3.2 Health service utilisation patterns associated with LTC admissions among general population

Despite the provision of homecare taking place within the context of the wider healthcare system, there is a notable absence of studies that concentrate on how
the healthcare system influences the transition to LTC. Where studies have examined health system factors this has largely been as part of a broader set of predictors of LTC admissions. In most of these studies, the health service use outcome examined was short-term nursing home stays prior to the long-term admission. These short-term stays are commonly for periods of respite. For those studies that have analysed this form of health service utilisation, there appears to be a significant positive association between prior nursing home use and LTC admissions (13, 16, 17, 19). Other authors have found prior acute care admissions to be predictive of LTC admission (13, 16, 20). For Gaugler et al., utilisation of acute care is a ‘consistent predictor’ of LTC admission. However, these studies do not explore why acute care appears to act as a predictor on LTC admissions. This suggests further research is needed in this area and is discussed further in section 2.11.2 below.

The effect of community care utilisation on LTC admissions has been examined in a number of studies with varying results. In some of these studies, community care appears to have a protective effect on LTC admission. For example, Greiner et al. examined the use of personal care assistants who help with personal care such as washing and dressing. The analysis indicated that use of personal care assistants was associated with a 46% lower odds of LTC admission (19). In contrast, other studies have found utilisation of community care to be associated with increased odds of LTC admission (13, 16, 18). For example, in a meta-analysis of predictors of LTC admission in the US, Gaugler et al. found formal help through community care service utilisation was associated with 23% increased odds of LTC admission (16).

The analysis of the effect of receipt of informal care on LTC admission has also produced inconsistent results. In some systematic reviews the absence of an informal carer has been found to be a ‘consistent predictor’ of LTC admission (16). In other reviews having an informal carer increased the risk of LTC admission (13). The inconsistency in the results for utilisation of community and informal care may be due to a variety of factors. These include the baseline cognitive or functional care needs of the care recipient, the timing of utilisation of these supports, the
nature of these services, their availability and accessibility. These factors are discussed further in section 2.4.2 below.

2.3.3 Clinical characteristics associated with LTC admissions among general population

The clinical characteristics associated with LTC admissions have been studied extensively (13, 16-19, 23, 102, 105). These characteristics largely stem from what has been termed the ‘geriatric giants’ of ageing (21). These are the major categories of disability associated with old age. They include immobility, falls, incontinence and impaired memory. The influence of each of these aspects has been examined in a number of systematic reviews and meta-analyses (16, 17). However, their importance in the transition to LTC is largely based on the underlying functional and cognitive impairment with which they are associated.

Functional impairment appears to be a critical determinant in LTC admissions. Often functional impairment is measured through a recipients’ capacity to independently undertake Activities of Daily Living (ADLs), such as eating, dressing or bathing (26). According to Fong et al. impairment in ADLs is one of the main measures of older adults’ risk of LTC admission (24). Indeed, a number of studies have found higher levels of ADL dependency to be associated with LTC placement (13, 16, 19, 24). For Gaugler et al., ADL impairment was one of the strongest predictors of LTC admission (16). This association between ADL dependency and LTC admission has been studied largely by counting the reported number of impairments or grouping the degree of impairment (one or more impairments, 3 or more impairments etc. (16)). However, some authors have examined the effect of different types of ADL impairment on LTC admission (19, 24). Fong et al. found that difficulty with bathing was the strongest predictors of subsequent LTC admission (24). Difficulty in dressing was also found to be important. However, difficulty walking, eating, transferring and toileting were not found to be independently significantly associated with LTC admission after controlling for confounders. Fong et al. believe that the importance of bathing in predicting LTC admission may be
attributable to the need for more assistance with bathing than in other ADL activities (24).

Instrumental Activities of Daily Living (IADLs) are activities necessary to live independently in the community (cooking, household chores, managing medications, using the telephone, managing money and shopping) (26). An individual’s degree of dependency in IADLs has also been examined in a number of studies. These studies suggest that increased impairment in IADLs may increase an individual’s risk of LTC admission (13). Greiner et al. found requiring help with money management to be an independent risk factor (19). As the authors note, this may be a marker of worse cognitive impairment (19).

Cognitive impairment has been found to be one of the strongest predictors of nursing home placement in a number of studies (16-18, 22, 23). Some studies have established this association with general measures of cognitive impairment, such as the Mini Mental Examination (MMSE), while others have found diagnosis of Alzheimer’s Disease or dementia to be the underlying risk factor (16, 17, 19). Luppa et al. state that dementia has such a strong effect on nursing home placement that researchers must control for dementia when analysing factors associated with LTC admission amongst dementia and non-dementia specific populations. Otherwise cognitive impairment will overshadow the importance of functional impairment for those without dementia (17).

The strength of the effect of dementia on LTC placement is demonstrated in the differences between the rate of LTC admission for those with dementia compared to general elderly population-based samples. Luppa et al. found that for those with dementia, the rate of LTC admission increased from 20% in the first year after diagnosis, to 50% after 5 years; whereas for the general elderly population this was rate was only 6-7% after 3 years (17, 106).
2.4 Risk factors for LTC admissions for people with dementia

As dementia is so critical to LTC admissions it is appropriate to examine the risk factors associated with LTC admissions specifically for this population. The approach to this review is the same as for the risk factors for the general population. That is to examine the socio-demographic, health service utilisation and clinical patterns of people with dementia that appear to be predictive of LTC admissions.

2.4.1 Socio-demographic characteristics associated with LTC admissions among people with dementia

The effect of the age of the person living with dementia and the age of the carer on LTC admissions appears to vary between studies. Some studies have found increased age of the person living with dementia to be predictive of LTC admission (22, 59), while in others increased age was not predictive of LTC admission (57, 103). Similarly, in some studies, the age of the carer was a significant predictor of LTC admission (57), whereas in other studies it was not found to be significant (84). As part of a recent systematic review of predictors of LTC admission in people with dementia, Cepoiu-Martin et al. did a sub-group analysis of the effect of age for different study follow-up periods. This analysis suggested that in studies with a longer period of follow-up (more than 48 months), increased age was no longer associated with LTC admission. The authors believe this may be because of the effect of further deterioration in the severity of dementia (84). This suggests that cognitive function may be more important than age in triggering LTC admissions. This may explain the inconsistency in the effect of age on LTC admission found between studies.

It appears that for people with dementia being married acts as a protective factor on the risk of LTC admission (22, 57, 84). In line with this, co-residency between the carer and care recipient also appears to lower the risk of LTC admission when compared with those who live alone (22, 62, 84, 107). Study findings on the effect of the relationship between the recipient and the carer (if the carer is a spouse, an adult child or another relative) appear inconsistent. In some studies, an adult child
as a carer was associated with a shorter time to LTC admission (22). In other studies, the relationship between the care recipient and the carer was not a significant predictor of LTC admissions (57, 84).

In their meta-analysis, Cepoiu-Martin et al. found the relationship between the care recipient and the carer was not a significant predictor of LTC admission. However, in the subgroup analysis by type of relationship, it would appear that LTC admission was more likely if the carer was a spouse as opposed to an adult child (84). This inconsistency between study findings may be because these studies have not accounted for other commitments, such as employment or young dependents, which adult children may have. These other commitments would limit the time available to support the recipient.

Finally, the effect of the duration of caregiving, hours of caregiving provided and income on LTC admission varies between studies. Consequently, the systematic reviews that have accounted for these factors conclude that the evidence of the effect of each of these factors on LTC admission is inconclusive (22, 57).

2.4.2 Health service utilisation patterns associated with LTC admissions among people with dementia
There appears to be variation in the findings of the effect of utilisation of community care services (such as respite, day care and home-help for support with household chores) on LTC admission for people with dementia. The recent systematic review of 59 studies by Cepoiu-Martin et al. found that in some studies these services were associated with an increased risk, while in others they acted as a protective factor (84).

Such inconsistency in the effect of community care services on nursing home placement was also found for older adults in the general population (see section 2.3.2). The inconsistency in findings between studies may be due to a variety of factors. In some studies, the recipients may have had higher cognitive and/or functional care needs at the time that baseline data were collected. This would
mean these recipients will be further along the trajectory towards LTC than perhaps those who participated in other studies. Also the timing of utilisation of these community care supports may be critical. Utilisation of these services at a later stage in the trajectory to LTC may mean the services are initiated when the care recipient’s needs have exceeded that which community care services can support (57, 84, 101). As Cepoiu-Martin et al. write, “at some point it becomes increasingly difficult to meet a patient’s needs with community care services” (84 p.2). When this happens, community care services can then appear to expedite the transition to LTC as they act as point of information on LTC options for families (57).

Finally, inconsistency in study findings may be due to health system factors. The nature, availability and access to community care services may be critical. A recent study mapped community care services for people with dementia across the EU. This study found that availability and access to community care varies between different countries (108). In tandem with this, Cepoiu-Martin et al. acknowledge that “in most countries, resources available for community care are limited” (84 p.19). However, how the availability and accessibility of community care services impact on LTC admissions appears to be absent in these studies. The inconsistency and limitations in the findings suggests that further research is needed on the effect of community care services on LTC admission for people with dementia.

2.4.3 Clinical characteristics associated with LTC admissions among people with dementia

The progressive nature of dementia affects an individual’s cognitive and physical functioning. In this regard, the measures of cognitive and functional impairment associated with LTC admission in the general population are also applicable to those with dementia. For example, a number of studies have found that increased ADL dependency is predictive of LTC admission in people with dementia (22, 57, 62, 84, 109). The increase in cognitive impairment of people with dementia may drive the increase in functional impairment. For example, Gaugler et al. found a positive association between severity of cognitive impairment and functional impairment (57).
Cepiou-Martin examined whether there are differences in risk of LTC admission for different types of dementia. This analysis suggested that the type of dementia was not predictive; rather the severity of the dementia appeared to be more critical (84). A number of studies have also found the risk of LTC admission increases with the severity of dementia (22, 57, 62, 107, 109).

One particular characteristic of dementia that does not apply to the general population is the behavioural and psychological symptoms of dementia (BPSD). These symptoms include agitation, depression, apathy, repetitive questioning, psychosis, aggression, difficulties with sleep, wandering and socially inappropriate behaviours (110). They bring a particularly complex and intense set of challenges, explored in greater detail in section 2.5.2.2 below. However, in terms of the individual risk factors for LTC admission, it should be noted that a number of studies have found that when an individual presents with BPSD, this increases their risk of LTC admission (22, 57, 62, 63, 84). Finally, the other clinical characteristics associated with LTC admission for people with dementia found in the literature include incontinence, falls, limited mobility, malnutrition and impairment in IADLs, such as cooking, driving and shopping (22, 84, 107).

Overall, it would appear that there has been extensive research examining the factors which affect an individual’s risk of LTC admission. These factors appear to stem largely from the socio-demographic and clinical characteristics of the individual, as well as their healthcare utilisation history. However, there are contradictory and inconclusive findings in this research. This suggests that further research is needed for a more in-depth understanding of the factors that influence LTC admission. For example, in Fong et al.’s recent analysis, the amount of variance explained in the prediction of LTC admission was 50%. According to Fong et al., this amount of variance is “quite comparable to, and in fact slightly surpass, those of prior studies which have also examined nursing home placement risk” (24 p.575). Other studies have explained 40-45% of variance in LTC admission (16, 25). In their meta-analysis of 12 data sources, Gaugler et al. acknowledged that many studies
still include a considerable amount of unexplained variance in the prediction of nursing home entry (16). This has led researchers to look beyond solely the needs of the care recipient and take a more holistic view of the requirements for sustainable homecare. This “re-think in targeting to older people” (111 p.45) has resulted in increased recognition of the role of carers in the provision of homecare (57, 86).

2.5 Carers and caregiving
Carers are often described as the backbone or cornerstone of the provision of care for older people (1, 11, 30, 112, 113). They are critical to the success of community care policies and for the “sustainability of our chronic health care system” (114 p.2). Consequently, the OECD have emphasised that to meet the anticipated challenges in the provision of LTC “it is necessary to focus on both formal and family care arrangements” (1 p.1). Therefore, the last three decades have seen a considerable expansion in research on carers and caregiving. This section provides an overview of the international literature on carers, this includes discussion of the definition of carers and a profile of carers as found in international research. The role of carers in the provision of homecare is discussed along with the supports available to carers and the positive and detrimental aspects of the caregiving role.

2.5.1 Definition of carers
Firstly, it would be appropriate to discuss the variation in terms applied in the literature and offer an operational definition for ‘carers’. Pearlin et al. argue that ‘caregiving’ refers to the activities undertaken in the provision of support to older people whose physical and/or mental health may have compromised their capacity to live independently in the community (27). Those older people who need this support are referred to as ‘care recipients’ in this thesis. The individuals who carry out these tasks are commonly referred to as informal caregivers (largely in North America and Australasia), carers or family carers (largely in Europe). Therefore, in this thesis a distinction is made between caregiving (that is the provision of care to an older care recipient), and those who undertake the role.
There are a variety of definitions for carers in the literature. In some definitions the emphasis is placed on the informal or voluntary nature of the role (30, 114). This is to distinguish the role from healthcare professionals who are also involved in the provision of care. Other definitions look at the types of activities involved. For example, for Roth et al. “the defining characteristics of carers is the provision of unpaid on-going help in activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability” (115 p.2). For others, the carer is the person who takes primary responsibility for the provision of care on an on-going basis (28, 29). For example, in Ireland, the National Carers’ Strategy defines a carer as “someone who is providing an on-going significant level of care to a person who is in need of that care in the home due to illness, disability or frailty” (11 p.8). This definition of a carer will be adopted for this thesis.

It is also important to note that some authors distinguish between ‘primary carers’ as the individuals who provide the greatest amount of support and ‘secondary carers’ as other family members and friends who supplement the role of the carer (28, 30). As a number of researchers have found that the main responsibility of care for an older person is often left to one person, this thesis is concerned with primary carers (29, 113, 114, 116, 117).

2.5.2 Profile of carers

A profile of carers as found in international literature is provided. However, it should be noted that this profile will vary depending on the study population; especially if the study concerns spousal carers, adult child carers or dementia carers. Therefore, these have been discussed separately below. However, while the profile of carers may vary, there are commonalities between carers (49).

It is estimated that across the OECD, more than one in ten adults aged over 50 years provide unpaid help with ADLs to people with functional impairments. One in three adults aged over 50 provide unpaid help with Instrumental Activities of Daily Living (IADLs), such as shopping and housework (1). Carers are largely close relatives, such as a spouse or adult child of the care recipient. An OECD analysis
suggests that 32% of carers provide care to a spouse, 36% to a parent, 18% to another relative (sibling or aunt/uncle) and 18% provide care to a neighbour or friend, with some carers providing care to more than one individual (1).

A number of national and international studies have found that the majority of carers are female, with proportions varying between studies from 66%-76% (1, 48, 113). An analysis of European carers found female carers are largely wives, daughters or daughters-in-law. This suggests an individual’s sex and relationship to the care recipient may influence whether they become a carer. Indeed Dwyer et al. propose a hierarchy of caregiving in terms of those who are most likely to enter the caregiving role. According this this hierarchy, spouses are regarded as the most likely individuals to become carers. Adult children, particularly daughters, are more likely to enter the role in the absence of a spouse, if the spouse is deceased or otherwise unable to provide the required level of care (32, 33, 118).

The age ranges of carers vary depending on the study population. It is estimated that approximately 45% of all carers are aged over 65 and 47% of spousal carers are aged 75 years and older (113). There is a wide variation in the hours of caregiving that carers provide. The OECD estimate that in northern countries just over 50% of carers provide less than ten hours of care per week, 20% of carers provide more than 20 hours of care per week; whereas in southern Europe, more than 30% of carer are providing more than 20 hours of care a week (1). There are variations in these estimates between different studies. A national sample of carers in the United States estimated that most carers provided an average of 29 hours of care a week (113). In contrast, a study of carers across Europe found carers spent an average of 45.6 hours per week providing care (48).

The hours of caregiving can also vary significantly depending on the study population - whether the carer is a spouse or co-resident carer, adult child carer and providing care to a recipient with higher care needs, particularly for someone with dementia. The variation in hours of care provided is just one example in how the profile of carers can vary depending on the study context. Indeed, the literature
suggests that characteristics of spousal carers are quite distinct from adult child carers. Dementia caregiving can be particularly challenging. Therefore, profiles for these carers are discussed separately below.

**2.5.2.1 Spousal carers in comparison to adult child carers**

A number of studies have found that spousal carers are more likely to be older than adult child carers (50, 118, 119). As spousal carers tend to be older, they are more likely to have their own set of health conditions that can make caregiving more onerous (1, 118-120). That said, as adult children tend to take up the role after the spousal carer is deceased or otherwise unable to provide care, the care recipients of adult children tend to be older than those of spouses. Pinquart and Sorenson found care recipients of spouses are on average five years younger than those of adult children. Consequently, the authors suggest that spouses may experience less dementia-related symptoms in the provision of care than adult children, given the progressive nature of dementia (118).

It appears that spousal carers are also more likely to have lower socio-economic status than adult children (113, 118, 120). They are less likely to be employed, have lower levels of education and lower levels of income (1, 113, 118). Spousal carers have also been found to have poorer psychological health, particularly higher levels of depression compared to adult child carers (37, 50, 118, 120). There are a number of reasons for this. The degree of closeness between spouses and the impending loss of the spouse may be particularly stressful (118). Spouses are also more likely to live with the care recipient, consequently they are more likely to provide more intense levels of care (measured in caregiving hours) than adult children. As spousal carers are more likely than adult child carers to reside with the care recipient they often provide support during the night. This can be particularly stressful. Finally, as spousal carers are more likely to have their own health difficulties this can exacerbate the psychological health consequences of caregiving (50, 118, 119, 121).

The discussion thus far suggests a very negative comparison when spousal caregiving is compared to adult child caregiving. However, adult child caregiving
brings its own set of challenges. The provision of homecare by adult child carers involves an alteration in previous family roles. The adjustment to this can be difficult as parents struggle to maintain independent living, becoming aware of their dependency and need for those who were previously dependents of them to now take on caregiving responsibilities. In tandem with this, adult child carers are more likely to be female (118). Increasing female labour force participation along with the need for double-income households over the last thirty years limits the time available to meet the demands of caregiving (121). These adult child carers often struggle to balance their caregiving responsibilities with responsibilities to younger dependents, work commitments and social commitments. Consequently, adult child carers are often referred to as ‘sandwich carers’, to reflect these commitments to both older and younger dependents. It is anticipated that the combination of delayed childbearing with increasing life expectancy may increase the need for sandwich carers in the future. Therefore, awareness of the particular struggles of adult child carers is critical for health service researchers and health policy makers (121).

2.5.2.2 Dementia carers

The provision of care for a person living with dementia brings a particular set of challenges that separates dementia caregiving from other chronic conditions associated with old age. The World Health Organisation succinctly summarised the symptoms of dementia and the carer’s role in responding to these symptoms over the progression of the disease. These are outlined in Table 2.1 below. As presented in the table, dementia compromises an individual’s memory, is commonly associated with disorientation and impairs an individual’s ability to perform everyday activities. This leads to considerable dependence on others (30, 122). The cognitive impairment as a result of dementia and the associated disorientation this brings undermines an individual’s awareness of danger. Consequently, considerable supervision is required. This need for supervision has been described as one of the main care needs in dementia care (121).
Table 2.1 Dementia carers role in responding to symptoms of dementia

<table>
<thead>
<tr>
<th>Stages of dementia</th>
<th>Symptoms of dementia</th>
<th>Carer’s role</th>
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<tbody>
<tr>
<td>Early stage</td>
<td>Loss of short term memory; may experience difficulty with communication such as word finding; disorientated in familiar places; loss of track of time including time of day, month or year; difficulty managing money; difficulty with more strenuous household tasks; changes in mood or behaviour: loss of interest in previous hobbies or activities; depression or anxiety; may act out of character in an aggressive or angry way on occasion.</td>
<td>The diagnosis is often as the carer becomes aware of the changes and encourages the recipient to seek assessment. Following the diagnosis the carer then becomes more aware of the need for care. This involves: providing the recipient with reminders about upcoming events or tasks; providing help with IADLs such as managing money, shopping or household cleaning.</td>
</tr>
<tr>
<td>Middle stage</td>
<td>Considerable loss of short term memory; may be disorientated at home as well as outside the home; Difficulty comprehending time, day, place and events; Increasing difficulty with communication (both speech and comprehension); requiring assistance with ADLs such as toileting, bathing and dressing; Unable to independently undertake IADLs such as cooking, shopping or household chores; requires substantial support to live alone safely; changes in behaviour may include wandering, repeated questioning, disturbed sleep, hallucinations; may present with inappropriate behaviours such as aggression or disinhibition.</td>
<td>The carer provides support with IADLs and ADLs as well as supervision and managing behaviours that challenge.</td>
</tr>
<tr>
<td>Late stage</td>
<td>Generally unaware of time and place; difficulty comprehending the context around them; disorientated at home; does not recognize relatives or friends; may have difficulty swallowing; considerable difficulty with ADLs; may have incontinence; may no longer be mobile; escalation of behaviours that challenge to include non-verbal agitation (kicking, hitting, screaming or moaning) and/or aggressive behaviours directed at the carer.</td>
<td>The recipient’s care needs means the carer has to provide considerable amounts of care. This includes: 24-hour support and supervision, full assistance with all ADLs and managing behaviours that challenge.</td>
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*Table from World Health Organisation (2012 p.72) (30)*
Scommegna argues that providing care to a person living with dementia is the “most time-intensive type of elder care” (121 p.6). For example, Kasper et al. compared the hours of care provided to those aged 65 and over with and without dementia. They found that those with dementia received twice the number of hours than those without dementia (122). The demanding nature of dementia care can mean the caregiving role “encompasses all the caregiver’s life” (119 p.236).

Another particular challenge in dementia care provision is managing BPSD. These symptoms affect up to 90% of people with dementia (123). They are regarded as the “most complex, stressful and costly aspects of care” (110 p.1). A number of studies have found BPSD to have a strong impact on the level of stress carers experience (124).

The way in which these symptoms affect carers’ stress alter over the progression of the disease. During the early stages, at the onset of symptoms, carers can find it hard to understand why the recipient is acting in a manner contrary to their personality prior to the disease (123). As the disease progresses, dementia undermines the individual’s communication and comprehension. This can result in repetitive questioning. This can be disheartening for carers to experience. The person living with dementia may also start to wander or not sleep at night; consequently the levels of care required can become quite intense. Finally, it can be extremely strenuous for the carer to manage the psychosis and/or aggression associated with dementia.

The increase in cognitive impairment of people with dementia may also drive an increase in functional impairment. As described in section 2.4.3 above, Gaugler et al. found a positive association between the severity of cognitive impairment and functional impairment (57). Consequently carers of people with dementia also have to respond to the functional care needs of the recipient. These functional needs include ADLs and IADLs. As the cognitive capacity of an individual with dementia becomes increasingly compromised, this can make help with ADLs and IADLs particularly challenging.
A number of studies have found that carers of people with dementia are more likely to experience poor physical health and psychological morbidity (37, 116, 124). Carers of people with dementia have significantly higher rates of depression when compared with socio-demographically comparable groups of non-carers and to carers of people without dementia (37). A recent meta-review found “clear support” that providing care to a person living with dementia is a risk factor for poor physical health and stress (124 p.5). The impact of care provision on the carer is discussed further in section 2.7 below.

### 2.5.3 Role of carers

The role of carers often involves the provision of assistance with IADLs and/or ADLs, depending on care recipients’ care needs. This can include personal care, such as toileting, bathing or dressing. Such assistance is often accompanied with support in interactions with the health system. This includes organising and accompanying the older person to doctor or hospital visits. It can also include nursing care, such as injections, medication management, wound care and incontinence management. Incontinence management can be particularly challenging. It can be physically demanding as the carer has to transfer the older person to change an incontinence pad, where these are used. If the recipient is using a catheter, the carer has to be alert for possible infections. Poorly managed incontinence can result in damage to the older person’s skin. It is also associated with odour and leakages (36). Therefore, incontinence management can be unpleasant for the carer and care recipient. Carers can find it exhausting and it is often regarded as a driver of the stress carers’ experience (30, 37).

As the care recipient’s functional and/or cognitive needs escalate over time, especially so as the needs for personal care and/or nursing care increase, the carer is required to respond to a care recipient’s needs both day and night (30). Carers providing this level of care often experience poor sleep (119). The supervisory nature of the role means carers are often in “a constant state of forever listening, watching and being aware of changes that may indicate something was wrong”
Both this intensity and unpredictability of the role make this level of care incompatible with continuing with employment (1). The changing nature of the role means it is “impossible to plan anything on a daily basis” (117 p.793). The escalation in care needs also limits a carer’s opportunity for social activities. Carers can feel the role is both isolating and “engrossing and consuming” (117 p.794). As entry into the role is often unplanned, carers can feel unprepared for the role and lacking in the skills required to provide the level of care needed (38). Thus carers need a considerable degree of support in the provision of homecare.

2.6 Supports to carers

Table 2.2 presents the range of supports available for carers identified in the international literature. Support is applied as an umbrella term, as this can be in the form of a service, financial support, training for carers or assistive technology. As presented in Table 2.2, these supports can either be directed at the carer or at the care recipient. Those that are directed at the care recipient indirectly support the carer as they assist the carer in the provision of homecare (125). A common support service is a homecare package. This involves a personal care assistant providing support in ADLs. Carers also require support in terms of information on what services are available and how to access these services. Assistive technology supports include hoists for transferring, commodes or grab rails.
Table 2.2 Supports for carers

<table>
<thead>
<tr>
<th>Support directed at carer</th>
<th>Support directed at care recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on services available, entitlement/eligibility criteria and how to access these services.</td>
<td>Respite (emergency, in-home or residential).</td>
</tr>
<tr>
<td>Training on care recipients condition and how to respond to care needs (incontinence management, behaviours that challenge, manual handling etc.).</td>
<td>Homecare packages for support in ADLs/home help for domestic tasks.</td>
</tr>
<tr>
<td>Financial support – allowances or benefits and housing adaptation.</td>
<td>Community nursing services.</td>
</tr>
<tr>
<td>Carer support groups.</td>
<td>Allied Health Professional services at home (Occupational Therapy/Speech and Language Therapy/Physiotherapy).</td>
</tr>
<tr>
<td>Individual counselling.</td>
<td>Mental health services (psychiatry).</td>
</tr>
<tr>
<td></td>
<td>Day care services.</td>
</tr>
<tr>
<td></td>
<td>Assistive technology/equipment - hoists, commodes etc.</td>
</tr>
<tr>
<td></td>
<td>Meals on Wheels.</td>
</tr>
<tr>
<td></td>
<td>Transport services.</td>
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</tbody>
</table>

The supports that are regarded as the most critical vary between studies. For example, a survey of carers across Europe found that respite was the most requested form of help (48). However, a more recent study with carers in five European countries found homecare packages and home help had the greatest impact for the carer to continue providing care to the care recipient at home (114).

In a study of sons caring for a parent with dementia, McDonnell and Ryan also found that home help was a ‘lifeline’, “without this it would be impossible to care for their parent at home” (117 p.794).

It would appear that there is a difference between the range of supports that are available to carers in theory and the extent to which these actually offer support in practice. For example, the European study of carers found that less than a third of carers had used any support service in the previous six months (48). This varied
between countries. Systematic service provision was only found in Sweden, Germany and the UK.

A number of studies have also found that carers do not always use the services that are, in theory, available to them. There are a range of reasons for this. In some cases the carer feels it is better to hold off on using the service until ‘it is really necessary’ or that it is their duty to care and so are apprehensive to accept external support (114). Where the service is directed towards the recipient, there may be resistance from the recipient. This is especially the case with regard to respite services and home help or homecare package schemes (48). However, the most prominent issues do not appear to stem from the apprehension of the carer or recipient to use the services, but the difficulties carers face in trying to identify and receive supportive services. These difficulties centre on the accessibility, availability and consistency of the services.

For example, a number of studies have found that carers struggle to find information on what services are available, the eligibility criteria and how to access the services (38, 48, 108, 114, 117). This struggle stems partly from the difficulty carers face in navigating the healthcare system. The complex procedures in accessing services and the lack of consistent information from health and social care professionals adds to the struggle (48, 114, 117). Chambers and Ryan found that the “lack of information was a major source of concern for the carers in the study” (38 p.99). The constant search for information resulted in carers feeling anxious and frustrated (38).

There also may be limited availability in services with inadequate coverage, especially in rural areas (48). Support services from community nursing have been found to be inconsistent and irregular (38). Other services such as hours of care and respite services have also been found be limited (38). This limited availability “added to the stress experienced by participants” (38 p.795). It appears that in some EU countries, the limited availability of respite can result in acute care acting as a substitute for respite (48). It should be noted though that there is considerable
variation in the availability of services between healthcare systems (48, 108). Finally, where carers have been able to access those services that are available, there appears to be issues with the quality and inflexibility of these services (48, 49).

Overall, it would appear that there is limited degree of supports for carers. Colombo et al. argue that despite the critical role carers play in the provision of community care, supports to carers are “often tokenistic, provided as a recognition that they perform a socially useful and difficult task” (1 p.4). The high demands of caregiving, coupled with the lack of support carers receive, often results in the caregiving role having a substantial impact on the carer. This is explored next.

2.7 Impact of the caregiving role on carers

The caregiving role can be a significant change in a carer’s way of life (38). This is especially so as the care recipient’s condition deteriorates, requiring carers to provide very intense levels of care. Traditionally the caregiving literature has concentrated on the negative impact caregiving can have on a carer, particularly in terms of their psychological morbidity. As this thesis is concerned with the influence of carer stress on transition to LTC, the detrimental impact of caregiving on a carer’s experience of stress is explored in detail below. However, researchers have more recently also recognised the positive impacts of caregiving, which will be discussed first.

2.7.1 Positive impacts of caregiving role for carers

Researchers have identified a range of positive aspects of the caregiving experience. These centre on the carer’s reaction to the role, positive appraisal of the role itself and how caregiving has impacted the relationship between the carer and the care recipient.

A study of carers across the EU found that 80% of carers felt caregiving was a worthwhile experience (48). A number of studies suggest carers find the provision
of care gives the carer a sense of meaning in their lives (30, 40, 126). Carers have also reported that the role has increased their self-esteem (40).

Providing care has also been appraised as positive. Carers have reported finding substantial satisfaction in being in a position to be able to provide care to keep the care recipient at home (39-41). A range of studies have also found that the provision of care has improved the relationship between the carer and the care recipient. Carers often report that they feel closer to the recipient as a consequence of providing care (39, 41, 49).

The extent that carers perceive the positive aspects of the role can vary depending on the characteristics of the carer, the physical and psychological morbidity of the care recipient and the amount of support available to the carer (127). It appears that those providing care to recipients with substantial needs may still perceive positive aspects, but these may be outweighed by the negative aspects. A national study of carers in the United States, for example, found that those who helped with self-care or mobility were less likely to report positive aspects and more likely to report considerable negative aspects (39).

More recently, Alvira et al. analysed the positive and negative aspects of caregiving for carers of people with dementia across eight EU countries. The study examined a range of potentially positive and negative reactions to caregiving, this included self-esteem, financial problems, health problems in the carer, carer burden and psychological distress. The findings suggest that the most prominent reactions were carer burden and psychological distress. Consequently the authors believe that “most informal carers’ reaction to care provision are negative” (116 p.1419).

2.7.2 Negative impacts of caregiving role for carers

As the OECD have acknowledged, “there is a growing concern about increased psychological distress, strain and overall health deterioration endured by carers” (1p.97). The literature on the negative impact that caregiving can have on a carer is substantial. Rather than presenting an exhaustive discussion of this literature, this
section focuses on key areas. These are the impact on carer’s physical health, financial impact, social impact and impact on carer’s psychological health.

2.7.2.1 **Impact on carer’s physical health**

Scommegna argues that there is substantial evidence that prolonged caregiving is detrimental to a carer’s physical health (121). There are a number of ways the carer’s health can be affected by the caregiving role. The role can be physically demanding, especially where it involves lifting and moving the care recipient or frequent interruptions in sleep. The intense nature of the role may mean the carer has little opportunity for exercise and may also have a poor diet which could exacerbate health conditions (128). There is a substantial literature to show the association between the chronic stress of caregiving and poor physical health in the carer (42, 128, 129).

A number of systematic reviews and meta-analyses have found carers are more likely to experience poor health when compared to non-carers (42, 43, 115). For example, Capistrant et al. found providing care for 14 hours or more a week significantly increased a carer’s risk of developing cardiovascular disease (CVD) and hypertension. This analysis adjusted for socio-demographic factors and a range of health risk factors. For those who provided the same level of care for at least two years the risk doubled (46, 47). Other studies have also found caregiving is associated with weakened immunity, slower wound healing, pain and weakness in the upper and lower body, exhaustion and mortality (39, 44, 45, 130). Damjanovic et al. suggest that chronic stress in carers providing care to a person with Alzheimer’s disease may shorten the carer’s life by four to eight years (129).

The impact on a carer’s physical health has been found to vary depending on the carer’s age, their socio-economic status and the level of support the carer receives (128). It has also been found to vary depending on the characteristics of the care recipient, such that higher intensity caregiving appears to be a stronger risk factor for poorer health as well as dementia caregiving (42, 128). In a meta-analysis of the
correlates of physical health of carers, Pinquart and Sorenson found that BPSD had the strongest association with poor physical health in the carer (128).

2.7.2.2 Financial impact
A study of carers from across the EU found that the caregiving role had resulted in a decline in carers’ income. This decline was such that carers had less than average disposable income (48). OECD analysis also suggests that carers are at higher risk of poverty (1). In different countries carers may receive allowances or benefits to support them in the caregiving role. However, the study of carers across the EU found only 4% of carers receive such allowances, though there was substantial variation between countries (60% in Germany and 2% in Greece) and in the value of the allowances (48).

Carers can experience a drop in income by having to meet out-of-pocket expenses for health services, medications, medical equipment and assistive technologies for the care recipient. Carers income may also decreases from a change in employment status to cater for the time required for caregiving (48). Often the high demands of caregiving can result in the carer having to move to part-time work or cease employment altogether (1). The OECD found carers were less likely to be employed than non-carers even controlling for levels of education, house ownership and marital status (1). This may be due to the nature of the caregiving role. When the role impacts on the carer’s opportunity to work it is usually because care needs have intensified, as the needs intensify they also become unpredictable (as discussed above). This results in increased absences from work and makes it more difficult to continue with work.

2.7.2.3 Social impact
The literature on the social impact of caregiving is more sparse than the other negative aspects of caregiving. Nonetheless this has been outlined briefly below. The provision of care can restrict the carers social life (49). This is most pronounced as the care recipients condition deteriorates and the role intensifies. For example, a study of support needs of carers in Northern Ireland found carers can feel isolated.
The need for constant care meant carers lost out on opportunities for social interaction outside of the caregiving role (38). The caregiving role can also mean carers are unable to continue with hobbies and social activities that they undertook prior to the role of carer (117).

2.7.2.4 Impact on carer’s psychological health

The impact caregiving can have on a carer’s psychological health is perhaps one of the most analysed components in the caregiving literature. According to Pinquart and Sorenson “a substantial literature shows that providing care to an older family member is associated with increased psychological distress” (42 p.250). A number of systematic reviews have found carers are more likely to have psychological morbidity compared to non-carers (37, 42, 43, 131, 132). For example, a systematic review and meta-analysis of psychological health in carers and non-carers found the largest difference between carers and non-carers was in carer’s levels of depression, stress and well-being (42). Even after controlling for prior psychological morbidity, carers are more likely to experience greater levels of psychological morbidity as a result of the caregiving role (1, 50). The OECD estimate that “the prevalence of mental health problems among carers is 20% higher than among non-carers” (1 p.98).

The features of caregiving that increase a carer’s risk of experiencing psychological morbidity have been extensively examined. It would appear that in dementia caregiving, the BPSD have the greatest impact on the level of psychological morbidity carers experience (133, 134). The extent that the care recipient requires assistance in ADLs has also been found to be associated with carer psychological morbidity (133, 134), although this association is more moderate in dementia carers than non-dementia carers (134). Carers are also more likely to experience greater psychological morbidity when a higher amount of care is required (measured in hours of care) (51, 116, 134). However, as with ADLs, this association is more moderate in dementia carers than non-dementia carers (134). The financial difficulties carers experience as well as the isolation and lack of family support have also been found to be significantly correlated with psychological morbidity (51,
Co-residency between the carer and care recipient and chronic health conditions in the carer have also been associated with psychological morbidity (133).

As part of a meta-analysis of the correlates of carer psychological morbidity Pinquart and Sorenson undertook a series of sensitivity analyses of effect estimates (134). It would appear that the strength of the relationships between the correlates of carer psychological morbidity vary depending on the sampling method. In representative probability samples, care recipient impairments in ADLs and cognitive impairment, and the extent of care provided had stronger association with psychological morbidity than with convenience samples (134). These correlates also vary between dementia and non-dementia populations. The association between the BPSD and psychological morbidity overshadow all other correlates in dementia populations. Finally, for spousal carers, impairments in ADLs and the BPSD have stronger relationships with psychological morbidity than for adult child carers (134).

2.8 Definition of carer stress

The literature on the psychological health effects of caregiving is extensive. The most commonly analysed aspects of psychological morbidity associated with caregiving are stress and burden. However, there is a lack of clarity on their distinction and how they interact in the caregiving process. For example, although the concept of carer burden (proposed by Zarit et al. (135)) is one of the most commonly analysed variables in the literature, there is no single definition or uniform conceptualisation of carer burden (135-137). Furthermore, virtually every dimension of the psychological health effects of caregiving (from the BPSD, to anxiety and depression) have been referred to as burden (138). Consequently, the term ‘burden’ has been used in many different ways in the literature.

There is also a tendency of some researchers to use the concepts and associated measures interchangeably (137, 139, 140). For example, studies discuss ‘carer stress’ yet apply measures of burden (60), measures of depression (141), or
measures of strain (54); or assess ‘carer strain’ and apply measures of distress (142). More recently, a team of researchers in the UK developed an instrument to measure Quality of Life in carers of people with Parkinson’s disease. Despite applying rigorous methods to the development of the instrument, the fourth scale of the instrument has been interchangeably labelled as a measure of ‘strain’ and ‘stress’ by the authors of the instrument (140).

A number of researchers have acknowledged this lack of clarity by framing the examination of carer burden within the context of Pearlin et al.’s. Stress Process Model (27, 143, 144). Critical to the understanding of burden is the model’s distinction between objective and subjective primary stressors (52). Objective stressors include care recipient’s functional disability and behaviours that challenge. Subjective stressors are the carer’s appraisal of objective stressors. Thus, within this model, burden is not understood as a separate construct from stress, rather it is a carer’s subjective appraisal of his or her situation (27, 51, 52). This interpretation of carer burden and stress has been adopted for the purposes of this thesis. The Pearlin et al. Stress Process Model is discussed in greater detail in the next section.

2.9  Carer stress as a risk factor for Institutionalisation

The work on the psychological health effects of caregiving has led to the contention that such psychological morbidity of the carer could increase the risk of institutionalisation of the care recipient. That is, as the carer is critical to the continuation of homecare, if the level of stress they experience becomes too great this could jeopardize the continuation of homecare (53-57, 88). The most prominent advocate of this belief is Leonard Pearlin who proposed a conceptual model for the analysis of the process and consequences of carer stress. This is the Stress Process Model (27). This is the most widely used theoretical model in the analysis of carer stress (52).
2.10 The Stress Process Model

Pearlin et al. believe that carer stress ought to be analysed as a process and proposed the Stress Process Model (27). The stress process consists of the interconnection of the following domains: the background and context of stress; primary objective and subjective stressors; secondary stressors, mediators of stress and the outcomes of the process. According to this model, the stress from providing care drives a process that ultimately results in the termination of homecare and LTC placement of the care recipient. Each of these domains are discussed below.

The background and context of stress concerns the socio-demographic characteristics of the carer, the degree of family support and the availability of community-based support services. According to Pearlin et al. model, these factors can help reduce carer’s stress. Stress then acts as a mediator of the effect of these factors on institutionalisation.

Primary stressors concern the care needs of the recipient, their degree of intensity and carers’ reaction to these needs. The stress carers experience stems from these care needs. Consequently they are regarded as being at “the heart of the stress process...driving the process that follows” (27 p.586-587). As discussed in section 2.8 above, Pearlin et al. distinguish between objective and subjective primary stressors. Objective stressors consist of the care needs of the care recipient. These needs include the care recipient’s degree of functional and cognitive impairment. Subjective stressors are the carer’s appraisal of objective stressors. Zarit believes “this distinction between objective and subjective stressors represents one of the most important concepts for understanding caregiver burden” (52 p.905).

Therefore, as referred to in section 2.8 above, within this model burden is not understood as a separate construct from stress, rather it is a carer’s subjective appraisal of the demands of caregiving that are required to meet the care recipient’s needs (27, 51, 52). Pearlin et al. propose two types of subjective stressors. The first is the extent the carer experiences ‘overload’ in caregiving. That is, the carer’s perception of the “relentlessness and uncompromising nature” of caregiving (27 p.587). The other subjective stressor is relational deprivation. This is
where the increasing demands in caregiving causes the carer to feel disconnected and isolated.

As the care recipient’s condition deteriorates, this leads to secondary stressors. Secondary stressors include strains as a result of the caregiving role. For example, it can be very difficult for a carer to provide care when a recipient resists a carer’s support. A carer can also experience strains in activities outside of caregiving, often presenting as family conflict, difficulties continuing employment, financial strains and restriction in the carer’s social life. Each of these strains are classified as ‘role strains’ in the model. Further secondary stressors are ‘intrapsychic strains’ described as “role captivity” where carers can feel a “loss of self” (27 p.589). That is a loss of their own identity as caregiving takes over the carer’s time. Overall, the model suggests that stress stems from the way the care recipient’s needs increase and caregiving takes over the carer’s way of life.

According to Pearlin et al. coping and social support may act as potential mediators of the relationship between stressors and LTC admissions. Coping is regarded as the behaviours and practices carers’ employ to manage the situation, while social support is support from friends and family that may prevent secondary stressors (27).

There are a number of outcomes to the Stress Process Model. These operate at different stages of the caregiving process. They include depression and anxiety and deterioration in the carer’s physical health as a result of the stress of caregiving. The central outcome of the model is the termination of the caregiving role. Pearlin et al. acknowledge that while the model proposes the components of carers’ stress, the pathways that join these components “are still unclear” (27 p.591). That is, they are not fully specified in the model. This is discussed further in section 2.14 below.

Gerontological researchers have applied the Pearlin et al. model extensively in the analysis of carer stress and its relationship with institutional care utilisation (both to acute and LTC) by care recipients (22, 51, 53, 57-60, 62, 132, 145). From these
studies, it would appear that the stress carers experience as a consequence of the provision of homecare is a considerable risk factor in a care recipient’s institutional care use. The following section reviews the literature on the relationship between carer stress and institutional care use.

2.11 Carer stress as a risk factor for institutional care use: Findings from the literature

This section discusses findings from the literature that examines carer stress as a risk factor for institutional care utilisation. Authors have examined the relationship between carer stress and both LTC and acute care utilisation. Thus each of these are presented separately.

2.11.1 Carer stress and LTC utilisation

The relationship between carer stress and LTC utilisation has been analysed in a great number of longitudinal studies (14, 28, 53-55, 58-64, 66-75, 77-83, 146). The period of follow-up in these studies varies considerably, from 6 months to 18 years, averaging 3.9 years (64, 79, 83). In many of these studies, higher levels of carer stress have been found to be associated with subsequent utilisation of LTC by the care recipient (14, 28, 53-55, 58-64, 67-75, 146, 147). Retrospective studies have also found carer stress to be a significant factor in LTC admission of care recipients (148-150). Consequently, it is believed that there is a “strong link between caregiver stress and nursing home entry” (54 p.155). As so many studies have found a significant association it is believed that this association “has been well demonstrated” in the literature (87 p.383). Indeed, for some authors, this association is so strong, stress has been regarded as the principal determinant of LTC admission (55). More recently, a study of factors associated with LTC use across the EU concluded that “controlling for variation across countries, caregiver burden appeared the most consistent factor associated with institutionalisation”. (62 p.9)

However, the findings of these studies are not entirely consistent. Where carer stress has been found to have a significant effect on LTC utilisation, estimates of the
size of the effect vary between studies (60, 64, 68, 151). In other studies carer stress was not found to be a significant risk factor for LTC utilisation (76-83). The association between carer stress and institutional care use has been examined as part of a number of systematic reviews (22, 57, 84). In each of these reviews carer stress was regarded as a significant factor in LTC utilisation, with the most recent review concluding that “caregiver burden had a consistent effect on the risk of LTC placement” (84 p.18). However, this statement was based on a narrative review, not a meta-analysis. The review by Gaugler et al. also found carers who indicated greater stress were more likely to be those for whom the care recipient was admitted to a nursing home. However, the analysis was confined to whether carer stress was a significant predictor and the direction of the effect (positive or negative) (57). As with all of the previous systematic reviews in the area, a meta-analysis was not conducted. Therefore the reviews to date offer no clarity on the size of the pooled effect of carer stress on institutional care utilisation. This suggests a need for a systematic review and meta-analysis.

A number of interventions studies have been conducted that aimed to reduce the level of stress carers experience as a consequence of the provision of homecare. From the systematic reviews of these studies it would appear that these interventions have had varying degrees of success (124, 152-154). The systematic reviews also suggest there that there is a lack of good quality evidence across studies and limited evidence of the explanatory mechanisms at work in the intervention (152, 153). It would appear that psycho-educational interventions have a significant effect on carer burden. However, the size of this effect was smaller in better quality studies (154).

In most cases, the reviews did not look at the effectiveness of the intervention on reducing institutional care use (152, 153). However, in the systematic review and meta-analysis by Pinquart and Sorensen of 127 intervention studies, LTC admission was included as an outcome (154). The authors found that only multicomponent interventions reduced the risk of LTC admission, though the size of this effect was small. These interventions were regarded as multicomponent as they did not just
target the psychological morbidity of the carer, but they included education and support for the carer in the provision of care such as respite (including day care, in-home respite, and respite in a nursing home). Thus it would appear that only interventions that supported the carer in the provision of care had significant, though small, effects in delaying LTC admission (154).

2.11.2 Carer stress and acute care utilisation

The impact of carer stress as a potential risk factor for LTC admissions has conventionally concentrated on the transition from community to LTC. However, as discussed in section 2.3.2 above, a number of authors have found prior acute care admission to be predictive of LTC admissions (13, 16, 20). In addition to these studies, there is a growing body of evidence to suggest that LTC admissions are often arranged when the care recipient is admitted to acute care (85, 86). For example, for the last six years for which data are available (2008-2013), the largest proportion of admissions to long-stay beds in LTC facilities in Ireland were from acute hospitals (52% in 2013) (155-160). From this it would appear that acute care may play an important role in the transition to LTC. Despite this, acute care appears has been largely overlooked in the examination of carer stress and the transition to LTC. Therefore, it is important for this thesis to expand the scope of analysis by also examining the association between carer stress and acute care admissions.

A number of studies have examined the relationship between carer stress and acute care admissions (87-97, 161, 162). These studies followed up participants for an average of 3 months (varying from 1 month to 3 years) (87, 95). In many of these studies, carer stress was found to be a risk factor for subsequent acute care admissions (87-94). For example, a study of factors predictive of hospitalisation in people with Alzheimer’s disease reported that carer stress “appears to be a considerable risk factor” for hospitalisation (89 p.426). A more recent study concluded that “interventions directed toward the reduction of caregiver burden and improving caregiver well-being may not only delay LTC placement and prevent the deterioration of caregiver health but also reduce care recipient adverse health outcomes” including hospitalisation of care recipients (87 p.390). However, in the
studies that found carer stress had a significant effect on acute admissions, the size of the effect appears to vary between studies. In other studies, carer stress was not found to be significantly related to acute care admissions (95-97).

2.11.3 Importance of carer stress as a risk factor is a common theme in literature

Despite the inconsistency between the results of these studies, the cumulative effect of these studies’ findings suggests that carer stress is a considerable factor in both LTC and acute care utilisation. Indeed, the importance of carer stress as a risk factor is a common theme in the literature. To demonstrate how prevalent this theme is in the literature, a selection of quotes that illustrate this sentiment is provided in Text box 2.1 below.

Text Box 2.1: Carer stress as a risk factor for institutionalisation: examples from in the literature

1. Carer stress as a risk factor for LTC utilisation

“Caregiver characteristics are more important than patient characteristics to placement decisions, especially the subjective dimension of caregiver burden” (53 p.56-57).

“Our analysis confirms for a nationally representative sample of chronically disabled elders the strong link between caregiver stress and nursing home entry” (54 p.155).

“Interventions that reduce caregiver burden should be in a position to effectively change the institutionalization process” (59 p.441).

“Caregivers’ stress was found to be the main determinant of institutionalization” (55 p.81).

“The association of caregiver burden with long-term care placement has been well demonstrated” (87 p.383).

“Subjective burden represents an important predictor of the institutionalization of persons with dementia” (61 p.160).

“Carer psychological morbidity predicts care breakdown and care home admissions” (56 p.539).

“Controlling for variation across countries, caregiver burden appeared the most consistent factor associated with institutionalisation” (62 p.9).
“Caregiving stressors are more important than measures of functional or cognitive impairment when explaining why persons with dementia enter Nhs” (57 p.191-192).

“Clearly, institutionalization decisions lie heavily with the family member who provides the bulk of assistance at home, and those who have emotional difficulty adapting to care demands will likely seek residential long-term care options for disabled elderly relatives” (28 p.226).

“Caring for these patients at home is a stressful and demanding process that affects caregivers’ psychological and physical well-being and jeopardizes the feasibility of continued home care” (22 p.66).

“Studies that have included both patient and caregiver variables as predictors have consistently found that caregiver variables, such as burden and physical health, emerge as stronger predictors of institutionalisation than patient variables”. (163 p.55).

“Caregiver burden had a consistent effect on risk of LTC placement across studies” (84 p.18).

2. Carer stress as a risk factor for acute care utilisation
“Caregiver's burnout appears to be a considerable factor” (89 p.426).

“Close attention to the family burden and suitable, timely support for family may help prevent hospitalisation due to the disease” (90 p.291).

“Carer stress was a significant reason contributing to LOS (length of stay)” (91 p.6).

“The consequences of high levels of caregiver burden include an increased risk of hospitalization” (94 p.308).

“Interventions directed toward the reduction of caregiver burden and improving caregiver well-being may not only delay long-term care placement and prevent the deterioration of caregiver health but also reduce care recipient adverse health outcomes” (87 p.390).

2.12 Degree of rigour applied in current evidence
The belief that carer stress is a risk factor for admission to institutional care (acute or LTC) is highly prevalent in the literature, such that it no longer appears to be rigorously questioned.
Bowling defines rigour in the process of research as “the systematic approach to research design, the awareness of the importance of interpretation and not perception or assumption, the systematic and thorough collection, analysis and interpretation of the data” (164 p.138). With this definition in mind, this section presents examples of the way in which the degree of rigour applied in the literature to date seems limited.

This is demonstrated in three ways. Firstly, there is a lack of clarity on the basis in which researchers claim that carer stress is a risk factor for institutional care use. Secondly, there is inconsistency in the literature between findings presented in articles and the discussion of results. Thirdly, studies which make this claim often fail to adjust for key confounders. Each of these aspects are discussed in turn below.

2.12.1 Lack of clarity in the basis of claims

There are a number of elements in which there appears to be a lack of clarity in the literature. Firstly, this is apparent in the interchangeability in the measurement of stress, as described in section 2.8 above. One example of this is where studies measure stress yet apply measures of depression (141).

The appropriateness of the measures used to conclude that carer stress is a risk factor for subsequent acute or LTC utilisation can also be questioned. For example, a study in the United States that followed Medicaid Home Care Support recipients and their carers for 3 months, found carer ‘perceived burden’ was associated with hospitalisation of care recipients (162). However, the measure of perceived burden was “caregiver not satisfied with the support provided by others” (162 p.1083). This measure does reflect one way in which carers may express their perception of difficulties in the role. However, it is not a composite nor comprehensive measure. Thus it is questionable if it is an appropriate measure to evaluate the association between carer stress and increased hospitalisation of the care recipient, which was the reported aim of the study.
In a similar vein, a study of carers and care recipients in Taiwan followed recipients for a month following hospital discharge (93). In this study carer stress was measured by carers’ expressed need (yes/no) to participate in a support group. The study found care recipients of carers who wished to participate in a support group were 5.3 times more likely to be re-hospitalised. The authors argue that “it is reasonable to conclude that caregivers who report a need for a support group are under more stress and have more difficulty in handling caregiving” (93 p.1401). However, carers may wish to participate in a support group for social interaction or other reasons. Again it is questionable is this is an appropriate measure of carer stress.

A further example of lack of clarity can be found in a study by Livingston et al. published in the *Lancet Psychiatry* in 2014 (56). In the study, the authors state that “carer psychological morbidity predicts care breakdown and care home admissions” (56 p.539). To support this claim, the authors cite an intervention study by Brodaty and Gresham from 25 years earlier (1989). This intervention was found to reduce carer psychological morbidity and delay LTC placement of care recipients (165). However, as discussed above, a systematic review and meta-analysis by Pinquart and Sorensen published in 2006 found that interventions purely for psychological morbidity did not affect the risk of LTC admission of care recipients. Only interventions that included support for the carer in the provision of care (such as respite and day care) had significant, though small, effect in LTC admission (154). Had Livingston et al. accounted for the Pinquart and Sorensen systematic review and meta-analysis, they may have presented a more tentative statement of the relationship between carer stress and LTC admission.

A recent article by Stephan et al. demonstrates a final example of how the clarity in the literature can be questioned. In this study, healthcare professionals and carers across the EU were asked, in an open-ended question, for their perceived reasons for potential LTC placement of a person living with dementia (166). Three themes are presented, firstly ‘perceived reasons relating to the older person’ (consisting of 14 categories), secondly ‘perceived reasons relating to the carer’ (consisting of 2
categories, one of which was carer burden) and thirdly ‘perceived contextual reasons’ (consisting of 6 categories). The authors argue that the most frequently perceived reason for LTC placement related to carer burden (166). However, data in the article showed that substantially more participants gave reasons related to the participant (n=931) than related to the carer (n=744). However, this was not discussed by the authors.

Furthermore, the categorisation of reasons for LTC placement is unclear. The authors provide no operational definition of what constitutes burden, so a range of reasons are included in the category. In contrast, in theme one (‘reasons related to the older person living with dementia’) there is much overlap in categories. For example, within this theme there is a lack of clarity on what distinguishes the category ‘health problems’ (described as physical or mental health problems) from the separate categories of ‘cognitive symptoms’ and ‘neuropsychiatric symptoms’. There are also separate categories for ‘overall deterioration’ and ‘general care dependency’, without clarity as to what distinguishes the two or how they are different from the category ‘health problems’. Finally, there are separate categories for ‘staying alone not possible’ and ‘need for structure’ which they describe as a need for supervision.

The lack of distinction between these categories suggests they could have been merged. If this had been done this would have made a much larger category than the category of ‘carer burden’. This lack of clarity in the way the data has been analysed gives cause to question if it is fair to say carer burden was the most frequently provided reason (as the authors suggest) and therefore could be regarded from this data as a dominant risk factor for LTC placement.

2.12.2 Inconsistency between data and discussion of results
The inconsistency between the data presented in articles and the discussion of results is, unfortunately, not an uncommon feature in the literature. For example, Kuzuya et al. examined the association between carer burden and hospitalisation and mortality of care recipients (87). The authors found the risk of hospitalisation
was 1.51 times higher for recipients whose carer had the highest quartile of burden scores. However, in the sensitivity analysis, the association between higher carer burden and hospitalisation or mortality was mainly found in those who did not use community-based services (day care, home help, or nursing home respite stays). For those who used these services, there was no association between higher levels of burden and adverse health outcomes of care recipients, bar those who used day-care services. This sensitivity analysis suggests utilisation of community care services may be crucial, yet the authors do not account for this in their discussion or when they conclude that “interventions directed toward the reduction of carer burden and improving carer well-being may not only delay LTC placement and prevent the deterioration of caregiver health but also reduce recipient adverse health outcomes” such as hospitalisation and mortality (87 p.390).

The study by Reckrey et al. provides a further example of the inconsistency between the data and discussion of results. In this study, no association was found between carer burden and healthcare utilisation. Yet the authors in their discussion and conclusions still assume one exists: “While caregiver burden increased utilization in some populations, the contribution of caregiver burden to health care utilization in our frail, medically ill population may be overshadowed by the contribution of medical illness” (145 p.1044). Consequently, the authors suggest that burden was associated with healthcare utilisation in other studies “because utilization among healthier patients is less closely tied to medical morbidity” (145 p.1044). However, no evidence is provided to support this claim. According to the Pearlin et al. model, carers’ levels of burden would be higher as the levels of frailty and morbidity of recipients’ are higher (27). Therefore, if the population in the Reckrey study is frailer than in other studies, carer burden should still be associated with healthcare utilisation.

Finally, inconsistency between the data and discussion of results is apparent in the study by Verbeek et al. (62). This was a study of factors associated with LTC admission of people with dementia in eight EU countries. The authors conclude in both the Abstract and Discussion that “caregiver burden appeared the most
consistent factor associated with institutionalisation” (62p.9). However, an examination of the results presented suggests the findings do not fully support this assertion. Firstly, the authors examined differences between people with dementia who were recently admitted to a nursing home (between 1-3 months), compared to those living at home with dementia who were regarded as at risk of admission. This analysis does not take into account the effect of admission on carer perceptions of burden. For example, previous research has found that carers are likely to experience considerable reductions in burden after nursing home admission (58). Given that LTC admission can alleviate burden, the analysis, as presented, is not an accurate test of whether burden is associated with subsequent LTC admission. Rather it demonstrates differences between two independent groups. This association could be confounded by other factors.

In addition, while the authors do provide a more appropriate test of the association between burden and subsequent LTC admission within the article, it is also questionable whether the reported results support their conclusions. The authors followed people with dementia and their carers who lived at home and analysed the differences at baseline between those who had a LTC admission after three months and those who did not. The univariate analysis found that those who had made the transfer to LTC had an informal caregiver who experienced a higher caregiver burden at baseline than people who remained at home (t=-2.31; p=0.021). However, this association did not survive adjustment for other factors. The overall multivariate analysis using a multi-level model found three other factors that explained the transition from living at home to LTC at follow-up. These were: living situation, neuropsychiatric symptoms and cognitive status. Unfortunately, the authors did not report the overall multivariate model including burden. Therefore, it is not possible to know the results for caregiver burden when other factors have been taken into account. If burden is a consistent factor in LTC admission, it should remain so after taking both the characteristics of the person living with dementia and the carer into account. The actual reported results therefore contrast with the conclusions of the article, and it seems that burden is not a consistent factor in LTC admission when controlling for these other important factors.
2.12.3 Failure to adjust for key confounders

The final aspect in which one could question the degree of rigour in the literature is where authors fail to adjust for key confounders in the relationship. One such confounder is the care needs of the recipient, particularly their level of cognitive and/or functional impairment. As described in section 2.3.3 above, other studies have found a care recipient’s cognitive and/or functional status to be critical to subsequent healthcare utilisation.

A study by Hooley et al. examined the relationship between carer burden and hospitalisation or death of the recipient in the following six months. The authors found carer burden was a significant risk factor for these outcomes (94). Therefore the authors believe “the consequences of high levels of caregiver burden include an increased risk of hospitalization” (94 p.308). However, in their analysis Hooley et al. did not account for the recipient’s characteristics, particularly their level of care needs, which could have influenced hospitalisation.

Similarly, Nobili et al. conducted a pilot RCT of an intervention for carers of people with dementia (55). In the discussion of the results the authors concluded that the principal determinant of LTC admission of the care recipient was the level of carer stress (55). However, this is based on a bivariate analysis comparing mean stress scores for those admitted and those not admitted. The authors did not account for other potentially influential characteristics, such as the levels of cognitive or functional impairments’ of the care recipient. Failure to adjust for the care needs of the recipient means vital factors in LTC utilisation are missed. If stress is to be considered a risk factor, this ought to remain significant after adjusting for the care needs of the care recipient – i.e. to be independent of other factors.

Another potential key confounder is the availability and accessibility of community care to support carers in the provision of homecare. For example, the Kuzuya et al. study found community care may be a critical factor in LTC admission (discussed in section 2.12.2 (87)). However, the influence of community care is often omitted from the analysis of the relationship between carer stress and institutional care use.
For example, Gaugler et al. analysed an intervention for carers of people with Alzheimer’s disease (58). This study found that carers of those who had an LTC placement were more likely to experience higher levels of burden compared to those who did not transition to LTC. However, the extent that those who experienced the outcome utilised community care services prior to LTC placement was not accounted for in the analysis. This could have affected the relationship between burden and LTC use in the study.

Similarly, in another study of carers of people with Alzheimer’s disease, Aneshensel et al. argue that carer stressors have the strongest impact on care recipient’s LTC placement (53). The authors believe “background-contextual factors and disease characteristics have only limited associations with institutionalization” (53 p.54). As part of the study the authors took into account where participants resided. This had the strongest effect size for LTC placement (HR=1.640). The authors believe this may be due to different stages in the caregiving career for carers between these sites. However, they do not account for whether this difference may be due to differences in the availability or accessibility to community care in these locations.

Finally, a study by Dramé et al. found, for those carers who reported burden, their care recipients’ were three times more likely to be admitted to LTC (64). However, as with the Gaugler et al. and Aneshensel et al. study, Dramé et al. did not take into account the extent of community services available to support carers. Despite this, the authors argue that “it is of compelling importance to intervene on modifiable risk factors in order to limit as much as possible the number of persons potentially requiring admission to long-term care facilities” (64 p.164). The authors regard the only modifiable risk factor to be carer burden. Yet, community care is in many respects a modifiable risk factor, although it appears often to be ignored in this literature.
2.13 Application of Bradford-Hill Criteria to carer stress as a risk factor for institutional care use

This section evaluates the degree of evidence available on whether carer stress can be considered a risk factor for institutional care use using the Bradford-Hill criteria (167). Bradford-Hill developed a set of criteria for assessing evidence of causation. This is one of the most frequently applied criteria to assess if a variable is a risk factor for an outcome (168, 169). The criteria are described below.

1. **Strength:** The larger the size of the effect of the exposure on the outcome the stronger the evidence that the exposure is a risk factor for the outcome.

2. **Consistency:** The association between the exposure and outcome should be found in different studies in different areas.

3. **Coherence:** Establishing that a variable is a risk factor for an outcome is given more weight if the relationship between the exposure and outcome is in line with current knowledge.

4. **Dose-response:** Increase in the degree of exposure increases the risk of the outcome. However, Carneiro & Howard point out that the exposure should not be disregarded as a risk factor purely because a dose-response relationship does not exist (169).

5. **Specificity:** The establishment of a variable as a risk factor is aided if there is evidence that the outcome was specifically caused by the exposure. However, as Carneiro & Howard note, often outcomes can be the result of more than one exposure (169).

6. **Plausibility:** This relates to knowledge of an underlying mechanism behind the exposure causing the outcome. However, as with dose-response, absence of a known mechanism does not mean the exposure is no longer a risk factor for the outcome (169).

7. **Reversibility:** This is where the outcome does not occur or is reduced if the exposure is removed or reduced. This criteria is typically tested in randomised trials addressing the proposed risk factor.

8. **Temporality:** The exposure must happen before the outcome. Temporality is best measured through longitudinal designs. Establishing temporality is
more limited in cross-sectional study designs. In such instances what may be occurring is reverse causality; this is where what was deemed an exposure is actually a result of the outcome (167-169).

Table 2.3 below applies the Bradford-Hill criteria to the evidence available on carer stress as a risk factor for institutional care use (discussed in section 2.9 to section 2.12.3 above).
Table 2.3 Bradford-Hill criteria against available evidence in literature on carer stress as a risk factor

<table>
<thead>
<tr>
<th>Bradford-Hill criteria</th>
<th>Evidence to date</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strength</strong></td>
<td>The strength of the effect of carer stress on institutional care use (both acute and LTC) varies between studies. The systematic reviews in the area have largely been narrative. The review by Gaugler et al. (2009) was confined to whether carer stress was a significant predictor and the direction of the effect (positive or negative) (57). As with all of the previous systematic reviews in the area, a meta-analysis was not conducted. Therefore, from the evidence to date it is not possible to know what is the actual size of the pooled effect of the association between carer stress and institutional care utilisation.</td>
</tr>
<tr>
<td><strong>Consistency and coherence</strong></td>
<td>An association between carer stress and institutional care use has been found in different studies in different areas (see section 2.11). However, as discussed in section 2.12, the degree of rigour in these studies is questionable. There is a lack of clarity in the basis of the claims made, inconsistency between the data and discussion of results and many studies have failed to adjust for key confounders. All of these factors undermine the degree of weight behind the belief that carer stress is a risk factor for institutional care use.</td>
</tr>
<tr>
<td><strong>Dose-response</strong></td>
<td>From the literature there would appear to be a dose-response relationship, certainly many studies have found higher levels of carer stress to be associated with increased risk of institutionalisation (section 2.11). However, the questionable degree of rigour in the literature undermines the extent to which a dose-response relationship exists.</td>
</tr>
<tr>
<td><strong>Specificity</strong></td>
<td>It is not possible to apply this criterion to carer stress as a risk factor for institutional care use. As described in section 2.3 above, there is a considerable degree of literature on the wide variety of risk factors (bar stress) on institutional care use.</td>
</tr>
<tr>
<td><strong>Plausibility</strong></td>
<td>This criterion largely relates to biological studies. At present the Pearlin et al. Stress Process Model appears to be the closest example of a 'mechanism' behind carer stress increasing the risk of institutional care use (27). However, as discussed above, while the model proposes the components of carers stress, the pathways that join these components are not specified in the model.</td>
</tr>
</tbody>
</table>
The intervention studies to date provide the best assessment of whether reducing the degree of stress carers experience removes likelihood of the outcome. However, as presented in section 2.11.1, these interventions appear to have varying degrees of success. It appears that only interventions that did not just target carer psychological morbidity but also supported the carer in provision of care had significant, though small, effects in LTC placement (OR: 0.51; 95% CI:0.30-0.88) (49).

A number of longitudinal studies have found carer stress at baseline was significantly associated with institutionalisation at follow-up. However, the degree of rigour in this literature is questionable (section 2.12).
2.14 Theoretical models for thesis

This section provides a discussion of the theoretical models underpinning the thesis. These theoretical models were proposed by Pearlin et al., Andersen and Luppa et al. (22, 27, 170-172).

The Pearlin et al. Stress Process Model is specifically concerned with carer stress. The model proposes that carer stress drives a process that ultimately results in LTC admissions of care recipients (27). This model is the presented in Figure 2.1 below. The model is described in detail in section 2.10 above and so will not be described again here.

Andersen proposed a Behavioural Model of Health Service Use (170, 171), according to which health services utilisation is a function of the predisposing, enabling and need characteristics of the individual (see Figure 2.2). The Andersen model has been used in a number of studies that examined the association between carer stress and health service utilisation (18, 22, 59, 62, 96, 162). The model comprehensively presents factors which influence any form of health service utilisation. However, it is not specific to the role of carer stress in LTC admissions.

Following a systematic review of predictors of institutionalisation in people with dementia, Luppa et al. proposed a model of factors which influence institutionalisation (22). This encompassed both the Anderson Model for Health Service Use and the Pearlin et al. Stress Process Model (27, 170, 171). As can be seen in Figure 2.3 below, Luppa et al. considered the socio-demographic characteristics of the care recipient and the carer are equivalent to what Pearlin et al. regarded as the background or context of stress and what Andersen classified as the predisposing variables. Luppa et al. demonstrate that Andersen’s need variables are the stressors identified in Pearlin et al.’s Stress Process Model. In the Luppa et al. model, primary stressors are the care recipient’s needs (degree of frailty, cognitive impairment etc.) and how intense the caregiving demands are as a result of these needs (caregiving hours). In line with the Pearlin et al. model, Luppa et al. describe carer stress as stemming “directly from the needs of the patients” (22.
However, unlike the Pearlin et al. model, Luppa et al. regard the carer’s appraisal of primary stressors and the caregiving situation as secondary stressors (as opposed to subjective primary stressors in the Pearlin et al. model (22, 51)). These secondary stressors are what Zarit refers to as caregiver burden (135). This is the stress the carer experiences as a consequence of providing care.

For Luppa et al., personal and social resources and community care act as what Andersen referred to as enabling variables. In the Luppa et al. model, stress can either directly affect institutional care utilisation or stress may mediate the effect of community care on institutional care utilisation, as Pearlin et al. proposed (see section 2.10). However, Luppa also proposes that this path may be bi-directional; therefore community care may mediate the effect of stress on institutional care utilisation. Figures 2.1 to 2.3 present the Andersen, Pearlin et al., and Luppa et al. models. As can be seen from these figures, each of the models present how groups of factors may influence institutional care utilisation. However, they do not specify the direction of the paths between the factors within each group, nor do they offer much clarification of how individual factors interact between the groups. For example, it is not clear from these models how the amount of caregiving hours required interacts with the degree of community care support received. In many respects, the amount of caregiving hours required both influences and is influenced by the degree of community support received.

According to Nilsen, a ‘good theory’ “provides a clear explanation of how and why specific relationships exist” (173 p.2). This includes specifying the direction of relationships between variables. As the Andersen, Pearlin et al., and Luppa et al. models do not specify the direction of the paths between the factors within each model group, they cannot be regarded as theories in the classic sense of theories (173). Rather they should be regarded as theoretical models as they are closely related to theory, but do not provide a clear explanation of the specific mechanisms of change (173).
Despite this limitation, as these models are widely used in the analysis of factors influencing health service utilisation and carer stress, they have been adopted in this thesis (22, 27, 170). The Andersen model was adopted as it is one of the commonly applied models to predict healthcare utilisation. However, this model is not specific to the role of carer stress in LTC admissions. The Pearlin et al. model proposes that carer stress drives a process that results in LTC placement of the care recipient. It is the most widely used theoretical model in the analysis of carer stress (52), therefore it was important to include this model in the thesis. However, the model does not have as comprehensive a set of variables potentially influential in health service utilisation as the Andersen model. The Luppa et al. model was adopted as it combines the Andersen and Pearlin et al. models. Therefore, it provides a more comprehensive set of variables potentially influential in health service utilisation and the transition to LTC than is provided in the one model alone.
Figure 2.1 Pearlin et al. Stress Process Model

Source Pearlin et al. (27)
Figure 2.2 Original Andersen Behavioural Model of Health Service Use
Figure 2.3 Luppa et al. Model of factors influencing institutionalisation

Source Luppa et al. (22)
2.15 Caregiving in Ireland

Research concerning carers in Ireland is not as extensive as the international caregiving literature. However, as Chapters 6 to 8 are drawn from data within Ireland, it is important to set out the context of caregiving in Ireland. This has been outlined below. A profile of Irish carers from national data is provided first. The supports available to carers are discussed as well Irish research findings on the impact of the caregiving role for carers in Ireland.

2.15.1 Profile of Irish carers

In the 2011 Census in Ireland, 4.1% of the population identified themselves as carers (174). This proportion increased by 13.7% from the 2006 to the 2011 Census (175). A number of national datasets have found that the majority of carers in Ireland are female (61% in the 2011 Census; 64% in the 2010 Quarterly National Household Survey (QNHS)) (174, 176). This reflects findings from international studies of carers that the caregiving role is dominated by females (see section 2.5 above).

In 2011, the greatest proportion of carers were between 40-55 years of age, although the proportion of carers aged 75 and over increased by 39.5% between Census 2006 and Census 2011. This demonstrates “the increasing role of older persons in the provision of voluntary care” (175 p.34) and reflects the concerns raised by international gerontological researchers for the welfare of carers given the ageing population (see section 2.5 above).

In the 2011 Census, the average hours of care provided by carers in Ireland was 33.6 per week, with 21% of carers providing 43 or more hours per week (175). However, the degree of intensity of caregiving (measured by hours of care provided) varies between studies. This variation may be due to the differences between sampling methodologies between the surveys. Surveys have also found that carers who resided in the same household as the care recipient reported spending more time providing care than those who did not reside with the
recipient, reflecting findings in the international caregiving literature (see sections 2.5.2-2.5.3 above).

Data from the first wave results from The Irish Longitudinal Study on Ageing (TILDA) of those providing help to older persons requiring assistance in ADLs was analysed in a 2012 report. Findings indicated that the majority of carers were related to the care recipients (80%), with the main carers being predominately a spouse (44%) (177). As with the Census data, TILDA findings showed that the majority of main caregivers were aged 50 and over, highlighting the substantial contribution of the older population to caregiving in Ireland (177).

Research conducted by the National Centre for the Protection of Older People (NCPOP) in 2014 found that carers had been providing care for an average of 6.8 years (SD=6.0). The type of care most frequently provided was help with housework (84.4%) and support with basic ADLs such as helping the recipient bath or shower (55.4%), walking (43.3%), help with dressing or undressing (40%), and eating (32.8%) (178).

2.15.2 Supports for carers in Ireland
This section outlines the type of State supports for carers in Ireland. Broadly speaking, there are two main ways the State supports carers, through the provision of health and social services and through financial supports. Each of these types of support are discussed below. The economic crisis in 2008 and subsequent government programme of austerity had a substantial impact on both the extent of health and social service provision as well as financial supports to carers. Therefore this is also discussed below.

2.15.2.1 Health and social services
In Ireland, the national health service agency is the Health Service Executive (HSE). The HSE is responsible for the delivery of public acute and community care services. The main state-funded community support services for older people consist of community-based public health nursing and homecare support packages.
Homecare packages aim to provide multi-disciplinary support for older people and their carers to enable the continuation of homecare. They are initiated in the community following a home assessment by a public health nurse or community registered general nurse or following a hospital admission. As packages are based on the needs of the care recipient they vary widely. Typically they include community health nursing. The level of community nursing involvement will vary considerably depending on the care recipient’s needs and availability of staff resources in the area and at different times of the year.

Packages also include home-help for domestic tasks and/or personal care assistants for intimate personal care, such as washing or dressing. The number of hours a family may be supported by either home-help or personal care assistants can range between an hour a week to a maximum of 21 hours a week. This will also vary depending on the individual’s needs, resource availability in the area and when the individual has applied for these services. Respite may also be provided, again depending on the older person’s needs and if the service is available locally.

As well as supporting the older person and their carer through home visits, public health nurses and community registered general nurses provide links to other services such as Meals on Wheels, Physiotherapy, Occupational Therapy, Speech and Language Therapy and Social Work. Again, access to these services will vary depending on where the individual lives and the time of year – if that service is still available in the area.

Public access to LTC facilities is provided through the Nursing Home Support Scheme. The scheme provides financial assistance towards the cost of long term care services. It is administered by the HSE through the ‘Fair Deal’ scheme (179). This scheme means that, based on a means test of income and assets, applicants make a contribution towards the cost of LTC (which varies, depending on the outcome of the means test) and the State pays the balance, irrespective of whether the chosen nursing home is a public, private, or voluntary nursing home. In 2014
the average national rate for a LTC bed under the scheme was €896 per week and 79% of nursing home beds in Ireland were funded by the scheme (180).

In 2013, Hallberg et al. published a study which mapped dementia care services in eight European countries. The types of services included home-help and care with ADLs, meal services, nursing services and allied health professionals services. From this study, the make-up of the type of care services for older people in Ireland was found to be similar to other EU countries (108). However, taking into account the discussion on supports to carers from international literature (section 2.6), it is noteworthy that the majority of State services in Ireland appear to be directed at the care recipient and not the carer.

In a national study of carers by the College of Psychiatry in Ireland and the Carers’ Association, 29% of carer reported that the could not access any State services. Furthermore, of those who could access State services, 74% of carers reported that they were inadequate to meet their needs as a carer. This suggests a need to examine the extent that State services are actually supporting carers in the provision of homecare in Ireland.

**2.15.2.2 Financial supports**

Financial supports to carers are administered by the Department of Social Protection. There are three main forms of financial support, the Carer’s Allowance, Carer’s Benefit and the Carer’s Support Grant (formerly known as the Respite Care Grant). Each type of financial support has separate eligibility criteria. The Carer’s Allowance comprises financial support for carers within certain income thresholds. This allowance is for carers who reside in the same household as a care recipient who requires full-time care. As the allowance is means-tested many families do not qualify to receive this allowance (179, 181).

Carer’s Benefit is provided to those carers who have left employment for a maximum of two years to provide full-time care. Recipients of Carer’s Benefit are required to have a certain degree of Social Insurance contributions in order to
qualify. The Carer’s Support Grant is an annual cash payment for those providing full time care for at least 6 months of the year (179). It should be noted that national studies have found that only 11%-13% of carers receive any financial supports (176, 177). Table 2.4 below provides details of the maximum amount each of these financial supports provided in 2016.

Table 2.4 Financial Support for carers in Ireland

<table>
<thead>
<tr>
<th>Carer’s Allowance rates 2016</th>
<th>Maximum weekly rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers aged under 66 caring for 1 person</td>
<td>€204</td>
</tr>
<tr>
<td>Carers aged under 66 caring for 2 or more people</td>
<td>€306</td>
</tr>
<tr>
<td>Carers aged 66 and over caring for 1 person</td>
<td>€242</td>
</tr>
<tr>
<td>Carers aged 66 and over caring for 2 or more people</td>
<td>€363</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carer’s Benefit rates 2016</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring for 1 person</td>
<td>€205</td>
</tr>
<tr>
<td>Caring for 2 people</td>
<td>€307.50</td>
</tr>
</tbody>
</table>

| Carer’s Support Grant 2016 (formerly the Respite Care Grant)   | €1700 (annually)    |

2.15.2.3 Cuts to supports for carers following economic crisis

Following the economic crisis in Ireland in 2008 and the subsequent Government programme of austerity, funding for both the HSE and Department of Social Protection was reduced. Consequently, the degree of support from health and social services as well as financial supports for carers was reduced.

HSE funding was reduced over a number of government budgets, falling by 22% from 2009 to 2013 (182). As a result, health and social care services for community care have been reduced since the crisis. Data on home help hours is one of few measures of healthcare system activity in the community (183). Home-help hours have decreased by 18% between 2008 and 2012 (182). However, prior to the economic crisis community care services were believed to be under-funded (184). Economic austerity has further compromised the potential for community care services to support care recipients and carers in the community.
The reduction in financial supports available for carers over a number of budgets included the following:

- In the 2010 budget, the Government reduced the Carer’s Allowance (by €442 a year) and the Carer’s Benefit (by €426 a year); the Christmas bonus for carers was also removed (€220).
- In the 2012 budget the Carer’s Respite Grant was reduced by over €300.
- In 2014 the telephone allowance was removed.

It is estimated that these cuts have reduced carer’s household incomes by €800-€1,000 per year (185).

Research on the impact of these cuts for carers in Ireland is limited. In 2014 the Neurological Alliance of Ireland in association with Care Alliance Ireland conducted a survey of carers providing care for people with neurological conditions. In this survey, 82% of carers reported that they were impacted by cuts to homecare packages in the three years prior to the survey. Carers also reported that they were affected by cuts to respite services (77% of carers). Cuts in home help-hours affected 70% of carers. The study found that just over 20% of carers reported that respite was completely inaccessible. For those carers who could access respite, the respite grant had been cut. In the years prior to the survey there had also been changes in the provision of Medical Cards which affected carers and recipients access to healthcare services (181). It is believed that the overall effect of these cuts has intensified the pressure carers experience (181). Consequently, carers in Ireland may be experiencing more stress in the provision of care as a result of the economic crisis.

2.15.3 Impact of caregiving role

2.15.3.1 Financial and social impact

Research in Ireland suggests that providing care can have a significant negative impact on carers financially and socially. Data from the QNHS indicates that carers are more likely to work part-time or stop paid employment (176). Indeed in a 2014 survey, 42% of carers reported to have stopped working in order to provide care
This can have a substantial impact on carers’ financial well-being. For example, O’Shea et al. found that over two-thirds of carers reported difficulties meeting financial commitments. A national survey of carers in Ireland found 46% of carers were worried about not having enough money for the future.

A number of studies of carers in Ireland have reported that carers feel isolated as a consequence of providing care. The caregiving role limits a carer’s opportunities for social and leisure activities. In a national survey of carers by O’Brien et al., 59% of carers reported to be worried about the loss of their social life outside of the caregiving role. Care Alliance Ireland believes the social impact of caregiving can be particularly intense for rural carers. This is because of the “lack of specialists services, lack of respite, difficulty accessing medical support, isolation and lack of companionship, lack of privacy, information gaps, lack of alternatives to family care, poverty and the additional cost of living in a rural area, and difficulties with transport and employment.”

### 2.15.3.2 Impact on physical and psychological morbidity

From the research conducted in Ireland to date, it would appear that caregiving can have a substantial impact on Irish carers’ physical and psychological health. For example, in 2009, two thirds of carers who looked after someone in the same household in Ireland reported that their health and/or lifestyle had been affected by their caregiving responsibilities. Similarly, in the national survey of carers by O’Brien et al., 57% of carers reported to be physically drained by the caregiving role. A number of studies have also found carers to report high blood pressure, back problems and sleep deprivation as a consequence of providing care.

It would appear that carers in Ireland experience a range of psychological health effects as a consequence of providing care. This includes high levels of stress, depression and anxiety, with rates varying between studies. For example, in the survey of carers by O’Brien et al. 43% of carers reported feeling stress, whereas the study by the Care Alliance Ireland found 41% of carers reported stress as a
consequence of the caregiving role (187, 188). These same studies found the rate of depression in carers was between 18%-21% (187, 188).

2.16 Conclusions

In examining the sustainability of homecare, gerontological researchers have increasingly recognised the critical role carers play in its’ provision. However, this does not come without substantial costs for carers. The literature demonstrates the potential negative impact caregiving can have on a carer’s physical health, financial well-being, social life and psychological health. The literature on the psychological health effects of caregiving has led to a contention that the level of stress carers experience could undermine the sustainability of homecare. The most prominent advocate of this is Pearlin who proposed the Stress Process Model to demonstrate how the components of stress interact to drive a process that ultimately results in the termination of homecare.

A number of studies have found that carer stress is a risk factor for subsequent LTC admission or admission to acute care. Consequently the belief that carer stress is a risk factor for subsequent institutional care use (acute or LTC admissions) is a common theme in the literature. However, there is inconsistency between study findings, a questionable degree of rigour applied in the literature and the limited evidence to date that carer stress could meet the Bradford-Hill criteria for risk factors. This suggests a need to critically review if carer stress can be regarded as a risk factor for institutional care use. This is the focus of this thesis. To support this analysis the theoretical models underpinning the thesis are Andersen Model of Health Service Use, the Pearlin et al. Stress Process Model and the Luppa et al. model which combines the Pearlin et al. and Andersen models. These theoretical models enable the thesis to explore the role of carer stress in institutional care use and ask – to what extent does carer stress influence institutional care use by community-dwelling older people? The aims and objectives of the thesis are set out in the following chapter.
Chapter 3  Aims and objectives of the thesis

3.1  Aims of the thesis

Chapter 2 demonstrated that many studies have described carer stress to be a risk factor in LTC admissions. Consequently the belief that carer stress is a considerable risk factor in LTC admissions is a common theme in the literature. However, there is inconsistency between study findings, a questionable degree of rigour in the literature and limited evidence that meet the Bradford-Hill criteria for risk factors. This suggests a need to critically review whether carer stress can indeed be regarded as a risk factor for institutional care use. This is the focus of this thesis and is addressed over a number of inter-connected studies.

Firstly, as Chapter 2 demonstrated, the size of the effect of carer stress on both LTC and acute care admissions has varied between studies. The previous systematic reviews in the area have not included a meta-analysis and therefore offer no clarity as to the actual size of the pooled effect of carer stress on subsequent institutional care use. This literature gap is addressed in Study 1, a systematic review and meta-analysis, which is presented in Chapter 5.

To build on the findings from the meta-analysis, a qualitative study was conducted (Study 2). This is presented in two parts. The first part examines the extent that healthcare professionals and carers regard carer stress as a risk factor in LTC admissions. Indeed, what do healthcare professionals and carers perceive to be the key factors driving admissions to LTC? How do healthcare professional and carers’ perceptions of the main factors influencing LTC admissions compare with the Stress Process Model proposed by Pearlin et al. and the Luppa et al. model (as described in Chapter 2 (22, 27))? Many of the studies that claim carer stress is a key risk factor in LTC admissions have not adjusted for the care needs of the care recipient (section 2.12.3). Yet these are potentially key confounders and have been found to be critical to subsequent LTC admission in many studies (sections 2.3 and 2.4). Therefore, an analysis of how healthcare professionals and carers compare the
influence of carer stress to the care recipient’s needs in the transition to LTC will be undertaken. Finally, community care services are often omitted from the analysis of the relationship between carer stress and LTC admissions (section 2.12.3). This suggests a need to examine how community care services interact with carers’ experience of stress – to what extent do they alleviate the stress carers’ experience? Each of these aspects is addressed in the first part of Study 2, which is presented in Chapter 6.

Despite the fact that the successful provision of homecare depends greatly on the wider healthcare system, there is a notable absence of studies that concentrate on healthcare system factors in admission to LTC. Where studies have examined healthcare system factors, this has largely been as part of a broader set of potential predictors of LTC admissions, rather than looking solely at health system factors. Furthermore these studies largely focus on the transition from community to LTC. However, a number of studies have found acute admissions to be predictive of LTC admission (section 2.3.2). There is also a growing body of evidence to suggest that LTC admissions are often arranged when the care recipient is admitted to acute care (section 2.11.2). Yet the role of acute care has been largely overlooked in the examination of carer stress and the transition to LTC.

In tandem with this, where studies have examined the association between utilisation of community care services and LTC admissions, there appears to be a variation in these findings. Furthermore, how the availability and accessibility of community care services impact on LTC admissions appears to be absent in these studies. The inconsistency and limitations in the findings suggests that further research is needed on the interconnection between carer stress, community care, acute care and LTC admissions. This is addressed in the second part of Study 2 part, which is presented in Chapter 7.

The theoretical models underpinning the thesis are from Andersen, Pearlin et al. and Luppa et al. (22, 27, 170). Luppa et al. combined the Andersen and Pearlin et al. models. As the Luppa et al. model is based on the Pearlin et al. model, the
applicability of the Pearlin et al. and Luppa et al. models to the relationship between carer stress and institutional care utilisation by community-dwelling older people will be examined. This will provide insights to key questions derived from Chapter 2, namely – to what extent does carer stress affect institutional care use? Does carer stress mediate the relationship between community care and institutional care use? How do other hypothesised factors in the models affect the relationship between carer stress and institutional care use? Each of these questions are addressed in Study 3 which is presented in Chapter 8.

3.2 Overall thesis aim and specific objectives
The overall aims of the thesis and the aims and objectives for each of the studies in the thesis are provided below.

**Overall aim of the thesis:** To explore the role of carer stress in institutional care utilisation, particularly LTC utilisation, by older care recipients.

**Overall research question:** To what extent does carer stress influence institutional care utilisation by older care recipients, particular the admission of older people to LTC?

3.2.1 Specific study aims and objectives

**Aim 1:** To systematically review and meta-analyse the prospective association between carer stress and institutional care utilisation by community-dwelling older people (Study 1).

**Objectives:**

(i) To identify all the relevant literature;
(ii) To examine the strength of the effect of carer stress on subsequent institutional care utilisation by community-dwelling older people;
(iii) To investigate differences between the strength of the effect with measures of stress, burden and depression;
(iv) To assess if the effect is stronger with acute care utilisation or nursing home placement;
(v) To examine if the size of the effect varies when more factors are taken into account;
(vi) To examine if the size of the effect varies with study size or quality.

Aim 2: To explore healthcare professionals’ and carers’ perceptions of the main factors influencing long-term care admissions of people with dementia and how stress influences these factors, if at all (Study 2 part 1).

Objectives:
(i) To explore the key factors which influence the decision to transfer an older care recipient to LTC;
(ii) To examine the implications of carer stress on this decision;
(iii) To analyse how healthcare professionals and carers compare the influence of carer stress to care recipients’ needs when deciding that LTC is necessary;
(iv) To examine how community care services interact with carers’ experience of stress.

Aim 3: To explore healthcare system factors which influence long-term care admissions of people with dementia (Study 2 part 2).

Objectives:
(i) To examine how the availability and accessibility of community care services impact on LTC admissions;
(ii) To investigate how the interconnection between community and acute care impact on LTC admissions;
(iii) To examine why a substantial proportion of admissions to LTC are from acute care.
Aim 4: To quantitatively examine hypothesised factors that may influence care stress and institutional care utilisation by community-dwelling older people (Study 3).

Objectives:

(i) To examine the applicability of the Pearlin et al. and Luppa et al. models to the relationship between carer stress and institutional care utilisation by community-dwelling older people;

(ii) To assess if carer stress mediates the relationship between utilisation of community care and utilisation of institutional care;

(iii) To quantitatively examine the findings from the previous qualitative study (Study 2).
Chapter 4  Methodology

4.1  Overview
The previous chapters set the study in context by reviewing the literature, presenting the theoretical models and setting the aims for the thesis. This chapter discusses the methodological choice and the research design for the thesis. The chapter provides an outline of pragmatism as a philosophical approach to the thesis. This is followed by a discussion of mixed methods research and the rationale for adopting a mixed methods approach in this thesis. Following this, the research design adopted for the thesis is discussed. This is a multi-phase mixed method approach with specific studies to address each aim of the thesis. How the findings of each study were integrated to inform the overall thesis question is also described.

4.2  Introduction
This thesis employs both quantitative and qualitative methodologies through a mixed methods design. In order to understand mixed methods it is first necessary to clarify how quantitative and qualitative research differs. Quantitative research is traditionally associated with the natural sciences. In this approach, the research matter under investigation is regarded as external to the researcher. It can be objectively measured so as to test theory. In contrast, the focus of qualitative research is not about measuring an objective reality, but expanding understanding of how individuals interpret their world and their perceptions of meanings they assign to their world. As Sandelowski describes, “knowledge accumulation is less about knowing more, than about having more perspectives from which to know” (191 p.128). In qualitative research the understanding of subjective meanings is then used to generate theory.

For many researchers, qualitative and quantitative approaches to research can be combined within an overall study. Combining these two approaches in one research study is referred to as mixed methods research. In mixed methods research, the
traditional separation of quantitative and qualitative research is overcome through
the paradigm of pragmatism (192). This is the paradigm in which this thesis is set.

4.3 Philosophical approach: Pragmatism

Pragmatism is regarded by many researchers as the most appropriate paradigm for
mixed methods research (193). Morgan offers the most convincing discussion of
how pragmatism overcomes the traditional dichotomy between quantitative and
qualitative research strategies (194). A framework for this discussion is provided in
Table 4.1 below.

Table 4.1 Distinguishing features of Pragmatism

<table>
<thead>
<tr>
<th>Relationship to research process</th>
<th>Qualitative approach</th>
<th>Quantitative approach</th>
<th>Pragmatic approach</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Subjectivity</td>
<td>Objectivity</td>
<td>Intersubjectivity</td>
</tr>
<tr>
<td>Connection of theory and data</td>
<td>Inductive</td>
<td>Deductive</td>
<td>Abductive</td>
</tr>
<tr>
<td>Inference from data</td>
<td>Context</td>
<td>Generality</td>
<td>Transferability</td>
</tr>
</tbody>
</table>

(Source: Morgan (194 p.71))

As can be seen from the table, quantitative and qualitative research is often
regarded as separate as they take either an objective or subjective approach to the
research process. However, for some, making a distinction on such grounds is
naive. This is because research is never purely objective or subjective (194, 195). As
Morgan argues, in the process of conducting research, the researcher will naturally
rotate between both subjective and objective approaches (194). Morgan refers to
this as an intersubjective approach. As Morgan writes, “in a pragmatic approach
there is no problem with asserting both that there is a single ‘real world’ and that
all individuals have their own unique interpretation of the world” (194 p.72).

A second common means of distinguishing quantitative and qualitative research has
been on the basis of their approach to theory. Conventionally, qualitative research
has been regarded as inductive. Data are collected and analysed in order to
generate theory. In contrast, quantitative research has been regarded as deductive.
That is, data are collected and analysed so as to test theory. However, Morgan argues that “it is impossible to operate in either an exclusively theory or data-driven fashion” (194 p.71). In a pragmatic approach, the researcher takes an abductive approach to theory (194). In this way, the researcher moves back and forth between induction and deduction. For example, in a qualitative component of a mixed-methods study, the researcher may generate theory (induction) and then test the theory generated (deduction) in a subsequent quantitative component of the study (194). This thesis took both an inductive and deductive approach to theory and data, this is explored further below.

The final way in which the pragmatic paradigm moves beyond the traditional dichotomy between qualitative and quantitative methodologies is the extent to which the study results can be inferred to other settings. In a qualitative approach, results are often regarded as specific to the context in which the data were generated. In contrast, quantitative researchers are concerned with how generalisable study results are. To move beyond such traditional distinctions, Morgan, argues that the focus ought to be on the factors affecting the extent to which the study results can be applied to other contexts (194).

4.3.1 How the thesis sits within a pragmatist paradigm

This thesis sits within a pragmatist paradigm in four ways. Firstly, a primary concern in a pragmatist paradigm is the research question. This drives the researcher’s approach to the research process and is seen as more important than the underlying philosophical assumptions behind the question (192). Tashakkori and Teddlie refer to this as the “dictatorship of the research question” (193 p.21). In line with a pragmatist paradigm, the methodology chosen for the thesis has been driven by the research question and corresponding objectives set to answer this question. This is explored further below.

Secondly, as both quantitative and qualitative methodologies were employed, the thesis repudiates the traditional dichotomy between quantitative and qualitative research. Instead the thesis builds on the strengths of both approaches to answer
the research question. Thus a practical applied research philosophy was utilised in the methodological choices for the thesis (192).

Thirdly, by undertaking both quantitative and qualitative studies, the thesis includes both objectivity and subjectivity in the research process. This is what Morgan refers to as intersubjectivity in a pragmatic paradigm (194). Finally, the thesis adopted what Morgan refers to as abductive reasoning. To illustrate this, Study 1 employed a quantitative methodology. The findings of this study were integrated into Study 2, which formed the qualitative component to the thesis. The theoretical findings generated in these studies were then tested in Study 3, a quantitative study. Thus the thesis moved between induction and deduction to answer the overall thesis question.

4.4 Rationale for mixed methods thesis

As the thesis employs a mixed methods design, it would be constructive to clarify what is meant by mixed methods and provide a justification for why mixed methods was chosen as the most appropriate approach to the thesis.

4.4.1 What is mixed methods?

Many definitions of mixed methods are provided in the literature. Creswell and Plano Clarke provide the most comprehensive definition which encompasses the core characteristics of mixed methods research. That is, in a mixed methods study both quantitative and qualitative data are collected and analysed. Both forms of data are then mixed or integrated to answer the research question (192).

By collecting and analysing both quantitative and qualitative data, mixed method studies draw on the strengths of each form of data (193). Johnson and Onwuegbuzie believe that the combination of methods allows mixed methods studies to produce findings that are more extensive than would have been produced had one method been employed (195). Tashakkori and Teddlie echo this by arguing that, “social phenomena cannot be fully understood using either purely
qualitative or purely quantitative techniques. We need a variety of data sources and analyses to completely understand complex multifaceted realities” (193 p.16).

4.4.2 Justification for mixed methods in this thesis

In line with the pragmatist paradigm, a mixed methods approach was employed for this thesis given the complexity of the research question. One method alone would not allow an analysis of the extensive and multifaceted factors at play in the relationship between carer stress and institutional care utilisation by care recipients. Concurrently, the triangulation of the findings of each of the three studies in the thesis enabled a rigorous analysis and a more complete understanding of the research question (196-198). In many respects, the rationale for employing mixed methods in the thesis echoes why many Health Services Research studies employ mixed methods – for comprehension and to address the complexity of the phenomenon under investigation (199).

4.5 Study design

Creswell and Plano Clark acknowledge that “the design and conduct of any two mixed methods studies will never be exactly alike” (192 p.54). However, there are key principles considered important in the design of a mixed methods study (192, 198, 200). Each of these are addressed below.

4.5.1 Overall study design: Multiphase sequential design

The first key principle is the overall study design. The overall study design adopted for this thesis was a multiphase sequential design (192). It was multiphase as the research was conducted over a series of three studies, with studies two and three building on the findings from the first study. There were two parts to Study 2, therefore the thesis design consisted of four phases, as depicted in Figure 4.1 below.
• A systematic review and meta-analysis of the impact of carer stress on institutional care utilisation by community-dwelling older people

• Qualitative analysis of healthcare professionals' and carers' perceptions of the influence of carer stress in long-term care admissions of people with dementia

• Qualitative analysis of healthcare system factors which influence long-term care admissions of people with dementia

• Structural analysis of hypothesised factors that may influence carer stress and institutional care utilisation by community-dwelling older people

Figure 4.1 Study Design: Multiphase sequential design

To determine the extent to which carer stress influences health service utilisation of older care recipients it was necessary to first assess the impact of carer stress on subsequent institutional care utilisation by community-dwelling older people. This was addressed in Study 1, a systematic review and meta-analysis (Chapter 5). Following Study 1, a qualitative study was conducted (Study 2). This qualitative study built on the findings of the first study. There were two parts to the qualitative study, each presented in separate chapters. The first part explored healthcare professionals’ and carers’ perceptions of the influence of stress on LTC admissions of people with dementia (Chapter 6). The second part analysed healthcare system factors which influence LTC admissions of people with dementia (Chapter 7). The findings from the qualitative study informed the subsequent quantitative study (Study 3, Chapter 8). This was a structural quantitative analysis of hypothesised factors that may influence carer stress and institutional care utilisation by community-dwelling older people. This was a secondary analysis of The Irish Longitudinal Study on Ageing (TILDA) dataset.
4.5.2 Emergent design

The second key principle in the design of mixed methods studies is whether the design is fixed or emergent (192). In studies with a fixed design, the design of the study is set from the outset of the study. In emergent designs, the methods evolve during the study (192). For this thesis, the mixed method design was more emergent than fixed. That is, the qualitative study arose from the findings from the meta-analysis. The findings in both the qualitative study and the meta-analysis then informed the questions for the final quantitative analysis with the TILDA dataset.

4.5.3 Timing or sequencing

Creswell and Plano Clark and O’Cathain note that the researcher ought to articulate the timing or sequencing of the qualitative and quantitative components of a mixed methods study (192, 198, 200). This includes both when the data were collected and analysed as well as when they were integrated into the study. As the thesis took a multiphase sequential approach, quantitative and qualitative components were collected and analysed over phases (see Figure 4.1). It should be noted that though the qualitative study is presented in two parts, data collection for both parts (Chapters 6 and 7) was undertaken simultaneously. As Study 3 was a secondary analysis of the TILDA dataset it did not involve primary data collection. As each phase informed a subsequent phase, the analysis and integration of each study findings was sequential, rather than integrating the analysis of each study’s findings solely at the end of the thesis.

4.5.4 Priority

Priority relates to the weighting the quantitative and qualitative methods have in answering the research question. One method may be given more weight than the other. Alternatively, each method may have equal weighting (192). In this thesis, both methods were regarded as having equal weight as both equally informed the response to the thesis question.
4.6 Methods

In each chapter that presents the results of the three studies (Chapters 5-8), a detailed discussion of the methods for each study is provided. Therefore these have not been described here to avoid repetition.

4.7 Integration of findings

This section concerns the approach taken to analyse the quantitative and qualitative components of the thesis together. In a mixed methods study, this is referred to as integration. This is the interaction between the quantitative and qualitative components of a study so as to generate new understandings (198). For O’Cathain, integration is critical (198). If the findings of the quantitative and qualitative work are not integrated, the researcher has effectively conducted separate qualitative and quantitative studies (198). Rather, integrating the separate components together means the learning from a mixed methods study achieves a “whole greater than the sum of its parts” (201 p.40).

Teddlie and Tashakkori provide a typology of mixed methods integration strategies (202). According to this typology, the integration strategy for this thesis was an iterative sequential mixed analysis. This is the integration of data from a sequential study which has more than two phases. As referred to above (see Figure 4.1), three studies were conducted for the thesis. The learning generated from each study generated additional questions which were addressed in a subsequent study. In this way, data integration from the quantitative and qualitative studies was connected throughout the thesis. This was done to comprehensively answer the overall research question.

4.8 Summary

Given the complexity of the relationship between carer stress and institutional care utilisation of care recipients, particularly in admission to LTC, a mixed methods approach was chosen as the most appropriate and comprehensive means of answering the research question. This approach was based on a pragmatist paradigm. In this manner, the research question dictated the methods chosen to
answer each objective of the thesis. These methods were both quantitative and qualitative and formed a multiphase sequential overall design to the thesis. Each study informed both the overall thesis question and the questions generated from a previous study. Thus data integration was connected throughout each phase of the thesis. Based on the overall methodological approach to the thesis described in this chapter, the next four chapters (Chapters 5-8) provide a detailed discussion of the methods and results of each study in the thesis.
Chapter 5  Systematic review and meta-analysis of the impact of carer stress on subsequent institutionalisation of community-dwelling older people

5.1 Overview
This chapter presents Study 1, a systematic review and meta-analysis. The analysis reported in sections 5.5 to 5.7 has been published as Donnelly et al. (Donnelly NA, Hickey A, Burns A, Murphy P, Doyle F. Systematic Review and Meta-Analysis of the Impact of Carer Stress on Subsequent Institutionalisation of Community-Dwelling Older People. PLoS ONE. 2015;10(6):e0128213.) (203). A copy of the publication is included in appendix 1. The chapter provides a brief outline to the background and focus of the systematic review. The methods used are discussed in detail. It then presents the results. These include the characteristics of included studies and the overall effect size found. These findings are then explored in greater detail in a sensitivity analysis and meta-regression. The chapter concludes by providing a discussion of the findings, their implications for the thesis and how the findings inform subsequent thesis chapters.

5.2 Introduction
As discussed in Chapter 2, the caregiving role provided by family members and informal carers to older care recipients is often regarded as hazardous to a carer’s psychological well-being and their physical health. Therefore, in examining the sustainability of homecare, gerontological researchers have increasingly recognised the needs of the carer as well as the care recipient. This work has given much attention to the psychological health effects of caregiving, leading to a contention that such psychological morbidity of the carer could increase the risk of utilisation of institutional care by the care recipient (acute or LTC utilisation).

Before reviewing this contention, it is important to note that though there is extensive literature on the psychological health effects of caregiving, particularly carer stress and burden, there is a lack of clarity on their distinction and how they
interact in the caregiving process. For the purpose of the thesis, carer stress and burden have been understood within the context of the Pearlin et al. Stress Process Model (27, 144). However, this lack of clarity remains prevalent in the literature. As Zarit notes, virtually every dimension of the stress process (from the primary stressors such as behaviours that challenge, to the outcomes of the Stress Process Model, including anxiety and depression) has been referred to as burden (138). Consequently, the term ‘burden’ has been used in many different ways in the literature. Furthermore, there is a tendency of some researchers to use the concepts and associated measures interchangeably (137). For example, studies discuss ‘carer stress’ and apply measures of burden (60), measures of depression (141), or measures of strain (54); or assess ‘carer strain’ and apply measures of distress (142).

Given the lack of clarity and consequential interchangeability in the measurement of psychological morbidity, any review of the area must incorporate a wide number of exposures employed to measure carer stress. Brodaty et al. also adopted this approach in a similar systematic review (204). Therefore, in order to avoid omitting a substantial proportion of the literature, the review had to include a wide number of exposures that are measured under the umbrella term of ‘carer stress’, namely: stress, burden, depression, distress, anxiety, burnout, and strain.

As referred to above, a number of cohort studies have found that higher levels of caregiver stress, burden, and depression can predict admission of the care recipient into a nursing home (14, 54, 76). Carer stress has also been found to be associated with care recipients’ utilisation of acute care (89-91, 161, 162, 205). Consequently, as discussed in Chapter 2, carer stress has begun to be regarded as a considerable risk factor in utilisation of acute and LTC. Indeed statements such as “carer psychological morbidity predicts care breakdown” (56 p.1) are highly prevalent in the literature. However, the assertion that higher levels of carer stress could jeopardize homecare has not been subject to meta-analysis.
Indeed, the majority of reviews of the predictors of institutional care utilisation (acute or LTC) have not accounted for the level of carer stress (13, 16, 17, 206, 207). Gaugler et al. did include carer stress in a systematic review of factors that consistently predict nursing home admission in people with dementia (57). This review found that, carers who indicated greater emotional stress were more likely to admit the care recipient to a nursing home. However, the analysis was confined to whether carer stress was a significant predictor and the direction of the effect (positive or negative). Unlike the current study, the review did not analyse the size of the effect of stress on nursing home placement (57). Finally, when both carer and care recipient characteristics have been analysed together in cohort studies, the strength of the association between carer stress and institutional care utilisation has varied between studies, suggesting potential heterogeneity in these effects (14, 28, 89).

Given the absence of a review in the area, this study systematically reviewed and meta-analysed the prospective association between carer stress and institutional care utilisation by care recipients. As discussed above, for the purposes of the review, ‘carer stress’ was used as an umbrella term to incorporate the wide number of exposures that are used synonymously in the measurement of the psychological health effects of caregiving. Institutional care utilisation included both acute and LTC utilisation.

5.3 Objective
To systematically review and meta-analyse the prospective association between carer stress and institutional care utilisation by community-dwelling older people.

5.4 Methods
5.4.1 Study design
The PRISMA guidelines for the conduct and reporting of systematic reviews and meta-analyses were adhered to in the conduct of this review (208).
5.4.2 Eligibility criteria

5.4.2.1 Types of studies
Both naturalistic observational and intervention studies that measured carer stress at baseline and acute or LTC utilisation at follow-up were included. Control groups from controlled intervention studies with carers were also included. Where data from control groups alone could not be obtained, combined intervention and control groups were included. Sensitivity analyses examined the differential effect of study design on estimates. The effect of excluding those studies where data from control groups alone could not be obtained was also examined. Studies were excluded if they were cross-sectional, retrospective or not written in English. Articles were not limited by year of publication.

5.4.2.2 Types of participants
Care recipients were community-dwelling older people (aged 65 and over) with chronic care needs that were cared for by an informal carer. The study was not confined to participants of a particular demographic group. Thus participants with dementia and without dementia that have an established caregiving arrangement in the community were included. Carers were the informal carer who takes primary responsibility of the care recipient. Articles with data on stress in professional or paid carers were excluded.

5.4.2.3 Types of exposures
As mentioned above, different measures of psychological morbidity have been analysed in the prediction of institutional placement. In order to avoid omitting a substantial proportion of the literature, it was necessary to include a wide number of exposure measures that are used under the umbrella term ‘carer stress’, namely: stress, burden, depression, distress, anxiety, burnout, and strain. Given the range of possible exposure variables, they were considered in a hierarchical manner. Composite scale measures of burden and stress which have been tested for validity and reliability were given priority. These were followed by composite measures of depression, distress, anxiety, or strain which have also been tested for validity and reliability. Where studies included more than one measure, both were recorded.
and analysed separately in a sensitivity analysis. For the overall effect estimate the above hierarchy was used.

5.4.2.4 Types of outcomes
As described above, institutional care utilisation was both acute and LTC utilisation. Acute care utilisation included both Emergency Department visits and/or hospital admissions. LTC utilisation was admission to a nursing home.

5.4.3 Search methods
5.4.3.1 Information sources
A systematic literature search was undertaken in January 2014 in the following databases: CINAHL, Medline (OVID), PsycInfo, Web of Knowledge, and EMBASE.

5.4.3.2 Search terms
A list of the search terms for the population, setting, exposures and outcomes and all possible synonyms for these terms was prepared (see appendix 5.1). These terms were then used to search each of the selected databases. The search results were reviewed against a selection of twelve key articles from the literature to ensure the search strategy employed was comprehensive. The search terms were revised a number of times according to how sensitive they were to pick up the key articles in the literature. Once the database search was found to not omit key articles in the literature, thus providing confidence that the search strategy was comprehensive, the search terms were then finalised.

The final search terms employed were: carer or caregiver; aged or elderly or Alzheimer or dementia; stress or burden or burnout or distress or anxiety or depression or strain; nursing home or long term care or long term care utilisation or care home or homes for the aged or institutionalisation or acute care or hospitalisation or hospital admission or hospital readmission or emergency department or accident and emergency. Appendix 5.2 provides an example of the search strategy for Medline (OVID).
5.4.4 Data collection and analysis

5.4.4.1 Study selection
The first reviewer screened all titles and abstracts of papers identified by the literature search (NAD). Given resource constraints, a second reviewer (another PhD Scholar) undertook duplicate screening on a random selection of fifteen percent of identified titles and abstracts. Disagreements were discussed with a third reviewer (the PhD primary supervisor). All studies identified as potentially relevant were retrieved and read in full to determine eligibility for inclusion.

5.4.4.2 Data extraction
Data extraction was conducted by using a pre-defined data extraction template. Extracted data included design characteristics; study population and country; sample size; length of follow up; sample selection; age and sex of participants; the exposure and outcome measures; and results. Where there were insufficient data in the published paper authors were contacted to provide further information.

5.4.4.3 Quality assessment
Quality assessment was undertaken with the Crowe Critical Appraisal Tool (CCAT) (209-211). The CCAT was developed based on a wide number of previous critical appraisal tools, general research methods theory and reporting guidelines (209). The tool is considered a reliable means of appraising a wide range of research designs and has undergone testing for reliability and validity (209, 210). Crowe et al. report intraclass correlation coefficients of 0.83 (consistency) and 0.74 (absolute agreement) (209, 210). The CCAT has also been used to assess study quality in a number of recent meta-analyses (212, 213).

Based on the CCAT, papers included in the review were appraised in eight categories. These were preliminary appraisals (such as the title and abstract), the introduction, design, sampling, data collection, ethical matters, results and discussion. Within each category a number of items were examined such as sampling method, sample size and bias. Scoring was a combination of objective and subjective assessment, where each category is scored from 0 (no evidence) to 5
(highest evidence). Total scores for each study are presented as a percentage. Thus the tool enables direct comparison of scores obtained in the quality assessment of articles included in the review (209, 211). To examine the impact of study quality on effect estimates in a meaningful way, studies were grouped by quartiles of CCAT scores in the sensitivity analysis. However, continuous scores were maintained for the meta-regression.

5.4.4.4 Statistical analysis

The standardised mean difference (SMD) between stressed and non-stressed carers was the primary measure of effect. This approach is recommended when there is variance in measurement of exposures (e.g., mean and SD of stress, burden, or depression scores or proportions stressed, burdened, or depressed) and outcome status (acute or long term care utilisation) (214, 215). As studies reported a combination of mean and SD scores or proportions stressed or not, the metaeff command in Stata 12·0 was employed (216). This command enabled the calculation an effect size and its standard error by using methods described in the Cochrane Handbook of Systematic Reviews of Interventions (216, 217). Thus data were transformed to a common effect size metric.

As significant heterogeneity was expected among the exposures, populations and outcomes, effects were estimated in a random effects model for all included studies (215). The \( I^2 \) test was employed to describe the percentage of total variation across studies that was due to heterogeneity rather than chance (218). An assessment of publication bias or small study effects was assessed visually with a funnel plot and more formally with Egger’s test. Effect sizes were interpreted according to Cohen’s D guideline for interpretation. According to this guideline, an effect size of 0.0 to 0.1 is considered negligible, 0.2 to 0.4 is small, 0.5 to 0.7 is moderate and 0.80 or greater than is considered large (219).

A pre-planned sensitivity analysis of estimates was conducted according to study size by tertile; the decade studies were published and regions in which studies were conducted. Study quality was examined by quartiles of CCAT scores. The use of
adjusted or unadjusted estimates and dementia populations compared to non-dementia populations was also examined. The sensitivity analysis also included different follow-up periods; study design and LTC in comparison to acute care utilisation.

The impact of different exposure measures was examined in a number of ways. Firstly, differences between estimates solely with measures of stress, burden, depression or distress were examined separately. Where the same scale was used to measure ‘stress’, ‘distress’ and ‘burden’, the original classification by the authors of the scale was applied. For example, the General Health Questionnaire was classified as ‘distress’, an approach also adopted in a similar systematic review (153, 220). Differences in estimates between studies applying the Zarit Burden Interview (ZBI) were compared with studies that applied other measures of burden. It was also possible to examine estimates solely with measures of burden and stress, according to the Stress Process Model (27), and with measures of psychological distress, as adopted in a similar systematic review (204). Finally, differences in estimates within studies that measured both burden and depression were examined.

Given the methodological diversity of included studies, significant heterogeneity was anticipated. Therefore a meta-regression was planned to understand the extent to which heterogeneity was related to the characteristics of the studies (221). This included the year studies were published, study size and quality, whether the estimates were adjusted for, the type of outcome and exposure measure and the period of follow-up.

In order to undertake the meta-regression, the distribution of the effect size variable was assessed for normality (see appendix 5.3). Year of publication, study size and study quality (with percentage of CCAT scores) were assessed in the meta-regression as continuous scores. The distribution of these variables were also assessed for normality (see appendix 5.3). Sharp discusses alternative methods for estimation of between-study variance ($\tau^2$) in Stata (222). The default method is the
restricted maximum likelihood method; alternatives are the Empirical Bayes and Method of Moments calculation. Sharp advises that the basis of using the empirical Bayes method is less clear, so asserts that this method should be used with caution (222). There is no established guidance on which is the most appropriate of the alternative methods. Each study characteristic was examined with all three methods (see appendix 5.3). As the restricted Maximum Likelihood Method is the default method and is the most conservative method, this method was chosen in the final analysis of the meta-regression for the thesis. Study characteristics found to be significant were then entered into a meta-regression with multiple covariates to assess their overall contribution to heterogeneity in effect estimates (221).

5.5 Results
5.5.1 Study selection
Figure 5.1 presents a flow diagram of the search strategy. After duplicates were removed the search retrieved 4,701 articles, of which 4,582 were excluded (4,367 on review of abstract and a further 215 after full text assessment). A further 65 articles were omitted. These were 27 repeat publications from the same dataset (see appendix 5.4) and 38 studies where adequate data was not available following contact with authors. Details of these studies are presented in appendix 5.5. Thus data from 54 datasets were included in the analysis.
5.5.2 Study characteristics

Characteristics of included studies are displayed in appendix 5.6. Eighteen studies were conducted in Europe, twenty-six in North America, eight studies in Asia, and two were conducted in Australia. In the majority of cases, the research design adopted was a cohort study (80% of studies). In 74% of studies the study population was dementia care recipients and carers dyads.
There was substantial variation in the types of exposure measures included. Twenty-seven studies measured caregiver burden, of these seventeen studies used the Zarit Burden Interview (ZBI). One study used items from the ZBI and two studies measured burden with the Family Caregiving Burden Inventory (FCBI). A further seven studies used seven different measures of burden (see appendix 5.6).

Ten studies measured carer stress, two of these studies with the Relative Stress Scale. The other eight studies used eight different measures of stress. Six studies measured carer distress: three used the General Health Questionnaire, two used the Neuropsychiatric Inventory Distress scale (NPI-D), and the sixth used a measure from the InterRAI home care assessment tool (see appendix 5.6).

Carer strain was measured in two studies. One study measured carer anxiety using the anxiety scale of the Hospital Anxiety and Depression Scale (HADS). Nineteen studies measured depression, thirteen of these with the Centre for Epidemiologic Studies Depression Scale (CES-D). Three studies used the Geriatric Depression Scale. Three other studies used three different measures of depression.

Eleven studies utilized more than one measure. Six studies measured both carer burden and depression. Two studies measured carer stress and depression. One study measured carer burden and anxiety. One study measured carer stress and distress and one study measure carer distress and depression.

A number of studies referred to the same measure as a measure of burden, stress, or distress. This interchangeability was apparent both within and between studies. For example, within some studies the same measure was referred to as both a measure of stress and burden, while in different studies the same measure was referred to as a measure of burden, stress or distress (71, 146, 223, 224). In forty-two studies the outcome measure was admission to LTC, in seven studies it was admission to acute care. In five studies the outcome was admission to both acute and long term care (see appendix 5.6).
5.5.3 Synthesis of results: Meta-analysis

As detailed in the methods section, a hierarchical approach for the exposure measure was adopted to estimate the overall effect size. The forest plot using best estimates from individual studies is displayed in Figure 5.2. With the hierarchical approach the meta-analysis found that, while carer stress has a significant effect on subsequent institutionalisation of care recipients, the overall effect size across the 54 studies was negligible according to Cohen’s guidelines (SMD=0·05; 95% CI: 0·04 - 0·07) (219).

![Forest plot](image)

**Figure 5.2 Overall Forest Plot demonstrating the association between carer stress and institutional care utilisation**
There was evidence of statistically significant heterogeneity ($I^2=79.2\%$; $p<.001$) and funnel plot asymmetry (see Figure 5.3). Furthermore, the Egger’s bias coefficient (bias=1.45; $p<.001$) strongly indicated the presence of asymmetry and publication bias. This suggested the presence of small studies that overestimate the effect of stress (225).

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{Funnel_Plot}
\caption{Funnel Plot}
\end{figure}

5.5.4 Additional analysis: Sensitivity analyses

Summary estimates for each of the sensitivity analyses are displayed in Table 5.1. To examine the impact of the type of measure on estimates, measures of stress, burden, depression or distress were separated out. Where the same scale was used to measure ‘stress’, ‘distress’ and ‘burden’, the original classification by the authors of the scale was applied.
Table 5.1 Sensitivity analyses

<table>
<thead>
<tr>
<th></th>
<th>No. of studies</th>
<th>SMD</th>
<th>95% CI</th>
<th>$I^2$</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study size</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small</td>
<td>19</td>
<td>0.28</td>
<td>0.13 - 0.44</td>
<td>53.5</td>
<td>&lt;0.003</td>
</tr>
<tr>
<td>Medium</td>
<td>17</td>
<td>0.11</td>
<td>0.05 - 0.18</td>
<td>57.7</td>
<td>&lt;0.002</td>
</tr>
<tr>
<td>Large</td>
<td>18</td>
<td>0.05</td>
<td>0.03 - 0.07</td>
<td>90.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Decade published</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1980s</td>
<td>3</td>
<td>0.40</td>
<td>0.16 - 0.63</td>
<td>0.0</td>
<td>&gt;0.494</td>
</tr>
<tr>
<td>1990s</td>
<td>14</td>
<td>0.26</td>
<td>0.18 - 0.34</td>
<td>0.0</td>
<td>&gt;0.478</td>
</tr>
<tr>
<td>2000s</td>
<td>23</td>
<td>0.05</td>
<td>0.03 - 0.07</td>
<td>77.5</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>2010+</td>
<td>14</td>
<td>0.04</td>
<td>0.02 - 0.07</td>
<td>86.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Quality score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1: CCAT score &lt; 50%</td>
<td>13</td>
<td>0.26</td>
<td>0.12 - 0.41</td>
<td>69.5</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Group 2: CCAT score 50-57%</td>
<td>12</td>
<td>0.21</td>
<td>0.09 - 0.33</td>
<td>67.4</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Group 1: CCAT score 58-67%</td>
<td>15</td>
<td>0.05</td>
<td>0.03 - 0.07</td>
<td>84.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Group 1: CCAT score ≥68%</td>
<td>14</td>
<td>0.05</td>
<td>0.01 - 0.09</td>
<td>82.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Adjustment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unadjusted estimates</td>
<td>44</td>
<td>0.14</td>
<td>0.10 - 0.18</td>
<td>81.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Adjusted estimates</td>
<td>10</td>
<td>0.01</td>
<td>0.00 - 0.02</td>
<td>46.6</td>
<td>&lt;0.051</td>
</tr>
<tr>
<td><strong>Population</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia population</td>
<td>40</td>
<td>0.03</td>
<td>0.02 - 0.05</td>
<td>72.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Non-Dementia population</td>
<td>14</td>
<td>0.15</td>
<td>0.08 - 0.22</td>
<td>38.0</td>
<td>&gt;0.074</td>
</tr>
<tr>
<td><strong>Follow up</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A year or less</td>
<td>26</td>
<td>0.09</td>
<td>0.05 - 0.14</td>
<td>77.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Over a year</td>
<td>28</td>
<td>0.04</td>
<td>0.02 - 0.05</td>
<td>77.2</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Study design</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohort</td>
<td>43</td>
<td>0.11</td>
<td>0.08 - 0.14</td>
<td>82.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Intervention</td>
<td>11</td>
<td>0.01</td>
<td>0.00 - 0.02</td>
<td>32.9</td>
<td>&gt;0.136</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long term care</td>
<td>42</td>
<td>0.06</td>
<td>0.04 - 0.08</td>
<td>74.2</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Both acute and long term care</td>
<td>5</td>
<td>0.27</td>
<td>0.13 - 0.41</td>
<td>0.0</td>
<td>&gt;0.433</td>
</tr>
<tr>
<td>Acute care</td>
<td>7</td>
<td>0.05</td>
<td>0.00 - 0.09</td>
<td>92.4</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
Table 5.1 Sensitivity analyses continued

<table>
<thead>
<tr>
<th>Region conducted</th>
<th>No. of studies</th>
<th>SMD</th>
<th>95% CI</th>
<th>$I^2$</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Europe</td>
<td>18</td>
<td>0.02</td>
<td>-0.00 - 0.05</td>
<td>53.3</td>
<td>&lt;.004</td>
</tr>
<tr>
<td>USA</td>
<td>20</td>
<td>0.07</td>
<td>0.04 - 0.09</td>
<td>83.4</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Canada</td>
<td>6</td>
<td>0.13</td>
<td>0.04 - 0.22</td>
<td>81.5</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Asia</td>
<td>8</td>
<td>0.14</td>
<td>0.05 - 0.23</td>
<td>0.0</td>
<td>.844</td>
</tr>
<tr>
<td>Australia</td>
<td>2</td>
<td>0.31</td>
<td>0.05 - 0.58</td>
<td>0.0</td>
<td>.475</td>
</tr>
<tr>
<td>Differences between measures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any measure of burden</td>
<td>27</td>
<td>0.07</td>
<td>0.05 - 0.10</td>
<td>81.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Any measure of stress</td>
<td>10</td>
<td>0.23</td>
<td>0.09 - 0.38</td>
<td>72.8</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Any measure of distress</td>
<td>6</td>
<td>0.09</td>
<td>-0.01 - 0.18</td>
<td>89.5</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Any measure of depression</td>
<td>19</td>
<td>0.03</td>
<td>0.00 - 0.05</td>
<td>47.8</td>
<td>.011</td>
</tr>
<tr>
<td>Zarit Burden Interview</td>
<td>17</td>
<td>0.06</td>
<td>0.04 - 0.09</td>
<td>85.2</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Any other measure of burden</td>
<td>10</td>
<td>0.19</td>
<td>0.04 - 0.35</td>
<td>51.9</td>
<td>.028</td>
</tr>
<tr>
<td>Studies with more than one measure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td>6</td>
<td>0.24</td>
<td>0.07 - 0.42</td>
<td>84.9</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Depression</td>
<td>6</td>
<td>0.04</td>
<td>-0.00 - 0.07</td>
<td>71.1</td>
<td>.004</td>
</tr>
</tbody>
</table>
It would appear that the magnitude of the estimate with measures of stress (SMD = 0.23; 95% CI: 0.09 - 0.38) is higher than that of the estimate with any other exposure measure. This estimate would still be considered ‘small’ according to Cohen’s guidelines (219). In contrast, the estimate with measures of burden are lower (SMD = 0.07; 95% CI: 0.05 - 0.10). Estimates with measures of depression fall within this range with confidence intervals which overlap with estimates of burden (SMD = 0.03; 95% CI: 0.00 - 0.05).

A number of studies in the sensitivity analysis of the estimate with measures of stress used non-validated measures. This was explored in a further sensitivity analysis of those studies measuring stress. Of these studies, for those that used a validated measure of stress (that is the psychometric properties of the scale have been reported) the effect size was approximately half (n=6; SMD = 0.17; 95% CI: 0.02 - 0.36) of that of those studies that did not use a validated measure or report if the psychometric properties of the scale had been tested (n=4; SMD = 0.30; 95% CI: 0.12 - 0.48).

Overall, the number of studies included in these estimates varies, thus it cannot be said with confidence that there is a stronger effect estimate with a particular type of exposure. However, it would appear that irrespective of whether we examine the effect of stress, burden, depression or distress on institutionalisation separately or combined these measures the effect remains significant, but small to negligible according to Cohen’s guidelines (219).

It was also possible to examine estimates solely with measures of burden and stress according to the Pearlin et al. Stress Process Model (27). In this case, the size of the effect is also negligible according to Cohen’s guidelines (SMD = 0.06; 95% CI: 0.04 - 0.08). Similarly, it was possible to examine estimates with measures of psychological distress, as adopted in a similar systematic review (204). Again, the size of the effect is negligible according to Cohen’s guidelines (SMD = 0.05; 95% CI: 0.01 - 0.09).
The impact of the particular exposure measure on effect estimates was further explored by comparing studies which applied the Zarit Burden Interview (ZBI) (SMD =0·06; 95% CI: 0·04 - 0·09) to those that applied any other measure of burden (SMD =0·19; 95% CI: 0·04 - 0·35). While the SMD between the two estimates appears somewhat different, the effect sizes would still be considered small to negligible according to Cohen’s guidelines (219).

Finally, in terms of the effect of different exposure measures, a sensitivity analysis examined differences in estimates within studies that measured both burden (SMD =0·22; 95% CI: 0·05 - 0·39) and depression (SMD =0·03; 95% CI: -0·00 - 0·07). Again, although the SMD between the two estimates appears quite different, the effect sizes would still be considered small to negligible according to Cohen’s guidelines (219).

To investigate how effect estimates varied according to study size, studies were grouped by tertile. Consistent with the findings of the Egger’s test, there is a notable reduction in the size of the effect for studies with larger sample sizes. For example, the effect estimate in studies with the smallest samples (SMD=0·28; 95% CI: 0·13 - 0·44) was higher compared to larger studies (SMD=0·05; 95% CI: 0·03 - 0·07). The forest plot with estimates grouped according to study sample size is provided in Figure 5.4.
The sensitivity analysis also examined estimates according to the decade in which the study was published. It would appear that in each of the last four decades the effect estimates have decreased (1980s: SMD=0.40; 95% CI: 0.16 - 0.63; to 2010 and later: SMD=0.05; 95% CI: 0.02 - 0.07), as displayed in Figure 5.5.

Figure 5.4 Forest plot by sample size
Figure 5.5 Forest plot by decade published

There was a wide variation in study quality, with CCAT scores ranging from 30% to 95% (see appendix 5.6). To examine the impact of study quality on effect estimates in a meaningful way, studies were grouped by quartiles of CCAT scores. As presented in Table 5.1, effect estimates reduce as study quality improves. The effect estimate changes considerably for those studies with unadjusted estimates (SMD=0.14; 95% CI: 0.10 - 0.18) compared to those studies with adjusted estimates (adjusting for factors such as age, sex, type and severity of dementia, spousal carer and ADL rating) (SMD=0.01; 95% CI: 0.00 - 0.02).
As displayed in Table 5.1, the sensitivity analysis also examined the differential effect of the study design on estimates. The estimate with cohort studies appears higher (SMD=0·11; 95% CI: 0·08 - 0·14) than that of intervention studies (SMD=0·01; 95% CI: 0·01 - 0·02). In three cases it was not possible to get data on control groups alone, despite contact with authors. Therefore a sensitivity analysis examined the impact on estimates when these three studies were excluded. However the effect size remained negligible (SMD=0·07; 95% CI: 0·05 - 0·09) (219).

Finally, as displayed in Table 5.1, the sensitivity analysis included an examination of the impact on estimates depending on the whether the sample was a dementia population (SMD=0·03; 95% CI: 0·02 - 0·05) or non-dementia population (SMD=0·15; 95% CI: 0·08 - 0·22); the period of follow-up (over a year: SMD=0·04; 95% CI: 0·02 - 0·06; a year or less: SMD=0·09; 95% CI: 0·05 - 0·14); the region in which studies were conducted and the outcome (long term care: SMD=0·06; 95% CI: 0·04 - 0·08; acute care: SMD=0·05; 95% CI: 0·00 - 0·09). While estimates vary slightly, in all cases the estimates remain small to negligible according to Cohen’s guidelines.

5.5.5 Meta-regression

Given significant heterogeneity was found in the overall effect size, a meta-regression was conducted to investigate the contribution of different study characteristics to the level of heterogeneity (222, 226).

First, each study level characteristic was examined individually, as presented Table 5.2. The meta-regression suggested that there is a significant negative association between the year of publication and the size of the effect (coefficient=-0.012; p=<0.001). The year in which studies were published also made a substantial contribution to the level of heterogeneity (accounting for 29.7% of heterogeneity). Figure 5.6 presents a bubble plot of the fitted regression line with the size of the circles reflecting the relative weight of the study. This has also been presented as a weighted scatterplot in appendix 5.3.
Table 5.2 Meta-regression with single covariates

<table>
<thead>
<tr>
<th>Study characteristic</th>
<th>Coefficient (SE)</th>
<th>95% CI</th>
<th>Covariate P Value</th>
<th>Joint test for all covariates P Value</th>
<th>Heterogeneity $\tau^2$</th>
<th>Proportion of between-study variance explained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of publication</td>
<td>-0.012 (0.003)</td>
<td>-0.018 - -0.006</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.009</td>
<td>29.65%</td>
</tr>
<tr>
<td>Adjusted</td>
<td>-0.120 (0.047)</td>
<td>-0.215 - -0.025</td>
<td>0.014</td>
<td>0.014</td>
<td>0.009</td>
<td>24.54%</td>
</tr>
<tr>
<td>Study size</td>
<td>-0.000 (0.000)</td>
<td>-0.000 - 0.000</td>
<td>0.802</td>
<td>0.802</td>
<td>0.014</td>
<td>-9.50%</td>
</tr>
<tr>
<td>Study quality (CCAT %)</td>
<td>-0.134 (0.093)</td>
<td>-0.321 - -0.053</td>
<td>0.157</td>
<td>0.157</td>
<td>0.014</td>
<td>-8.97%</td>
</tr>
<tr>
<td>Outcome</td>
<td>0.063 (0.053)</td>
<td>-0.043 - 0.169</td>
<td>0.235</td>
<td>0.235</td>
<td>0.013</td>
<td>-5.30%</td>
</tr>
<tr>
<td>Measure - depression</td>
<td>-0.143 (0.084)</td>
<td>-0.311 - 0.025</td>
<td>0.093</td>
<td>0.463</td>
<td>0.014</td>
<td>-9.87%</td>
</tr>
<tr>
<td>Measure - burden</td>
<td>-0.050 (0.067)</td>
<td>-0.185 - 0.084</td>
<td>0.456</td>
<td>0.456</td>
<td>0.013</td>
<td>-5.30%</td>
</tr>
<tr>
<td>Measure - distress</td>
<td>-0.118 (0.096)</td>
<td>-0.310 - 0.075</td>
<td>0.226</td>
<td>0.226</td>
<td>0.013</td>
<td>-5.30%</td>
</tr>
<tr>
<td>Measure - strain</td>
<td>-0.082 (0.179)</td>
<td>-0.442 - 0.278</td>
<td>0.650</td>
<td>0.650</td>
<td>0.013</td>
<td>-5.30%</td>
</tr>
<tr>
<td>Follow-up for 1-2 years</td>
<td>-0.030 (0.070)</td>
<td>-0.172 - 0.112</td>
<td>0.674</td>
<td>0.513</td>
<td>0.017</td>
<td>-11.38%</td>
</tr>
<tr>
<td>Follow-up or over 2 years</td>
<td>-0.090 (-0.077)</td>
<td>-0.246 - 0.066</td>
<td>0.252</td>
<td>0.252</td>
<td>0.017</td>
<td>-11.38%</td>
</tr>
</tbody>
</table>
Whether studies included unadjusted or adjusted estimates (adjusting for factors such as age, sex, type and severity of dementia, spousal carer and ADL rating) also made a considerable contribution to heterogeneity (accounting for 24.5%; \( p = 0.014 \)). As presented in Table 5.2, it was also possible to examine the contribution of study quality, study size, outcome, and type of exposure measure and the period of follow-up, though it would appear these all explained less heterogeneity than would be expected by chance (226).

Those variables found to be significant were entered into a meta-regression with multiple covariates (Table 5.3). In this model, the year in which studies were published and whether studies included adjusted or unadjusted estimates accounted for 46% of heterogeneity. The remaining heterogeneity was small (\( \tau^2 = 0.007 \)) (226).
Table 5.3 Meta-regression with multiple covariates

<table>
<thead>
<tr>
<th>Study characteristic</th>
<th>Coefficient (SE)</th>
<th>95% CI</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of publication</td>
<td>-0.011 (0.003)</td>
<td>-0.017 - 0.005</td>
<td>0.001</td>
</tr>
<tr>
<td>Adjusted</td>
<td>-0.094 (0.041)</td>
<td>-0.177 - 0.011</td>
<td>0.027</td>
</tr>
</tbody>
</table>

Model Heterogeneity $\tau^2$: 0.007
Proportion of between study variance explained: 45.51%
Model P Value: 0.001

5.6 Discussion

5.6.1 Summary of evidence
The results of the review suggest that while carer stress has a significant effect on subsequent institutionalisation of care recipients, the size of this effect is small to negligible according to Cohen’s guidelines (219). The sensitivity analysis reinforced this overall effect size. Firstly in terms of the type of measure, whether the exposure was a measure of burden, stress, distress, or depression the effect size remained small to negligible. Similarly, whether the outcome was acute or LTC the effect size was found to be negligible. This was also the case when examining estimates solely with measures of stress or burden, according to the Stress Process Model (27). The effect size for studies with estimates that had adjusted for other factors (bar stress) were substantially lower than with studies with un-adjusted estimates.

Consistent with the finding of the sensitivity analysis, the meta-regression found a negative association between the year in which studies were published and the size of the effect of stress. This association between year of publication on effect size was also found to contribute substantially to the level of heterogeneity as did the use of adjusted or unadjusted estimates.

Taking the findings together, while carer stress is significant predictor of institutionalisation, the size of this effect suggests that other factors may be more crucial in institutional placement than carer stress. When systematically reviewing
the association between other factors (bar stress) and acute care utilisation, a number of studies have found prior hospital admissions and duration of previous hospital stay and co-morbidity to be predictive of admission to acute care (206, 207). Other studies found functional and cognitive impairment and prior nursing home use to be predictive of admissions to LTC (13, 16, 17, 57) (see Chapter 2). This review suggests that future research should perhaps concentrate on these and other factors in the prediction of institutional care utilisation as it appears that carer stress is not the most critical determining factor of institutionalisation in older care recipients.

The sensitivity analyses indicated that in each of the last four decades, effect estimates have decreased. They are also lower in studies with larger samples. This was consistent with both the funnel plot and findings of the Egger’s test, suggesting that small studies over-estimate the size of the effect of carer stress on institutional care utilisation of care recipients. Study quality was also found to have a substantial impact on estimates; with estimates reducing as study quality improves.

These findings suggest that, over time, as studies have increased in size, quality has improved, and more factors have been taken into account, the size of the effect has reduced. This suggests that the significant association found between carer stress and institutional care utilisation in initial studies in this area may have resulted in a belief that higher levels of carer stress can undermine the sustainability of homecare. However, in later years this does not appear to have been critically evaluated, with researchers possibly relying on these initial studies to provide evidence for such contentions (56, 165).

The present findings therefore suggest a need to re-examine this assertion in the literature – while carer stress has a significant effect on subsequent institutional care utilisation by care recipients, the actual size of this effect is small to negligible. This would suggest that carer stress is not a critical determining factor of institutional care utilisation by older care recipients, and that strong statements to the contrary are not based on the evidence available (56, 62).
Such publication bias in psychology is not uncommon. An examination of publication bias in psychology found that barely-significant values were much more frequently reported than values that just failed to reach the conventional threshold for statistical significance (227). For example, a study which replicated 100 articles in psychology, found a considerable number of reproduced results produced weaker evidence than was found in the original article (228). In 97% of original studies effects were statistically significant. However, the authors found only 36% of reproduced results had significant effects (228). The article also found the mean effect size of reproduced results was half that found in the original articles. The authors believe that publication bias towards publication of significant results may explain the difference between the number of positive results from original articles and the number of reproduced results (228). Such publication bias impedes the publication of non-significant replication studies (229, 230). Consequently we see the continued publication of numerous ‘undead’ theories or what Ioannidis describes as ubiquitous false positive claims (230, 231).

The findings should not be interpreted as undermining the significance of chronic stress on carers, or the importance of RCTs aimed at reducing carer stress. The level of stress experienced by a carer is important both of itself and for its potential impact on the carer, such as impaired psychological well-being and physical health (42), including weakened immunity and wound healing (44, 232). Indeed, a number of meta-analyses and systematic reviews have concluded that carers are more likely to have poor psychological and physical health outcomes when compared to non-carers (42, 43) (see Chapter 2). However, as stress appears to have a negligible effect on institutional care utilisation, it is unlikely that RCTs in this area will have an effect on institutionalisation rates.

Finally, the findings suggest carer stress may not be considered a substantial risk factor in institutionalisation according to two of the Bradford-Hill criteria (see Chapter 2, section 2.13). According to this criteria, the larger the size of the effect of the exposure on the outcome, the stronger the evidence that the exposure is a risk factor for an outcome. As stress appears to have such a small to negligible
effect on institutionalisation, this would suggest it may not be as strong a risk factor as was previously believed in the literature (see Chapter 2, section 2.11). In tandem with this, as stress appears to have such a weak effect on institutionalisation, it is unlikely that carer stress would meet the Bradford-Hill criterion of reversibility (where the outcome does not occur if the exposure is removed or reduced) (167-169).

5.6.2 Interchangeability of measures
The review found substantial inconsistency across the measurement of psychological morbidity in carers. This inconsistency was apparent in a number of ways. Firstly, the same exposure was assessed with a range of measures. As described earlier, in seven different studies burden was measured seven different ways.

Inconsistency was also seen within and between studies. For example, within some studies the same measure was referred to as both a measure of stress and burden, similarly in different studies the same measure was referred to as a measure of burden, stress, or distress (71, 146, 223, 224).

The tendency of some researchers to regard measures of carer burden and depression as synonymous with measures of stress has been acknowledged in the literature (137). This meant that it was necessary to combine these exposures in the present review. However sensitivity analyses did not suggest substantially different effects for these separate measures on care recipient institutional care utilisation. This confusion in the caregiving literature points to a need for the development of an agreed taxonomy to enable more concise identification of interactions relating to psychological morbidity in the caregiving process.

5.6.3 Strengths and limitations
Given the lack of clarity and consequential interchangeability in the measurement of psychological morbidity, the search strategy had to incorporate a wide number of exposures that are measured under the umbrella term ‘carer stress’. It could be
argued that these exposures represent distinct concepts that when pooled may result in misclassification bias. However, there was theoretical and methodological support to pool the exposure measures. This was in addition to the practical considerations outlined above given the contradictory literature.

Firstly, Cramer et al., have developed a network approach to mental disorders and comorbidity. According to this approach, symptoms are viewed not as indicators of latent conditions but as components in a network (233). Borsboom et al. employed this network model to show that half of the symptoms in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) are connected (234). As recommended by Bradburn et al. and Take et al. to enable pooling, the primary measure of effect was the standardised mean difference using a random effects model (214, 215). By standardization, the results were transformed to a common scale and the random effects model combined data under the assumption that the effect is not fixed between populations but varies around a typical value. Finally, despite the wide variation in exposure measures the meta-regression found that differences in the type of exposure measure explained less heterogeneity than would be expected by chance, providing further support for pooling measures.

The sensitivity analysis examined major aspects of study design that could affect estimates. This included dementia or non-dementia populations, cohort or intervention studies, and the period of follow-up. These were found to have a minimal impact on estimates. However, there may still be un-measured confounders. These may include the effect of community care utilization or the degree to which access to LTC varies over time and between health systems - given the availability of beds, differential professional assessments and criteria to access LTC. The region in which studies were published was accounted for in the sensitivity analysis. Estimates between regions were found to be small to negligible. However, it would not be appropriate to give too much weight to this comparison given health system variation within and between countries as well as over time. This would be more appropriate in future research.
Finally, the lack of access to unpublished data could also be regarded as a limitation. However, both the funnel plot and the Egger’s bias coefficient strongly indicated the presence of publication bias, suggesting small studies overestimate the effect of stress (225). Therefore, had it been possible to access unpublished data, it is likely that the effect sizes found would have been even smaller than what was found.

5.7 Conclusion
The results of this review suggest that while carer stress has a significant effect on subsequent institutional care utilisation by care recipients, the size of this effect is small to negligible. The sensitivity analysis reinforced this finding, irrespective of the type of measures used. The results also highlight the problematic nature of the contradictory literature in terms of the interchangeability in the measurement of stress.

The findings of this systematic review are at odds with the strong contention that higher levels of carer stress could undermine the sustainability of homecare (55, 56, 235). The results suggest that publication bias, or at least small study effects, have contributed to this belief. The findings should not be interpreted as undermining the significance of chronic stress on carers. As referred to above, a number of meta-analyses and systematic reviews have concluded that carers are more likely to have poor psychological and physical health outcomes when compared to non-carers. However, the size of the effect of carer stress on subsequent institutional care utilisation suggests that other factors may be more crucial in institutional care utilisation than carer stress.

5.8 Implications for this thesis
The findings from the review and meta-analysis have two major implications for the thesis question. Firstly, a carer is ultimately responsible for the decision to cease the continuation of homecare. However, carer stress appears to have a small to negligible effect on institutional placement of care recipients, according to a very biased literature. Therefore, a more in-depth examination of the factors which do
exert influence on admission to LTC and the role of carer stress in this process is needed. This is explored in the following chapter (Chapter 6), which provides the results from a qualitative study of carers and healthcare professionals who are key to the LTC admission process.

The second major implication of these findings relate theoretical models for the thesis, especially for the Pearlin et al. model and the Luppa et al. model as this is based on Pearlin et al. model. (22, 27). As discussed in Chapter 2, for Pearlin et al. the stress carers’ experience as a consequence of providing care drives a process that ultimately results in the termination of homecare. However, the meta-analysis suggests that carer stress has a negligible effect on institutionalisation of care recipients (both in acute and LTC utilisation). Therefore, the findings in the meta-analysis appear to contrast with these theoretical models. This suggests a need to re-evaluate the applicability of these models to the relationship between carer stress and institutional care utilisation by care recipients. This is addressed in the next chapter and in Chapter 8 which presents the results of the secondary analysis of the TILDA dataset.
Chapter 6  “There’s no help out there”: How influential is carer stress in LTC admissions of people with dementia? Qualitative findings from healthcare professionals and carers

6.1 Overview
This chapter presents the results of the first part of Study 2. This part of the study explored the influence of carer stress in LTC admissions from the perspective of healthcare professionals and carers. Qualitative interviews were undertaken with healthcare professionals and carers and the results analysed thematically. The findings are discussed in the context of the Pearlin et al. and Luppa et al. theoretical models and broader caregiving literature. The chapter concludes by examining the implications of the findings for this thesis.

6.2 Introduction
According to the Pearlin et al. Stress Process Model (27), and a number of studies (14, 28, 53-55, 58-64, 66-75, 146) the stress from providing care drives a process that ultimately results in the termination of homecare and LTC placement of the care recipient. However, the meta-analysis reported in the previous chapter indicates that carer stress is only negligibly associated with either acute (SMD =0·05, 95% CI=0·00 - 0·09) or LTC admissions (SMD =0·06, 95% CI=0·04 - 0·08) (203). The results suggest a need to re-examine the belief that carer stress could undermine the sustainability of homecare and that other factors are probably more important in LTC admissions and need to be investigated. Therefore, a qualitative component to the thesis was undertaken to build on the findings of the meta-analysis. As described in Chapter 4, this qualitative component consisted of two parts, with separate objectives. This chapter presents the results of the first part of this study.

6.3 Objective
The objective of the first part of the qualitative study was to explore healthcare professionals’ and carers’ perceptions of the key factors that influence LTC
admission of people with dementia, and the extent to which carer stress features in this decision, if at all.

6.4 Context
The study was conducted in the context of the Irish healthcare system. In Ireland, the national health service agency, the HSE, provides the majority of public acute and community care services (see Chapter 2, Section 2.15). The main State-funded community support services for older people consist of community-based public health nursing and homecare support packages. These packages include community health nursing, home-help for domestic tasks, and/or personal care assistants for intimate personal care, such as washing or dressing. Respite may also be provided, depending on the person’s needs and where they live. Other HSE services for older people in the community include Physiotherapy, Occupational Therapy, Speech and Language Therapy and Social Work.

Public access to LTC facilities is provided through the Nursing Home Support Scheme. This scheme is administered by the HSE through the ‘Fair Deal’ scheme (179). Under the scheme, applicants contribute to the cost of LTC and the State pays the balance (see Chapter 2, section 2.15).

6.5 Methods
A qualitative methodology was deemed the most appropriate for this study as it has an “unrivalled capacity to constitute compelling arguments about how things work in particular contexts” (236 p.1). A qualitative approach provides an opportunity to develop insights into the lived experiences of healthcare professionals and carers. The study focused on their perceptions of the critical factors in the decision that LTC was necessary. The study was also concerned with developing a more in-depth understanding of the role of carer stress in this process.
6.5.1 Study design
The study sought the perspectives of two distinct groups of individuals: healthcare professionals that are key decision-makers regarding the transition to LTC and carers. Thus the design for this study was a two-phase semi-structured in-depth qualitative interview study.

6.5.2 Sample
The study adopted a purposive sampling strategy. Participants were selected because of their extensive knowledge of LTC admissions in Ireland or direct experience of the process of transition of a family member to LTC (237).

6.5.2.1 Study groups
The study groups consisted of healthcare professionals and carers from all around Ireland. Healthcare professionals were hospital and community-based professionals that were key decision-makers regarding the transition to LTC. The carers were carers of people with dementia. This study focused on carers of people with dementia on advice from a consultant Geriatrician and as dementia caregiving has been acknowledged as the most stressful form of caregiving (121). Therefore, should carer stress be a risk factor in LTC admissions, it is likely that this would be most apparent amongst carers of people with dementia. The carers in this study were those who, with their family, had decided homecare was no longer sustainable so had started the process of applying for LTC. This may have been either applying to the ‘Fair Deal’ scheme or intending to pay privately for LTC. Carers who had gone through the process in the last six months were also included. The inclusion criteria are outlined in appendix 6.1

6.5.2.2 Ethical approval
Ethical approval for the study was obtained from the Research Ethics Committees (RECs) of the Royal College of Surgeons in Ireland (RCSI) (Ethics Reference number: REC1057b) and a major teaching Hospital in Dublin. The approval letter from the RCSI REC is provided in Appendix 6.2.
6.5.2.3 Sampling procedure

Sample size guidelines for qualitative interviews according to the literature range between 20-30 interviews (238). Other guidelines suggest 10-15 (239). Given these guidelines, a rough estimate of 15-20 interviews was envisaged for each study group (healthcare professionals and carers). However, the precise number of interviews conducted was dictated by data saturation. Data saturation involves interviewing participants until no new data emerges (237). A total of thirty-eight interviews were conducted; twenty-two with healthcare professionals and sixteen with carers.

6.5.2.4 Recruitment

In compliance with REC requirements, participants were not contacted directly. Therefore, a number of simultaneous recruitment strategies were employed. Healthcare professionals were identified through contacts of a consultant in geriatric medicine. Healthcare professionals were also identified through snowballing contacts in the Division of Population Health Science in RCSI and the wider RCSI community. The Participant Information Leaflet was circulated by post by the PhD Scholar and in person to aid in recruitment (see appendix 6.3). Participants were also provided with postcards containing information about the project and contact details of the PhD supervisor and PhD Scholar to pass on to colleagues in order to drive recruitment (see appendix 6.4).

The PhD Scholar also prepared a press release on the study to coincide with National Carers Week (see appendix 6.5). This was picked up in a number of healthcare websites (see appendix 6.6) and on local radio. The study was also advertised in the major teaching Hospital, by the Institute of community health nursing in Ireland and by the Centre for Ageing Research and Development (CARDI) Ireland (see appendix 6.7).

Carers were identified through a number of strategies:
(a) Community-based healthcare professionals identified carers that met the inclusion criteria (see appendix 6.1). The healthcare professional informed eligible carers of the project and went through the Carer Participant Information Leaflet during routine visits (see appendix 6.8). The healthcare professional left the study postcard and Participant Information Leaflet with the carer (appendices 6.4 and 6.8). These documents contained the contact details of the PhD supervisor and PhD Scholar. Carers who wished to participate then contacted the PhD Scholar.

(b) The PhD Scholar applied to the Carers Association, Care Alliance Ireland, and Caring for Carers for access to carers. These organisations advertised the study in organisational newsletters, websites and on Facebook (see appendix 6.9). Staff in these organisations that worked directly with carers informed eligible carers of the project and left the study postcard and Carer Participant Information Leaflet with the carer (see appendices 6.4 and 6.8). Carers then contacted the PhD Scholar.

(c) The study was also advertised on Facebook, through on-line carer forums, or other carer websites such as Redpandacare.com and seniorcare.ie (see appendix 6.10).

6.5.3 Data collection

During the initial contact with healthcare professionals and the carer the PhD Scholar went through the relevant Participant Information Leaflet with each participant (appendices 6.3 and 6.8). This was done to ensure informed consent – that participants were fully aware of the study aims, what was involved and answer any questions the participant had. Participants were informed of their right to refuse to participate or withdraw from the study at any time and of the confidentiality of study data. The REC in the teaching hospital raised concerns regarding the risk of elder abuse in overly stressed carers and requested clarification on the procedures in place where confidentiality would need to be breached in such cases. Following this, a protocol was developed on the procedures for managing cases where confidentiality might need to be breached (appendix
The Carer Information Leaflet also outlined the limits of confidentiality (appendix 6.8).

Once informed consent had been obtained through signed consent forms (see appendix 6.12), data were collected through semi-structured interviews. Semi-structured interviews are a method of data collection which has been reported to be the most appropriate technique when seeking in-depth understanding of a phenomenon (237). These interviews provided an opportunity to gain an understanding of the critical factors influencing the decision to transfer an older care recipient to LTC. This was from the perspective of those who are central to the process of admission to LTC.

Interviews were conducted from May to August 2015. They were held in a location convenient for participants. Each interview lasted approximately an hour. Interview guides were prepared and reviewed during data collection (see appendices 6.13-6.14). Interviews were conducted in two parts. The first part consisted of a relatively unstructured narrative section. This allowed carers to tell their own story of becoming a carer and how the caring situation progressed. Healthcare professionals were asked to describe their role in LTC decision-making. This narrative section was undertaken to capture participants’ insights on how they recognise the need for LTC.

The narrative section was followed by a more semi-structured section. This explored the LTC decision-making process and the role of carer stress in this process. Splitting the interview in this way ensured the interview was led by the participants own story. It also gave time for the participant to relax into the interview and for rapport to develop between the PhD Scholar and the participant. This interview strategy has also been adopted in other studies using semi-structured interviews (240). After interviews, participants were offered the opportunity to review interview transcripts should they wish. One participant opted to review the transcript.
6.5.4 Analysis

According to Yardley’s evaluative criteria of qualitative research, there ought to be transparency in all stages of the analytical process (241). Thus a detailed description of how the data were analysed is provided. Interviews were audio-recorded and transcribed verbatim for analysis. Data analysis was supported with the data management software NVivo10.

Interviews were analysed thematically. Thematic analysis involves systematically analysing each interview transcript to identify codes. These codes are then amalgamated into key themes that address the research question (242). As thematic analysis is not tied to any particular discipline or set of theoretical constructs it is a widely used analytical approach in qualitative research (237).

Data analysis began by the PhD Scholar undertaking line-by-line coding of each transcript. Appendix 6.15 provides an example of how two codes emerged from line-by-line coding. Once each transcript was coded an initial coding framework was developed. This coding framework was based on anticipated themes, the theoretical models, findings of the systematic review and emergent themes.

Themes were developed using the ‘One Sheet of Paper’ (OSOP) method. This method was developed by the Health Experiences Research Group (HERG) at the University of Oxford (243). This enabled comparison of codes within a theme to ensure consideration for nuances in the analysis. The PhD Scholar and the supervisory team reviewed and discussed the initial coding framework. The coding framework is presented in Figure 6.1 below.
Figure 6.1 Coding Framework: Study 2 Part 1
6.6 Results

6.6.1 Profile of respondents
A total of twenty-two healthcare professionals were interviewed, the majority of whom were female (n=18). The largest group of professionals (n=13) worked in nursing and included Public Health Nurses, Community Registered General Nurses, Clinical Nurse Managers and Clinical Nurse Specialists. These professionals were based both in the community and in hospitals. Some professionals worked in both settings. The other professional groups interviewed were Social Workers (n=3), GPs (n=2), and one Geriatrician, Psychologist, Occupational Therapist and Manager for Older Person’s Services. Participants had been supporting older people and their families transitioning to LTC for a number of years (ranging from 4 to 22 years).

All of the sixteen carers interviewed were providing care to a person living with dementia. The majority of carers were female, three male carers participated. Nine participants were providing care to a spouse (6 spouse carers were female), while seven were providing care to a parent (7 were daughters providing care). Carers were on average 60 years of age. The average age of the care recipients was 78 years of age.

6.6.2 Overview of findings
Three main themes emerged from the analysis (see Figure 6.1 above). Firstly, that carer stress is an important aspect of the journey to LTC. Secondly, the LTC decision has to be based on the care recipient’s needs, rather than carer stress. Therefore, while carer stress is acknowledged as an important aspect in the journey to LTC, it is not seen to be a driver of LTC admissions. The final theme examines dementia-related care needs that influence LTC admissions.

6.6.3 Carer stress is an important aspect of the LTC journey
For many healthcare professionals, carer stress was an important aspect to consider when supporting families in the provision of homecare and in the journey to LTC. Two main reasons emerged from the analysis of this. Firstly, the caregiving
responsibility often falls to one person. Secondly, carers are required to meet high demands in the caregiving role. They feel unsupported and powerless to meet these demands. Concurrently, they have an immense commitment to the role. The combination of these factors causes carers to feel they cannot cope and so experience stress.

6.6.3.1 Sole carer

It would appear that the provision of care is quite often left to one person. This was irrespective of whether the carer was an adult child or a spouse of the care recipient. There may be other siblings, adult children or in-laws available who are either completely un-involved or who may ‘call in for a visit’. However, they are not hands-on in the provision of care. In some cases, the carer had an adult child or sibling who would take over care for a few hours. On the whole, the caregiving role was left to one person. As described by this healthcare professional:

“Oh, it’s one family member who everything has been thrown at and everybody else has kind of left them at it.” (Healthcare professional 8)

Some carers that participated felt this may have been because the other family members were not living with the care recipient and therefore did not realise the extent of care that was required. In some cases, that lack of support from other family members led to conflict within the family.

“As Dad’s needs grew and as I felt more and more, kind of left alone with this role…I did have the old screaming match [with a sibling]…I did kind of say “where are you?” [intonation] and he said “well you took this on” and I said to him “not as an only child.” (Carer 4)

Other carers expressed their reluctance to ask for help. There were a number of reasons for this, including pride, recognising the commitments other family
members had, protecting the dignity of the care recipient, or protecting their children from the extent of the care that was needed. As this carer described:

“No, no, I’d no support. No, I did it all myself and half the time they didn’t know. I didn’t tell them about the awful incontinence things that were happening. I didn’t tell them half of what was happening.” (Carer 7)

Overall it appeared that carers were largely left to provide the majority of care on their own. The effect of provision of this care on carer stress is explored below.

6.6.3.2 Inability to meet caregiving demands drives carer stress

Carers spoke about the demands of caregiving as being “twenty-four-seven”. The carer had to be constantly alert to respond to the needs of the care recipient. As this carer described:

“I was finding it more and more difficult to cope with the whole situation. The constant fact of being here twenty-four-seven and trying to get the meals ready and trying to get her to eat and drink and do all these things...I had to sit with my wife all the time...my nerves were shattered...I had no escape from it...even when you’d tried to sleep you’d have an ear and one eye open because you are listening. Because there was a problem that she could fall out of bed...it takes over your whole life.” (Carer 10)

Carers described how the intensity of the recipient’s needs meant that the caregiving role became all-encompassing. The role of carer limited their opportunity to work, to socialise or plan for anything outside of caregiving. Prior to the caregiving role, carers’ had medium or longer term plans for their own future. These included plans for travel in retirement, career progression or to meet a partner and start a relationship. However, the care recipient’s needs had to be
prioritised and so carers described how their own life was “on hold” (Carer 4) as everything they did revolved around the care recipient. As this carer described:

“You felt your life was no longer your own as a carer.” (Carer 14)

In addition to the demanding nature of the role, there was a sense of powerlessness in the role. This was apparent in carers’ description of the unpredictability of caregiving. A care recipient’s needs could change quite rapidly.

“From one week to the next, you just don’t know what’s going to happen.” (Carer 11)

There was also a sense of powerlessness in the face of the escalating needs of the care recipient and the struggle carers experienced in trying to meet these needs. As this carer, who cared for her husband, described:

“He started to deteriorate... just his health went so bad that his health, sure events came out of my hands. Everything came out of my hands, all these events came out of my hands.” (Carer 1)

The sense of powerlessness was compounded by the fact that the majority of the care was left to the carer alone. As carers struggled to meet the care recipient’s needs at home, they turned to healthcare services for support. However, carers described receiving the recipient’s dementia diagnosis as part of a hospital consultation and then being “turfed out on the street” (Carer 6) without any supports or any direction of where to go to access support.

All carers repeatedly described the struggle they faced in navigating and accessing healthcare services, particularly community care services. In the Irish context, these services appear to be under-resourced, limiting their availability. There was also
substantial inequity in availability of services. For those who did manage to access the services, the manner of services delivery undermined its quality. Each of these aspects are explored in the next chapter.

The findings indicate that services which are essential to the continuation of homecare were inadequate. Carers undoubtedly experience stress as they struggle to meet the care recipient’s care needs. This stress was, in many respects, overshadowed and possibly caused by the stress they described from the lack of sufficient community care services to support homecare.

“When you started looking for the care, that’s when you realised that everything was up against you...we were just cut adrift and that was it...it’s very annoying. It’s very annoying. It’s very frustrating, it’s very frustrating. You’re going through all this and there is no help out there. There’s nothing....it just seems like Ireland is no place for an old person any more. In terms of any kind of care.” (Carer 3)

At the same time, carers expressed an immense commitment to the role. There was a clear desire to respond to the care needs of their loved-one. Carers spoke about not wanting anyone else to take over the caregiving role, because it was their spouse or their parent. So carers resisted ‘giving-up’ on the role. This was born out of a mix of both pride in undertaking the role and guilt in admitting they could no longer continue to provide the levels of care the recipient required. This commitment to the role meant carers were reluctant to start the journey towards LTC.

Overall, the findings suggest that the commitment carers had to the role, along with the intense nature of the role, feeling alone and powerless in meeting high and unpredictable care demands caused carers to feel stressed (see Figure 6.2). This stress was exacerbated by the lack of community care services to provide carers with the supports and resources necessary to continue homecare. Healthcare
professionals also recognised the lack of requisite resources to support carers and acknowledged that this was likely to cause carers to experience stress.

“If the carer is presenting as stressed...it means they are struggling to find or don’t have enough resources to meet the demands...their loved-ones physical and emotional needs.” (Healthcare professional 13)
Figure 6.2 Imbalance in demands in caregiving, powerlessness and commitment to role results in stress
6.6.4 Carer stress is not a driver of LTC admissions

A second major theme to emerge from the analysis was that both healthcare professionals and carers did not regard carer stress as a driver in the LTC admission process. Three reasons emerged from the analysis to underpin this view. Firstly, that all carers were stressed and so continued to provide care irrespective of the stress they experienced; secondly, that stress was something which is transient and could be addressed, so carer stress alone would not lead to a recommendation of LTC; finally, admission to LTC is based on the care recipient’s needs first and foremost, not the level of stress a carer is experiencing. These findings are described in detail below.

6.6.4.1 All carers are stressed

Healthcare professionals were asked whether they would suggest LTC to a family if a carer appeared to be particularly stressed. Some participants quickly dismissed this by responding that all carers are stressed. Thus the professional would not suggest LTC on the basis of carer stress alone. As this healthcare professional described:

“All my carers are stressed. There’s none of my carers that aren’t stressed...If it’s stress alone, no.” (Healthcare professional 7)

6.6.4.2 Stress is transient

Healthcare professionals also felt that as carer stress is transient, it would not be appropriate to suggest LTC solely on the basis of carer stress. If a carer was stressed, healthcare professionals would first look at other avenues to try and relieve that stress.

“I don’t think all carers just because you’re stressed you tell them to go into, you have to work in the community to see what you can do for them first...a break once or twice a week can totally reduce stress...I’ve seen it
The first way that healthcare professionals would address carer stress was by seeing if the family had a homecare package. If the family were in receipt of a package, the professional would check if the package needed to be increased. As described above, homecare packages involve a care assistant and/or home help coming into the family home for a number of hours a week to help with personal care, such as washing or dressing. This is done to also give the carer a break.

Healthcare professionals would also look at other options such as a day centre or respite care, where it was available. Other supports discussed included having more support from healthcare professionals including Social Work, Allied Health Professionals, such as an Occupational Therapy (OT), or Community Nursing visit the family more regularly. However, as discussed in the next chapter, these community care services are minimal to non-existent and so were limited in the extent to which they could alleviate carer stress. Healthcare professionals also suggested exploring other options for other family members to provide more support, where possible.

Education was also reported to be an important mechanism to reduce carer stress, for example, by training the carer in how to manage a care recipient’s behaviours that challenge, manual handling, nutrition and incontinence management. Finally, to address carer stress, healthcare professionals suggested that the carer joined a carer support group. That is if they had enough support available to leave the care recipient during this time. Healthcare professionals felt that if the carer could meet with other carers in similar situations, it could reduce the isolation the carer experienced and relieve their stress. Some carers spoke about how beneficial they found attending such carer support groups:
“It is because you know what they’re talking about when they’re talking about looking after this or this happened or that happened... They’re similar stories so it’s great. You know, just to get the break is brilliant altogether.” (Carer 16)

6.6.4.3 LTC decision based on care recipient’s needs

Finally, interview findings indicated that, in the decision to transition to LTC, the care recipient’s needs outweigh the level of carer stress. All of the healthcare professionals interviewed emphasised this. However, there appeared to be slightly different approaches to this. For some healthcare professionals, the idea that carer stress would drive LTC admissions ignored the autonomy of the care recipient. These professionals described the autonomy of the care recipient to be critical in the LTC decision. That is the wishes of the care recipient to remain at home had to be respected and facilitated, as much as is possible, irrespective of the carer’s concerns. For another group of professionals (n=5), recognising that the carer was not coping with the increased care needs could also influence whether they would suggest LTC to a family. As this professional described:

“I suppose a lot of it would come from the carers and them saying that they are struggling at home, that they are not managing because the patient or their relative is now incontinent or that they are getting up three or four times a night or maybe they are not sleeping at night at all...if the carer is explicitly saying...“I don’t know how much longer I can do this.” I suppose we would really listen to that and then try and get them to plan for the future and to plan for alternative care for their relative.” (Healthcare professional 1)

However, it should be noted that these healthcare professionals emphasised that they would not start the LTC discussion solely on the basis of carer stress - if the care recipient’s needs did not warrant transitioning to LTC. Also healthcare professionals would only start the discussion around LTC if the carer was unable to...
cope and the family were already in receipt of the maximum level of community supports available. If the family had maximum supports and still could not meet their loved-ones needs, then suggesting LTC to the family was the only option available to healthcare professionals.

The second group of professionals emphasised that it is not carer stress, but the escalation of the recipient’s needs to the point at which they cannot be met at home that causes LTC admissions. These professionals felt the decision that LTC is necessary is most pressing at the point where the care needs require twenty-four hour care. As this healthcare professional described:

“Normally it’s one person doing twenty-four hour care would ring alarm bells in my head... rather than you’re pulling somebody because the carer is stressed.” (Healthcare professional 8)

This would suggest that once twenty-four hour care is required, “the care needs are so great it’s impossible to match at home” (Healthcare professional 2). When carers’ cannot meet their loved-ones’ needs at home they are undoubtedly stressed. Therefore, the escalation of care recipients’ needs to a point where they are beyond that which can be met at home drives both carer stress and the need for LTC. However, it appears that it is these care needs which drive the LTC admission, not carer stress. This is because the care needs are so intense that homecare is no longer feasible, irrespective of the level of carer stress. In describing the LTC decision, carers also emphasised how this decision was driven by the inability to meet their loved-one’s needs at home, as this carer described.

“It happened because I could no longer look after him... when I tried to do something for him he’d just lash out at me... so it got that I knew I was doing him no favours if I kept him at home...I didn’t do it because I wanted to do it. I did it because I had to do it...because he wasn’t being
cared for because I couldn’t care for him... I knew there was nothing I could do for him.” (Carer 14)

6.6.5  Dementia-related needs critical in LTC admissions

The third and final theme to emerge from the analysis was the dementia-related needs which are critical to LTC admissions. Participants identified a range of dementia-related needs that were influential in LTC admissions. This theme explores the specific needs that appeared to be the most dominant in nursing home placement.

6.6.5.1  Safety

As dementia advances, it can compromise a care recipient’s awareness of danger. This was described in a number of ways. Firstly, carers described how they would get calls from neighbours, for example, because their loved-one was walking about with “a brick of money in his pocket” (Carer 2). Participants also discussed safety concerns in scenarios whereby the care recipient would turn on a tap, the gas or electric cooker, then get distracted and walk away.

Healthcare professionals described a range of assistive technologies to support people to live safely at home for as long as possible. These included GPS trackers, exit alarms for the doors and windows, smoke and carbon monoxide detectors synchronised to personal alarm systems, falls alarms, flood alarms, heat alarms, memory aides, gravity alerts, dose-set medication systems that will alarm and only give out medication at certain times of the day. However, as dementia progresses, these technologies were described as becoming inadequate in the provision of care. At the more extreme end, advanced dementia can lead to psychotic episodes. This can result in significant safety concerns. Healthcare professionals described the challenge in managing these safety concerns.
“You have obviously to keep as much independence as possible and manage the risk. But then it comes to a time when it is just not feasible... I would have had carers that...would have had everything. But...no matter what we did with medication from a behaviour management point of view, from a communication point of view, from checking that there was no delirium. You know whatever management techniques we did in the community....none of them are meeting the needs.”

(Healthcare professional 3)

As concerns around safety increase, extensive supervision is required. The need for supervision is one example of where carers turn to community care services in the struggle to meet the recipient’s needs. The HSE homecare packages cover personal care (such as washing and dressing), but they do not cover supervision or a “sitting service” (Healthcare professional 15). Healthcare professionals described the difficulty they faced supporting families who just needed supervision. This would often result in the professional ‘gaming’ the system in order to get the package. As one professional described:

“You would end up maybe changing the wording to say that the actually do need help with personal care, like prompting or supervision with dressing themselves, which actually they don’t need. But you’re just saying that so that they get the homecare package.” (Healthcare professional 22)

The Carers Association and the Alzheimer’s Society of Ireland provide these supervision services. However, as these organisations are charities, resource constraints results in significant waiting lists for these services. Consequently, it is very difficult for healthcare professionals to offer services to people where supervision is required. Therefore, if a recipient is to remain at home and needs supervision, this has to be provided by the carer.
The levels of supervision often increase to the extent that twenty-four hour supervision is required. As the responsibility of providing care is often left to one individual, as discussed above, it is not feasible that one person alone could provide twenty-four hour supervision on an on-going basis. Whilst the carer may be eager to postpone the transition to LTC for as long as possible, there comes a time when providing such level of supervision is no longer possible.

“They can’t provide twenty-four hour supervision...if you’ve been told your loved one needs twenty-four hour supervision and you can’t provide it, you don’t have a choice.” (Healthcare professional 7)

This requirement for substantial, often twenty-four hour supervision, demonstrates two critical points. Firstly, that carers have to provide such high levels of supervision alone, with minimal to no support from community care services, places carers in extremely stressful situations. Secondly, as the carer cannot provide this level of supervision continuously, they are left with no option but LTC. This carer’s description of coming to the decision that LTC is necessary illustrates both of these points.

“She can’t be on her own at all now. She needs somebody with her the whole time...who knows exactly what they’re doing and unfortunately that’s not me...you’re kind of taking pot shots in the dark when you’re a carer because most of us come into it with no training and no knowledge...you don’t know if you’re adding to the agitation by what you’re doing...you’re worried that something will happen the minute that you’re not looking or that minute that you’re doing something else for two seconds...I suppose keeping the person safe and making sure that you are doing right by them that’s a big consideration when you’re talking about full-time care....basically the main consideration is we can’t keep her safe anymore and we can’t.” (Carer 5)
6.6.5.2 Drop in baseline status following acute admission

Participants discussed how detrimental an Emergency Department visit or an admission to acute care can be for a person living with dementia. The Emergency Department and acute medical wards are unfamiliar environments for people with dementia. They also involve interaction with many different healthcare professionals. One healthcare professional described acute care as “a completely unsuitable environment for anyone with dementia.” (Healthcare professional 3)

Consequently, people with dementia can become quite confused and distressed during an Emergency Department visit or an admission to acute care. Healthcare professionals emphasised how an acute admission can result in a drop in the functional and/or cognitive baseline status of the care recipient (their normal functional and/or cognitive capacity prior to the admission). This drop in baseline status may mean the recipient is then on the journey to LTC. They may go home from acute care, but not return to their cognitive or functional status prior to the admission. Alternatively, the deterioration of the care recipient during the admission may be to such an extent that it is no longer possible to return home. The admission to LTC then happens from acute care, as this professional described of care recipients:

“It can take so much from you physically that you might have been in a better place before you came into hospital, but you are not now. That that’s taken so much from you that you are at a new baseline as it were and physically you just can’t go home.” (Healthcare professional 6)

6.6.5.3 Mobility

As the care recipient’s risk of falling increases, the level of supervision required increases. Once the recipient becomes completely immobile, transferring the recipient from the bed to a commode or shower, etc. becomes extremely difficult. It may be possible to do a transfer with a hoist. However, access to hoists in the community are very limited, they require specialist training and need two people to
use, though as described above, often there is just one person providing care at home.

Participants spoke about possible adaptations to the house to keep the care recipient at home, such as a lift to access the bathroom upstairs. However, many houses are not big enough to accommodate a lift. This then leaves the carer with no choice but to consider LTC. As this carer described:

“It was the fact that the house isn’t big enough to bring in a lift...So the fact that the [ability to] walk went was the biggest decision that we just said we just can’t do it anymore here...Mobility was the biggest factor I’d say.” (Carer 16)

6.6.5.4 Incontinence
All participants reported that managing incontinence at home was extremely difficult. It required the carer to be up during the night to change the incontinence pad or catheter bag or change bed linen and clean their loved-one when there was a bed wetting incident. It involved endless washing of bed linen, clothes, carpets etc. It was also physically very demanding to have to quickly transfer loved-ones to a commode etc.

One healthcare professional felt incontinence management was particularly challenging for adult children providing care to their parents. A carer who provided care for her father echoed this belief when describing the factors that influenced the LTC decision.

“His ability to use the toilet correctly....I mean I haven’t reared any kids and it’s my Dad, I don’t want to be taking Dad to the toilet. So that was a big, it was a big kind of like, one of the last things that I really was holding off on and certainly Dad wouldn’t have been looking for that kind of assistance.” (Carer 4)
6.6.5.5 Sleep

Dementia can affect a person’s body clock. They may be confused about time, believing night time is day time and so are up during the night wandering. Or they may be incontinent and so need changing during the night. Carers spoke about how intense caregiving becomes in these circumstances.

“I didn’t get a night’s sleep. Because he could be up a few times in the night...I’d get him back to bed. And he’d be only back in bed a while and he’d be up again...I used to be wrecked. It was twenty-four hours. You know. It was really. There was no let up.” (Carer 7)

When the person living with dementia is not sleeping and requires care during the night, the carer is essentially providing twenty-four hour care. This has a substantial influence on the LTC decision. As this healthcare professional described:

“For them to be supporting them at night is like a huge strain. No, it’s not sustainable.” (Healthcare professional 17)

6.6.5.6 Behaviours that challenge

The BPSD are commonly referred to as behaviours that challenge as they can be difficult for those providing care to cope with. Participants spoke about trying to manage the different types of BPSD, particularly trying to manage verbal and physical aggression. The two quotes below illustrate how these behaviours can be quite distressing for carers.

“You’d automatically help him to do something and then, he’d lash out at you, you know, and it just got very difficult...He would just push you away...sometimes you just feel like sitting down and crying.” (Carer 14)
“There was times when he’d strike out at me, you know. Give me a few wallops... Now nothing that I couldn’t handle... but [sighs] the aggression and the constant harping at you, you know. That was awful.” (Carer 7)

Healthcare professionals spoke about the techniques they use to manage such behaviours. If these cannot be managed, homecare may no longer be feasible. This may be because the carer cannot provide the level of care required due to the aggression or because the aggression poses a danger to the carer or the care recipient.

Overall, findings indicated that a transition to LTC is inevitable when the specific needs of the older person have increased to such an extent that they cannot be met at home. This is especially so when twenty-four hour care is required. This may be twenty-four hour supervision, in the case of concerns around safety, risk of falls, night time care, or nursing needs in terms of incontinence. This suggests that carer stress is not as influential in the LTC decision as the needs of the recipient. As this healthcare professional described:

“I suppose if their care needs are not being met is huge... Because their need is so high it can’t be met in the community... there’s a level they get to you can’t maintain them at home...there is a stage when it comes for some people where they do need twenty-four care.” (Healthcare professional 9)

6.7 Discussion

6.7.1 Summary of findings

The study findings appear to support those of the meta-analysis (Chapter 5) (203). Carer stress does not appear to be a driver of LTC admissions of people with dementia. In this regard, the Pearlin et al. model (27) does not appear to comprehensively account for the factors that influence the LTC decision-making process suggested in this study.
The findings indicate that the imbalance in the demands of caregiving, the powerlessness carers felt in meeting these demands, the commitment carers had to the role and the lack of community supports for homecare results in carers feeling they cannot cope and so are stressed. However, it does not appear to be the stress which drives the LTC admission. Rather, it is that the care needs of the person living with dementia escalate to a point at which they cannot be met at home. This largely seems to be because the care needs intensify to such an extent that twenty-four hour care is required. As there is often just one carer providing the bulk of care, it is not feasible that they provide this intense level of care on an on-going basis. In tandem with this, it is understandable that carers feel they are stressed when they are providing such high levels of care.

In order to continue providing homecare, carers turn to the support of healthcare services, particularly community care services. However, these services are frequently minimal to non-existent. This leaves carers in extremely stressful situations. They are trying to respond to care needs that are increasing to a level that cannot be met by a carer at home alone or with the limited support of community care services or other family. Therefore, the escalating needs, beyond that which can be met by a carer, appears to drive both carer stress and LTC admissions. In this way, carer stress appears to be a natural epiphenomenon of the LTC journey, rather than a driver of admissions.

6.7.2 Findings in the context of the literature

As discussed in Chapter 2, the theoretical models for the thesis were proposed by Pearlin et al. Andersen and Luppa et al. (22, 27, 170). The Pearlin et al. model proposed that carer stress drives a process that ultimately results in the termination of homecare and LTC placement of the care recipient. The Andersen model concerns a range factors which influence health service utilisation; it is not specific to care stress. The Luppa et al. model is based on both the Andersen and Pearlin et al. models. Therefore the findings are interpreted in the context of the Pearlin et al. and Luppa et al. models (22, 27).
The study found that factors in the Pearlin et al. and Luppa et al. models were a source of stress for carers. However, these factors did not emerge as influential in the LTC decision. Rather, the findings suggest that carer stress is an indicator that the carer is finding it difficult to cope with the care recipient’s needs. It is the care recipient’s needs which drive the LTC decision, not the level of carer stress. Therefore, the Pearlin et al. and Luppa et al. models do not accurately reflect the study findings of the factors that influence the LTC decision-making process. This is demonstrated below.

According to Pearlin et al. and Luppa et al., the needs of the care recipient are primary stressors in the stress process. Pearlin et al. describe these needs as being at “the heart of the stress process” (27 p.586), while Luppa et al. describe carer stress as stemming “directly from the needs of the patients” (22 p.67). In both the Pearlin et al. and Luppa et al. models these needs include the cognitive and functional impairment of the care recipient. Luppa et al. also include caregiving hours as a primary stressor to reflect the “magnitude of the care demanded by these needs” (22 p.67). In line with these models, healthcare professionals and carers in the present study discussed how intense caregiving becomes when substantial levels of care are required to meet care recipients’ high levels of need. This intensity resulted in carers feeling they had “no escape” (Carer 10) from the caregiving role.

In the Pearlin et al. model, this intensity of caregiving leads to “role captivity” where carers can feel a “loss of self” (27 p.589). This is where the recipient’s care needs increase to the extent that caregiving takes over the carer’s entire life - the carer can then experience a loss of their own identity. In this study, this loss was apparent in carers’ description of feeling their life was ‘on hold’ and ‘no longer their own’ (section 6.6.3.2). Other studies have also demonstrated such role captivity (38, 117, 244). For example, in some of these studies carers have also perceived the provision of care resulted in their lives being placed “on hold” (38 p.101). In other
studies the role was described as “engrossing and consuming” (117 p.794), while in other studies carers have expressed feeling that “time is not your own” (244 p.282).

As role captivity was apparent in carers’ description of the role, the study findings appear to reflect the Pearlin et al. model and international literature. However, whilst the loss of self may be a reflection of the intensity of caregiving, it did not emerge in the analysis as a factor which influenced LTC admissions. This is in contrast with the Pearlin et al. model. Despite feeling a loss of their own identity or that their life was ‘on hold’, carers appeared to have little choice but continue to provide care.

In both the Pearlin et al. and Luppa et al. models, lack of support from family can be a source of carer stress. This was also apparent in this study as carers were largely left to provide the majority of care on their own. For Pearlin et al., this lack of support from family can lead to family conflict in terms of disagreements about the level of care needed and provided by family members. Indeed, international research has found that lack of family support correlates with carer psychological well-being (116). Again, carers that participated in this study described experiencing such family conflict, though it did not emerge in the analysis as a factor which influenced the LTC admission. This is another way in which the findings contrast with the Pearlin et al. and Luppa et al. models.

Ultimately the study found that carers’ stress arose out of the imbalance between the demands of caregiving, the powerlessness carers felt in meeting these demands, the commitment carers had to the role and the lack of community supports for homecare. This struggle between feeling overwhelmed, without the resources to meet the demands and yet committed to the role, is not apparent in the Pearlin et al. or Luppa et al. models. Stress arising from the process of appraising demands and the perceived resources to meet these demands is akin to Lazarus’s cognitive transactional theory of stress (143). Lazarus’ theory was not included in the thesis from the outset as it is a general theory of the stress response.
and not specific to carer stress, nor the role of such stress in the termination of homecare. However, the theory is “one of the most influential in health psychology” (245 p.309). Therefore, it may be important to re-interpret the study findings in the context of this theory, due to the inherent limitations of the Pearlin et al. and Luppa et al. models.

According to Lazarus, the ‘stressor’ (stressful event) interacts with an individual’s characteristics, their environment, their appraisal of the situation and the resources available to the individual (143). Where a stressor places demands that are perceived by an individual to exceed available coping resources, that individual will experience stress. The two central processes in Lazarus’s theory are the cognitive appraisal of the situation and coping. There are both primary and secondary forms of appraisal. In the Lazarus model, primary appraisal consists of examining if the stressor is a threat, harm, challenge or benign. Secondary appraisal consists of assessing the resources available to cope with the stressor.

The primary appraisal process proposed in Lazarus’s theory involves assessing the gravity of the situation, if the stressor is a threat or benign. If the stressor is perceived as benign, it can be dealt with easily or is deemed irrelevant by the individual. So they can just walk away from it. Carers’ commitment to the caregiving role could be regarded as a form of primary appraisal. Carers’ commitment meant the challenges of caregiving could not be avoided (it could not be benign). Irrespective of the intense demands of the situation, walking away or ‘giving-up’ is not a straightforward option for carers. This contributed greatly to the stress they experienced.

In the primary appraisal process, certain features of an event have been identified that increase the likelihood of it being appraised as stressful. For example, events that are unpredictable in nature are more likely to be appraised as stressful (246). This was apparent when carers described the continuous change in the care recipient’s needs or their aggression towards the carer; consequently the demands of caregiving were often unpredictable.
An individual is also more likely to experience stress when they feel they have no control over the situation (246, 247). This was reflected in the sense of powerlessness carers expressed in trying to meet the care recipient’s increasing care needs. This sense of powerlessness was illustrated by one carer’s description that “everything came out of my hands” (carer 1). The sense of powerlessness was not just apparent in the struggle to meet the care recipient’s needs, but also in the all-encompassing nature of the role which “takes over your whole life” (carer 10) or in the feeling that “your life was no longer your own” (carer 14). Such powerlessness expressed here could be regarded as the role captivity and loss of identity described in the Pearlin et al. model (27). It also echoes Seligman’s theory of ‘Learned Helplessness’. That is, when individuals perceive that they cannot control the outcome of a situation they will begin to show signs of helplessness and depression (247).

What is most interesting in applying Lazarus’s theory is the influence of external resources on carer stress. The influence of healthcare services on carer stress is often overlooked in the caregiving literature. Yet, this study’s findings suggest that the stress carers experience from the difficulty in meeting the care recipient’s demands is exacerbated by the lack of support from the healthcare system, particularly community care services.

When a carer cannot meet a recipient’s needs at home they will rely on community care services if there is any chance of homecare continuing. For example, in a study of sons caring for a parent with dementia, McDonnell and Ryan found that home help was a ‘lifeline’, “without this it would be impossible to care for their parent at home” (117 p.794). However, when carers find that critical supports they need to enable the continuation of homecare are not available due to minimal or non-existent services, the carer feels “cut adrift” (Carer 3) and are left in an intensely stressful situation. Inconsistent and irregular community support and lack of information on how to access these supports has been found to be a major source of concern for carers in other studies (38).
Not only is the absence and paucity in community services a significant source of carer stress, but when carers receive services that are inadequate this can exacerbate carers’ stress (248, 249). For example, Hong and Casado found that if the carer is dissatisfied with the service or it is of poor quality this can result in significant levels of stress (249). According to Pearlin et al. and Luppa et al., community care can potentially alleviate stress. For Pearlin et al. community care can help the carer “escape some of the vicissitudes and hardships of caregiving one might otherwise experience” (27 p.586), while for Luppa et al. community care “may offer the opportunity for caregivers to accommodate the range of care demands while receiving assistance” (22 p.75). In contrast to these models, the study findings suggest carers’ interaction with inadequate and poor quality care services can exacerbate the stress they experience rather than reducing this stress. This is another departure from the Pearlin et al. and Luppa et al. models. Lazarus’s theory appears more applicable in the context of this study’s than the Pearlin et al. and Luppa et al. models.

In summary, carers’ descriptions of the stress they experienced in providing care appears to reflect the theories of stress proposed in the literature. This was apparent in both the application of the Lazarus cognitive transactional theory of stress and the Pearlin et al. and Luppa et al. models (22, 27, 143). However, while the study found that factors in the Pearlin et al. and Luppa et al. models were a source of stress for carers, these factors did not emerge as influential in the LTC decision. Therefore, the Pearlin et al. and Luppa et al. models do not comprehensively account for the study findings in relation to the factors that influence the LTC decision-making process. Rather the findings suggest that while stress is an indicator of carers’ inability to cope with care recipients’ needs, the LTC decision is based on the needs of the care recipient, not the level of carer stress. Therefore, these findings appear to support those of the meta-analysis which found the size of the effect of carer stress on institutional care utilisation was small to negligible (Chapter 5) (203).
The study found that homecare is unsustainable when the care recipient’s needs cannot be met at home. The specific needs that appeared in this study to be most influential in LTC admissions have also been found to be predictive of such admissions in international cohort studies and systematic reviews. These needs included safety (250, 251), dropping baseline cognitive and/or functional status following a hospital admission (252, 253), mobility (250, 251, 254), incontinence (252, 253), sleep (250, 255, 256) and behaviours that challenge (166, 250, 251), but not stress per se (203). The findings suggest that, to meet these care needs, carers rely on the healthcare system. Indeed, as Ryan writes “as family carers move along the caregiving continuum, it appears that home care is sustained only with the increasing intervention from health and social service” (257 p.328).

6.7.3 Future research
As the study findings contrast with the Pearlin et al. and Luppa et al. models, they suggest a need for an alternative model of factors influencing LTC admissions. Carer stress does not appear to drive LTC admissions. Rather, the findings suggest that LTC admissions are driven by the care recipient’s needs. When these needs cannot be met by the carer alone, nor with the limited support of community care services, carers have no option but LTC. In tandem with this, it appears that the factors which drive LTC admissions also drive carer stress. These stem from the care recipient’s needs and the lack of community care services to meet these needs. This proposed alternative to the Pearlin et al. and Luppa et al. models is presented in Figure 6.3 below.
6.7.4 Strengths and limitations
As described in Chapter 4, Study 2 consisted of two parts - the present findings and the results presented in the following chapter. As both of these parts were conducted and analysed simultaneously, they have similar strengths and limitations. To avoid repetition, the strengths and limitations are addressed in the following chapter.

6.8 Conclusions
Carer stress appears to be an important aspect of the journey to LTC. However, it does not appear to be such stress that is the primary driver of LTC admissions. Rather, it is that the care needs of the care recipient may be so intense that they cannot be met at home, neither by the carer nor with the limited support of community care services. The intensity of these needs and the lack of resources to meet them appears to contribute greatly to carer stress. Thus, carer stress appears to be a natural epiphenomenon of the situation - the deteriorating health of a loved-one and of the overall journey to LTC, rather than an independent driver of LTC admissions.
6.9 Implications for this thesis

It would appear that the stress process in the Pearlin et al. and Luppa et al. models reflects carers’ experience of the provision of homecare. However, in contrast with these models, the findings suggest carer stress is not a driver of LTC admissions. These findings support the results of the meta-analysis (Chapter 5) (203).

The study also suggests a need for an alternative theoretical model in which carer stress is an epiphenomenon of the LTC journey, rather than a driver of LTC admissions. Chapter 8 builds on these findings through a secondary analysis of the Irish Longitudinal Study on Ageing (TILDA) which examines the proposed alternative to the model.

The apparent stress that carers experience in the interaction with healthcare services (either due to the lack of these services or poor quality services where they are available), suggests the healthcare system is not adequately supporting carers in homecare. Therefore, the effect of healthcare services on LTC admissions will be examined in both of the next two chapters (Chapter 7 and Chapter 8).
Chapter 7  “We don’t have the infrastructure to support them at home”: How health system factors impact on LTC admissions of people with dementia.

7.1 Overview

This chapter presents the results from the second part of Study 2. This part of the study examined how health system factors impact on LTC admissions of people with dementia in Ireland. The chapter provides a brief background to the analysis. The results of the thematic analysis of in-depth semi-structured interviews with healthcare professionals and carers are explored in detail. The chapter concludes by discussing the findings in the context of the literature and the implications of these findings for the thesis.

7.2 Introduction

As presented in the previous two chapters, carer stress does not have as strong an effect on LTC admissions as was previously believed. These results suggest the need to further examine the components that enable successful provision of sustainable homecare, i.e., to look more broadly at factors that mitigate against the continuation of homecare other than the needs of the care recipient or the carer.

The previous qualitative chapter indicated that as a care recipient’s needs increase they cannot be met by the carer alone. The support from healthcare services is critical to the sustainability of homecare. However, the apparent stress that carers experience from the lack of support from healthcare services suggested the healthcare system is not adequately supporting carers in homecare. This suggested a need to examine the effect of healthcare services on LTC admissions of people with dementia.

Despite the fact that the successful provision of homecare depends greatly on the wider healthcare system, there is a notable absence of studies that concentrate on the impact of the healthcare system on admission to LTC (see Chapter 2). Where
studies have examined healthcare system factors, this has largely been as part of a broader set of potential predictors of LTC admissions rather than looking solely at health system factors. These studies have identified the importance of community care services for people with dementia, options for service reconfiguration, potential cost savings and the potential association between admissions to acute and LTC (12, 13, 16-19, 57, 59, 84, 101, 107, 258, 259). It may be a strength of the study to look at a broader set of factors than healthcare system factors alone. However, by examining a broad set of factors, this undermines the extent that the nuances and complexity within the healthcare system and carers’ interaction with the system can be analysed.

In tandem with this, these studies largely focus on the transition from community to LTC, yet a number of studies have found acute admissions to be predictive of LTC admission (see Chapter 2). There is also a growing body of evidence to suggest that nursing home placements are often arranged when the care recipient is admitted to acute care (see Chapter 2). However, the role of acute care has been largely overlooked in the examination of carer stress and the transition to LTC. Finally, there is an absence of studies that consider how community, acute and LTC are interconnected and the implications this has on the transition to LTC. Given the previous findings (Chapter 5 and 6), along with the limitations in the literature, this chapter examined how health system factors impact on LTC admissions in Ireland.

### 7.3 Objective

As Studies 1 and 2 suggest carer stress is not a driver of LTC admissions, the objective of this study was to develop an in-depth understanding of how community and acute care impact on LTC admissions of people with dementia. The study also sought to examine the how the interconnection between these sectors affects the transition to LTC.
7.4 Context
Chapter 2 described State-funded community support services for older people (Section 2.15). The main State funded services for community-dwelling older people are community-based public health nursing and home care support packages. However, as outlined previously, these were subject to significant budget cuts following the economic crisis in 2008 (182, 183) (see Chapter 2, section 2.15). It should also be noted that community care services were fragmented and under-funded prior to the economic crisis (184).

7.5 Methods
As referred to above, this chapter presents the results from the second part of Study 2, the qualitative component of the thesis. Please see the previous chapter for a detailed discussion of the methods employed for this study. Thematic analysis was employed for both studies. The coding framework for the results presented in this chapter was reviewed and discussed by the research team and is presented in Figure 7.1 below.
Health system factors

Theme 1: Insufficient and inequitable community services
- Under-resourcing community care
- Manner of service delivery
- Inequity in service availability
- Difficulty navigating services
- No community supports for crisis

Theme 2: Constrained community services impact on acute care
- Acute care used to access community and LTC

Theme 3: Pivotal influence of acute admissions
- Difficulty coming to decision
- Baseline drop in acute care

Theme 4: Lack of intermediate care settings
- Decision taken out of carers hands

Figure 7.1 Coding framework: Study 2 part 2
7.6 Results

7.6.1 Profile of respondents
The study sample was the same for both parts of Study 2. Therefore the profile of respondents was presented in the previous chapter (see section 6.6.1).

7.6.2 Overview of findings
The study found that LTC admissions of people with dementia are affected by inadequacies in the healthcare system in four ways. Firstly, community care services were identified as insufficient and inequitable, limiting their effectiveness in supporting sustainable homecare. Secondly, such limits in community care services increase subsequent acute care admissions. Thirdly, the findings suggest that admission of people with dementia to acute care can accelerate the journey towards LTC. Finally, people who require more care than current community care services can accommodate are forced into 24-hour nursing care facilities by the lack of intermediate care settings between home and 24-hour nursing care. The coding framework presenting each of these themes and their interconnection is presented in Figure 7.1 above.

7.6.3 Insufficient and inequitable community services
The study found that the support that community care services provide to families is a significant factor in the sustainability of homecare. This emerged quite strongly from the healthcare professional interviews, as this professional described:

“I mean the reasons people are going into nursing homes is because there isn’t enough support in the community.” (Healthcare professional 5)

The inadequacies in community care services were apparent in a number of ways. Firstly, services were limited due to constraints in resources. Secondly, the manner in which these services are delivered appears to undermine their quality. The study also found inequity in availability of these services. Carers also faced difficulties in
navigating community care services. Each of these aspects is explored in detail below.

### 7.6.3.1 Under-resourcing of community care services

The under-resourcing of community care services emerged as a strong theme in the analysis. Carers frequently described how they received little to no direction or support from community care services. This led one carer to describe the community care services provided as “appalling” (Carer 2). Healthcare professionals also described how under-resourcing of community care services means families are provided with little to no supports to enable the continuation of homecare.

> “There’s no facilities to enable them to stay at home longer....I mean they’re basically relying on the family and home help. If that’s available to them, at the moment it’s not....the only other thing we can offer them is respite. Sure they’re only allowed four weeks and then they have to start paying....so like it’s a vicious circle...there isn’t a lot there for them...So they would look to long-term care quicker.” (Healthcare professional 12)

The paucity in community supports was apparent not only in the types of services available, but also the extent of those services where they were available. One of the main State-funded support service for community care in Ireland is the homecare package scheme, as described in section 2.15 of Chapter 2. The maximum homecare package available was twenty-one hours a week, which is three hours of support a day. Both healthcare professionals and carers spoke about how little support this actually provided to families. As one carer described “What would one or two hours a day be to me?” (Carer 7). As homecare hours were so limited, some expressed the view that they served to lower the threshold for nursing home placement. As this professional described:
“The maximum you can get is twenty-one hours. So anything beyond that, well they’re going to need long-term care. Which shouldn’t really be the case, because twenty-one hours is really very little when you think of a seven day week.” (Healthcare professional 22)

The maximum package normally translates to an hour long visit three times a day. Some carers felt that if the package could be altered to be a block of hours at a time, rather than split over the day, this could be more effective. This would allow the carer to get out of the house. One carer felt this would have allowed him to maintain a part-time job alongside the caregiving role. Healthcare professionals also spoke about the value of block hours of homecare support. However, professionals described attempting to access block hours from the local health office as “a massive big fight” (Healthcare professional 3).

The impact of this under-resourcing of services on community-based healthcare professionals was also quite apparent. Professionals were clearly frustrated by how this under-resourcing constrained the service they could provide. They described how over-stretched they were. This limited the time they had available to visit families. They felt these constraints had undermined their professional practice and consequently their role in the provision of homecare:

“It’s counterproductive...we go out and we do an assessment for home help...We submit all the paperwork and then it doesn’t happen...because there is no money there...then we’re the people at the frontline having to say to somebody “Yes I do understand what you’re saying. I do identify the needs of your loved-one but sorry we don’t have the resources to put it in”. It’s like, well why are you here?...it’s very hard to be asked to do a job and then not have the tools to do it.” (Healthcare professional 15)
7.6.3.2 Manner of service delivery can undermine quality

As described in section 2.15 of Chapter 2, the homecare package scheme involves personal care assistants providing support with the care recipient’s personal care, such as washing and dressing. Given pressure to reduce the cost of the homecare package, there is a growing trend for the HSE to outsource the service to private care providers. Often private providers have high staff turnover rates. Consequently, families have different care assistants from private providers calling to the house to support them over the week. This carer, who cared for her husband, demonstrated how distressing it was when the care assistants constantly changed:

“You wouldn’t know who you were going to get at the door that morning...So he didn’t know where he was...The whole situation was like a time bomb when they were here because I was trying to keep my husband calm, because he would get very agitated and be shouting and roaring and everything and then they’d [the care assistant] look at me...as if they were afraid and I would try and keep them calm and I am trying to keep him calm...they were more trouble than...they were worth.” (Carer 1)

As discussed in the previous chapter, the paucity of community care services is a source of stress for carers. However, receipt of these services does not necessarily result in a reduction of stress. As the previous chapter suggested, receipt of community care can also be a source of stress for carer. The experiences of Carer 1 above reinforce this point. This experience demonstrates that when the service is inadequate and of poor quality this can exacerbate the stress carers experience.

However, four carers reported positive experiences. For those who had positive experiences, there had been continuity in the personal care assistant. This provided routine and stability and helped reduce some of the stress they experienced. One of these carers felt this “really helped to keep me sane during that time” (Carer 9). These families had a more positive outlook on the quality of the homecare package.
scheme compared to those families who did not have the same degree of continuity of the personal care assistant.

Healthcare professionals recognised the variation in service delivery by different care agencies. They spoke about how certain agencies were more skilled in dementia care services than others. However, as the more specialised agencies are largely from the non-profit sector, budget constraints limit the availability of their services. Professionals spoke about the ‘fight’ they have to advocate that a family should receive support from these more specialised agencies and the long waiting lists for the services. As this professional described:

“The Alzheimer’s Society of Ireland and the Carer’s Association are fantastic but they’ve a waiting list for months….often they’re gone into long-term care before they even get a response from them.”
(Healthcare professional 15)

7.6.3.3 Inequity in service availability

Respondents raised the considerable degree of inequity in availability of community care services nationwide. There appears to be substantial variation in the availability of services between HSE regions and neighbouring geographical areas. There also appeared to be a lack of transparency in relation to factors influencing waiting times to access services, with some professionals questioning if this was based on priority of need. As this professional described:

“The other problem is it depends where you live... in one area I had home help immediately and in the other area, the other side of the road, there was a waiting list...the other bit is if you shout really loud you get it...But the people who actually sit there on the waiting list, sit on the waiting list.” (Healthcare professional 8)
7.6.3.4 Difficulty navigating services

The study found that carers experience great difficulties in navigating community care services. Carers repeatedly spoke about how they struggled or are still struggling to find out what services are available, whether they are eligible for them and how to access them as this carer explains:

“I don’t understand...how to be successful in delivering those care packages...You just keep ringing and getting fobbed off basically...“no, they are not providing this.” Who are ‘they’? Why? What’s the application process?...Can you give me the instructions?...There seems to be some service somewhere, but there is no care pathway through it.” (Carer 2)

Healthcare professionals recognised that families struggle to navigate services. They described following-up on referrals made as a consequence of an acute admission. In many cases, prior to the acute admission, families were completely unaware of the existence of the community-based nursing service.

7.6.4 Constrained community services impact on acute care

The second major theme is that constraints in resources for community services impact on acute care. This was apparent in two ways. Firstly, community care services do not have the capacity to respond to families who are experiencing a crisis in the provision of care. As a result, families have no option but to go to acute care. Secondly, the study found that acute care is used as a means to access both community care and LTC.

7.6.4.1 Families are forced to go to acute care at times of crisis

Participants described community care services as being so over-stretched that they do not have capacity to respond to families who are experiencing a crisis in the provision of homecare, however short-term this crisis may be. This crisis may involve the carer being unwell or otherwise unable to provide care. Healthcare
professionals described how, in such circumstances, they have no option but to advise the family to go to the local Emergency Department for the care recipient to be admitted to acute care.

“If they can’t manage they are forced into an acute hospital…it’s not advice anyone wants to give...there is no emergency nursing home beds, emergency respite beds. There is nothing out there for people that if they’re really struggling at home there is nothing to support them through that.” (Healthcare professional 1)

7.6.4.2 Acute care used as a means to access both community and LTC

It is not just at times of crisis that constrained community services can affect acute care utilisation. The under-resourcing of these services means there are substantial waiting lists to access these services, especially homecare packages. This is compounded by the difficulties carers faced navigating community care services. Consequently, carers described using acute care as a means to access these services.

“You find yourself almost in a situation of not taking your elderly parent home from an acute hospital service because there is nothing there. So you have to bed block here, to wait for somebody to put a package in place... There is no joined up thinking.” (Carer 2)

Healthcare professionals also reported that they would advise families to bring their loved-ones to acute care to force them on the healthcare system to accelerate accessing these services. This was reported not only for homecare packages but also as applications for the Nursing Home Support Scheme (see sections 2.15 and 6.4), can take a considerable length of time (between 6-18 months), delaying access to LTC beds.
“Quite often, I unfortunately would have to suggest to them that they go into hospital...They’ve a different budget...So it’s easier to get a homecare package or a nursing home placement through the hospital...you have to get the family to say “No I’m not taking them home until it’s in” and that’s, unfortunately, the way it is.” (Healthcare professional 8)

That community care services were described as so over-stretched healthcare professionals advise families to go to acute care to access services is of concern. This is especially so given how detrimental an Emergency Department visit or an acute care admission can be for a person living with dementia (see section 6.6.5.2 in Chapter 6). This poses considerable difficulties for the person living with dementia, the carer and places massive pressure on the hospital system. This is explored further below.

7.6.5 Pivotal influence of acute admissions

The third major theme derived from analysis of the interviews highlights that there are multiple paths to LTC, presented graphically in Figure 7.2. The first is what some healthcare professionals described as the ‘ideal scenario’. That is, the person living with dementia transitions from the community to LTC. This scenario is what is most often assumed when researchers analyse the care recipient factors that influence LTC admissions. However, this study found that admission to LTC rarely happens this way. Rather, it would appear that an admission to acute care can be pivotal, often acting as a catalyst to the LTC transition. As this professional described:

“Most people will resist long-term care as long as they possibly can...but almost inevitably there’d be a hospital admission which is the straw that breaks the camel’s back” (Healthcare professional 11)
The person living with dementia may return home from acute care, but are on the path to LTC as a result of the acute admission. Alternatively, it may be impossible to return home and so the transition happens from acute care.

Figure 7.2 Multiple paths to LTC

There were three reasons identified highlighting why an acute admission can be so pivotal. Firstly, families find it difficult to come to the decision that LTC is necessary and so avoid having to make the decision for as long as possible. The acute admission forces the urgency of the decision. Secondly, the decision is forced as the baseline status of the person living with dementia can drop in acute care (see section 6.6.5.2). Finally, during the admission, the combination of the drop in the baseline status of the person living with dementia and healthcare professionals strong advice that LTC is necessary, can then take the decision out of the carer’s hands.
7.6.5.1 Difficulty coming to the LTC decision

Carers struggle with feelings of guilt which makes it difficult to come to the decision that LTC is necessary. There is an expectation from both family and their own expectation that they will be able to provide care. Consequently, they can feel they are betraying their loved-ones wishes or have failed in their role by needing LTC. Text Box 7.1 illustrates some of the emotional turmoil carers experience as a consequence of the LTC decision.

Text Box 7.1: Difficulties carers face in coming to the LTC decision

Example 1: Feelings of guilt, resentment and grief

Carer 10: Cared for wife with Parkinson’s Dementia

“There’s guilt when you make this decision or when you even think about it. You have the feeling of guilt...why is it my wife? Why do I have to put her into a nursing home? ...why should I have to do that? Because a nursing home is not the most, the best, or the most pleasant....then...you have...the grieving phase. I feel that I am grieving at the moment for, I don’t know what, lost opportunities, lost qualities in one’s life and all the things that you would have wanted.” (Carer 10)

Example 2: Sadness with not being able to meet expectations to continue in caregiving role

Carer 5: Cares for mother with Alzheimer’s Disease

“I suppose as a family...where we come from...my grandparents were minded at home and the expectation would be that she would be minded at home (crying) but I know in my heart and soul I can’t do it....It is because you’d love to, like you know you always make promises to people that you’ll mind them. But you don’t ever factor in this disease into that promise.... it is a hard decision to reach and partly because you don’t want to give in that you couldn’t do it, you know and partly because this is your parent and you want them with you and not in a nursing home.” (Carer 5)
Both of these quotes also demonstrate that journey to LTC is stressful for carers (see section 6.6.3). As carers’ loved-ones’ health deteriorate, it can be quite distress to watch a loved-one becoming more frail and vulnerable. The quotes also demonstrate how the commitment to the caregiving role and the inability to meet the care needs of that role results in carers experiencing stress (see section 6.6.3.2).

The experiences that carers shared also suggests that recognising the need for LTC and coming to the decision is a complex and stressful process for carers. Even when carers recognised that their loved-ones needs are increasing, it takes some months to accept that LTC will be necessary. Healthcare professionals recognised how difficult it is for carers to accept the idea of LTC. So they introduced the idea slowly. This is done first by suggesting that the carer completes the application form for the Nursing Home Support Scheme, ‘Fair Deal’. Healthcare professionals presented the application for Fair Deal as a safety-net and emphasised that “applying for it doesn’t mean you are agreeing to anything” (Healthcare professional 3). It was felt that this helps to bring the carer “that first step on” (Healthcare professional 15) in the LTC journey. The difficulty this carer faced in starting the Fair Deal application form illustrates how coming to a LTC decision is a complex and difficult process for carers.

“I could not even look at that form. Sometimes I’d peep at it and I’d read one question and I’d shove it back into the envelope....you’d think it was hot coal I was putting my hand on because mentally I could not put him away.” (Carer 1)

As it is such a difficult decision, families tried to avoid it for as long as possible. However, avoiding the decision meant that when the recipient’s needs deteriorated to the extent that they could not be met at home, neither by the carer or with the limited support of the community care system, this became a crisis in homecare provision and the family were then forced to go to acute care, as illustrated in in the follow quote.
“People don’t apply for it on time…even though we often do advise them to do it; they don’t. They keep putting it off…and it gets to crisis….you can’t speed up the Fair Deal process. There is no priority list...irrespective of whether you are in hospital or at home, it's still the same process. So then they end up going into A&E, because there is just no, the carer can’t mind them at home; they can’t afford to pay for respite; they can’t afford a private nursing home; they can’t afford homecare hours. So they end up in A&E, they are admitted...and they end up in hospital for months, and months and months, waiting for a bed.” (Healthcare professional 3)

7.6.5.2 Drop in baseline status
As discussed in the previous chapter, healthcare professionals repeatedly emphasised how an acute admission can result in a drop in the functional and/or cognitive baseline status of the person living with dementia. When this occurs it can accelerate the LTC journey. As this professional described:

“Like it does often happen where, that’s a big thing, where patients sometimes walk into the hospital and then they get de-conditioned or deteriorate in the hospital and they can’t go home.” (Healthcare professional 2)

7.6.5.3 LTC decision taken out of carer’s hands
During the acute admission, the recipient will be re-assessed by the multi-disciplinary team. This assessment examines the recipient’s needs and whether the carer, along with the available community care supports, can meet these needs. Where there is a gap and the care needs cannot be met at home, then LTC may be required, as illustrated in Figure 7.3 below.
Figure 7.3 Long-term care decision based on whether recipient’s needs can be met by carer along with community supports

It appears that where the recipient’s needs cannot be met by the carer in combination with community supports, then the LTC decision is taken out of the carer’s hands. This is partly due to the reduction in the functional and/or cognitive baseline status of the person living with dementia during the admission (see section 6.6.5.2). It is also as a result of the influence of healthcare professionals in acute care. Carers repeatedly spoke about how healthcare professionals initiated and lead on the LTC decision.

“It was the hospital decided for me...I really, I knew the way he was in the hospital I couldn’t take him home...It was just that he got so sick and my GP said to me “you can’t take him home” and in the hospital they said you can’t.” (Carer 7)

Community-based professionals felt that while they may advise families to start planning for the future care of their loved-one, it is the validation of this advice by hospital-based professionals during an acute admission that often triggers the LTC transition. Such professionals appear to play a huge role in supporting families in the decision. By taking the lead on the decision, they can help remove some of the guilt carers’ experience in coming to the decision. They can also help carers to see
that the need for LTC is not based on an inability on their part, but that it is no longer feasible to meet their loved-ones’ care needs at home.

“The majority of families don’t want long-term care….they feel that they’ve failed. And you try to explain that it’s not a failure on their behalf, it’s just the fact that, you know, we don’t have the infrastructure to support them at home.” (Healthcare professional 17)

7.6.6 Lack of intermediate care settings between home and LTC

The final theme to emerge from the analysis was the lack of intermediate care settings between home and LTC. There is a lack of alternative LTC settings for older people who do not actually require 24-hour nursing care, but who do require more supervision and support than is available as part of current community care services. In these circumstances, families have to choose between home or 24-hour nursing care. This is a choice between “one extreme or the other” (Healthcare professional 18). As this healthcare professional described:

“We have home, with a paltry amount of home support, or nursing home. And there’s very little in between.” (Healthcare professional 5)

There were two main homecare situations which were particularly affected by this. Firstly, where an older person’s care needs exceed that which can be accommodated between the maximum of twenty-one hours a week homecare package and the carer. These families then have to look at nursing home placement. The second situation was those families where substantial supervision is required should cognitive impairment compromise the care recipient’s safety awareness (see section 6.6.5.1). For these families, whilst their loved-ones’ nursing care needs might be low, as the community care support for supervision is so minimal, the lack of alternative care settings means that families have to look to nursing home placement.
A number of healthcare professionals compared the minimal choice of care settings in Ireland to that in other countries. These professionals gave examples of independent living facilities, such as sheltered accommodation or care homes in the UK; dementia villages in the Netherlands; or assisted living in the USA. These settings cater for older people who do not require intensive nursing home interventions. Therefore, whilst the older person’s care needs cannot be met at home, they can be met in a setting that enables a degree of independent living and a lower level of support than would be provided in a nursing home. Healthcare professionals described how families in Ireland do not have many options for such facilities. Therefore, when the care needs of their loved-one cannot be met by the carer alone, nor with the support of the community care system, families have no choice but nursing home placement.

7.7 Discussion

7.7.1 Summary of findings
This study demonstrates how LTC admissions of people with dementia are affected by inadequacies in the healthcare system. This was shown in four ways. Firstly, community care services are insufficient and inequitable, which limits their effectiveness. Secondly, such limitations in community care increase the probability of acute care admissions. Thirdly, admission to acute care can accelerate the journey towards LTC for a person living with dementia. Finally, the lack of intermediate care settings between home and 24-hour nursing care, can force people who require more care than current community care services can accommodate into 24-hour nursing care facilities.

Each of these factors individually and in combination are extremely stressful for carers. Carers are undoubtedly experience stress as they struggle to meet the care recipient’s care needs (see section 6.6.3). The lack of sufficient health care services, particularly community care, to support carers in homecare exacerbates the stress carers’ experience. Such homecare services have been described as a ‘lifeline’ (117), as described in Chapter 6 (section 6.7.2). The supports which are critical to the
continuation of homecare were found to be ineffective in adequately supporting carers. Carers are then left in an intensely stressful situation. This reinforces the findings of the previous chapter.

In tandem with this, receipt of such services does not equate with an automatic reduction on carer stress. As this study demonstrates, the constant change of care assistants undermined the quality of the homecare package. Consequently, interaction with poor quality services can also exacerbate the stress carers’ experience. This suggests receipt of community care is also a source of stress for carers (see section 6.7.2). The study also found significant inequity in availability of services. Carers also reported challenges navigating the community care system and identifying what services were available. The combination of these aspects appeared to limit the effectiveness of community care services for people with dementia and added to the stress carers’ experience.

The findings suggest that limitations in community care services have a knock-on effect on acute admissions. Acute care was reported to be the only option for families experiencing a crisis in homecare provision. It was also reported to be a means to access both community and LTC. This is of concern considering the detrimental impact an acute admission can have on a person living with dementia (see section 6.6.5.2). Consequently, acute admissions often act as a catalyst to the LTC journey. In tandem with this, the capacity of acute care services is stretched, forcing one to question the appropriateness of using acute care as a means for accessing community and LTC services.

Overall, the findings suggest that the factors influencing the admission of an older person living with dementia into LTC are more multifactorial than solely the care recipient’s needs or the carer’s ability to respond to these needs. Healthcare system factors appear to be critical. The research findings suggest the importance of taking into account these healthcare system factors. To do otherwise would mean that vital components of sustainable homecare are missed.
7.7.2 Findings in the context of the literature

The under-resourcing of community care services is not unique to Ireland. Studies across the OECD (111) and more recently in Australia (260), and Canada (261) have also found community care services were limited due to resource constraints. Such constrained resources not only affect the care recipient and carer, but have also been found to disempower healthcare professionals (261, 262). It is thus understandable that professionals in this study expressed frustration at being restrained in the degree of support they could offer families due to resource limitations. Yet recent research from across the EU suggests that LTC admissions may be avoided for certain individuals if appropriate community services, especially personal care, were available (12, 258). If community care services cannot adequately support families in the provision of homecare, this potentially has an impact on the decision thresholds for admission to LTC.

The impact of community care on acute care has recently been noted by a number of authors. A number of studies have highlighted lack of access to out-of-hours primary care or community nursing, making acute care the only option for patients and families (263, 264). In this study, the scope of analysis was widened by demonstrating the ‘vicious circle’ between constrained community care services and increased accessing of the acute sector, and also how acute admissions can then accelerate LTC admissions.

A number of studies have also found that the LTC decision is made at a time of crisis, which is often during an acute admission (85, 265). However, this study provides further insight as to why it takes an acute admission to drive the decision. As Ryan writes, “moving into nursing home care is a major decision, probably one of the most difficult and stressful decisions a person is ever likely to have to make” (257 p.325). Thus it is understandable that carers seek to resist the transition to LTC for as long as is possible. The deterioration of the care recipient’s condition while in acute care often results in increased care needs (see Chapter 6, section 6.6.5.2). Following re-assessment of the recipient’s needs during the admission, healthcare professionals may recommend LTC to the family. Such advice from healthcare
professionals appears to be critical to the decision. In many respects, healthcare professionals help to legitimise and validate the decision for families (85, 266). This points to what Mamier et al. (267) describes as the need for healthcare professionals to provide ‘anticipatory guidance’ to avoid crisis situations which make the LTC admission urgent.

### 7.7.3 Strengths and limitations

As described above, the qualitative component of the thesis (Study 2) consisted of 2 parts. Chapter 6 presented the results of the first part and this chapter presented the results of the second part. Both chapters were drawn from the same methods of data collection and analysis. Therefore the strengths and limitations below are relevant to the entire qualitative component (Chapters 6 and 7).

The qualitative approach enabled the complexity and nuances in the role of carer stress to LTC admissions to be comprehensively examined. In doing so, Study 2 shed new light on factors that influence the transition to LTC. For example, Study 2 addressed the notable absence of studies that concentrate on health system factor in LTC admissions. Most notably, these were the critical role of community care and acute care as well as the detrimental impact the poor interconnection between these sectors can have in the transition to LTC. Study 2 also demonstrated that the stress carers experience from the difficulty in meeting the care recipient’s needs is exacerbated by the lack of support from the health system, particularly from the inadequate support from community care, as well as poor quality in these services.

Study 2 included the voice of carers and healthcare professionals. However, it did not include people with dementia. This is a limitation. Inclusion of people with dementia was considered at the outset. However, the LTC decision is often forced as the functional and/or cognitive care needs of the person living with dementia have increased to the extent that they cannot be met at home. Thus, by the time the LTC decision has been made, the person living with dementia has substantial cognitive and functional care needs. Therefore, it may not have been appropriate
or ethical to have undertaken an in-depth interview with a person living with dementia under such circumstances.

Another limitation may be the transferability of the findings. However, mapping of dementia care services across European countries suggests the nature of care services for people with dementia in Ireland is similar to other EU countries (108). This mapping analysis found availability and access to community care may vary between countries. Nonetheless, across European countries access and utilisation of care services for people with dementia was problematic (108). A recent systematic review of LTC admissions in dementia also found resources available for continuing care are limited in most countries (84). The economic crisis in Ireland appears to have intensified the under-resourcing of care services for people with dementia. Consequently the study demonstrates how critical these services are in LTC admissions of people with dementia.

Research Ethics Committee (REC) requirements meant participants could not be contacted directly. Therefore initial contact with potential participants had to be made by a gatekeeper. This approach has also been adopted in other studies with carers of people with dementia (117). This may have meant that carers who were experiencing very high levels of stress did not participate. This potentially limits the insights into the role of stress in the transition to LTC. However, this potential limitation was mitigated by the interviews with healthcare professionals. Healthcare professionals described a complete range of caregiving situations, including intensely stressful caregiving. For example, those who worked between acute and community settings emphasised the most extreme elements of dementia caregiving, including chronic psychosis. Had more stressed carers not participated, the situation they faced would have been captured in part through the healthcare professionals interviews.

The sample for this study consisted of carers of people with dementia. Therefore the findings may be particular to the dementia caregiving context. However, some elements of the findings may apply to carers of older people without dementia. For
example, the way stress is generated by the struggle carers face in meeting care recipient’s needs in terms of mobility, incontinence and a need for 24 hour nursing care, as these aspects of caregiving are not particular to dementia.

In tandem with this, dementia caregiving has been acknowledged as the most stressful form of caregiving (121) (see Chapter 2). Therefore, should carer stress be a risk factor in LTC admissions, it is likely that this would be most apparent amongst carers of people with dementia. That stress did not appear to be a risk factor in this context provides questions of whether an effect would be seen in less stressful contexts.

7.8 Conclusions
The combination of limitations in community and acute care has a substantial influence on the journey to LTC. It is critical for future research to recognise that analysing care recipient factors or carer factors on LTC admissions, in the absence of healthcare system factors, means we are missing what are critical components to sustainable homecare. We cannot fully understand the factors that are purported to predict LTC admissions – such as stress – without taking into account how healthcare system factors impact on homecare.

7.9 Implications for this thesis
Overall the findings demonstrate that the healthcare system is critical in the journey to LTC. The healthcare system also significantly impacts on carers’ stress during this time. Yet, as described in section 6.7.2, healthcare system factors are not included in the Pearlin et al. model as a sources of stress for carers. Therefore, these findings reinforce the proposed alternative theoretical model presented in the previous chapter.

As this study found that limitations in community care services appear to have a substantial influence on the discontinuation of homecare, it would be beneficial to quantify the effect of community care services on institutional care utilisation. The
study also found carers experience significant difficulties interacting with community care services. It would also be interesting to quantitatively analyse the association between carer stress and community care utilisation. Finally, for the overall thesis, it would be important to see how convincing the effect of carer stress is on institutional care use when compared with the care recipient’s needs alongside healthcare system factors. Each of these aspects are examined in the following chapter.
Chapter 8  Structural analysis of hypothesised factors influencing carer stress and institutional care utilisation by community-dwelling older people

8.1  Overview
This chapter presents the results from the structural analysis of hypothesised factors that influence carer stress and institutional care utilisation by community-dwelling older people. This was a secondary analysis of The Irish Longitudinal Study on Ageing (TILDA) dataset. The chapter provides a brief outline to the background to of the analysis. The methods and results are discussed in detail. The findings are then explored in the context of theoretical models and the overall thesis question.

8.2  Introduction
As described in Chapter 2, a number of studies have found higher levels of carer stress to be associated with admission of older care recipients to LTC. This included both prospective and retrospective analyses (14, 54, 76, 148, 150, 268). However, such findings were contradicted by the meta-analysis of prospective studies (Study 1, Chapter 5) (203).

Subsequent qualitative research suggested that although carer stress was an important factor in the LTC journey, it did not appear to be stress *per se* that drives the nursing home placement. Rather, it is that the care needs of the older person escalate to a point at which they cannot be met at home, neither by the carer nor with limited community supports (Study 2, Chapter 6). The qualitative analysis also found healthcare system factors are critical to the journey to LTC. Under-resourced community care increases carer stress and the probability of acute care admissions. Acute admissions often act as a catalyst in the journey to LTC (Study 2, Chapter 7). A number of studies have also found that nursing home placements are often arranged when the care recipient is admitted to hospital (85, 86).
Study 2 suggested that carer stress is an epiphenomenon of the journey towards LTC, rather than a driver of LTC admissions. These findings contrast with the theoretical models proposed by Pearlin et al. and Luppa et al. (22, 27). Consequently an alternative theoretical model was presented to reflect these findings (see Chapter 6).

The findings of Study 2 suggest a need to test these existing models in the literature along with the proposed alternative theoretical model (Study 2, Chapter 6). In order to do this, a secondary data analysis was conducted to examine hypothesised factors that influence carer stress and institutional care utilisation (utilisation of both acute and LTC).

As discussed in Chapter 2, the Pearlin et al. and Luppa et al. models present how groups of factors may influence institutional care utilisation. The directions of the paths between factors within and between the groups are not specified in these models. Therefore, the thesis adds to these models by specifying and then testing the direction of the paths between each of the factors. The direction of the paths was informed by the models, the findings of the literature review (Chapter 2) and the qualitative study (Chapters 6 and 7). This is described further below.

8.3 Objective
To examine hypothesised factors that may influence carer stress and institutional care utilisation in community-dwelling older people cared for by a spouse.

8.4 Methods
8.4.1 Study design and participants
This is a secondary analysis of cross-sectional data from Wave 1 of TILDA. TILDA is a nationally representative cohort study of community-dwelling adults aged 50 years and over in the Republic of Ireland (26). The sample frame was derived from the Irish Geo-directory. The Geo-directory is compiled by the national postal service and ordnance survey Ireland. It provides a list of all household addresses in Ireland. Addresses within geographical clusters were selected at random. Household
members aged 50 years and over and their partners were invited to participate. The overall response rate was 62% (n=8,175). Data collection consisted of a computer assisted personal interview (CAPI), a self-completion questionnaire for more sensitive data and a health assessment by trained nursing staff. The data collected includes a range of variables on participants’ physical and mental health along with social and financial circumstances. Further details on the study design and sample selection are provided by Kenny et al. (26), Whelan and Savva (269) and Kearney et al. (270).

The data for the first wave of TILDA was collected between October 2009 and July 2011. As the analysis concerned the factors which influence carer stress and institutional care utilisation of care recipients, it was necessary to include data on both carers and their care recipients. A task-based inclusion criterion was used to define care recipients and spousal carers. Information from the spouse who received care was used where both partners were respondents in the study. Respondents were asked whether they had difficulties with ADLs and IADLs (26). They were also asked who most often helped them with these activities. A respondent in the study was then recorded as a spousal carer if their spouse reported that they had helped them with at least one care-based task and a non-carer if they did not.

Of the total sample (n=8,175), 205 spousal carers and care recipients participated in wave 1. There was not a sufficient sample size to do a longitudinal analysis from waves 1 to 2 as there were only 25 carers and care recipient dyads in both waves (271), so the present study was limited to the cross-sectional sample (n=205).

8.4.2 Measures

8.4.2.1 Frailty

A composite measure of frailty was developed to reduce the number of parameters in the analysis. The measure was developed according to the Rockwood definition of frailty. For Rockwood, frailty is the accumulation of health deficits (272, 273).
This definition was adopted as it reflects recipients’ care needs that healthcare professionals and carers in Study 2 believed influence institutionalisation (see Chapter 6). The construction of the measure and the items included were based on the procedure for constructing a frailty index as described by Searle et al. (274). The frailty index counts an individual’s health deficits. These deficits centre on the care recipients’ level of disability and chronic conditions. The greater number of deficits an individual has, the more likely they are to be frail (272-274). There were a number of variables included in the measure of frailty; these are described in sections 8.4.2.1.1 to 8.4.2.1.3 below. Section 8.4.2.1.4 describes how the individual scores in each of these variables were combined to give an overall frailty score.

8.4.2.1.1 Disability
A number of measures of disability were incorporated. These questions were asked to the care recipient and not the carer. They included impairment in Activities of Daily Living (ADLs). Care recipients were asked “Because of a health or memory problem, do you have any difficulty doing any of the activities on this card?” These activities were dressing, walking across a room, bathing or showering, eating, getting in or out of bed and using the toilet, including getting up or down (26). Impairment in Instrumental Activities of Daily Living (IADLs) was also included. Again care recipients were asked “Because of a health or memory problem, do you have any difficulty doing any of the activities on this card?” These activities were preparing a hot meal, doing household chores, shopping for groceries, making telephone calls, taking medications and managing money (26).

A range of items concerning mobility were also included. Care recipients were asked how many times they had fallen in the last year. They were also asked about fear of falling and whether this limits their activities (“Do you ever limit your activities, for example, what you do or where you go, because you are afraid of falling?”). Steadiness when walking, standing and getting up from a chair was also included (“Do you have difficulty getting up from a chair after sitting for long periods?”). Care recipients were asked if they had a difficulty climbing a flight of
stairs and difficulty lifting ten pounds (“Do you have difficulty lifting or carrying weights over 10 pounds (5 kilos), like a heavy bag of groceries?”) (274).

Different definitions of urinary incontinence were reviewed. The International Continence Society (ICS) definition of urinary incontinence is a complaint of any involuntary loss of urine (275). This definition is reported to be suitable for epidemiological studies. However, a more conservative definition of incontinence is an involuntary loss of urine that is a social or hygienic problem (275). This more conservative definition was adopted for this study. Consequently care recipients were recorded as urinary incontinent if they answered yes to both of the following questions: “During the last 12 months, have you lost any amount of urine beyond your control?” and “Do you ever limit your activities, for example, what you do or where you go, because of urinary incontinence?”

8.4.2.1.2 Chronic conditions
The World Health Organisation defines chronic conditions as health problems that require ongoing management over a period of years or decades (276). Chronic conditions were ascertained by a self-report of a doctor’s diagnosis of a number of chronic conditions. The chronic conditions that were included were selected based on the World Health Organisation classification and were those included in the Searle procedure for constructing a frailty measure (274, 276). Care recipients were asked, “Has a doctor ever told you that you have any of the conditions on this card?” These were: chronic heart failure, heart attack, stroke, cancer, diabetes, arthritis and chronic lung disease.

8.4.2.1.3 Weight loss, exhaustion and self-rated health and mental health
A number of authors have in argued that unintended weight loss can be a sign of frailty (272-274, 277). Therefore unintended loss of 10lbs or more in the last year was included in the measure. Weight lost was ascertained by the following question “In the past year, have you lost 10 pound (4.5kg) or more in weight when you were not trying to?” This threshold of 10lbs is the same as is used in the Searle measure of frailty (274). Self-reported exhaustion is also regarded as a sign of frailty and so is
included in number of measures of frailty (272, 273, 277). Care recipients’ self-reported exhaustion was defined as reporting that “everything I did was an effort” and “I could not get going” for three or more days in the past week. Both of these items are from the twenty item Centre for Epidemiological Studies Depression scale (CES-D). These items and way of measuring self-reported exhaustion is the same as the Searle and Fried measures of frailty (274, 277).

Finally, self-rated mental health and self-rated health compared to others of the same age were also included. These were taken from care recipients responses to the questions “What about your emotional or mental health? Is it...” and “In general, compared to other people your age, would you say your health is...”. In both questions the comparators were excellent, very good, good, or poor (26).

8.4.2.1.4 Coding of the frailty measure
Each of the variables included were coded as binary, where ‘0’ represents absence of the deficit and ‘1’ is presence of the deficit (274). However, self-rated health mental health and self-rated health were graded between ‘0’ and ‘1’, such that each of the components of the two self-rated health measures represent a larger deficit (“Excellent”=0, “Very good”=0.25, “Good”=0.5, “Fair”=0.75 and “Poor”=1). This was done so that each item in the measure reflected the procedure for deriving a measure of frailty proposed by Searle (274). The individual scores on each of the variables were combined to an overall index score. According to Searle’s procedure, an individual’s degree of frailty is the number of deficits they have out of the total number of deficits included in the measure. However, to enable a comparison of the degree of care recipient frailty with the degree of carer stress, the scale was standardised to be a z-score. The effect size then represents a 1-standard deviation (SD) increase in frailty.

8.4.2.2 Cognition
Individuals with severe cognitive impairment (MMSE score <15) that were unable to provide informed consent to participate were excluded from wave 1 of TILDA. Interviewers determined an individual’s ability to consent. Thus the proportion of
people with severe cognitive impairment was low. However, those with moderate (MMSE score <20) or mild cognitive impairment (MMSE <20-25) were included (2, 26), thus care recipients degree of cognitive impairment was included in this analysis.

Cognitive impairment was purposefully not included in the measure of frailty for this analysis. From Study 2, it would seem that the assessment for homecare services concentrate more on functional ability rather than cognitive impairment (see Chapter 6). Hence healthcare professionals described ‘gaming’ the system in order to support care recipients that had cognitive impairment but not functional impairment (see Chapter 6, section 6.6.5). Therefore, cognitive impairment was kept separate from the measure of frailty to explore this further in the analysis.

There are a number of cognitive tests in TILDA. In the study sample, the number of participants with complete MMSE scores was low (n=157). The verbal fluency task was selected as an alternative measure (278). This test is a measure of expressive language and executive function including mental flexibility. Care recipients were asked to name as many animals as they can in a minute. Higher scores indicate greater cognition (279). This measure is also used as an assessment of cognition in national ageing studies, including the English Longitudinal Study of Ageing (ELSA), the Survey of Health, Ageing and Retirement in Europe (SHARE) and the Health and Retirement Study (HRS) (26).

8.4.2.3 Caregiving hours
This is the reported number of hours the carer has provided in caregiving to the care recipient in the last month. The distribution of the variable was highly skewed, with many people reporting zero hours. Therefore the variable was transformed into a binary variable. The threshold for this was the maximum homecare package of 21 hours a week (91 hours a month) as found in Study 2 (see Chapter 7). Healthcare professionals in Study 2 reported that once a recipient requires more than the 21 hours a week, they then need to look to LTC. Therefore the variable
was dichotomised such that ‘0’ represented less than 21 hours of care a week provided by the carer and ‘1’ represented 21 or more hours of care a week.

8.4.2.4 Household composition
This variable was included as Study 2 found that caregiving can become quite intense when one carer alone has to meet the recipients increasing care needs (see Chapter 6). The variable measures whether there is only the carer and care recipient in the household.

8.4.2.5 Socio-economic status (education)
It was not possible to measure socio-economic status based on income due to a high number of missing cases. Therefore the highest level of education achieved was selected a proxy measure of socio-economic status. This proxy measure is widely regarded as an alternative measure of socio-economic status (280). The cut-off point was if the care recipient had no more than primary education.

8.4.2.6 Medical card and medical insurance
According to Andersen and Luppa et al., a medical card or medical insurance act as enablers to health service utilisation (22, 170, 171). Therefore both variables were included in the analysis. Each variable was coded such that ‘0’ represented absence of medical card or medical insurance and ‘1’ represented presence of medical card or medical insurance.

8.4.2.7 Community care
For Luppa et al., community care may mediate the relationship between need variables and institutional care utilisation (22). In this analysis, community care is a composite variable of utilisation of community nursing, home help, personal care attendant, day centre and respite. These services were selected as Study 2 found they were the most influential services in the journey to LTC (see Chapters 6 and 7). This is a binary variable (if the care recipient reported that they had utilised any of these services in the past 12 months).


8.4.2.8 Location
According to Andersen, the recipient’s location can enable utilisation of services (170, 171). This was also found in Chapter 7. That is, access to services depended on where you lived. The measure of location used was whether the recipient lives in Dublin (city or county) or outside of Dublin. As the numbers were small it was not possible to have anything less aggregated than this.

8.4.2.9 Carer self-rated health
This was analysed as a continuous variable with ‘0’ represented ‘excellent’ self-rated health and ‘1’ being ‘poor’ self-rated health compared to others of the same age.

8.4.2.10 Carer stress
Carer stress was measured with the 4-item short form of the perceived stress scale (PSS-4). This measures the extent to which respondents perceive their lives as stressful in the previous month (281). Carers were asked to indicate their perception of being able to control important things in their life; their confidence in handling problems; if things were going their way and if difficulties were increasing to the extent they could not be overcome (26). The scale has been used in a number of studies to measure carer stress (97, 282, 283). The Cronbach’s alpha for the scale in the entire TILDA sample was 0.63. The Cronbach’s alpha for the scale for 205 spousal carer’s included in the analysis was 0.68. This reliability level is considered adequate (284). To enable a comparison of the effect size of carer stress on institutional care utilisation with the meta-analysis the scale was standarized to be a z-score (203). The effect size represents a 1-standard deviation (SD) increase in stress.

8.4.2.11 Outcome
The outcome in the analysis is care recipient self-reported utilisation of institutional care. In separate questions, care recipients were asked if they had an emergency department visit, overnight hospital admission and spent time in a nursing home in the last 12 months. These three questions were combined to form a binary variable
measuring any of these three forms of healthcare utilisation in the previous 12 months. This outcome also reflects the outcome of the meta-analysis (Chapter 5) (203).

Ideally it would have been possible to analyse utilisation of acute care as part of the path to LTC, as found in Chapters 6 and 7. However, the number of TILDA participants that reported to have used LTC services was very small (n=4/205). Therefore, the outcome includes utilisation of institutional care in both acute and LTC settings. In this regard, the analysis is measuring institutional care services that are utilised as part of the journey to LTC, prior to the actual admission to LTC.

8.4.3 Analysis

Statistical analysis was conducted using path analysis. Path analysis is a form of structural equation modelling which enables examination of the strength of direct and indirect relationships between variables (285, 286). An advantage of path analysis over multiple regression analysis is that it forces the researcher to explicitly specify how variables relate to each other, enabling the researcher to disentangle complex relationships (286).

As discussed above, the path model was developed based on the Pearlin et al. and Luppa et al. models (22, 27, 170). These models suggest how groups of factors may influence institutional care utilisation. However, they do not specify the direction of the paths between the factors within each group or how factors interact between the groups. Therefore, the thesis adds to these models by specifying and then testing the direction of the paths between each of the factors.

The direction of the paths between each of the factors was informed by the literature review (see Chapter 2) and the findings of the qualitative analyses (see Chapters 6 and 7). Figure 8.1 presents the overall path model that is tested in the analysis. For transparency, Figure 8.2 presents the model along with information to show how the literature, theoretical model and Chapters 6 and 7 informed each of the paths in the model. As can be seen from both Figure 8.1 and Figure 8.2, this
model tested hypothesised factors that may influence carer stress, community care utilisation and institutional care utilisation according to the literature, the theoretical models and the findings from Study 2. This model formed the first path model tested. This model was re-specified a number of times. For clarity, Figure 8.3 presents a flow chart of the different hypothesis tested in each part of the analysis and the corresponding models. The first part of the analysis (model 1) tested the overall path model, as discussed above. The second part of the analysis tested the hypothesis that carer stress mediates the relationship between community care utilisation and institutional care utilisation (as proposed by Pearlin et al. and Luppa et al. (22, 27)). If stress is a mediator, the coefficient for the effect of community care utilisation on institutional care utilisation should decrease when stress is added to the model (287). Therefore, to test for mediation, two models were specified. One without carer stress (model 2A) and then with carer stress added (model 2B).

The third part of the analysis tested the hypothesis that carer stress is an epiphenomenon of the journey towards LTC (model 3). This hypothesis was developed following the findings of Study 2 (see Chapter 6). The fourth part of the analysis tested the hypothesis that care recipients’ needs have a significant direct effect on carers stress (as proposed in the Pearlin et al. and Luppa et al. models (22, 27)). This hypothesis was tested in two models, the first in which stress has a direct effect on institutional care use (model 4A) and the second in which institutional care use has a direct effect on stress (model 4B). Model 4B was a second means of testing the hypothesis that carer stress is an epiphenomenon of the journey towards LTC (see Chapter 6).

As Study 2 suggested that community care can also be a source of stress for carers, the final part of the analysis tested the hypothesis that both care recipients’ needs and community care utilisation have a significant direct effect on carer stress. Again this hypothesis was tested in two models, one in which stress has a direct effect on institutional care use (model 5A) and the second in which institutional care use has a direct effect on stress (model 5B). This final model (model 5B) was a third means
of testing the hypothesis that carer stress is an epiphenomenon of the journey towards LTC (Study 2, Chapter 6).

As the outcome was binary (institutional care utilisation) it was tested through a binary logit model. To enable this, the path analysis was conducted using Stata 14.0 Generalised Structural Equation Model (GSEM) estimation command. So as to aid interpretation and comparison to other findings, in models the paths to binary variables are displayed as Odds Ratios (OR), the paths to continuous variables are displayed as logged coefficients. Akaike and Bayesian Information Criteria (AIC and BIC) scores were calculated to compare relative model fit between the sequence of fitted models (models 1 to 5B). Lower AIC and BIC values are regarded as better fitting models (285). However, Kline argues that ‘closer to fit’ does not mean ‘closer to the truth’ (285). He advises that researchers avoid “fit statistic tunnel vision” where a researcher “becomes so preoccupied with overall model fit that other crucial information, such as whether the parameter estimates actually make sense, is overlooked.” (285 p.192). Therefore, models were not rejected solely on the basis of fit statistics, but analysed in terms of what was theoretically meaningful to the thesis.

The overall sample size was 205. However, only 171 carers completed the PSS. Given the size of the sample, the need to bootstrap the models was examined. Kline discusses a simulation study that found that bootstrapped estimates were generally less biased with sample of 200 or more. With smaller samples the bootstrapped estimates had relatively large standard errors (285, 288). Therefore, Kline advises caution with bootstrapping with smaller samples as these “will not typically render accurate bootstrapped results” (285 p.178). Instead Kline recommends the most straightforward option is to use robust standard errors. Therefore all models were estimated with robust standard errors. These were calculated using the Huber-White method (289). Three methods for calculating direct and indirect effects were reviewed (290-292). Effects were calculated using the nlcum command as this is the recommended command in the Stata Manual (292).
Figure 8.1 Path model for the analysis of TILDA care recipients and carers
Figure 8.2 Direction of paths in the model informed by the literature, theoretical models and Study 2
Part 1: Model 1: To test hypothesised factors influential to carer stress, community care utilisation and institutional care utilisation

Part 2: To test the hypothesis that carer stress mediates the relationship between community care utilisation and institutional care utilisation

Model 2A: Path model without stress
Model 2B: Path model with stress

Part 3: Model 3: To test the hypothesis that carer stress is an epiphenomenon of the journey towards LTC

Part 4: To test the hypothesis that care recipients' needs have a significant direct effect on stress

Model 4A: Stress to institutional care use
Model 4B: Institutional care use to stress

Part 5: To test the hypothesis that both care recipients' needs and community care have a significant direct effect on stress

Model 5A: Stress to institutional care use
Model 5B: Institutional care use to stress

Figure 8.3 Flow chart of different models tested
8.5 Results

8.5.1 Descriptives

Table 8.1 presents descriptive statistics for carers and care recipients. As can be seen from the table the sample was relatively young, care recipient’s mean age was 66 (SD=11.2), carer’s mean age was 65 (SD=10.1). Sixty-five percent of care recipient’s reported at least one impairment in ADLs (n=134). Forty-seven percent of carers provided help with ADLs (n=96). Carers provided an average of 59 hours of caregiving in the previous month. However, there was a substantial amount of variation around this figure (SD=141).

Table 8.1 Descriptive statistics for carers and care recipients

<table>
<thead>
<tr>
<th></th>
<th>Carer n=205</th>
<th>Care Recipient n=205</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Predisposing variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (Years), M (SD)</td>
<td>65 (10.1)</td>
<td>66 (11.2)</td>
</tr>
<tr>
<td>% Women (n)</td>
<td>50% (102)</td>
<td>50% (103)</td>
</tr>
<tr>
<td>% Employed (n)</td>
<td>26% (53)</td>
<td>10% (21)</td>
</tr>
<tr>
<td><strong>Enabling variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Post Primary (n)</td>
<td>60% (122)</td>
<td>59% (121)</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Lives outside of Dublin (n)</td>
<td>77% (158)</td>
<td>77% (158)</td>
</tr>
<tr>
<td>Household composition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Lives with spouse only (n)</td>
<td>71% (145)</td>
<td>71% (145)</td>
</tr>
<tr>
<td>% Medical card (n)</td>
<td>64% (132)</td>
<td>72% (147)</td>
</tr>
<tr>
<td>% Medical Insurance (n)</td>
<td>25% (52)</td>
<td>20% (42)</td>
</tr>
<tr>
<td><strong>Need variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-rated health compared to others of same age M (SD)</td>
<td>0.20 (0.40)</td>
<td>0.52 (0.50)</td>
</tr>
<tr>
<td>Self-rated mental health M (SD)</td>
<td>0.13 (0.34)</td>
<td>0.28 (0.45)</td>
</tr>
<tr>
<td><strong>ADL impairment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% At least 1 reported ADL impairment (n)</td>
<td>12% (24)</td>
<td>65% (134)</td>
</tr>
<tr>
<td><strong>IADL impairment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% At least 1 reported IADL (n)</td>
<td>9% (18)</td>
<td>80% (164)</td>
</tr>
<tr>
<td>% Carers support with ADLs (n)</td>
<td>47% (96)</td>
<td></td>
</tr>
<tr>
<td>% Carers support with IADLs (n)</td>
<td>67% (138)</td>
<td></td>
</tr>
<tr>
<td>Chronic Conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% 2 or more chronic conditions (n)</td>
<td></td>
<td>80% (163)</td>
</tr>
<tr>
<td>Frailty M (SD)</td>
<td>23.9 (11.6)</td>
<td></td>
</tr>
<tr>
<td>Incontinence limits social activities</td>
<td>12% (25)</td>
<td></td>
</tr>
<tr>
<td>Hours of caregiving in last month M (SD)</td>
<td>59 (141)</td>
<td></td>
</tr>
</tbody>
</table>
Table 8.1 continued

<table>
<thead>
<tr>
<th></th>
<th>Carer n=204</th>
<th>Care Recipient n=203</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Exhaustion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Everything I did was an effort occasionally - all the time (n)</td>
<td>9% (18)</td>
<td>29% (59)</td>
</tr>
<tr>
<td>% I could not get ‘going’ occasionally - all the time (n)</td>
<td>8% (16)</td>
<td>25% (52)</td>
</tr>
<tr>
<td><strong>Cognitive impairment M (SD)</strong></td>
<td></td>
<td>17.5 (6.6)</td>
</tr>
<tr>
<td><strong>Perceived stress scale M (SD)</strong></td>
<td></td>
<td>4.2 (3.2)</td>
</tr>
</tbody>
</table>

**Healthcare utilisation in last 12 months**

<table>
<thead>
<tr>
<th>Social and community care</th>
<th>Care Recipient n=205</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Community nurse (n)</td>
<td>23% (48)</td>
</tr>
<tr>
<td>% Home help (n)</td>
<td>8% (16)</td>
</tr>
<tr>
<td>% Personal care attendant (n)</td>
<td>5% (10)</td>
</tr>
<tr>
<td>% Day centre (n)</td>
<td>3% (7)</td>
</tr>
<tr>
<td>% Respite (n)</td>
<td>2% (4)</td>
</tr>
<tr>
<td><strong>Any of the social and community care services</strong></td>
<td>28% (57)</td>
</tr>
<tr>
<td><strong>Primary care</strong></td>
<td></td>
</tr>
<tr>
<td>GP visits M (SD)</td>
<td>8.68 (12.4)</td>
</tr>
<tr>
<td>GP visits Median (Interquartile Range)</td>
<td>5 (9)</td>
</tr>
<tr>
<td><strong>Acute Care</strong></td>
<td></td>
</tr>
<tr>
<td>ED visits M (SD)</td>
<td>0.73 (2.1)</td>
</tr>
<tr>
<td>ED visits Median (Interquartile Range)</td>
<td>0 (1)</td>
</tr>
<tr>
<td>Hospital admissions M (SD)</td>
<td>0.53 (1.4)</td>
</tr>
<tr>
<td>Hospital admissions Median (Interquartile Range)</td>
<td>0 (1)</td>
</tr>
<tr>
<td>ED visits and hospital admissions M (SD)</td>
<td>1.26 (2.9)</td>
</tr>
<tr>
<td>ED visits and hospital admissions Median (Interquartile Range)</td>
<td>0 (1)</td>
</tr>
<tr>
<td><strong>Long-term care</strong></td>
<td></td>
</tr>
<tr>
<td>% One week or less in nursing home (n)</td>
<td>1% (2)</td>
</tr>
<tr>
<td>% Up to 1 month in nursing home (n)</td>
<td>1% (2)</td>
</tr>
<tr>
<td><strong>% Any institutional care use (acute and/or LTC use) (n)</strong></td>
<td>36% (73)</td>
</tr>
</tbody>
</table>

Table 8.2 provides descriptive statistics by outcome. Overall, 36% of the sample reported institutional care utilisation in the previous 12 months (n=73/205). Those who reported institutional care utilisation were slightly younger than those who did not, though this difference was not statistically significant. Of those who reported utilisation of institutional care, 73% (n=53) lived with the spouse only, compared to
27% (n=20) who lived with the spouse and others. Levels of cognition were slightly lower in those who utilised institutional care (M=16.3, SD=6.1) than those who did not (M=18.2, SD=6.1), though this difference was not statistically significant. Care recipient who experienced the outcome were significantly more frail (OR: 1.05; 95% CIs:1.02-1.08; p=<0.001). Finally, the level of carer stress was significantly higher where the carer’s care recipient had experienced the outcome (M=5.1, SD=3.4) compared to those who had not (M=3.7, SD=3.1), (OR: 1.15; 95% CIs:1.04-1.27; p=<0.01).
Table 8.2 Descriptive statistics by outcome

<table>
<thead>
<tr>
<th>Predisposing variables</th>
<th>Institutional care utilisation (acute and/or LTC use)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (n=73)</td>
<td>No (n=132)</td>
</tr>
<tr>
<td>Care recipient age (Years), M (SD)</td>
<td>65 (10.5)</td>
<td>67 (11.5)</td>
</tr>
<tr>
<td>Carer age (Years), M (SD)</td>
<td>64 (10.0)</td>
<td>65 (10.2)</td>
</tr>
<tr>
<td>% Care recipient women (n)</td>
<td>53% (39)</td>
<td>48% (64)</td>
</tr>
<tr>
<td>% Carer Employed (n)</td>
<td>22% (16)</td>
<td>28% (37)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Enabling variables</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Care recipient Education</td>
<td></td>
</tr>
<tr>
<td>% No more than primary (n)</td>
<td>38% (28)</td>
</tr>
<tr>
<td>Carer Education</td>
<td></td>
</tr>
<tr>
<td>% No more than primary (n)</td>
<td>48% (35)</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
</tr>
<tr>
<td>% Lives outside of Dublin (n)</td>
<td>78% (57)</td>
</tr>
<tr>
<td>Household composition</td>
<td></td>
</tr>
<tr>
<td>% Lives with spouse only (n)</td>
<td>73% (53)</td>
</tr>
<tr>
<td>% Care recipient medical card (n)</td>
<td>74% (54)</td>
</tr>
<tr>
<td>% Care recipient medical insurance (n)</td>
<td>18% (13)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Need variables</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Care recipient self-rated health compared to others of same age</td>
<td>0.67 (0.47)</td>
</tr>
<tr>
<td>Carer self-rated health compared to others of same age</td>
<td>0.16 (0.37)</td>
</tr>
<tr>
<td>Care recipient self-rated mental health</td>
<td>0.30 (0.46)</td>
</tr>
<tr>
<td>Carer self-rated mental health</td>
<td>0.15 (0.36)</td>
</tr>
<tr>
<td>Table 8.2 continued</td>
<td>Institutional care utilisation (acute and/or LTC use)</td>
</tr>
<tr>
<td>----------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Yes (n=73)</td>
</tr>
<tr>
<td>ADL impairment</td>
<td></td>
</tr>
<tr>
<td>% At least 1 reported ADL (n)</td>
<td>67% (49)</td>
</tr>
<tr>
<td>IADL impairment</td>
<td></td>
</tr>
<tr>
<td>% At least 1 reported IADL (n)</td>
<td>86% (63)</td>
</tr>
<tr>
<td>Carers support with ADLs (n)</td>
<td></td>
</tr>
<tr>
<td>Chronic Conditions</td>
<td></td>
</tr>
<tr>
<td>% 2 or more chronic conditions (n)</td>
<td>79% (58)</td>
</tr>
<tr>
<td>Care recipient exhaustion (n)</td>
<td></td>
</tr>
<tr>
<td>Yes (n=72)</td>
<td>No (n=132)</td>
</tr>
<tr>
<td>Carer exhaustion (n)</td>
<td></td>
</tr>
<tr>
<td>Yes (n=73)</td>
<td>No (n=132)</td>
</tr>
<tr>
<td>Incontinence limits social activities (n)</td>
<td></td>
</tr>
<tr>
<td>Yes (n=73)</td>
<td>No (n=132)</td>
</tr>
<tr>
<td>Cognitive impairment M (SD)</td>
<td></td>
</tr>
<tr>
<td>Yes (n=73)</td>
<td>No (n=132)</td>
</tr>
<tr>
<td>Frailty</td>
<td></td>
</tr>
<tr>
<td>Hours of caregiving in last month, M (SD)</td>
<td></td>
</tr>
<tr>
<td>Yes (n=60)</td>
<td>No (n=111)</td>
</tr>
<tr>
<td>Perceived stress scale (SD)</td>
<td></td>
</tr>
<tr>
<td>Yes (n=60)</td>
<td>No (n=111)</td>
</tr>
</tbody>
</table>
8.5.2 Results from the models

8.5.2.1 Part 1: Test hypothesised factors influencing carer stress and institutional care utilisation

As referred in the flow chart above (Figure 8.3), the first model tested hypothesised factors that may influence carer stress, community care utilisation and institutional care utilisation. The results for model 1 are presented in Figure 8.4 below. In this model age was significantly related to cognition but not to frailty. The path from age to frailty was assessed in subsequent models (see appendix 7). Household composition was not related to caregiving hours. Socio-economic status was also not related to caregiving hours. Those with lower socio-economic status had over 3.5 times higher odds of having a medical card (OR: 3.68; 95% CIs: 1.80-7.52; \( p=0.001 \)).

A recipient was twice as likely to receive community care per standard deviation increase in frailty (OR: 2.04; 95% CIs: 1.45-2.87; \( p=0.001 \)). Community care was not related to cognition. Location, household composition, medical card and medical insurance were not related to receipt of community care in this model. A recipient had nearly 2.5 times higher odds of receiving community care if their carer was providing over 21 hours of care a week. As caregiving hours can both influence and be influenced by receipt of community care, this was examined in two versions of the model. One in which caregiving hours influence receipt of community care (Figure 8.4) and one which receipt of community care influences caregiving hours (see Appendix 7). As the thesis is concerned with the journey to LTC, the hypothesis that caregiving hours influence receipt of community care was tested in the model. This is because receipt of community care appeared to be central to the journey to LTC in Study 2 (see Chapters 6 and 7).

In this model the care recipient’s frailty (b=0.11; 95% CIs: -0.01-0.02; \( p=0.197 \)) and cognitive impairment (b=0.01; 95% CIs: -0.01-0.03; \( p=0.323 \)) did not influence the level of stress carers experienced, which was unexpected. This is explored further below.
Finally in terms of institutional care utilisation, caregiving hours were not found to be significantly related to institutional care utilisation. Those receiving community care had over twice the odds of institutional care utilisation, though the p-value was just past the conventional threshold (OR: 2.14 95% CIs:0.98-4.65, p= 0.055). The association of carer stress and institutional care utilisation was much higher than expected. The model found a 47% increase in odds of institutional care utilisation per SD increase in stress (OR: 1.47 95% CIs:1.05-2.06, p= <0.05).

Figure 8.4 Model 1
(Notes: AIC: 3412.801 BIC: 3529.107. *p<0.05, **p<0.01, ***p<0.001. Paths to binary variables are ORs, paths to continuous variables are logged coefficients)

8.5.2.2 Reducing the number of parameters
According to what Jackson referred to as the N:q rule, in structural equation modelling the ratio of cases (N) to parameters (q) should preferably be 20:1 (293). The reliability of the results decreases as the ratio of cases to parameters decreases below 10:1 (285, 293). The variables included model 1 resulted in 23 parameters, which exceeds this rule (285, 293). Therefore, variables were removed from model
1. These were variables that did not add any substantial meaning to the model to aide answering the thesis question.

The first variable was location, as the limitations in this variable were recognised from the outset. Medical insurance was also removed as this did not emerge in either Chapters 6 or 7 as a factor in accessing community or LTC. Carer’s self-rated health was also removed as this was not critical to the model and had very wide confidence intervals. Finally, sex and whether the carer was employed were removed as these were not found to be significant in model 1 and were not critical factors in the qualitative findings.

The paths within the model were also reviewed. The path from caregiving hours to institutional care utilisation was removed as it was not found to be significant. Furthermore, the qualitative work found receipt of community care is central to the LTC journey. Caregiving hours would therefore act via receipt of community care. The path from socio-economic status to caregiving hours was also removed, as this was not found to be significant. Finally, as previously found, healthcare professionals would review families’ receipt of community services before applying for LTC, the path from frailty and cognitive impairment to stress was removed. Frailty and cognitive impairment then acted via community care.

As age was not found to be significantly related to frailty in model 1 (Figure 8.4) this path was reviewed (see appendix 7). However, it was decided to keep the path from age to frailty as this was more theoretically meaningful. As age is also related to receipt of a medical card, a path between these variables was inserted in the model. The direct effect of age on medical card status was significant. However, the fit statistics of the model increased (see Table 8.3). This path from age to medical card status was not retained as it is not pertinent to answering the thesis question and resulted in higher fit statistics. As the confidence intervals for medical card status were wide and the variable was not pertinent to the thesis question, the model was revised to exclude this variable. This resulted in lower fit statistics (see Table 8.3).
As described above, caregiving hours is the number hours a carer has provided in help to a care recipient in the last month. This is a self-report variable and subject to recall bias. It was included in the model as it is included in the Luppa et al. model as a measure of intensity of caregiving. The influence of caregiving hours was re-examined (see appendix 7). However, it was not found to be related to cognition, frailty, stress or institutional care utilisation. Therefore, it was decided to remove this variable as it is not adding much meaning to the mode. Table 8.3 below presents the reduction in the fit statistics following these changes.

<table>
<thead>
<tr>
<th>Removed parameter</th>
<th>AIC</th>
<th>BIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Removed location (Dublin city or county vs outside of Dublin)</td>
<td>3409.967</td>
<td>3492.688</td>
</tr>
<tr>
<td>Removed path from caregiving hours to institutional care utilisation</td>
<td>3409.967</td>
<td>3492.688</td>
</tr>
<tr>
<td>Removed path from socio-economic status to caregiving hours</td>
<td>3221.919</td>
<td>3304.995</td>
</tr>
<tr>
<td>Removed medical insurance</td>
<td>3023.026</td>
<td>3096.132</td>
</tr>
<tr>
<td>Removed carer self-rated health</td>
<td>3032.751</td>
<td>3095.888</td>
</tr>
<tr>
<td>Age influencing medical card status</td>
<td>3301.032</td>
<td>3370.815</td>
</tr>
<tr>
<td>Removed medical card status</td>
<td>2806.888</td>
<td>2860.056</td>
</tr>
<tr>
<td>Removed caregiving hours</td>
<td>2813.666</td>
<td>2866.834</td>
</tr>
</tbody>
</table>

### 8.5.2.3 Part 2: Test the hypothesis that stress is a mediator

For Pearlin et al. and Luppa et al., stress may act as a mediator in the journey to LTC (22, 27). Therefore the second part of the analysis tested the hypothesis that stress mediates the relationship between community care and institutional care utilisation. As described above, if stress is a mediator, the coefficient for the effect of community care utilisation on institutional care utilisation should decrease when stress is added to the model (287). Therefore, the model was specified without carer stress (Figure 8.5) and then with carer stress added (Figure 8.6).
In model 2A (Figure 8.5), those receiving community care were found to have twice the odds of utilising institutional care (acute care or LTC). When stress was added to the model (model 2B, Figure 8.6), the direct effect of community care on institutional care utilisation remains significant and increases. This would suggest that stress neither fully nor partially mediates the effect of community care on institutional care utilisation.

The indirect effect of stress in the model was not found to be significant (Table 8.4). According to Zhao et al.’s typology of mediation, this represents ‘direct-only non-mediation’ (287). That is, carer stress does not mediate the effect of community care on institutional care utilisation. Whether stress acts as a moderator was also examined. However, this was not found to be significant, suggesting carer stress does not moderate the effect of community care on institutional care utilisation (see Table 8.4).
Table 8.4 Direct effect of community care and indirect effect of stress

<table>
<thead>
<tr>
<th></th>
<th>Coeff.</th>
<th>C.I. (95%)</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct effect of community care on institutional care utilisation without stress in model</td>
<td>0.69</td>
<td>0.06-1.32</td>
<td>0.031</td>
</tr>
<tr>
<td>Direct effect of community care on institutional care utilisation with stress in model</td>
<td>0.77</td>
<td>0.02-1.51</td>
<td>0.044</td>
</tr>
<tr>
<td>Indirect effect through stress</td>
<td>0.17</td>
<td>-0.04-0.39</td>
<td>0.119</td>
</tr>
<tr>
<td>Effect of stress as a moderator</td>
<td>0.72</td>
<td>0.36-1.46</td>
<td>0.367</td>
</tr>
</tbody>
</table>

8.5.2.4  Part 3: Test the hypothesis that stress is an epiphenomenon of the journey towards LTC

Study 2 suggested that stress could be an epiphenomenon of the journey towards LTC (see Chapter 6). This hypothesis was tested in model 3. This model found that institutional care utilisation has significant effect on carer stress (Figure 8.7).

Utilisation of community care and institutional care had an equal contribution to stress. The size of the effect of institutional care utilisation on stress and the effect of receipt of community care on stress was similar. This supports the hypothesis that stress is an epiphenomenon of the journey to institutional care.

Figure 8.7 Model 3
(Notes: AIC: 2860.565 BIC: 2913.733. *p<0.05, **p<0.01, ***p<0.001)

The fit statistics in the model 2B (in which stress has a direct effect on institutional care utilisation (Figure 8.6) (AIC: 2813.666 BIC: 2866.834) are slightly lower than those for model 3 (in which institutional care utilisation had a direct effect on stress (Figure 8.7) (AIC: 2860.565 BIC: 2913.733)). However, this difference is not a substantial. Therefore the model in which stress influences institutional care
utilisation was not rejected solely on the basis of the fit statistic. Both models are theoretically meaningful to the thesis.

3.2.5 Part 4: Test the hypothesis that care recipients needs have a significant direct effect on stress

As described above, the direction of the effects between factors influencing the journey to LTC are not clear in the Pearlin et al. and Luppa et al. models (22, 27). Therefore, the model was revised to test the hypothesis that care recipients’ needs have a significant direct effect on carer stress (as proposed in the Pearlin et al. and Luppa et al, models (22, 27)). This is presented in two models, one in which stress had a direct effect on institutional care utilisation (model 4A (Figure 8.8)) and the second in which institutional care use had a direct effect on stress (model 4B Figure 8.9).

![Figure 8.8 Model 4A](image)

(Notes AIC: 2809.345 BIC: 2865.836. *p<0.05, **p<0.01, ***p<0.001)

As can be seen in Figure 8.8, cognition does not appear to be associated with stress. This may be because the TILDA sample is a relatively young sample in which those with more severe cognitive impairment were excluded (see section 8.4.2.2). Frailty was found to be significantly associated with stress (Coeff.=0.22; 95% CIs: 0.05-0.39; p<0.05). However, this effect slightly decreased in model 4B (Figure 8.9) (Coeff.=0.17; 95% CIs: 0.01-0.34; p<0.05). In model 4B (Figure 8.9) utilisation of institutional care had a significant direct effect on stress. This supports the hypothesis that carer stress is an epiphenomenon of the journey towards LTC.
8.5.2.5 Part 5: Test the hypothesis that both care recipients’ needs and community care have a significant direct effect on stress

As Study 2 suggested that community care can also be a source of stress for carers, the final part of the analysis tested the hypothesis that both care recipients’ needs and community care utilisation have a significant direct effect on carer stress. Again this was tested over two models, the first in which stress has a direct effect on institutional care use (model 5A), the second in which institutional care use has a direct effect on stress (model 5B).

In model 5A, none of the hypothesised stressors (cognition, frailty and receipt of community care) have a significant direct effect on stress, yet stress has a significant direct effect on institutionalisation. In model 5B (Figure 8.11), the hypothesised stressors again do not have a direct effect on stress. Only institutional care utilisation has a significant effect on stress. This model supports the hypothesis that carer stress is an epiphenomenon of the journey towards LTC.
8.6 Discussion

The findings appear to both support and deviate from the Pearlin et al. and Luppa et al. models of factors hypothesised to influence carer stress and institutional care utilisation (22, 27), whilst also supporting the proposed alternative model in a number of ways. This is explored below.

Firstly, carer stress was found to have a significant independent effect on institutional care utilisation. This supports the Pearlin et al. and Luppa et al. models. However, the findings suggest that the effects of institutional care utilisation on carer stress are as convincing as the effects of carer stress on institutional care use. This also supports the hypothesis generated in Study 2 that carer stress is an epiphenomenon of the journey towards LTC (see Chapter 6) and suggests that the relationship between institutional care use and carer stress may be bi-directional. That is, carers experience stress as they try to respond to the increasing care needs of their loved-one. This stress is exacerbated by the difficulties carers experience navigating and utilising fragmented and under-resourced community care services. Indeed, the analysis found receipt of community care has a considerable direct effect on stress (model 2B (Figure 8.6) and model 3 (Figure 8.7)). There are a number of ways this result could be interpreted. This could reflect the stress carers in the qualitative study described in their interaction with community care services. It could also reflect the stress carers experience as the care recipient’s condition
deteriorates to the extent that community care is necessary in the home. This is explored further below.

Furthermore, utilisation of community care and institutional care appears to contribute equally to stress (model 3 (Figure 8.7)). There was not a significant difference between the strength of the effect of receipt of community care and utilisation of institutional care on stress. This provides further support to the hypothesis that carer stress is an epiphenomenon of the journey towards LTC.

Underpinning the Pearlin et al. and Luppa et al. models is the belief that institutional care utilisation is a result of the interaction between ‘primary stressors’ (care recipients’ needs, such as the level of frailty and cognitive impairment) and the stress carers experience as a consequence of these needs. Pearlin et al. argue that care recipients’ needs are “the heart of the stress process...driving the process that follows” (27 p.586-587) (see Chapter 2). However, when the effects of frailty and cognition on stress were examined the results were surprising. Cognition did not have a significant effect on stress, which may be reflect the present sample. Those with more severe cognitive impairment were excluded from the first wave of TILDA (see section 8.4.2.2). Frailty was found to have had a modest effect on stress (model 4A, (Figure 8.8) and model 4B (Figure 8.9)). However, this effect disappeared when it was analysed alongside the effect of community care and institutional care utilisation on stress (model 5A (Figure 8.10) and model 5B (Figure 8.11)). Again, this may reflect the present sample, as the sample is relatively young and only 47% of carers provided help with ADLs. Frailty may have a stronger effect on stress for those carers who are providing care to older care recipients with more care needs who are closer to LTC than those in the present sample.

However, the findings suggest that in this sample, the stress carers are experiencing is generated from factors other than hypothesised ‘primary stressors’. If the care recipient’s needs do not to have a significant direct effect on stress, then we cannot associate the significant independent effect of stress on institutional care utilisation
with stress driven by care recipients’ needs. This is a substantial departure from the theoretical models of Luppa et al. and Pearlin et al. (22, 27).

In this sample, while the stress these carers are experiencing may not be generated by care recipients’ needs, it may be generated from the overall caregiving situation at home – the deterioration in the health condition of a spouse to the extent that community and institutional care is required. In their meta-analysis, Pinquart and Sorensen suggest the degree of closeness between spouses and the deterioration in the health condition of a spouse can be particularly stressful (118) (Chapter 2). This may help to explain the findings – that carer stress was found to have a significant effect on institutional care utilisation, yet care recipient’s needs were not found to be significantly associated with stress once health system factors were accounted for.

In further contrast with the Pearlin et al. and Luppa et al. models, it would appear that carer stress neither mediates nor moderates the effect of receipt of community care on institutional care utilisation. Those receiving community care were found to have twice the odds of utilising institutional care (model 2B (Figure 8.6), model 3 (Figure 8.7), model 4A (Figure 8.8), model 4B (Figure 8.9), model 5A (Figure 8.10), model 5B (Figure 8.11)). This again reflects findings in the qualitative study findings (Chapters 6 and 7) that receipt of community care is central to the journey to LTC.

When the effects of receipt of community care and institutional care were examined alongside the effects of care recipient’s needs on stress, only utilisation of institutional care was found to have a significant direct effect on stress. This supports the findings from the qualitative study that carer stress is an epiphenomenon of the journey towards LTC. The findings from the qualitative study in combination with the findings from the TILDA analysis suggests that carers experience stress as their loved-ones’ condition deteriorates to the extent that community care and institutional care are required. In this regard, stress is not a driver of utilisation of these services, but co-occurs with the requirement for these
services and the many difficulties carers experience in accessing and utilising these services. Therefore, this thesis proposed an alternative theoretical model to recognise the bi-directional relationship between carer stress and institutional care utilisation. Such a bi-directional relationship is not described in either the Pearlin et al. or the Luppa et al. models. Consequently, the alternation proposed model is presented in Figure 8.12 below.

Figure 8.12 Alternative of the theoretical model

8.6.1 Strengths and limitations
Employment of the TILDA dataset was a substantial strength to this study. TILDA has been internationally recognised as a leading dataset on ageing. As Kaiser has acknowledged, “TILDA is unique amongst longitudinal studies internationally in the breadth of physical, mental health and cognitive measures” (294 p.11).

The breadth of measures in TILDA meant it was possible to apply the theoretical models and findings in the qualitative study (Study 2) to a national sample of community-dwelling carers. This was conducted using a range of variables that have been tested for validity and reliability. In tandem with this, as the TILDA dataset has been harmonised with other leading longitudinal studies on ageing, it will be possible to compare the results in this study to other longitudinal datasets in other contexts (the English Longitudinal Study of Ageing (ELSA), the Survey of Health, Ageing and Retirement in Europe (SHARE) and the Health and Retirement Study (HRS)) (26).

There are also a number of limitations to the analysis. Firstly, the outcome was recall of health service utilisation in the previous twelve months, while the measure of stress was recall of stress in the previous month. Therefore, the health service
utilisation may have taken place prior to the carer stress, which may explain the contrast between the study findings and the findings of the meta-analysis (which was a prospective analysis). However, it was not possible to know when the health service utilisation took place in relation to the occurrence of carer stress as admissions dates were not recorded. Therefore, it is not possible from this analysis to determine how strong an independent effect carer stress has on subsequent institutional care utilisation. Instead, the analysis concerns the association between carer stress and institutional care utilisation by community-dwelling older people.

As discussed above, the sample is a relatively young and healthy sample. Those with more severe cognitive impairment were excluded and only 47% of spouses supported care recipients with ADLs. In this respect the sample is quite different from the sample in the qualitative study (Chapter 6 and 7). The care recipients of participants in the qualitative study were in the process of transitioning to LTC or had recently transitioned. The results should be interpreted with this in mind. They are an analysis of hypothesised factors that influence carer stress and institutional care utilisation in a cohort of younger adults that are less cognitively and functionally impaired than in the qualitative study. Also, as the sample was relatively young, very few people had used long-term services (n=4/205). Therefore the outcome used in this analysis was utilisation of both acute and LTC services. This also reflected the outcome of the meta-analysis. It also reflected the findings in the qualitative studies that utilisation of acute care is part of the transition to LTC, often acting as a catalyst in the transition. The outcome should not, therefore, be interpreted as LTC placement, but rather analysis of factors that influence the journey to LTC.

8.7 Conclusion
The findings of this secondary data analysis both support and contrast with the Pearlin et al. and Luppa et al. models of factors hypothesised to influence carer stress and institutional care utilisation, whilst also supporting the proposed alternative theoretical model. It appears that the effect of institutional care
utilisation on carer stress is as convincing as the effect of carer stress on institutional care utilisation.

This thesis proposes an alternative theoretical model to recognise the effect accessing and utilising care services has on carer stress. It would be constructive if future research could test this alternative model in a prospective analysis with an older cohort than was possible in the current analysis.
Chapter 9  Discussion

9.1  Overview
This thesis examined the extent to which carer stress influences institutional care utilisation by older care recipients, particularly admission to LTC. This was addressed using a mixed-methods approach over three inter-connected studies. This chapter summarises the aims and key findings of these individual studies. The findings from each study generated additional questions which were addressed in a subsequent study in the thesis. In this way the findings from the quantitative and qualitative components of the thesis were connected throughout the thesis. This chapter discusses these integrated findings and how they inform the overall thesis findings. The impact of the findings are identified using the Research Impact Framework by Kuruvilla et al. (295). The strengths and limitations of the thesis are discussed as well as the directions for future research arising out of the findings of the thesis. The chapter closes by discussing the conclusions of the thesis.

9.2  Introduction
In examining the sustainability of homecare, gerontological researchers have increasingly recognised the needs of the carer as well as the care recipient (1, 30, 112). This research has given a lot of attention to the detrimental aspects of caregiving, particularly the impact on a carer’s psychological health, such as stress and burden (37, 42, 43, 131, 132). This research led to the contention that such psychological morbidity of the carer could increase the risk of institutional care utilisation by the care recipient. The sentiment that there is a “strong link between caregiver stress and nursing home entry” (54 p.155) is a common theme in the caregiving literature (53-57, 59, 61, 62, 84, 87, 89-91, 94).

However, the inconsistency between study findings, the lack of rigour in the literature and the limited evidence to date to meet the Bradford-Hill criteria, suggested the need to critically review whether carer stress can indeed be regarded as a risk factor for institutional care utilisation by care recipients (167). This was
the focus of this thesis. Three theoretical models underpinned the thesis – from Pearlin et al., Andersen and Luppa et al. (22, 27, 170). Using these theoretical models, this thesis asked to what extent does carer stress influence institutional care utilisation by older care recipients, particularly admission to LTC? How strong is the effect of carer stress on acute and LTC admissions? What do healthcare professionals and carers perceive as the key risk factors in LTC admissions? How do healthcare professionals and carers compare the influence of carer stress to other factors influential in the transition to LTC? How do health system factors affect the relationship between carer stress and the transition to LTC? And finally, how do hypothesised factors in the theoretical models affect the relationship between carer stress and institutional care utilisation?

9.3 Aims of this thesis

These questions were incorporated into the three studies which made up the thesis. These studies addressed the four aims of the thesis. These were:

1. To systematically review and meta-analyse the prospective association between carer stress and institutional care utilisation by community-dwelling older people (Study 1).

2. To explore healthcare professionals’ and carers’ perceptions of the main factors influencing long-term care admissions of people with dementia and how carer stress influences these factors, if at all (Study 2 part 1).

3. To explore healthcare system factors which influence long-term care admissions of people with dementia (Study 2 part 2).

4. To examine the hypothesised factors that may influence carer stress and institutional care utilisation by community-dwelling older people cared for by a spouse (Study 3).
9.4 Summary of thesis findings

This section summarises the main findings of each of the three studies of the thesis as well as the overall thesis findings integrating the findings from these studies together.

9.4.1 Study 1: Systematic review and meta-analysis

The size of the effect of carer stress on both LTC and acute care admissions has varied among studies and had not been subjected to meta-analysis. This was addressed in Study 1 (Chapter 5). For the purposes of the review, ‘carer stress’ was used as an umbrella term to incorporate the wide number of exposures that are used synonymously in the measurement of carer stress. Institutional care utilisation was utilisation of both acute and LTC. These combined exposures and outcomes were separated in sensitivity analyses.

The meta-analysis found that, while carer stress has a significant effect on subsequent institutional care utilisation by care recipients, the overall effect size suggested that carer stress was not an important factor in subsequent institutionalisation of care recipients (219). The results also indicated a substantial degree of publication bias in the literature. The sensitivity analyses examined the size of the effect of carer stress on acute and LTC utilisation separately. In both outcomes the effect size was found to be negligible. Differences between exposure measures were also examined. This analysis found that whether the exposure was a measure of burden, stress, distress, or depression the effect size remained small to negligible.

The sensitivity analyses also found the effect size for studies with estimates that had adjusted for other factors (bar stress) were substantially lower than for studies with un-adjusted estimates. Further, in each of the last four decades, effect estimates have decreased. They are also lower in studies with larger samples and better quality studies. Taking these findings from the sensitivity analyses together, it appears that over time, as studies have increased in size, quality has improved, and more factors have been taken into account, the size of the effect found for
carer stress on institutional care utilisation by care recipients has reduced. This suggested the absence of a meta-analysis in the area may have perpetuated the continuation of the belief that higher levels of carer stress can undermine the sustainability of homecare. The present study therefore has significant implications for the literature and theory in this area.

That carer stress was found to have a small to negligible effect on institutional care utilisation suggested a need to re-evaluate the belief that carer stress is “the main determinant of institutionalization” (55 p.81) or that “Carer psychological morbidity predicts care breakdown and care home admissions” (56 p.539). The findings indicated that factors other than carer stress are more critical in institutional care utilisation. This had two major implications for the thesis question. Firstly, a more in-depth examination of the factors which influence admission to LTC and the role of carer stress in this process was needed. This was addressed in Study 2 (Chapters 6 and 7). Secondly, the findings of the meta-analysis contrast sharply with the theoretical model proposed by Luppa et al. (22) and the Pearlin et al. model (27). This suggested the need to re-evaluate the applicability of these models by examining hypothesised factors that may influence carer stress and institutional care utilisation by care recipients. This was addressed in Studies 2 and 3 (Chapter 6 and 8).

9.4.2 Study 2 part 1: Qualitative analysis of healthcare professionals’ and carers' perceptions of the influence of carer stress in long-term care admissions of people with dementia

A qualitative component to the thesis was undertaken to build on the findings of the meta-analysis (Study 1). This qualitative component consisted of two parts. The first part was a qualitative analysis of healthcare professionals’ and carers’ perceptions of the key factors that influence LTC admissions of people with dementia (Chapter 6). This enabled an examination of their perception of the influence of carer stress on LTC admissions of people with dementia.
The study found that carer stress was an important part of the journey to LTC. However, LTC admissions of people with dementia appear to be driven by the care recipient’s need, rather than carer stress. This is because the care needs of the person living with dementia escalate to a point at which they cannot be met at home. The findings were interpreted in the context of the Pearlin et al. and Luppa et al. models (22, 27). The study found that factors in these models were a source of stress for carers. For example, how the intensity of care recipient’s needs resulted in role captivity and how the lack of family support led to conflict. However, while these factors were a source of stress for carers, importantly, they did not emerge in the analysis as factors which influenced the LTC decision.

These limitations in the models meant the findings were re-interpreted in the context of Lazarus’s cognitive transactional theory of stress (143). Re-interpreting the findings in the context of Lazarus’s theory, suggested that the stress carers experience from the difficulty in meeting the care recipient’s demands was exacerbated by the lack of support from the healthcare system, particularly community care services.

Community care services have been described as a ‘lifeline’ for homecare in other studies (117). When carers find this ‘lifeline’ actually offers very limited support this appears to amplify the stress they experience. Other studies also found inconsistent and irregular community supports to be a significant source of stress for carers (38). In tandem with this, the findings demonstrated that receipt of community care should not be automatically regarded as equating with a reduction in carer stress, this was in contrast with the Pearlin et al. and Luppa et al. models (22, 27). When carers do receive these community support services, yet find they are inadequate, inconsistent or of poor quality, this can exacerbate the stress they experience. Community support services therefore appear to be a potential source of stress for carers.

As the factors in the Pearlin et al. and Luppa et al. models were found to be a source of stress, but not a driver of LTC admissions of people with dementia, the
models did not appear to comprehensively account for the study findings of the factors that influence the LTC decision-making process. This suggested a need to propose an alternative model of factors influencing LTC admissions. In this alternative model, LTC admissions may be driven by the care recipient’s needs. This was because the study findings suggest that when the care recipient’s needs cannot be met at home, neither by the carer nor with the limited support available from community care services, carers have no option but to opt for LTC. At the same time, the findings suggest that as carers struggle to meet the care recipient’s needs and try to continue with homecare, they experience stress. Thus in the proposed model, the factors which drive LTC admissions may also drive carer stress. These factors appear to stem from the care recipient’s needs and the apparent lack of support from community care services suggested in the study. Therefore, the proposed alternative model suggested carer stress may be a natural epiphenomenon of the LTC journey, rather than a driver of LTC admissions. The proposed alternative to the Pearlin et al. and Luppa et al. models was quantitatively examined in Study 3.

9.4.3 Study 2 part 2: Qualitative analysis of healthcare system factors which influence long-term care admissions of people with dementia in Ireland

The second part of Study 2 built on the findings of Studies 1 and the first part of Study 2. Study 1 findings suggested the need to look more broadly at factors that mitigate against the continuation of homecare. In Study 2, the apparent stress that carers experienced in the interaction with healthcare services (either due to the lack of these services or poor quality services where they are available), indicated that the healthcare system is not adequately supporting carers of people with dementia in homecare. This suggested the need to examine the effect of healthcare services on LTC admissions of people with dementia.

The study found that LTC admissions were affected by inadequacies in the healthcare system in four ways. Firstly, community care services were identified as frequently insufficient and inequitable. This limited their effectiveness in supporting sustainable homecare. Secondly, such limits in community care services lead to an
increase in subsequent acute care admissions. Thirdly, the findings suggested that admission of people with dementia to acute care can accelerate the journey towards LTC. Finally, people who required more care than current community care services could accommodate were forced into 24-hour nursing care facilities by the lack of intermediate care settings between home and 24-hour nursing care. Each of these factors, individually and in combination, were identified as extremely stressful for carers.

The insufficiency and inequity in community services was apparent in how constrained the services were. This undermined the extent that services were available. This under-resourcing of community care has also been found in other international studies in the area (111, 260, 261). Healthcare professionals were clearly very frustrated by these resource constraints. These resource constraints disempowered professionals in their role in the provision of homecare (261, 262).

These limitations in community care were found to have a knock-on effect on acute care. Recent international studies have also highlighted how lack of access to out-of-hours primary care or community nursing means acute care is the only option for families in crisis (263, 264). Both healthcare professionals and carers also reported acute care to be a means of accessing community care and nursing home beds. This was because constraints in resources resulted in long waiting lists to access community and LTC services. The use of acute care as a means to access community or LTC does not appear to be addressed in the international studies in this area, suggesting that this is a novel contribution to the literature. However, this use of acute care in the Irish healthcare system is of concern considering how an acute admission can result in a deterioration in the baseline cognitive or functional status of a person living with dementia (see Chapter 6).

A number of studies have also found that the decision that a care recipient can no longer be looked after at home and needs to transition to LTC is often made during an acute admission (85, 265). This study widened the scope of analysis by demonstrating the ‘vicious circle’ between constrained community care services
and increased accessing of the acute sector, and also how acute admissions can then accelerate LTC admissions of people with dementia. There appeared to be two main reasons for acute admissions to act as a catalyst to the LTC journey. Firstly, carers try to resist the transition to LTC for as long as possible. The drop in baseline cognitive or functional status of a person living with dementia whilst in acute care resulted in increased care needs. During the acute admission healthcare professionals may recommend LTC to a family. This advice appears to be critical. Healthcare professionals help to legitimise and validate the decision for families (85, 266).

The findings demonstrated that the factors which influence LTC admission of a person living with dementia are more multifactorial than the care recipient’s need or the carer’s ability to respond to these needs. If researchers do not account for the healthcare system in the journey to LTC, then they are missing vital components of sustainable homecare in their analysis. We cannot fully understand the factors that influence the transition to LTC, or the role of carer stress in this process, if we do not account for the impact of healthcare system factors on the sustainability of homecare. These findings reinforced the need to quantitatively examine the Luppa et al. and Pearlin et al. models (22, 27), as well as the proposed alternative model of hypothesised factors that may influence carer stress and institutional care utilisation by care recipients. This was addressed in Study 3.

9.4.4 Study 3: Structural analysis of hypothesised factors that may influence carer stress and institutional care utilisation by community-dwelling older people

Study 3 built on the findings of the previous two studies. This study was a secondary analysis of TILDA data which examined hypothesised factors that may influence carer stress and institutional care utilisation by care recipients.

This analysis found carer stress had a significant independent effect on institutional care utilisation by care recipients. This finding is in line with the Luppa et al. and Pearlin et al. models (22, 27). The effect size found was considerably stronger than
that found in the meta-analysis. However, the outcome was recall of health service utilisation; it was not possible to know when this utilisation took place in relation to stress as admission dates were not recorded. Furthermore, as it was not possible to do a longitudinal analysis in Study 3, the analysis was cross-sectional. In contrast, the meta-analysis was prospective. Thus the effect size found in Study 3 is not the effect of carer stress on subsequent institutional care utilisation, unlike the meta-analysis. Therefore, comparison of the results in Study 1 and Study 3 need to be interpreted with this in mind.

After testing several models, the findings of this analysis suggested that the effect of institutional care utilisation on carer stress were as convincing as the effects of carer stress on institutional care use. This supported the hypothesis generated in the qualitative study that carer stress is an epiphenomenon of the journey towards LTC. Indeed, the analysis found receipt of community care had a substantial direct effect on stress. Furthermore, utilisation of community and institutional care appeared to contribute equally to stress.

In contrast with the Luppa et al. and Pearlin et al. models (22, 27), the analysis found care recipient’s needs (cognitive impairment and frailty) were not significantly associated with carer stress once utilisation of community care and institutional care was accounted for. This may reflect the study sample. Care recipients were relatively young, those with more severe cognitive impairment were excluded and only 47% of carers needed to provide help with ADLs. Had the sample been older with higher care needs, an association between these care needs and carer stress may have been found. As care recipients needs were not found to have a significant direct effect on stress, the significant independent effect of stress on institutional care utilisation in this sample cannot be associated with stress driven by care recipient’s needs.

Furthermore, when receipt of community care and institutional care were examined alongside the effect of care recipient’s needs on stress, only institutional care utilisation was found to have a significant direct effect on stress. This stress
may be a result of spousal caregiving, opposed to being generated by care recipients needs as the Luppa et al. and Pearlin et al. models suggest. That is, the stress carers experience as their spouses’ condition deteriorates to the extent that community care and institutional care are required. As Pinquart and Sorensen have suggested, the degree of closeness between spouses and the deterioration in the health condition of spouse may make spousal caregiving particularly stressful (118).

Overall, the findings suggest that carers experience stress as their loved-one’s condition deteriorates to the extent that community and institutional care is required. Stress then appears to co-occur with the requirement for these services. As the co-occurrence of stress and utilisation of institutional care is not represented in the Luppa et al. or Pearlin et al. models, the thesis proposed a novel, alternative theoretical model to recognise the bi-directional relationship between carer stress and institutional care utilisation.

9.4.5 Overall thesis findings

Carer stress is an important aspect of the journey to LTC. Carers experience stress as their loved-ones’ condition deteriorates and they find that they are unable to meet the care recipient’s care needs at home. Community care then becomes a ‘lifeline’ to meet these care needs and for homecare to continue. When carers find that this ‘lifeline’ is inadequate, this intensifies the stress that carers’ experience. In this regard, stress appears to co-occur with the requirement for these services and the many difficulties carers experience in accessing and utilising these services.

However, the thesis findings suggest stress is not a risk factor, in the true meaning of the term, for LTC admissions. This was found in both the meta-analysis and the qualitative interviews with healthcare professionals and carers. That both studies produced similar results using different methods reinforces the credibility of this finding. As Farmer et al. write “findings that are consistent across diverse data sources and confirmed by multiple data sets provide greater confidence in the credibility of interpretations” (296 p.390). In contrast, Study 3 found carer stress had an independent effect on care recipient institutional care utilisation. However,
this analysis was cross-sectional. Study 3 also found utilisation of community and institutional care contribute equally to stress. Consequently it appeared that the effect of institutional care utilisation on carer stress was as convincing as the effect of carer stress on institutional care utilisation, supporting the alternative model that carer stress is an epiphenomenon of the journey to LTC proposed in Study 2.

Three theoretical models underpinned the thesis (22, 27, 170). These models were selected as they are widely used in the analysis of factors influencing health service utilisation and carer stress. The models provide a comprehensive set of variables potentially influential in carer stress and care recipient’s transition to LTC. As the Pearlin et al. and Luppa et al models propose that carer stress is a driver of LTC utilisation by care recipients, the thesis drew heavily from these models (22, 27). However, the overall thesis findings suggest the Luppa et al. and the Pearlin et al. models do not offer an accurate account of the role of carer stress in the transition to LTC. This has considerable implications for those studies in the literature based on the belief that there is a “strong link between caregiver stress and nursing home entry” (54 p.155). Therefore, it may not be appropriate to continue investing in RCTs designed to address stress so as to reduce institutional care utilisation (56, 98, 99). The thesis findings suggest such RCTs may not be addressing a true risk factor for utilisation of institutional care. In tandem with this, as the thesis findings suggest the Luppa et al. and the Pearlin et al. models do not comprehensively account for the role of carer stress, an alternative model was proposed. This alternative model should be further tested and refined to further map the determining factors and the paths between these factors that are influential to the transition to LTC and the role of carer stress in this process. By specifying the direction of the paths between the factors this would enable researchers to move beyond the continued use of loose models or frameworks towards the development of a more robust theory, with testable hypotheses and specified mediating paths (173). Without such theory the literature may continue with potentially random findings that do not allow a cumulative evidence base to be established (297).
The thesis offers substantial insights into the critical influence of healthcare system factors in the transition to LTC. Conventionally, the analysis of predictors of LTC admissions has focused on the transition from community to LTC. The thesis demonstrates how important it is to widen the scope of analysis and look at the implications of community, acute and LTC together. Without analysing how the three sectors (community, acute and LTC) interact it is not possible to understand the transition to LTC.

The thesis found a community care services are substantially constrained due a lack of investment in community care services. International literature suggests Ireland is not radically different to other jurisdictions. Constraints in resources for community care services have also been found in a number of international studies (111, 260, 261). Such services for people with dementia appear to be particularly problematic in a number of countries. It would seem that dementia care services are not prioritised to the same extent as other chronic diseases, with budget allocation for dementia lagging behind other chronic diseases in many countries (298).

The thesis found that this lack of investment in community care, particularly in terms of homecare packages, community nursing and emergency respite, forces families into acute care. This can be either at times of crisis or as a means of accessing community or LTC services. This is of concern considering how detrimental acute care can be to baseline cognitive or functional status of people with dementia. People who may otherwise have remained in the community for longer are then placed on the trajectory for LTC.

This may not be a cost-effective use of healthcare services. Utilisation of acute care can be costly. It is estimated that the average overnight cost in a public hospital in Ireland is between €659–€1,000 (299). This is the cost of a private bed in a public hospital which at present is the best estimate of the true economic costs of care. However, this is an average cost for the entire population, older care recipients are likely to cost substantially more. The cost also varies depending on the category of
hospital and room occupancy. The average cost of a nursing-home bed is estimated to be between €800-€1500 per week (181).

It is frequently argued that utilisation of LTC services is more costly than community care at home. A recent study across eight EU countries found the cost of homecare to be significantly lower than nursing home costs (300). However, the cost of homecare can be considerable once the opportunity cost for informal care is included (301). Thus in analysing the costs of utilising home or LTC we need to account for the variation in costs between countries, the intensity of the care recipients’ needs and the valuation method for informal care (300).

Utilisation of acute care as a means of accessing community or LTC services is also of concern considering the pressure in acute care services. Utilisation under these circumstances adds to the trolley crises in Emergency Departments and ‘bed-blocking’. Bed-blocking is a common term for delayed discharges. This is where the care recipient no longer requires acute care, they are ready to be discharged but there is no nursing home bed available or sufficient community supports for homecare (302). Indeed, the HSE Emergency Department Taskforce attributes a key contributor to the trolley crises to be the growth in the total number of delayed discharges (‘bed-blockers’). They found this was a result of the growth in waiting times for the Nursing Home Support Scheme (‘Fair Deal’) and “demand for sufficient levels of homecare supports” (303 p.7). Bed-blocking is not unique to Ireland, it is also of concern in countries such as Australia, Austria, the Netherlands, Sweden and in the UK (302). Gaughan et al. examined whether increased supply of nursing home beds could reduce delayed discharges. This analysis found the supply of nursing home beds did affect delayed discharges, but this effect was modest (302). However, this analysis did not account for the effect of the supply of community care services, suggesting further examination is warranted to see if increased supply of community care services could affect delayed discharges.

Finally, the thesis found there is a lack of options in care settings for older people in Ireland. There appeared to be a choice between homecare with a maximum of 21
hours of community care support or 24-hour nursing home care. This suggested that the lack of choice forces older people who do not actually require 24-hour nursing care, but who do require more supervision and support than is available as part of current community care services, into nursing homes. Data from the Department of Health suggests that 12.8% of residents in LTC facilities in Ireland are low dependency (160). Low dependency is defined as “persons who need some support in the community and the more independent residents in residential accommodation who require little nursing care. They are usually independently mobile but may use a walking stick and have difficulty managing stairs” (160 p.22).

The need for alternative settings to enable older people who need some, but not 24-hour, support was also raised in the HSE review of the Nursing Home Support Scheme. This review recommended that sheltered housing “should be considered in the context of future service planning as an integral component of long-term care” (304 p.66).

Alternatives to the 24-hour nursing home model appear to work well in other jurisdictions. For example, in Denmark there has been a policy of de-institutionalisation of LTC for older people since the 1980s (305). This policy has meant that nursing homes have slowly been replaced by ‘service housing’. This is where older people live independently in their own apartments but have a statutory right to the same level of care as those who reside in a nursing home. As a result community care services, particularly home help services, have increased. There is also an option of 24-hour support within the apartment for those who require this. As a consequence of the de-institutionalisation policy, nursing homes are offered “only to those who need intense care and attention” (305 p.40). The number of nursing home beds has decreased while the numbers residing in ‘service housing’ doubled in the 1990s (305). It would be constructive to see if there are options for lesson-learning from this policy of de-institutionalisation in Denmark that could be transferred to the Irish context.
9.5 Impact of findings arising from this thesis

The impact of the findings arising from this thesis will be presented according to the Kuruvilla et al. Research Impact Framework (295). The framework was developed to help researchers systematically describe the contribution and impact of health research. The framework is structured around four broad areas: research-related impacts, policy impacts, service impacts and societal impacts.

Research-related impacts include the contribution to knowledge from the research, methodological contribution, dissemination of the research and development or support of research networks. Research can impact policy in different ways. This may be directly at a national governmental level or at a local or NGO level. Research can also impact policy by providing evidence for new policy-making or alteration of existing policy. Service impacts relate to how research can inform evidence-based practice, service delivery and quality of care. Finally, societal level impacts include how research can alter knowledge or behaviours, inform practice to improve individuals’ physical and psychological health or influence equity in access to healthcare for vulnerable groups (295). Kuruvilla et al. acknowledge that the impact of health research will not always meet all four of these areas, nor are the areas mutually exclusive. Instead, the framework provides a guide of potential areas in which health research can make an impact (295).

9.5.1 Research-related impacts

The research related contribution of the thesis can be seen in a number of areas; these include a theoretical contribution, publications and conference papers and research networks.

9.5.1.1 Theoretical contribution

The thesis contributes to the theoretical literature on the role of carer stress in the transition to LTC. The thesis was the first study to meta-analyse the effect of carer stress on institutional care utilisation, which represent a significant contribution to the caregiving literature. These findings were published in a prestigious journal (203).
The Pearlin et al. model is a widely used theoretical model in the analysis of carer stress. The meta-analysis and qualitative analysis findings suggest that this model does not comprehensively account for the factors that influence the transition to LTC. This represents a departure in the caregiving literature.

The influence of healthcare services on carer stress is often overlooked in the caregiving literature. However, the thesis found inadequate healthcare services can exacerbate the stress that carers experience. In this regard, the thesis sheds new light on the role of healthcare services on carers’ experience of stress. The qualitative analysis also offered new insights on the unintended consequences of inadequate community and acute care services for people with dementia. This included how influential this inadequacy is to the transition to LTC and how such inadequacy resulted in considerable difficulties for healthcare professionals that sought to manage care provision within the constraints of the system. Again, this is a novel contribution.

The thesis proposed an alternative model in which carer stress is a natural epiphenomenon of the LTC journey, rather than a driver of LTC admissions. The theoretical model was then empirically tested in a general population sample of older spousal carers and their care recipients. The findings suggest that a bi-directional association between stress and institutionalisation is supported, and this is an addition to several frameworks in the literature (22, 27, 170).

Finally, the thesis findings contribute to ongoing Health Service Research priority setting. Carer stress does not appear to drive LTC admissions. Therefore, it may not be an appropriate use of funding and researcher resources to continue investing in RCTs designed to address carer stress as the underlying mechanism to reduce LTC admissions (56, 98, 99). Certainly carer stress is an important part of the transition to LTC and carers need to be supported with interventions to reduce the stress they experience. However, RCTs designed to address LTC admissions by solely addressing
carer stress may need to more broadly consider the factors influencing LTC admissions.

9.5.1.2 Publications and conference presentations

The thesis has led to the development of two peer-reviewed publications, one of which was published in June 2015 (see appendix 1) (203), with a second paper under review at the time of thesis submission (see appendix 2). As a result of the thesis there have been two oral presentations at international conferences, five oral presentations at national conferences and four poster presentations at national conferences. These conferences included academics, service providers and policy-makers. At the time of thesis submission, the systematic review and meta-analysis (203) has been cited by two further publications. The thesis has also contributed to the discussion in the literature of the influence of carer stress in institutionalisation through a letter to the editor (see appendix 3)(306).

9.5.1.3 Research network

This thesis was undertaken as part of a structured PhD programme in Health Services Research. This PhD programme involved national and international placements with service providers and health service researchers. The national placement was with the HSE. This was with a project that is developing a Carer Needs Assessment Tool in collaboration with the international research organisation InterRAI. As part of this placement a literature review on international carer needs assessment tools was undertaken to inform the development of the Carer Needs Assessment Tool (307). Following the placement, the PhD scholar remained an active member of this project as the development of this assessment tool is ongoing.

The international placement was undertaken with the Health Experience Research Group (HERG) at the University of Oxford. The HERG is a research centre with an international reputation for excellence in qualitative research. The research undertaken by the HERG and the methods they have developed have been described by the NHS National Knowledge Service as the ‘Gold Standard’ for
research into patient experiences (308). During the time in Oxford, the PhD Scholar attended a short course run by the HERG on ‘analysing qualitative interviews’. The placement provided an opportunity to discuss the analysis of the qualitative interviews with experienced researchers in the field and begin to apply what was learnt from the course during the placement by starting the data analysis of the qualitative component of the PhD.

The thesis has led to on-going active contribution by the researcher to the Care Alliance Ireland Family Carers Research Group. This is a group of academics, service providers, NGO and advocacy organisations working on research with carers in Ireland. As evidence of participation in the group, the findings of the thesis were presented at a conference for researchers on caregiving in Ireland organised by Care Alliance Ireland (309). Participation in the group has facilitated networking with national and international researchers working on research on carers. For example, the literature review undertaken as part of the national placement informed an international literature review on carer assessments in healthcare settings to support carers in their interactions with the health care system in Canada (310).

9.5.2 Policy impacts

The thesis findings informed the contribution from the Irish Department of Health to the British-Irish Council social inclusion work-stream focus on carers. To support this contribution a document summarising the thesis findings and their implications for policy was submitted to the Department of Health (see appendix 4).

As outlined in the document, the thesis findings have a number of implications for policy. Firstly, Government Policy in Ireland, as in many OECD countries is to support people to continue living in their own homes for as long as is possible. However, as raised by healthcare professionals in Study 2, often the examination of carer stress as a driver of LTC admissions ignores the autonomy of the care recipient in the decision-making around transitioning to LTC. Secondly, the apparent fragmentation and under-resourcing of community care services
suggested in Study 2 conflicts with Government Policy to support people to remain at home. There is a considerable need to review community care policies to ensure sufficient and equitable access to community care. This includes access on a statutory basis, with standardised eligibility criteria and assessment tools for a policy of transparent access based on need, not by location or political interference.

As the Nursing Home Support Scheme is underpinned by legislation, this has resulted in resource prioritisation for LTC services. In contrast, the under-resourcing of community care appears to reflect the absence of the equivalent statutory basis for homecare. In tandem with this, media and political attention on acute care services and nursing home services appears to result in a prioritisation of these services over community care. This is counter-productive as inadequate community care impacts on acute and LTC services. As demographic pressure from the ageing population continue, deficits in community care will increasingly impact on acute and LTC services.

The thesis also demonstrates the need to review policy options for LTC services. This includes a policy of care provision outside of the 24-hour nursing home institutional model. This would be appropriate for older people who do not require 24-hour nursing care, but require more support than can be provided by community care. Such a policy of de-institutionalisation could involve provision of sheltered accommodation or assisted living facilities as are provided in other jurisdictions (see section 9.4.5). Table 9.1 provides recommendations for policy arising out the thesis findings, in particular the findings from Study 2.

**Table 9.1 Recommendations for policy**

<table>
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<th>Community care</th>
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<td>1 Provision of homecare services should be set up on a statutory basis.</td>
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<td>2 Standardise access to homecare across the country using standardised assessment tools and eligibility criteria to access services.</td>
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<tr>
<td>3 Investigate means-testing eligibility for homecare services to support more equitable access.</td>
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<td>4 Investigate utilisation of resources accessible through the Nursing Home</td>
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Support Scheme for homecare. This would support older people who do not require 24 hour nursing care, but more care than homecare services can provide to remain at home.

5 Regulation of homecare services

<table>
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<th>Long-term care</th>
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<tr>
<td>1 Review options for sheltered housing or assisted living facilities to support older people who do not require 24 hour care, but require more support than homecare services can provide.</td>
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### 9.5.3 Service impacts

As described above, the HSE in conjunction with an international research organisation, InterRAI, are developing a Carer Needs Assessment Tool. It is planned that the tool will be used as part of the comprehensive older person’s assessment undertaken for the Nursing Home Support Scheme (‘Fair Deal’). The PhD Scholar was part of the project during the national placement and remained an active member of the project team following the national placement. Thus it is possible for the thesis findings to directly feed into this project.

The thesis findings suggest that in assessing the sustainability of homecare, priority is given to care recipients’ care needs. The findings also suggest that in undertaking the carer assessment, it may not be appropriate to heavily weight carer stress as a risk factor in the sustainability of homecare. Instead, the assessment tool should support healthcare professionals to probe the sources of carer stress in order to determine the best course of action to reduce this stress.

The thesis findings also have a number of implications for community and acute care service delivery. Firstly in terms of community care, the findings suggest there is considerable need to increase resources for homecare packages and community nursing. This would ensure more families can access these services and the number of hour’s available increase to meet escalating needs beyond the current cut-off, which is proving insufficient for maintaining the care recipient at home as their health deteriorates.
The findings also suggest the manner of community care service delivery needs to be reviewed. For example, for those currently receiving the maximum number of homecare package hours, these hours are often spread throughout the day (an hour in the morning, afternoon and evening). On a case-by-case basis in consultation with the needs of the carer, providing homecare package hours in blocks of time rather than breaking them up throughout the day, would give carers a proper break. In tandem with this, the inconsistency in personal care assistants that are part of homecare packages is at odds with person-centred care and is distressing for care recipients, carers and personal care assistants.

To mitigate against inappropriate use of acute care, it may be constructive for General Practitioner (GP) primary care services to provide information leaflets on what community care services are available and how to access these services. This could improve carers’ navigation of community care to avoid utilisation of acute care as a means to access community care services. In addition to this, more emergency respite beds are required. This would support families that are experiencing a crisis in the provision of homecare having to utilise acute care services due to the lack of care options for families.

Finally, there is a need to evaluate how acute care services can better accommodate and support people with dementia. This may be through rapid access to geriatric wards to avoid people with dementia having to go through emergency departments. Cost-effectiveness analysis of this approach could inform evidence-based service delivery. Table 9.2 provides recommendations for service delivery arising out the thesis findings.

Table 9.2 Recommendations for service delivery

<table>
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<th>Carer Needs Assessment Tool</th>
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<th>Community care</th>
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reduce waiting lists and avoid inappropriate acute admissions.

2 Increase resources for homecare packages to enable more hours to be allocated through homecare packages.

3 Provide homecare package hours in a block of time (as opposed to one hour three times a day) on a case-by-case basis. This will give carers a proper break.

4 Provide consistency in personal care assistants that are part of homecare packages.

**Acute care**

1 Provide more emergency respite beds to avoid inappropriate use of acute care.

2 Primary care services provide information on what community care services are available and how to access these to improve carers’ navigation of community care.

3 Evaluate how acute care services can better accommodate and support people with dementia.

### 9.5.4 Societal impacts

The thesis findings have a number of potential societal impacts. Firstly, the findings contribute to the literature on carer stress. They demonstrate how stressful caregiving can be and the factors that contribute to this stress. Specifically, the findings shed new light on how the lack of support from healthcare services exacerbates carer stress. If carer stress is an indication that the carer is finding it difficult to meet the care recipient’s needs and requires further support in homecare, then interventions designed to address carer stress need to support carers in the provision of homecare. This is opposed to interventions which address stress in a generalised way, such as relaxation techniques or counselling. This may provide some explanation as to why such interventions have had varying degrees of success (124, 152-154). For example, in a recent meta-review of interventions to address carer stress, Gilhooly et al. found many interventions addressed stress in a generalised manner rather than specific sources of stress (124).

Such informed interventions are required in order to address carer stress. This is in tandem with high quality community care services that adequately support carers in the provision of homecare. Indeed, at some point we have to ask ourselves if it is appropriate that as a society we implicitly accept that carers experience such stress and are so poorly supported to provide homecare? Our ageing population will
result in increased demand for carers. Therefore it is imperative that carers are adequately supported in the provision of homecare.

The findings also have societal implications regarding the lack of prioritisation of community care services. As referred to above, families in Ireland have no statutory right to homecare services. Access is based on eligibility and not entitlement. Therefore, community care policies rely on families for homecare. This is despite the consequences this may have for family members’ psychological morbidity as well their physical health and the economic and social impact intense caregiving has on the carer. If we are to realistically support older people to live at home for as long as is possible then we need to address the inequity and under-resourcing of community care.

Finally, the impact of community care and LTC services on acute care services can also be regarded as a societal impact. The difficulties families face navigating community care and the length of time to access LTC beds pushes families into acute care to access community and LTC services. Consequently, acute care services face difficulties discharging ‘bed-blockers’. Older people are then on trolleys in over-crowded Emergency Departments. Such situations are de-grading and de-humanising. This is a very distressing situation for families and healthcare professionals in these services.
Table 9.3 Recommendations for society

<table>
<thead>
<tr>
<th>Community care</th>
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<tbody>
<tr>
<td>1  Carers need to be adequately supported in the provision of homecare.</td>
</tr>
<tr>
<td>2  Community care services need to be prioritised in order to realistically support older people to live at home for as long as possible.</td>
</tr>
<tr>
<td>3  There ought to be equity in access to community care as well as sufficient resourcing of these services.</td>
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</table>

9.6 Strengths and limitations of this thesis

Strengths of this thesis
The thesis was undertaken using a mixed methods approach. This enabled a more comprehensive examination of the research question than would have been possible had one method alone been employed (195). Employing both quantitative and qualitative methods in the thesis ensured a rigorous analysis of the complex and multifaceted factors at play in the relationship between carer stress and institutional care utilisation by care recipients.

Study 1 in the thesis was the first study to meta-analyse the prospective association between carer stress and institutional care utilisation by community-dwelling older people. The size of the dataset in the meta-analysis meant it was possible to undertake extensive sensitivity analyses. This enabled a rigorous examination of the size of the effect of carer stress for different outcomes, exposure measures, populations and publication periods.

The qualitative component of the thesis drew on findings from a substantial number of in-depth interviews (n=38). This enabled the complexity and nuances in the role of carer stress in precipitating LTC admissions to be examined comprehensively. In doing so, the qualitative component shed new light on factors that influence the transition to LTC. For example, the qualitative component addressed the notable absence of studies that concentrate on health system factors in the transition to LTC. Most notably, the critical role of community care and acute
care as well as the detrimental impact the poor interconnection between these sectors can have in the transition to LTC was highlighted.

The qualitative component of this thesis provided new insights into how community care services interact with carers’ experience of stress. This analysis demonstrated that receipt of community care services should not just be regarded as a means of alleviating carer stress. Rather, both the absence and receipt of these services can be a source of stress for carers, exacerbating an already stressful situation. Thus it is necessary to think critically about the role of community care in the analysis of carer stress.

Limitations of this thesis

The limitations of the individual studies were outlined in each results chapter. In terms of the overall thesis, there was a different cohort of carers and care recipients in each of the studies. Studies 1 and 3 were older people in general, whereas Study 2 was concerned with people with dementia. There were specific reasons for this, consequently the fact that the same question was tested among different cohort of carers and care recipients may strengthen the thesis findings. For example, Study 1 was not confined to people with dementia in order for the sensitivity analysis to examine differences in the strength of the effect of carer stress on institutional care utilisation between carers of people with dementia compared to those without dementia.

Care recipients in Study 2 were people with dementia who were in the process of transitioning to LTC or had transitioned in the previous six months. As described in Chapter 6, the study focused on carers of people with dementia on advice from a consultant Geriatrician and as dementia caregiving has been acknowledged as the most stressful form of caregiving (121). Therefore, should carer stress be a risk factor in LTC admissions, it is likely that this would be most apparent amongst carers of people with dementia. That stress did not appear to be a risk factor in this context questions whether an effect would be seen in less stressful contexts.
The sample of care recipients in Study 3 was comprised of participants in the TILDA study and was relatively young. Those with more severe cognitive impairment were excluded in the first wave of TILDA (the sample for Study 3). Therefore, the carers in Study 3 may have been experiencing less stress than the carers in Study 2. This may have meant that the analysis in Study 3 under-estimated the effect of carer stress on institutionalisation. However, carer stress was found to significantly affect care recipient institutional care utilisation and the effect size found was much higher than in the meta-analysis, albeit in terms of having recall of the outcome of interest. Furthermore, care recipient’s needs (cognitive impairment and frailty) were not found to be associated with stress once analysed alongside the effect of community and institutional care utilisation on stress. Had the care recipients in the TILDA analysis been frailer, with more severe cognitive impairment, their care needs may have been associated with stress. Thus the findings should be interpreted in this context.

There was not a sufficient sample size to do a longitudinal analysis in Study 3 as there were only 25 carers and care recipient dyads in both wave one and two of TILDA (271). Consequently, causality could not be examined as the study was limited to the cross-sectional sample of spousal carers and care recipients that participated in the first wave of TILDA (n=205).

The relatively small sample size in the TILDA analysis (n=205), restricted the number of parameters in the analysis. This was in accordance the N:q rule proposed by Jackson (293). To compensate for this care recipients’ needs were analysed with a composite variable (frailty). The care needs in the frailty variable were needs that healthcare professionals and carers in believed influence institutionalisation (see Chapter 6). The measure was developed according to the Rockwood definition of frailty and derived using an established procedure (272-274). Had the sample size been bigger it would have been interesting to examine how different elements of this frailty measure (care recipients’ disabilities or chronic conditions) affected carer stress and the transition to LTC.
Chapter 7 demonstrated the degree of inequity in access to community care services, with variation in the availability of services between geographical areas. However, the size of the sample in the TILDA analysis meant it was not possible to look at regional variation in access to community care. The sample would need to have been considerably larger for such an analysis to be possible.

9.7 Directions for future research

There are a number of directions for future research stemming from this thesis. Firstly, the systematic review and meta-analysis (Chapter 5) found continuous interchangeability in measurement of carer psychological morbidity. Future research should develop an agreed taxonomy of carer stress to avoid this interchangeability and offer clarity in the measurement of carer stress. The methods used in the developments of the behaviour change taxonomy by Michie et al. could provide a good starting point for the development of a carer stress taxonomy (311).

The qualitative study (Chapters 6 and 7) was conducted with carers of people with dementia. It would be interesting to explore healthcare professionals’ and carers’ perceptions of the main factors influencing LTC admissions of other population groups of older people – post-stroke, heart failure, chronic obstructive pulmonary disease, etc. This analysis could include the role of stress in the LTC transition. In tandem with this, the study could explore healthcare system factors which influence LTC admissions in such populations.

It would be constructive to test the proposed alternative theoretical model in comparison to the current models in a prospective structural analysis. This analysis could be undertaken with an older cohort of care recipients that have higher care needs, including more severe cognitive impairment, than was possible to include in Study 3 of this thesis. This may be possible in future waves of TILDA. As described above (section 9.4.5), testing this alternative model could mean the model is refined to more accurately map the determining factors and the paths between these factors that are influential in the transition to LTC, and the role of carer stress.
in this process. This could enable the development of an actual theory, rather than a model or framework (173).

If the sample size was sufficient, it would be interesting if this analysis explored the different elements of care recipient’s needs (ADLs, IADLs, chronic conditions etc.) that interact with carer stress and how these needs, along with stress, affect utilisation of LTC services. As the qualitative analysis suggested an acute care admission often is the catalyst to a LTC admission, this future analysis could also explore these potentially important interactions - to have acute care utilisation as a separate outcome that is on the path to LTC admission. This analysis could then look at how care recipients needs and carer stress interact to increase the risk of acute hospital admission and the magnitude of the effect of this acute admission on subsequent LTC admission.

It would also be constructive if this analysis explored further the interaction of community care with carer stress and the transition to LTC. If possible, this analysis could include the degree of intensity of utilisation of community care – how do more home help or personal care assistant hours affect carer stress? As the inconsistency in personal care assistants appeared to exacerbate the stress carers experienced (Chapter 6), it would be interesting to explore this quantitatively - are those carers who had consistency in personal care assistants significantly less stressed? Do their care recipients remain at home longer? This analysis could also account for the regional variation in access to community care – are carers in areas where there are more community support services less stressed? In tandem with this, for areas where the waiting lists to access these services are shorter, are these carers less stressed? Does quicker access to more support services affect the likelihood of utilising acute care or the timing of when the care recipient transitions to LTC? How does the availability of LTC between areas affect carers stress and utilisation of acute care?

It may also be constructive for this analysis to explore the proposed alternative theoretical model in different population groups and different healthcare systems.
This could include healthcare systems where availability and accessibility of community and LTC services vary, or the make-up of these services and their interconnection varies.

Finally, community care appears to be critical to the continuation of homecare, yet the qualitative analysis suggested community care services are under-funded and fragmented. Future research should include a cost-effectiveness analysis of homecare, with various levels of community care support, in comparison to bed blocking in acute care or residing in LTC. This analysis should account for variation in care recipients’ care needs. For example, those with dementia who require high levels of supervision, but low nursing care needs, compared to those with high nursing care needs. The results of such an analysis could then inform policy regarding community care and the cost-effectiveness of different forms of homecare compared to acute or LTC for those with different care needs.

9.8 Conclusion
The thesis found that while carer stress is an important aspect of the journey to LTC, carer stress per se does not appear to be a driver of LTC admissions. The thesis findings suggest that carers experience stress as the care needs of care recipients increase to beyond that which the carer can meet at home. Consequently, carers turn to community care services for support. Despite the fact that these services are critical to the continuation of homecare, they appear to be under-resourced and fragmented. This limits their effectiveness in the provision of homecare. The lack of support from community care appears to exacerbate the stress that carers experience.

Rather than being driven by carer stress, the thesis findings indicate that LTC admissions are instead driven by care recipients’ needs. This is because care recipients’ needs cannot be met at home, neither the carer nor with the limited support of community care services. In this regard, carer stress appears to co-occur with the requirement for LTC. Thus the thesis found carer stress may be an epiphenomenon of the journey to LTC.
As the theoretical models of Luppa et al. and Pearl et al. (22, 27) were not found to accurately account for the role of carer stress in the transition to LTC suggested in the thesis, this thesis proposed an alternative theoretical model. This model was tested in a population sample of spousal carers. This analysis found the effects of institutional care utilisation on carer stress are as convincing as the effects of carer stress in institutional care utilisation. This has considerable implications for the caregiving literature, but should be rigorously tested in future research.


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339. Okura T, Plassman BL, Steffens DC, Llewellyn DJ, Potter GG, Langa KM. Neuropsychiatric symptoms and the risk of institutionalization and death: The


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Appendix 1 PLoS ONE Publication

Systematic Review and Meta-Analysis of the Impact of Carer Stress on Subsequent Institutionalisation of Community-Dwelling Older People

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Abstract

Background
In the caregiving literature there is a common assertion that a higher level of carer stress is a critical determinant of premature entry of homecare. However, this contention has not been systematically assessed. We therefore systematically reviewed and meta-analysed the prospective association between various forms of carer stress and subsequent institutionalisation of community-dwelling older people.

Methods
Systematic literature search of prospective studies measuring carer stress at baseline and institutionalisation at follow-up. Given substantial interchangeability in the measurement of carer stress, we included a wide number of exposure measures, namely: carer stress, burden, depression, distress, anxiety, burnout, and strain. Institutionalisation included both acute and long-term care utilisation. The standardised mean difference between stressed and non-stressed carers was the primary measure of effect. We assessed study quality with the Crowe Critical Appraisal Tool (CCAT). Pre-planned sensitivity analysis included examination of estimates according to study size, decay period, study size according to qualities of CCAT scores, population, follow-up period, study design and impact of adjusted estimates.

Results
The search yielded 8,983 articles. After exclusions, we analysed data from 54 datasets. The meta-analysis found that while carer stress has a significant effect on subsequent institutionalisation of care recipients, the overall effect size was negligible (SMD=0.05, 95% CI=0.04-0.07). Sensitivity analyses found that the effect size was higher for measurements of stress than for other measures, though still relatively small (SMD=0.23, 95% CI=0.09-0.38). Thus, whether analysing the association between carer stress, burden, distress, or...
depression with either acute or long-term care, the effect size remains small to negligible. Concurrently, we found estimates reduce over time and were smaller with larger studies and those of higher quality, according to the CCAT scores.

**Conclusion**

Despite strong statements to the contrary, it appears that the effect of carer stress on subsequent care recipient institutionalisation is small to negligible. The current findings point to a biased literature, with significant small study effects. The results suggest a need to re-evaluate the degree to which carer stress predicts premature ending of home care. Concurrently, other factors may be more crucial in institutional placement than carer stress and should be investigated.

**Introduction**

The caregiving role provided by family members and informal carers to older care recipients is often regarded as hazardous to a carer’s psychological well-being and physical health. Indeed, a number of meta-analyses and systematic reviews have concluded that carers are more likely to have poor psychological and physical health outcomes when compared to non-carers [1, 2]. Therefore, in examining the sustainability of home care, gerontological researchers have increasingly recognised the needs of the carer as well as the care recipient. This work has given much attention to the psychological health effects of caregiving, leading to a contention that such psychological morbidity of the carer could increase the risk of institutionalisation of the care recipient.

Before reviewing this contention it is important to note that, while there is extensive literature on the psychological health effects of caregiving, particularly carer stress, burden, and depression, there is a lack of clarity on their distinction and how they interact in the caregiving process. Indeed, though burden is one of the most commonly analysed variables in the literature, there is no single definition or uniform conceptualisation of carer burden [3, 4]. A number of researchers have acknowledged this lack of clarity by framing the examination of carer burden within the context of a stress process model [5–7]. Critical to the understanding of burden is the model’s distinction between objective and subjective primary stressors [8]. Objective stressors include care recipient’s functional disability and behaviours that challenge. Subjective stressors are the carer’s appraisal of objective stressors. Thus, within this model, burden is not understood as a separate construct from stress, rather it is a carer’s subjective appraisal of his or her situation [5, 8, 9]. We have adopted this interpretation of carer burden and stress for the purposes of this systematic review.

Despite attempts to provide clarity around the psychological health effects of caregiving, virtually every dimension of the stress process (from the primary stressors such as behaviours that challenge, to the outcomes of the model, including anxiety and depression) has been referred to as burden [10]. Consequently, the term ‘burden’ has been used in many different ways in the literature. Furthermore, there is a tendency of some researchers to use the concepts and associated measures interchangeably [4]. For example, studies discuss ‘carer stress’ yet apply measures of burden [11], measures of depression [12], or measures of strain [13]; or assess ‘carer strain’ and apply measures of distress [14]; or refer to ‘carer burden’ as synonymous with carer burnout [15]. Given the lack of clarity and consequential interchangeability in the measurement of psychological morbidity, any review of the area must incorporate a wide number of
exposures employed to measure carer psychological morbidity. Brodaty et al., also adopted this approach in a similar systematic review [16]. Therefore, in order to avoid omitting a substantial proportion of the literature, we had to include a wide number of exposures that are measured under the umbrella term of ‘care stress’, namely: stress, burden, depression, distress, anxiety, burnout, and strain.

As referred to above, in the caregiving literature there is a commonly held assertion that, as a carer is a critical element of home care, if the level of stress on a carer becomes too great, the home care support provided by the carer may be jeopardized [12]. Indeed, a number of cohort studies have found that higher levels of caregiver stress, burden, and depression can predict admission of the care recipient into a nursing home [13–16, 19]. Other authors suggest that carer stress was the principal determinant of nursing home placement [20]. Kurzyna et al., also found carer burden to be an important risk factor for hospitalisation of care recipients [21]. This same study suggests that interventions aiming to reduce carer burden and improve carer well-being could delay long-term placement [21]. Furthermore, a recent publication in the Lancet Psychiatry [22] stated that “care psychological morbidity predicts care breakdown and care home admissions” (p. 1). However, the assertion that higher levels of carer stress could jeopardize home care has not been subject to meta-analysis.

Indeed, the majority of reviews of the predictors of institutionalisation have not accounted for the level of carer stress [23–27]. Gaugler et al., did include carer stress in a systematic review of factors that consistently predict nursing home admission in people with dementia [28]. This review found that, carers who indicated greater emotional stress were more likely to admit the care recipient to a nursing home. While this review considered separate measures of carer stress, the analysis was confined to whether carer stress was a significant predictor and the direction of the effect (positive or negative). However, unlike the current study, the review did not analyse the size of the effect [28]. Finally, when both carer and carer recipient characteristics have been analysed together in cohort studies, the strength of the association between carer stress and institutionalisation has varied between studies, suggesting potential heterogeneity in these effects [16, 29, 30].

Given the absence of a systematic review and meta-analysis in the area, we systematically reviewed and meta-analysed the prospective association between carer stress and institutional placement of the care recipient. For the purposes of the review, ‘care stress’ is used as an umbrella term to incorporate the wide number of exposures that are used synonymously in the measurement of the psychological health effects of caregiving.

Objective
To examine the effect of carer stress on subsequent institutional placement of community-dwelling older people.

Methods
Study design
The PRISMA guidelines for the conduct and reporting of systematic reviews and meta-analyses were adhered to in the conduct of this review [31].

Eligibility criteria
Types of studies. Both naturalistic observational and intervention studies that measured carer stress at baseline and acute or long-term care utilisation at follow-up were included. We assessed prospective observational studies, control groups from controlled intervention studies
with caregivers and, where data from control groups alone could not be obtained, combined intervention and control groups were also included. Sensitivity analyses examined the differential effect of study design on estimates and the effect of excluding those studies where data from control groups alone could not be obtained. We excluded studies if they were cross-sectional, retrospective or not written in English. Articles were not limited by year of publication.

Types of participants. Care recipients: Community-dwelling older people (aged 65 and over) with chronic care needs that are being cared for by an informal carer. We did not confine the study to participants of a particular demographic group or ethnicity. Thus participants with Dementia or other chronic disabilities who have an established caregiving arrangement in the community were included. Caregiver: Informal carer who takes primary responsibility of the care recipient. We excluded articles with data on professional or paid carers.

Types of exposure. As mentioned above, different measures of psychological morbidity have been analysed in the prediction of institutional placement. In order to avoid omitting a substantial proportion of the literature, we had to include a wide number of exposure measures that are used under the umbrella term ‘care stress’, namely: stress, burden, depression, distress, anxiety, burnout, and strain. Brodaty et al., also employed this approach in a similar systematic review [14]. Given the range of possible exposure variables, we considered them in a hierarchical manner, with composite measures of burden and stress which have been tested for validity and reliability given priority. These were followed by composite measures of depression, distress, anxiety, or strain which have also been tested for validity and reliability. Where studies included more than one measure, we recorded both and analysed these separately in a sensitivity analysis. This enabled an examination of differences between estimates solely with measures of stress, burden, depression or distress. It was also possible to examine estimates solely with measures of burden and stress according to the stress process model [15] and with measures of psychological distress, as adopted in a similar systematic review [16]. For the overall effect estimates we employed the above hierarchy to select the best estimate.


Search methods

Information sources. We undertook a systematic literature search in January 2014 in the following databases: CINAHL, Medline (OVID), PsycINFO, Web of Knowledge, and EMBASE.

Search terms. The search terms were caregiver, aged or elderly or Alzheimer or dementia; stress or burden or burnout or distress or anxiety or depression or strain; nursing home or long term care or long term care utilisation or care home or homes for the aged or institutionalisation or acute care or hospitalisation or hospital admission or hospital readmission or emergency department or accident and emergency. SI Appendix provides an example of the search strategy for Medline (OVID).

Data collection and analysis

Study selection. The first reviewer screened all titles and abstracts of papers identified by the literature search (NAD). Given resource constraints, a second reviewer (AB) undertook duplicate screening on a random selection of fifteen percent of found titles/abstracts. We discussed disagreements with a third reviewer (FD). All studies identified as potentially relevant were retrieved and read in full to determine eligibility for inclusion.

Data extraction. We conducted data extraction by using a pre-defined data extraction template. Extracted data included design characteristics, study population and country, sample size, length of follow up, sample selection, age and sex of participants, the exposure and
outcome measures and results. Where there were insufficient data in the published paper we contacted authors to provide further information.

Quality assessment. We conducted quality assessment with the Crowe Critical Appraisal Tool (CCAT) [12-14]. The CCAT was developed based on a wide number of previous critical appraisal tools, general research methods theory and reporting guidelines [15]. The tool has undergone testing for reliability and validity, with Crowe et al., reporting intraclass correlation coefficients of 0.83 (consistency) and 0.74 (absolute agreement) [12, 13]. A similar recent meta-analysis also employed the CCAT to assess study quality [14].

Based on the CCAT, we appraised papers included in the review in eight categories. These were preliminary appraisals (such as the title and abstract), the introduction, design, sampling, data collection, ethical matters, results, and discussion. Within each category we examined a number of items such as sampling method, sample size and bias. Scoring was a combination of objective and subjective assessment, where each category is scored from 0 (no evidence) to 5 (highest evidence). Total scores for each study are presented as a percentage. Thus the tool enables direct comparison of scores obtained in the quality assessment of articles included in the review [12, 14]. In the sensitivity analysis, to examine the impact of study quality on effect estimates in a meaningful way, we grouped studies by quartiles of CCAT scores. However, we maintained continuous scores for the meta-regression.

Statistical analysis. The standardised mean difference (SMD) between stressed and non-stressed carers was the primary measure of effect. This approach is recommended when there is variance in measurement of exposure (e.g., mean and SD of stress, burden, or depression scores or proportions stressed, burdened, or depressed) and outcome status (acute or long-term care utilisation) [16, 17]. As a last resort, we reported a combination of mean and SD scores or proportions stressed or not, we employed the metaff command in Stata 12.0 [14]. This command enabled the calculation of an effect size and its standard error by using methods described in the Cochrane Handbook of Systematic Reviews of Interventions [18, 19]. Thus data were transformed to a common effect size metric. We estimated effects in a random effects model [20] for all included studies. We employed the F test to describe the percentage of total variation across studies that was due to heterogeneity rather than chance [20]. We conducted an assessment of publication bias or small study effects visually with a funnel plot and more formally with Egger's test.

We conducted a pre-planned sensitivity analysis of estimates according to study size by tertile; the decade studies were published and regions in which studies were conducted; study quality by quartiles of CCAT scores; use of adjusted or unadjusted estimates; dementia populations compared to non-dementia populations; different follow-up periods; study design and long term care in comparison to acute care utilisation. We examined the impact of different exposure measures in a number of ways. Firstly, we examined differences between estimates solely with measures of stress, burden, depression or distress separately. Where the same scale was used to measure stress, distress and burden, we applied the original classification by the authors of the scale. For example, the General Health Questionnaire was classified as 'distress', an approach also adopted in a similar systematic review [41, 42]. We compared differences in estimates between studies applying the Zarit Burden Interview (ZBI) with studies that applied other measures of burden. It was also possible to examine estimates solely with measures of burden and stress, according to the stress process model [3], and with measures of psychological distress, as adopted in a similar systematic review [43]. We also examined differences in estimates within studies that measured both burden and depression. Finally, we did a further sensitivity analysis of those studies that applied measures of stress. Here, we examined the effect estimates for studies which used a validated measure of stress (that is, the psychometric
properties of the scale have been reported), in comparison with those studies that did not use a validated measure or report if the psychometric properties of the scale had been tested.

Given the methodological diversity of included studies, we anticipated significant heterogeneity. Therefore, we planned a meta-regression to understand the extent to which heterogeneity was related to the characteristics of the studies [43]. This included the year studies were published, study size and quality, whether the estimates were adjusted for, the type of outcome and exposure measure and the period of follow-up. We examined each study characteristic individually first. We then entered study characteristics found to be significant into a meta-regression with multiple covariates to assess their overall contribution to heterogeneity in effect estimates [43].

Results
Study selection
Fig. 1 presents a flow diagram of the search strategy. After duplicates were removed, the search retrieved 4,701 articles, of which 4,582 were excluded (4,367 on review of abstract and a further 215 after full text assessment). A further 65 articles were omitted. These were 27 repeat publications from the same dataset (see SI Appendix) and 38 studies where adequate data was not available following contact with authors. Details of these studies are presented in SI Appendix. Thus data from 34 datasets were included in the analysis.

Study characteristics
Characteristics of included studies are displayed in SI Appendix. Eighteen studies were conducted in Europe, twenty-six in North America, eight studies in Asia, and two were conducted in Australia. In the majority of cases, the research designs adopted were cohort studies (80% of studies) with study populations of caregivers and dementia care recipient dyads (74% of studies).

There was substantial variation in the types of exposure measures included. Twenty-seven studies measured caregiver burden and of these seventeen studies used the Zarit Burden Interview (ZBI). One study used items from the ZBI and two studies measured burden with the Family Caregiving Burden Inventory (FCBI). A further seven studies used different measures of burden (see SI Appendix).

Ten studies measured carer stress, two of these studies with the Relative Stress Scale. The other eight studies used eight different measures of stress. Six studies measured carer distress: three used the General Health Questionnaire, two used the Neuropsychiatric Inventory Distress scale (NPI-D), and the sixth used a measure from the InterRAI home care assessment tool (see SI Appendix).

Carer strain was measured in two studies. One study measured carer anxiety using the anxiety scale of the Hospital Anxiety and Depression Scale (HADS). Nineteen studies measured depression, thirteen of these with the Centre for Epidemiologic Studies Depression Scale (CES-D). Three studies used the Geriatric Depression Scale. Three other studies used three different measures of depression.

Eleven studies utilized more than one measure. Six studies measured both carer burden and depression. Two studies measured carer stress and depression. One study measured carer burden and anxiety. One study measured carer stress and distress and one study measured carer distress and depression.

A number of studies referred to the same measure as a measure of burden, stress, or distress. This interchangeability was apparent both within and between studies. For example, in one study the same measure was referred to as both a measure of stress and burden (reference 83),
Fig 1. Flow diagram records identified through database searching.

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S4 Appendix. The General Health Questionnaire was used to measure 'stress' (reference 47, S4 Appendix), 'distress' (reference 71, S4 Appendix), and 'burden' (reference 102, S4 Appendix).

In forty-two studies the outcome measure was admission to long-term care, in seven studies it was admission to acute care, while in five studies the outcome was admission to both acute and long term care (see S4 Appendix).
Synthesis of results: Meta-analysis

As detailed in the methods section, we adopted a hierarchical approach to the exposure measure to estimate the overall effect size. With this approach the meta-analysis found that, while carer stress has a significant effect on subsequent institutionalisation of care recipients, the overall effect size across the 54 studies was negligible according to Cohen’s guidelines (SMD = 0.05, 95% CI = 0.04–0.07) [44]. The forest plot using best estimates from individual studies is displayed in Fig. 2.

There was evidence of statistically significant heterogeneity ($I^2 = 79.2\%$; $p = <.001$) and funnel plot asymmetry (see Fig. 3). Furthermore, the Egger’s bias coefficient (bias = 1.45; $p = <.001$) strongly indicated the presence of asymmetry and publication bias, suggesting small studies overestimate the effect of stress [43].

Additional analysis: Sensitivity analyses

Summary estimates for each of the sensitivity analyses are displayed in Table 1. To examine the impact of the type of measure on estimates, the sensitivity analysis separated out measures of stress, burden, depression or distress. Where the same scale was used to measure ‘stress’, ‘distress’ and ‘burden’, we applied the original classification by the authors of the scale. For
example, the General Health Questionnaire was classified as 'distress', an approach also adopted in a similar systematic review [41, 42].

It would appear that the magnitude of the estimate with measures of stress (SMD = 0.23, 95% CI = 0.09-0.36) is higher than that of the estimate with any other exposure measure. This estimate would still be considered 'small' according to Cohen’s guidelines [44]. In contrast, the estimate with measures of burden are lower (SMD = 0.07, 95% CI = 0.05-0.10). Estimates with measures of depression fall within this range with confidence intervals which overlap with estimates of burden (SMD = 0.03, 95% CI = 0.00-0.05). However, a number of studies in the sensitivity analysis of the estimate with measures of stress used non-validated measures.

We undertook a further sensitivity analysis of those studies measuring stress. Of these studies, for those that used a validated measure of stress (that is the psychometric properties of the scale have been reported) the effect size was approximately half (n = 6; SMD = 0.17, 95% CI = -0.02-0.36) of that of those studies that did not use a validated measure or report if the psychometric properties of the scale had been tested (n = 4; SMD = 0.30, 95% CI = 0.12-0.48). Overall, the number of studies included in these estimates varies, thus it cannot be said with confidence that there is a stronger effect estimate with a particular type of exposure. However, it would appear that irrespective of whether we examine the effect of stress, burden, depression or distress on institutionalisation separately or combined these measures the effect remains significant, but small to negligible according to Cohen’s guidelines [44].

It was also possible to examine estimates solely with measures of burden and stress according to the stress process model [16]. In this case, the size of the effect is also negligible according to Cohen’s guidelines (SMD = 0.06, 95% CI = 0.04-0.08). Similarly, it was possible to examine estimates with measures of psychological distress, as adopted in a similar systematic review [17]. Again, the size of the effect is negligible according to Cohen’s guidelines (SMD = 0.05, 95% CI = 0.01-0.09).
We explored further the impact of the particular exposure measure on effect estimates by comparing studies which applied the Zarit Burden Interview (ZBI) (SMD = 0.06, 95% CI = 0.04 - 0.09) to those that applied any other measure of burden (SMD = 0.19, 95% CI = 0.04 - 0.35). While the SMD between the two estimates appears somewhat different, the effect sizes would still be considered small to negligible according to Cohen’s guidelines [44].

Finally, in terms of the effect of different exposure measures, the sensitivity analysis examined differences in estimates within studies that measured both burden (SMD = 0.22, 95% CI = 0.05 - 0.39) and depression (SMD = 0.03, 95% CI = -0.00 - 0.07). Again, although the SMD between the two estimates appears quite different, the effect sizes would still be considered small to negligible according to Cohen’s guidelines [44].

To investigate how effect estimates varied according to study size, we grouped studies by tertile. Consistent with the findings of the Egger’s test, there is a notable reduction in the size of the effect for studies with larger sample sizes. For example, the effect estimate in studies with the smallest samples (SMD = 0.28, 95% CI = 0.13 - 0.44) was higher compared to larger studies (SMD = 0.05, 95% CI = 0.03 - 0.07). The forest plot with estimates grouped according to their sample size is provided in Fig.4.

The sensitivity analysis also examined estimates according to the decade in which the study was published. It would appear that in each of the last four decades the effect estimates have decreased (1980s: SMD = 0.40, 95% CI = 0.16 - 0.63; to 2010 and later: SMD = 0.05, 95% CI = 0.02 - 0.07), as displayed in Table 1.

As presented in 5th Appendix, there was a wider variation in study quality, with CCAT scores ranging from 30% to 95%. To examine the impact of study quality on effect estimates in a meaningful way, we grouped studies by quartiles of CCAT scores. As presented in the table, effect estimates reduce as study quality improves. The effect estimate changes considerably for those studies with unadjusted estimates (SMD = 0.14, 95% CI = 0.01 - 0.18) compared to those studies with adjusted estimates (adjusting for factors such as age, sex, type and severity of dementia, spousal care and ADL rating) (SMD = 0.01, 95% CI = 0.00 - 0.02). Despite this change, the unadjusted estimate would still be considered a ‘small’ effect size according to Cohen’s guidelines [44].

As displayed in Table 1, the sensitivity analysis also examined the differential effect of the study design on estimates. The estimate with cohort studies appears higher (SMD = 0.11, 95% CI = 0.08 - 0.14) than that of intervention studies (SMD = 0.01, 95% CI = 0.01 - 0.02). However, the estimate with cohort studies would still be considered a ‘small’ effect size according to Cohen’s guidelines [44]. In three cases it was not possible to get data on control groups alone, despite contact with authors, therefore a sensitivity analysis examined the impact on estimates when these three studies were excluded, however the effect size remained negligible (SMD = 0.07, 95% CI = 0.05 - 0.09) [44].

Finally, as displayed in Table 1, the sensitivity analysis included an examination of the impact on estimates depending on the whether the sample was a dementia population or non-dementia population, the period of follow-up, the region in which studies were conducted and the outcome. While estimates vary slightly, in all cases the estimate remain small to negligible according to Cohen’s guidelines.

Meta-regression

Given significant heterogeneity was found in the overall effect size, we conducted a meta-regression to investigate the contribution of different study characteristics to the level of heterogeneity [46, 47]. Firstly, we examined each study level characteristic individually, as presented in Table 2. We examined the extent to which heterogeneity was related to the year in
Table 1. Sensitivity analyses.

<table>
<thead>
<tr>
<th>Study size</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small</td>
<td>19</td>
<td>0.28</td>
<td>0.13–0.44</td>
<td>53.5</td>
</tr>
<tr>
<td>Medium</td>
<td>17</td>
<td>0.11</td>
<td>0.05–0.18</td>
<td>57.7</td>
</tr>
<tr>
<td>Large</td>
<td>18</td>
<td>0.05</td>
<td>0.00–0.09</td>
<td>90.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Decade published</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990s</td>
<td>3</td>
<td>0.40</td>
<td>0.16–0.63</td>
<td>0.0</td>
</tr>
<tr>
<td>1990s</td>
<td>14</td>
<td>0.26</td>
<td>0.18–0.34</td>
<td>0.0</td>
</tr>
<tr>
<td>2000s</td>
<td>23</td>
<td>0.03</td>
<td>0.00–0.07</td>
<td>77.5</td>
</tr>
<tr>
<td>2000s</td>
<td>14</td>
<td>0.04</td>
<td>0.02–0.07</td>
<td>86.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality score</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1: OCAT score &lt; 50%</td>
<td>13</td>
<td>0.26</td>
<td>0.12–0.41</td>
<td>66.5</td>
</tr>
<tr>
<td>Group 2: OCAT score 50–74%</td>
<td>12</td>
<td>0.21</td>
<td>0.08–0.35</td>
<td>67.4</td>
</tr>
<tr>
<td>Group 3: OCAT score 75–88%</td>
<td>15</td>
<td>0.06</td>
<td>0.00–0.14</td>
<td>94.1</td>
</tr>
<tr>
<td>Group 4: OCAT score &gt;88%</td>
<td>14</td>
<td>0.05</td>
<td>0.01–0.09</td>
<td>82.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adjustment</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unadjusted estimates</td>
<td>44</td>
<td>0.14</td>
<td>0.10–0.18</td>
<td>81.7</td>
</tr>
<tr>
<td>Adjusted estimates</td>
<td>10</td>
<td>0.01</td>
<td>0.00–0.02</td>
<td>46.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Population</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia population</td>
<td>40</td>
<td>0.09</td>
<td>0.02–0.16</td>
<td>75.7</td>
</tr>
<tr>
<td>Non-Dementia population</td>
<td>14</td>
<td>0.15</td>
<td>0.08–0.22</td>
<td>56.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Follow up</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>A year or less</td>
<td>26</td>
<td>0.09</td>
<td>0.05–0.14</td>
<td>77.7</td>
</tr>
<tr>
<td>Over a year</td>
<td>28</td>
<td>0.04</td>
<td>0.02–0.05</td>
<td>77.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study design</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohort</td>
<td>43</td>
<td>0.11</td>
<td>0.08–0.14</td>
<td>92.3</td>
</tr>
<tr>
<td>Intervention</td>
<td>11</td>
<td>0.21</td>
<td>0.00–0.02</td>
<td>92.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long term care</td>
<td>42</td>
<td>0.06</td>
<td>0.04–0.08</td>
<td>74.2</td>
</tr>
<tr>
<td>Both acute and long term care</td>
<td>5</td>
<td>0.27</td>
<td>0.13–0.41</td>
<td>0.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Region conducted</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Europe</td>
<td>18</td>
<td>0.02</td>
<td>0.00–0.05</td>
<td>53.3</td>
</tr>
<tr>
<td>USA</td>
<td>20</td>
<td>0.07</td>
<td>0.04–0.09</td>
<td>80.4</td>
</tr>
<tr>
<td>Canada</td>
<td>6</td>
<td>0.13</td>
<td>0.04–0.22</td>
<td>81.5</td>
</tr>
<tr>
<td>Asia</td>
<td>8</td>
<td>0.19</td>
<td>0.06–0.33</td>
<td>0.0</td>
</tr>
<tr>
<td>Australia</td>
<td>2</td>
<td>0.31</td>
<td>0.05–0.58</td>
<td>0.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Differences between measures</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any measure of burden</td>
<td>27</td>
<td>0.07</td>
<td>0.05–0.10</td>
<td>61.1</td>
</tr>
<tr>
<td>Any measure of stress</td>
<td>14</td>
<td>0.08</td>
<td>0.05–0.10</td>
<td>72.8</td>
</tr>
<tr>
<td>Any measure of distress</td>
<td>6</td>
<td>0.09</td>
<td>0.00–0.18</td>
<td>90.5</td>
</tr>
<tr>
<td>Any measure of depression</td>
<td>19</td>
<td>0.15</td>
<td>0.08–0.23</td>
<td>87.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Studies with more than one measure</th>
<th>No. of studies</th>
<th>SMD 95% CI</th>
<th>I²</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burden</td>
<td>6</td>
<td>0.24</td>
<td>0.07–0.42</td>
<td>84.9</td>
</tr>
<tr>
<td>Depression</td>
<td>6</td>
<td>0.04</td>
<td>0.00–0.07</td>
<td>71.1</td>
</tr>
</tbody>
</table>

which studies were published, with year of publication as a continuous variable. From the table, it would appear that there is a significant negative association between the year of publication and the size of the treatment effect. In tandem with this, the year in which studies were published made a substantial contribution to the level of heterogeneity, with the proportion of heterogeneity accounted for at 29.7% (p = 0.001). Figure 3 presents a bubble plot of the fitted regression line with the size of the circles reflecting the relative weight of the study. Whether studies included unadjusted or adjusted estimates (adjusting for factors such as age, sex, type and severity of dementia, spousal care and ADL rating) also made a considerable contribution, accounting for 24.5% of heterogeneity (p = 0.014). As presented in Table 2, we also examined the contribution of study quality, study size, outcome, and type of exposure.
measure and the period of follow-up, though it would appear these all explained less heterogeneity than would be expected by chance [42].

We entered those variables found to be significant into a meta-regression with multiple covariates, presented in Table 3. In this model, the year in which studies were published and whether studies included adjusted or unadjusted estimates accounted for 46% of heterogeneity. The remaining heterogeneity was small ($I^2 = 0.007$) [47].

Discussion

Summary of evidence

Overall, the results suggest that while caregiver stress has a significant effect on subsequent institutionalisation of care recipients, the size of this effect is small to negligible according to Cohen’s guidelines [44]. The sensitivity analysis reinforced this overall effect size. Firstly, in terms of the
Table 2. Meta-regression with single covariates.

<table>
<thead>
<tr>
<th>Study characteristic</th>
<th>Coefficient (SE)</th>
<th>95% CI</th>
<th>Covariate P Value</th>
<th>Joint test for all covariates P Value</th>
<th>Heterogeneity I²</th>
<th>Proportion of between-study variance explained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of publication</td>
<td>-0.012 (0.003)</td>
<td>-0.018–0.006</td>
<td>0.001</td>
<td>&lt;0.001</td>
<td>0.009</td>
<td>26.65%</td>
</tr>
<tr>
<td>Adjusted</td>
<td>-0.130 (0.047)</td>
<td>-0.215–0.055</td>
<td>0.014</td>
<td>0.014</td>
<td>0.009</td>
<td>34.54%</td>
</tr>
<tr>
<td>Study size</td>
<td>-0.000 (0.000)</td>
<td>-0.005–0.000</td>
<td>0.802</td>
<td>0.802</td>
<td>0.014</td>
<td>-0.50%</td>
</tr>
<tr>
<td>Study quality (CCAT %)</td>
<td>-0.154 (0.003)</td>
<td>-0.211–0.098</td>
<td>0.157</td>
<td>0.157</td>
<td>0.014</td>
<td>-0.97%</td>
</tr>
<tr>
<td>Outcome</td>
<td>0.063 (0.053)</td>
<td>0.043–0.169</td>
<td>0.235</td>
<td>0.235</td>
<td>0.013</td>
<td>-5.30%</td>
</tr>
<tr>
<td>Measure—depression</td>
<td>-0.149 (0.084)</td>
<td>-0.311–0.025</td>
<td>0.093</td>
<td>0.483</td>
<td>0.014</td>
<td>-0.87%</td>
</tr>
<tr>
<td>Measure—burden</td>
<td>-0.050 (0.067)</td>
<td>-0.185–0.084</td>
<td>0.456</td>
<td>0.226</td>
<td>0.118</td>
<td>-0.95%</td>
</tr>
<tr>
<td>Measure—strain</td>
<td>-0.082 (0.179)</td>
<td>-0.443–0.278</td>
<td>0.650</td>
<td>0.650</td>
<td>-0.090 (0.277)</td>
<td>-0.246–0.068</td>
</tr>
<tr>
<td>Follow-up for 1–2 years</td>
<td>-0.080 (0.207)</td>
<td>-0.173–0.012</td>
<td>0.074</td>
<td>0.513</td>
<td>0.017</td>
<td>-11.38%</td>
</tr>
<tr>
<td>Follow-up or over 2 years</td>
<td>-0.090 (0.077)</td>
<td>0.246–0.068</td>
<td>0.252</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

doi:10.1371/journal.pone.0138213.g002

type of measure, while the estimate for studies that measured stress appeared to be higher than other measures, it was still relatively small. Thus, whether the exposure was a measure of burden, stress, distress, or depression the effect size remained small to negligible. Similarly, we found, whether the outcome was acute or long-term care the effect size was negligible. This was also the case when examining estimates sold with measures of stress or burden, according to the stress process model [44], or solely with measures of psychological distress, as also adopted in a similar systematic review [46]. Further, we found the effect size for studies with estimates that had adjusted for other factors to be substantially lower than with studies with un-adjusted estimates. While the un-adjusted estimate is larger than the adjusted, the un-adjusted estimate effect size is still small according to Cohen’s guidelines [44].

Taking the findings together, though carer stress is significant predictor of institutionalisation, the size of this effect suggests that other factors may be more crucial in institutional placement than carer stress. Indeed, when systematically reviewing the association between factors other than carer stress and institutionalisation, a number of studies found functional and cognitive impairment and prior nursing home use to be predictive of admissions to long-term care

Fig. 5. Bubble plot of fitted regression line.

doi:10.1371/journal.pone.0138213.g005
Table 3. Meta-regression with multiple covariates.

<table>
<thead>
<tr>
<th>Study characteristic</th>
<th>Coefficient (SE)</th>
<th>95% CI</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of publication</td>
<td>-0.011 (0.038)</td>
<td>-0.017–0.005</td>
<td>0.001</td>
</tr>
<tr>
<td>Adjusted</td>
<td>-0.004 (0.041)</td>
<td>-0.177–0.111</td>
<td>0.007</td>
</tr>
</tbody>
</table>

Model Heterogeneity v²: 0.07
Proportion of between-study variance explained: 45.01%
Model P Value: 0.001

doi:10.1371/journal.pone.0128213.003

[23–25, 28]. Prior hospital admissions and duration of previous hospital stay, co-morbidity and polypharmacy have been found to be predictive of admission to acute care [26, 27]. This review suggests that future research should perhaps concentrate on these and other factors in the prediction of institutionalization as it appears that carer stress is not the most critical determining factor of institutionalization in older care recipients.

The sensitivity analyses indicated that in each of the last four decades, effect estimates have decreased and are lower in studies with larger samples. This was consistent with both the funnel plot and findings of the Egger’s test, suggesting that small studies over-estimate the size of the effect of carer stress. We also found study quality to have a substantial impact on estimates, with estimates reducing as study quality improves. The findings of the sensitivity analysis were consistent with that of the meta-regression, which found that there was a significant negative association between the year of publication and the size of the treatment effects. Concurrently, results from studies using adjusted estimates also appear to differ from results of studies with unadjusted estimates.

These findings suggest that, over time, as studies have increased in size, quality has improved, and more factors have been taken into account, the size of the effect has reduced. This suggests that the significant association found between carer stress and institutionalization in initial studies in this area may have resulted in a belief that higher levels of carer stress can undermine the sustainability of home care. However, in later years this does not appear to have been critically evaluated, with researchers possibly relying on these initial studies to provide evidence for such contentions [48, 49].

The present findings therefore suggest a need to re-examine this assertion in the literature—while carer stress has significant effects on subsequent institutionalization of care recipients, the actual size of this effect is small to negligible. This would suggest that carer stress is not the most critical determining factor of institutionalization in older care recipients, and that strong statements to the contrary are not based on the evidence available [22]. Such publication bias in psychology is not uncommon. A recent examination of publication bias in psychology found that barely significant values were much more frequently reported than values that just failed to reach the conventional threshold for statistical significance [49]. This aversion to publish null results impedes the publication of non-significant replication studies [46, 50], resulting in the continued publication of numerous ‘indeed’ theories [51] or what Ioannidis describes as ubiquitous false positive claims [52].

The findings should not be interpreted as underestimating the significance of chronic stress on carers, or the importance of RCTs aimed at reducing carer stress. The level of stress experienced by a carer is important both of itself and for its potential impact on the carer, such as impaired psychological well-being and physical health [1], including weakened immunity and wound healing [53, 54]. Indeed, a number of meta-analyses and systematic reviews have concluded that carers are more likely to have poor psychological and physical health outcomes when compared to non-carers [1, 2]. However, as stress appears to have a negligible effect on
institutionalisation, it is unlikely that RCTs in this area will have an effect on institutionalisation rates.

Interchangeability of measures
While carer burden, depression, and stress were the most commonly applied measures, the review found substantial inconsistency across the measurement of psychological morbidity in carers. This inconsistency was apparent in a number of ways. Firstly, the same exposure was assessed with a range of measures. As described earlier, in seven different studies burden was measured using seven different ways. Inconsistency was also seen within and between studies. For example, within some studies the same measure was referred to as both a measure of stress and burden, while in different studies the same measure was referred to as a measure of burden, stress, or distress (references 47, 71, 85 and 102, 84 Appendix). The tendency of some researchers to regard measures of carer burden and depression as synonymous with measures of stress has been acknowledged in the literature (4). This tendency is most apparent in the case of 'burden' which has been applied to virtually every dimension of the stress process (103). Overall this meant that we had to combine these exposures in the present review—however sensitivity analyses did not suggest substantially different effects for these separate measures on care recipient institutionalisation. This confusion in the caregiving literature points to a need for the development of an agreed taxonomy to enable more concise identification of interactions relating to psychological morbidity in the caregiving process.

Strengths and limitations
Given the lack of clarity and consequential interchangeability in the measurement of psychological morbidity, the search strategy had to incorporate a wide number of exposures that are measured under the umbrella term 'caree stress'. It could be argued that these exposures represent distinct concepts that when pooled may result in misclassification bias. However, there is theoretical and methodological support to pool the exposure measures, in addition to the practical considerations outlined above given the contradictory literature.

Firstly, Cramer et al., have developed a network approach to mental disorders and comorbidity. According to this approach, symptoms are viewed not as indicators of latent conditions but as components in a network. Boomsma et al., employed this network model to show that half of the symptoms in the DSM IV are connected. As recommended by Bradburn et al., and Taie et al., to enable pooling, the primary measure of effect was the standardized mean difference using a random effects model. By standardization, the results were transformed to a common scale and the random effects model combined data under the assumption that the effect is not fixed between populations but varies around a typical value. Finally, despite the wide variation in exposure measures the meta-regression found that differences in the type of exposure measure explained less heterogeneity than would be expected by chance, providing further support for pooling measures.

The sensitivity analysis examined major aspects of study design that could affect estimates. This included dementia or non-dementia populations, cohort or intervention studies, and the period of follow-up. We found these had a minimal impact on estimates. However, there may still be unmeasured confounders. These may include the effect of formal care service utilisation or the degree to which access to long-term care varies over time and between health systems—given the availability of beds, differential professional assessments and criteria to access long-term care. We accounted for the region in which studies were published in the sensitivity analysis and found estimates remain small to negligible. However, it would not be appropriate
to give too much weight to this comparison given health system variation within and between countries. This would be more appropriate in future research.

Finally, the lack of access to unpublished data could also be regarded as a limitation. However, both the funnel plot and the Egger’s bias coefficient strongly indicated the presence of publication bias, suggesting small studies overestimate the effect of stress [13]. Therefore, had it been possible to access unpublished data, it is likely that the effect sizes found would have been even smaller than what was found.

Future research

The findings suggest the need to critically review the definition of carer stress, to offer some clarity around the terminology used and consolidate measures to enable more precise identification of the interactions relating to psychological morbidity in the caregiving process.

Future research should perhaps concentrate on other factors found to be associated with institutionalisation, such as the characteristics of the care recipient. This research could be expanded to account for the impact of the health system on long-term care provision. In tandem with this, as a carer is ultimately responsible for the decision to yield care, yet carer stress appears to have a small to negligible effect on institutional placement, qualitative work could be employed to enable more in-depth examination of the impact of carer stress on the decision to yield care.

Conclusion

The results of this review suggest that while carer stress has a significant effect on subsequent institutionalisation of care recipients, the size of this effect is small to negligible. The sensitivity analysis reinforced the effect size, irrespective of the type of measures used, carer stress has small to negligible effect on subsequent institutionalisation. The results also highlight the problematic nature of the contradictory literature. That is in terms of the interchangeability in the measurement of stress.

Results of this systematic review are at odds with the strong contention that higher levels of carer stress could undermine the sustainability of home care [20, 21], and suggest that publication bias, or at least small study effects, have contributed to this belief. The findings should not be interpreted as undermining the significance of chronic stress on carers. As referred to above, a number of meta-analysis and systematic reviews have concluded that carers are more likely to have poor psychological and physical health outcomes when compared to non-carers. However, the size of the effect of carer stress on subsequent institutionalisation suggests that other factors may be more crucial in institutional placement than carer stress.

Supporting Information

S1 Appendix. Medline (OVID) search strategy.
(DOCX)

S2 Appendix. Repeat publications from the same dataset.
(DOCX)

S3 Appendix. Characteristics of studies for whom adequate data was not available.
(DOCX)

S4 Appendix. Characteristics of included studies.
(DOCX)


“We don’t have the infrastructure to support them at home”: How health system inadequacies impact on long-term care admissions of people with dementia.

Abstract

Objectives: The provision of homecare takes place within the context of the wider healthcare system. However, there is a notable absence of studies concentrating on the influence of healthcare system factors on long-term care admissions. We address this absence by examining how inadequacies in the healthcare system impact on long-term care admissions of people with dementia. This is done in the context of the Irish healthcare system.

Methods: Thirty-eight qualitative in-depth interviews with healthcare professionals and family carers were conducted. Interviews focused on healthcare professionals’ and carers’ perceptions of the main factors which influence admission to long-term care. Interviews were analysed thematically.

Results: Long-term care admissions of people with dementia are affected by inadequacies in the healthcare system in three ways. Firstly, the economic crisis in Ireland appears to have exacerbated the under-resourcing of community care services. These services are also inequitable. Consequently, the effectiveness of community care is limited. Secondly, such limits in community care increase acute care admissions. Finally, admission of people with dementia to acute care can accelerate the journey towards long-term care.

Conclusions: Inadequacies in the healthcare system have a substantial impact on the threshold for long-term care admissions. We cannot fully understand the factors that predict long-term care admission of people with dementia without accounting for healthcare system factors on the continuation of homecare.

Introduction

The aging population across Europe has the potential to create considerable strain on long-term care service provision in the coming decades, particularly for people with
dementia. In light of this, there is great interest in identifying the factors which predict transition of people with dementia to long-term care (LTC) services. Gerontological researchers have conventionally focused on the characteristics of the older person that influence the transition from community to LTC use (22, 23, 57, 84). The psychological health effects on family carers responding to a care recipient’s needs have also been recognised. Such work has led to the belief that, as family carers are critical to homecare, if the level of stress carer’s experience as a consequence of providing care becomes too great, the homecare arrangement may break down (55, 56, 312). Indeed, a recent study of factors associated with long-term institutional care of people with dementia across Europe concluded that “caregiver burden appeared the most consistent factor associated with institutionalisation” (62p.9).

However, a recent systematic review and meta-analysis indicates that family carer stress does not have as strong an effect on LTC admissions as was previously believed. Although a significant association was found, the effect size was negligible (SMD= .05, 95% CI .04-.07) (203 p.12). The results of this review suggest the need to look wider than the needs of the care recipient or the carer that mitigate against the continuation of homecare.

Despite the provision of homecare taking place within the context of the wider healthcare system, there is a notable absence of studies that concentrate on healthcare system factors that influence admission of people with dementia to LTC. Where studies have examined healthcare system factors, they have identified the importance of community care services for people with dementia, options for service reconfiguration and potential costs savings (12, 258). However, they have not addressed the implications of community and acute care. Therefore, this study aimed to develop an in-depth understanding of how community and acute care, along with the interconnection between the sectors, impact admissions of people with dementia to LTC. To the best of our knowledge, this present study is the first to examine this.

This issue has been examined in this study in the context of the Irish healthcare system. The national health service agency, the Health Service Executive (HSE), provides the majority of public acute and community care services in Ireland. The
main state-funded community support services for older people are homecare package schemes which include community health nursing, home-help for domestic tasks or personal care assistants for intimate personal care. Respite may also be provided, depending on the person’s needs and where they live. Other HSE services for older people in the community include Physiotherapy, Occupational Therapy, Speech and Language therapy and Social Work. The Nursing Home Support Scheme provides access to LTC facilities (known as nursing homes, residential care homes, assisted living facilities and care homes in different countries) (12). The scheme provides financial assistance towards the cost of long term care services. It is administered by the HSE through the ‘Fair Deal’ scheme (179). This scheme means that, depending on income or resources, applicants contribute towards the cost of LTC and the State pays the balance.

Following the economic crisis in Ireland in 2008 and the subsequent government programme of austerity, there have been continuous cuts to HSE staff numbers and budgets (313, 314). For example, HSE funding has fallen by 22% from 2009 to 2013 (182). Consequently, community care services have been reduced since the crisis. Data on home help hours is one of few measures of healthcare system activity in the community (183). Home-help hours have decreased by 18% between 2008 and 2012 (182). However, it should be noted that community care services were fragmented and under-funded prior to the economic crisis (298).

**Methods**

**Study design**

This study aimed to develop an in-depth understanding of the role of healthcare system factors in LTC admissions of people with dementia, thus a qualitative approach was adopted. This allowed for the nuances and complexities within the healthcare system to be analysed. We obtained ethical approval for the study from the Research Ethics Committee (REC) of the Royal College of Surgeons in Ireland (RCSI) (Ethics Reference number: REC1057b).

**Sample**
Participants included healthcare professionals and family carers. Both hospital and community-based healthcare professionals that were key decision-makers regarding the transition to LTC were interviewed. Family carers were those providing care to a loved-one with dementia. They and their family had decided that homecare was no longer sustainable and so had started the process of applying for LTC for their family member, or had gone through the process in the last six months.

**Data collection**

Interviews were conducted from May to August 2015. In compliance with REC requirements, participants were not contacted directly. Therefore, a number of simultaneous recruitment strategies were employed. Healthcare professionals identified eligible family carers, informing them of the study and passing on study information which included the researcher’s contact details. Family carer support organisations advertised the study. The study was also advertised through a press release from RCSI, and in various healthcare and gerontological websites and newsletters.

All participants received information on the study prior to the interview. Once consent forms were signed, the data was generated through semi-structured individual interviews. Interviews were conducted by the first author and lasted an hour on average. They explored what participants perceived to be the critical factors influencing LTC admissions of people with dementia. Interviews were audio recorded and transcribed verbatim for analysis. All participants were provided with the opportunity to review the interview transcript, one participant did. Data saturation determined the final number of interviews conducted (239). A total of thirty-eight interviews were conducted; twenty-two with healthcare professionals and sixteen with family carers of people with dementia.

**Analysis**

Data analysis was supported with the data management software NVivo10. Interviews were analysed thematically. Themes were developed using the ‘One Sheet of Paper’ (OSOP) method, developed by the Health Experiences Research Group (HERG) at the University of Oxford (243). This enabled comparison of codes
within a theme to ensure consideration for nuances in the analysis. The coding framework was reviewed and discussed by the research team and is presented in Fig 1 below.

**Fig 1. Coding framework of healthcare system factors which influence LTC admissions**

**Results**

**Profile of respondents**

All family carers interviewed were providing care to a person with dementia. Thirteen women and three men participated. Nine participants were providing care to a spouse, while seven were providing care to a parent. Family carers were on average 60 years of age and were providing care to a loved-one who was on average 78 years of age.

A total of twenty-two healthcare professionals (HCPs) were interviewed, eighteen of whom were female. The largest group of professionals (n=13) worked in nursing and included Public Health Nurses, Community Registered General Nurses, Clinical Nurse Managers and Clinical Nurse Specialists. The other professional groups interviewed were Social Workers, GPs, a Geriatrician, Psychologist, Occupational Therapist and Manager for Older Person’s Services. These professionals were based both in the community and in hospitals.

**Overview of findings**

The study found that admissions of people with dementia to LTC are affected by inadequacies in the healthcare system in three ways. Firstly, community care services appear to be substantially constrained as a result of the economic crisis. These services also appear to be inequitable. Both these factors limit the effectiveness of community care in supporting sustainable homecare. Secondly, such limits in community care services increase acute care admissions. Finally, the findings suggest that admission of people with dementia to acute care can accelerate the journey towards LTC.
1.1 Constraints in community care services
The under-resourcing of community care services as a consequence of cuts within the Health Service Executive (HSE) emerged quite strongly in the analysis. Family carers frequently described how they received little to no direction or support from community care services. This led one family carer to describe the community care services provided as “appalling” (Family carer 2). The impact of this under-resourcing on community-based healthcare professionals was also quite apparent. Professionals were clearly frustrated by these constraints. They described how overstretched they were, limiting time available to visit families. They felt these constraints had undermined their professional practice and consequently their role in homecare.

“It’s counterproductive...we go out and we do an assessment for home help...We submit all the paperwork and then it doesn’t happen...because there is no money there... then we’re the people at the frontline having to say to somebody “Yes I do understand what you’re saying. I do identify the needs of your loved-one but sorry we don’t have the resources to put it in”. It’s like, well why are you here?...it’s very hard to be asked to do a job and then not have the tools to do it.” (HCP 15)

1.2 Manner of service delivery can undermine quality
As described above, the main State-funded support service for community care in Ireland is the homecare package scheme. This involves personal care assistants providing support with the care recipient’s personal care, such as washing and dressing. Given pressure to reduce the cost of the homecare package, there is a growing trend for the Health Service Executive (HSE), to outsource the service to private care providers. Often private providers have high staff turnover rates. Consequently, families have different care assistants from private providers calling to the house to support them. This family carer, who cared for her husband, demonstrated how distressing it was when the care assistants constantly changed:

“You wouldn’t know who you were going to get at the door that morning...So he didn’t know where he was...The whole situation was like a time bomb when they were here because I was trying to keep my husband calm, because he would get very agitated and be shouting and roaring and everything and then they’d [the care
However, four family carers reported positive experiences. For those who had positive experiences there was continuity in the personal care assistant. This provided routine and stability and helped reduce some of the stress they experienced. These families had a more positive outlook on the quality of the homecare package scheme compared to those families who did not have continuity in the personal care assistant.

1.3 Inequity in service availability
Respondents raised the considerable degree of inequity in availability of community care services nationwide. They emphasised that this inequity did not arise as a result of the economic crisis. The inequity was apparent in the substantial variation in the availability of services between even small geographical areas. There was also a lack of transparency in relation to factors influencing waiting times to access services, with some professionals questioning if this was based on priority of need. As this professional described:

“The other problem is it depends where you live... in one area I had home help immediately and in the other area, the other side of the road, there was a waiting list... the other bit is if you shout really loud you get it... the people who actually sit there on the waiting list, sit on the waiting list.” (HCP 8)

2. Constrained community services impact on acute care
The second major study finding indicates that constraints in community services impact on acute care in two main ways, each of which are described below.

2.1 At times of crisis families are forced to go to acute care
Community care services are so over-stretched that they do not have capacity to respond to families who are experiencing a crisis in care provision, however short-term this crisis may be. This crisis may involve the carer being unwell or otherwise
unable to provide care. Healthcare professionals described how, in such circumstances, they have no option but to advise the family to go acute care.

“If they can’t manage they are forced into an acute hospital...it’s not advice anyone wants to give...there is no emergency nursing home beds, emergency respite beds. There is nothing out there for people that if they’re really struggling at home there is nothing to support them through that.” (HCP 1)

2.2 Acute care used as a means to access both community and long-term care

It is not just at times of a family crisis that constrained community services can affect acute care utilisation. The under-resourcing of community care means there are substantial waiting lists to access homecare packages. Access to LTC beds, through the Nursing Home Support Scheme (described above), can also take a considerable length of time (between 6-18 months). Consequently, healthcare professionals described advising families to bring their loved-ones to acute care to force them on the healthcare system to accelerate accessing these services.

“Quite often, I unfortunately would have to suggest to them that they go into hospital...They’ve a different budget...So it’s easier to get a homecare package or, em, a nursing home placement through the hospital...you have to get the family to say “No I’m not taking them home until it’s in” and that’s, unfortunately, the way it is.” (HCP 8)

3. Pivotal influence of acute admissions

The third major study finding highlights that there are multiple paths to LTC, presented in Fig 2. The first is what could be referred to as the ‘ideal scenario’. That is, the person with dementia transitions from the community to LTC. This scenario is what is most often assumed when researchers analyse the care recipient factors that influence LTC admissions. However, this study found that admission to LTC rarely happens this way. Rather, it would appear that an admission to acute care can be pivotal, often acting as a catalyst to the LTC transition. The person with dementia may return home from acute care, but are on the path to LTC as a result of the admission. Alternatively, it may be impossible to return home and so the transition happens from acute care.
Fig 2. Multiple paths to LTC

There were two reasons an acute admission can be so pivotal. Firstly, the baseline status of the person with dementia can drop in acute care. Secondly, the decision to go to LTC can be taken out of the carer’s hands.

3.1 Drop in baseline status
Participants spoke about the inadequacies of A&E and acute wards for a person with dementia. The hospital is an unfamiliar environment, involving interactions with many different healthcare professionals. Consequently, people with dementia can become quite confused and distressed in acute care. Healthcare professionals repeatedly emphasised how an acute admission can result in a drop in the functional and/or cognitive baseline status of the person with dementia. When this occurs it can accelerate the LTC journey.

3.2 LTC decision taken out of family carer’s hands
Family carers have an immense commitment to the caregiving role. They experience feelings of guilt and grief at the thought of ending this role and handing over the care of their loved-one to a LTC facility. Consequently, carers resist embarking on the LTC journey for as long as possible. However, an acute admission often drives the decision and takes it out of the family carer’s hands. This is partly due to the reduction in the functional and/or cognitive baseline status of the person with dementia during the admission. It is also as a result of the influence of healthcare professionals in acute care. Family carer’s repeatedly spoke about how healthcare professionals lead on the LTC decision.

“It was the hospital decided for me...I really, I knew the way he was in the hospital I couldn’t take him home... It was just that he got so sick and my GP said to me “you can’t take him home” and in the hospital they said you can’t.” (Family carer 7)

Community-based professionals felt that while they may advise families to start planning for the future care of their loved-one, it is the validation of this advice by hospital-based professionals during an acute admission that often triggers the LTC
transition. Such professionals appear to play a huge role in supporting families in the decision. By taking the lead on the decision they can help remove some of the guilt family carer’s experience in coming to the decision. They can also help the family carer to see that the need for LTC is not based on an inability on their part, but that the care needs of their loved-one exceed that which can be met by the carer in conjunction with the limited support of the community care system.

“The majority of families don’t want long-term care….they feel that they’ve failed. And you try to explain that it’s not a failure on their behalf, it’s just the fact that, you know, we don’t have the infrastructure to support them at home.” (HCP 17)

Discussion

Summary of findings

This is the first study to demonstrate how LTC admissions of people with dementia are affected by inadequacies in the healthcare system. This was shown in the limitations in community care services. How such limitations in community care increased acute care admissions and how admission of people with dementia to acute care can accelerate the journey towards LTC for people with dementia.

The insufficiency and inequitability of community care services was seen in how constrained these services were. Such constraints were apparent both in terms of staff and resources. These constraints undermined the extent that services were available. As others have noted, community services were under-funded and fragmented prior to the recession (298). However, this under-funding appears to have been exacerbated as a consequence of the economic crisis.

Concurrently, the manner of service delivery resulted in great variation in the quality of services. This was most apparent for those families where the personal care assistants constantly changed. As the care assistants provide intimate personal care, when there’s no continuity of care this resulted in very distressing situations. Such a service appears to be counter-productive to supporting families in homecare. There also appears to be significant inequity in service availability. The combination of these aspects appears to limit the effectiveness of community care services for people with dementia.
The findings suggest that limitations in community care services have a knock-on effect on acute admissions. The under-resourcing of community care services means they do not have the capacity to respond to families in crisis. In these circumstances, acute care is the only option for families. Acute care was also reported as a means to access both community and LTC. This is of concern considering acute admissions often act as a catalyst to the LTC journey.

Overall, the findings suggest that the factors influencing the admission of an older person with dementia into LTC are more multifactorial than the care recipient’s needs or the family carer’s ability to respond to these needs. Healthcare system factors appear to be critical. While these are largely overlooked in the LTC literature, the present study suggests that not taking into account healthcare system factors means that vital components of sustainable homecare are missed. As dementia is a progressive disease, the care needs of the older person escalate. To meet these care needs, family carers rely on the healthcare system. However, it would appear that, in Ireland, inadequacies within community and acute care services along with poor interconnection between the sectors limit the ability of the healthcare system to effectively support people with dementia and their families. The capacity of the healthcare system to provide this support appears to have been further diminished as a result of economic crisis.

Findings in the context of other research

The under-resourcing of community care services are not unique to Ireland. Studies across the OECD and more recently in Australia, and Canada have also found community care services were limited due to resource constraints (111, 260, 261). A recent systematic review of LTC admissions in dementia found “in most countries resources available in the continuing care system are limited” (84 p.19). However, the economic crisis in Ireland appears to have aggravated this under-resourcing. Such constrained resources not only affect the care recipient and family carer, but have also been found to disempower healthcare professionals (261, 262). It is thus understandable that professionals in this study expressed such frustration at being prohibited in the degree of support they could offer families due to resource limitations. If community care services cannot adequately support families in the
provision of homecare, this has a substantial impact on the decision thresholds for admission to LTC.

The implications of community care on acute care have recently been noted by a number of authors. A number of studies have highlighted lack of access to out of hours primary care or community nursing, making acute care the only option for patients and families (263, 264). In this study we have widened the scope of analysis by demonstrating the ‘vicious circle’ between constrained community care services and increased accessing of the acute sector, and also how acute admissions can then accelerate LTC admissions of people with dementia.

A number of international studies have also found that the LTC decision is made at a time of crisis, which is often during an acute admission (85, 265). However, this study provides further insight as to why it takes an acute admission to drive the decision. Family carers resist transitioning to LTC for as long as is possible. The deterioration of the cognitive and/or functional status of the person with dementia while in acute care results in increased care needs. Following re-assessment of the needs of the person with dementia, healthcare professionals may recommend LTC to the family. Such advice from healthcare professionals appears to be critical to the decision. In many respects, healthcare professionals help to legitimise the decision for families (85, 266). This points to what Mamier et al. describe as the need for healthcare professionals to provide ‘anticipatory guidance’ to avoid crisis situations which make the LTC admission urgent (267).

**Limitations**

While this study included the voice of family carers and healthcare professionals, it did not include people with dementia. Inclusion of people with dementia was considered at the outset. However, as discussed above, the LTC decision is often forced as the care needs of the person with dementia have increased to the extent that they cannot be met by the family carer alone or with the support of the community care system. Thus, by the time the LTC decision has been made, the person with dementia has substantial cognitive and functional care needs. Therefore, it would not have been appropriate or ethical to have undertaken an in-depth interview with a person with dementia under such circumstances.
Another limitation may be the generalisability of the findings. However, mapping of dementia care services across European countries suggests the nature of care services for people with dementia in Ireland is similar to other EU countries (108). This analysis found availability and access to community care may vary between countries. Nonetheless, across European countries access and utilisation of care services for people with dementia was problematic (108). As discussed above, a recent systematic review of LTC admissions in dementia found resources available for continuing care are limited in most countries (84). Other others have also found budget allocation for dementia lags behind other chronic diseases in many countries (298). The economic crisis in Ireland appears to have intensified the under-resourcing of care services for people with dementia. Consequently the study demonstrates how critical these services are in LTC admissions of people with dementia.

**Conclusions**

Overall the findings demonstrate that the healthcare system is critical in the journey to LTC for people with dementia. This has implications for health policy makers and health services researchers. Firstly, it is important for health policy makers to recognised that poorly funded and inequitable community care services have a substantial impact on acute care and LTC admissions of people with dementia. Secondly, it is critical for health services researchers to recognise that analysing care recipient factors or family carer factors on LTC admissions, in the absence of healthcare system factors, means we are missing critical components to sustainable homecare. We cannot fully understand the factors which predict LTC admissions of people with dementia without accounting for healthcare system factors on homecare.
Appendix 3 Letter to the Editor: JAN Interactive

http://journalofadvancednursing.blogspot.ie/2015/06/what-leads-to-caregiver-burden.html

Thursday, 11 June 2015

How influential is carer burden in institutionalisation?

Nora-Ann Donnelly & Frank Doyle

Royal College of Surgeons in Ireland, Dublin

The recent article by Verbeek et al. (2015) analyses inter-country variation of factors associated with institutionalisation of people with dementia. It is very beneficial to have empirical data from a number of European countries on the factors which influence the admission of people with dementia to long-term care. However, we would like to put forward some comments for consideration regarding the authors’ conclusions, which we feel do not match the data presented in the article.

The authors conclude in both the Abstract and Discussion that ‘caregiver burden appeared the most consistent factor associated with institutionalisation’ (Verbeek et al. 2015 p.9). However, from our examination of the results as presented, the findings do not appear to fully support this assertion.

Firstly, the authors examine differences between people with dementia who were recently admitted to a nursing home (between 1-3 months), compared with those living at home with dementia who were regarded as at risk of institutionalisation. This analysis enables us to examine how these independent groups differ. However, it does not take into account the effect of institutionalisation on caregiver perceptions of burden. For example, previous research has found that carers are likely to experience considerable reductions in burden after nursing home admission (Gaugler et al. 2011). Given that institutionalisation can alleviate burden, the analysis, as presented, is not an accurate test of whether burden is associated with subsequent institutionalisation, but merely a demonstration of difference between two independent groups. This association could be confounded by other factors.

The authors do provide a more appropriate test of the association between burden and subsequent institutionalisation within the article, but again it is questionable whether the reported results support their conclusions. The authors followed people with dementia and their carers who lived at home and analysed the differences at baseline between those institutionalised after three months and those who were not. The univariate analysis found that those who had made the transfer to institutional long-term care had an informal caregiver who experienced
a higher caregiver burden at baseline than people who remained at home (t=-2.31; p=0.021). However, this association did not survive adjustment for other factors. The overall multivariate analysis using a multi-level model found three other factors that explained the transition from living at home to institutional care at follow-up. These were: living situation; neuropsychiatric symptoms; and cognitive status. Unfortunately, the authors did not report the overall multivariate model including burden. Therefore, we do not know the results for caregiver burden when other factors have been taken into account. If burden is a consistent factor in institutionalisation, it should remain so after taking both the characteristics of the person with the dementia and the carer into account. The actual reported results therefore contrast with the conclusions of the article, and it seems that burden is not a consistent factor in institutionalisation when controlling for these other important factors.

However, these results are actually more in keeping with our recent work, which has meta-analysed the association between carer stress, distress and burden and subsequent care recipient institutionalisation. We found, from 54 articles, that while carer stress has significant association with institutionalisation, the actual size of this effect is negligible (SMD=0.05, 95% CI=0.04-0.07; I²=79.2%; p=<0.001). Moreover, sensitivity analysis found that whether analysing the association between carer burden, stress, distress or depression the effect size remains small to negligible (Donnelly et al. 2015). Furthermore, there was evidence of significant small study effects (potential publication bias). These results, and indeed the results of Verbeek et al. suggest that other factors are more critical for institutionalisation than carer stress or burden.

Combined, these findings should not be interpreted as undermining the significance of chronic stress on a carer. Indeed, several meta-analyses and systematic reviews have demonstrated the detrimental impact care stress can have on a carer’s psychological well-being and physical health (Pinquart & Sorensen 2003, Schulz & Sherwood 2008). However, the results as presented do not support the contention that carer burden is an important predictor of institutionalisation. While it may be a significant predictor, it is not an important one, even if we would like it to be so. As a research community it is important that we direct our efforts towards factors which are truly predictive of health service utilisation, based on a rigorous review and evaluation of the available evidence.

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References


Appendix 4 British-Irish Council Submission

The role of carer stress in institutional care utilisation by community-dwelling older people

PhD Scholar: Nora-Ann Donnelly, Royal College of Surgeons in Ireland.  
PhD Primary Supervisor: Dr Frank Doyle, Royal College of Surgeons in Ireland.  
PhD Co-supervisors: Professor Anne Hickey, Royal College of Surgeons in Ireland; Dr Niamh Humphries, Royal College of Physicians in Ireland; Dr Christine McGarrigle, Trinity College Dublin.

Thesis summary  
Focus: The thesis examined the extent carer stress influences institutional care use by community-dwelling older people.
**Methods:** The thesis encompassed three studies:

**Study 1:** Systematic review and meta-analysis examining the strength of the effect of carer stress on subsequent institutional care utilisation (acute and long-term care admissions) of community-dwelling older people.

**Study 2:** Qualitative analysis of healthcare professionals’ and carers’ perceptions of the main factors influencing long-term care admissions of people with dementia.

**Study 3:** Secondary analysis of The Irish Longitudinal Study on Aging (TILDA) of the relationship between carer stress and institutional care use by community-dwelling older people.

**Results:**

**Study 1:** The meta-analysis found the size of the effect of carer stress on institutional care utilisation of community-dwelling older people was negligible. The results suggested a need to re-evaluate the degree to which carer stress predicts premature ending of home care.

**Study 2:** Found that nursing home placement is unavoidable when the older person’s care needs cannot be met by the carer or community care services. The results suggested that carer stress is a natural epiphenomenon of the long-term care journey, rather than a driver of such admissions. The study also found long-term care admissions of people with dementia are affected by inadequacies in the Irish healthcare system in four ways. Firstly, community care services appear to be insufficient and inequitable, which limits their effectiveness. Secondly, such limitations in community care increase acute care admissions. Thirdly, admissions of people with dementia to acute care can accelerate the long-term care journey. Finally, the lack of alternative care settings between home and nursing home care, forces people who do not require 24 hour care, but require more support than homecare services can provide, into 24 hour nursing home care.

**Study 3:** Suggested a bi-directional relationship between carer stress and utilisation of institutional care (acute and long-term care). That is, the effect of utilisation of institutional care by older care recipients on carers stress is as convincing as the effect of carer stress on institutional care use.

**Conclusions:** The thesis calls into question the claim that carer stress drives long-term care admissions. While carer stress is an important factor in long-term care admissions, the results suggest it is not a driver of such admissions. Rather that carer stress is a natural epiphenomenon of the journey to long-term care.

**Policy implications from thesis findings**

The fragmentation and under-resourcing of community care services (homecare packages and community nursing) conflicts with Government Policy to support people to remain at home. Access to community care services varies by area. Study participants also queried the degree of transparency in access. There are substantial waiting lists to access homecare packages. Where homecare packages are provided, the number of hours are inadequate for sustainable homecare. Under-resourcing of community care is not unique to Ireland. However, without adequate support carers cannot continue to provide homecare.
The legislative basis for the Nursing Home Support Scheme has resulted in resourcing priorities for long-term care services. In contrast, the under-resourcing of community care appears to reflect the absence of the equivalent statutory basis for homecare. In tandem with this, homecare services are not currently regulated. Study participants suggested this results in variation in the quality of these services.

There are substantial waiting lists to access homecare packages and long-term care beds. As a result, carers are advised by healthcare professionals to bring older care recipients to acute care to speed up access to community or long-term care. This is an inappropriate use of acute care and adds to ‘bed-blocking’ and trolley crises in acute care.

There is a lack of intermediate care (between home and 24-hour nursing care) in Ireland. As a result, older people who do not require 24-hour nursing care, but require more care than community care can provide, are then admitted to nursing homes. However, their care needs do not warrant 24-hour nursing care.

**Policy recommendations**

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<td>1  Provision of homecare services should be set up on a statutory basis.</td>
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<td>2  Standardise access to homecare across the country using standardised assessment tools and eligibility criteria to access services.</td>
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<tr>
<td>3  Investigate means-testing eligibility for homecare services to support more equitable access.</td>
<td></td>
</tr>
<tr>
<td>4  Investigate utilisation of resources accessible through the Nursing Home Support Scheme for homecare. This would support older people who do not require 24 hour nursing care, but more care than homecare services can provide to remain at home.</td>
<td></td>
</tr>
<tr>
<td>5  Regulation of homecare services</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Long-term care</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Review options for sheltered housing or assisted living facilities to support older people who do not require 24 hour care, but require more support than homecare services can provide. This will help carers by easing the transition to long-term care facilities as currently carers try to avoid 24 hour care for as long as possible. The long-term care decision is then forced upon carers during an acute admission and this adds to the ‘bed blocking’ crisis.</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 5.1 Synonyms of search terms

<table>
<thead>
<tr>
<th>Population</th>
<th>AND</th>
<th>Setting</th>
<th>AND</th>
<th>Exposure</th>
<th>AND</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Care givers</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Family carers</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Family caregivers</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Carer</td>
<td>Older persons</td>
<td>Community</td>
<td></td>
<td>Stress</td>
<td></td>
<td>Nursing home placement</td>
</tr>
<tr>
<td>Caregiver</td>
<td>Older people</td>
<td>Community-dwelling</td>
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<td>Burden</td>
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<td>Nursing home entry</td>
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<tr>
<td>Care giver</td>
<td>Older adults</td>
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<td></td>
<td>Carer stress</td>
<td></td>
<td>Nursing home admission</td>
</tr>
<tr>
<td>Family carer</td>
<td>Elderly</td>
<td></td>
<td></td>
<td>Caregiver stress</td>
<td></td>
<td>Long term care</td>
</tr>
<tr>
<td>Family caregiver</td>
<td>Aged</td>
<td></td>
<td></td>
<td>Carer burden</td>
<td></td>
<td>Long-term care</td>
</tr>
<tr>
<td>Care recipient</td>
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<td></td>
<td>Caregiver burden</td>
<td></td>
<td>Long term care admission</td>
</tr>
<tr>
<td></td>
<td>Distress</td>
<td></td>
<td></td>
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<td></td>
<td>Long term utilisation</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
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<td></td>
<td></td>
<td>Institutionalisation</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Institutionalization</td>
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<tr>
<td></td>
<td>Strain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Care home</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Homes for the aged</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Acute care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Acute care admission</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Acute care utilisation</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Hospitalisation</td>
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<td></td>
<td>Hospitalization</td>
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<td></td>
<td></td>
<td></td>
<td>Hospital admission</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Hospital readmission</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Emergency department</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Emergency department visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Accident and Emergency</td>
</tr>
</tbody>
</table>
Appendix 5.2 Medline (OVID) search strategy

#1 (carer$ or caregiver$).ab,kf,sh,ti.

#2 (dementia or alzheimer$ or elderly or aged).ab,kf,sh,ti.

#3 (stress or burden or burnout or distress or anxiety or depression or strain).ab,kf,sh,ti.

#4 (nursing home$ or Institutionali#ation or long term care or long term utilisation or care home or homes for the aged or acute care or hospitali#ation or (hospital admission or hospital readmission) or emergency department or emergency services department or (accident and emergency)).ab,ti,kf,sh.

#5 #1 AND #2 AND #3 AND #4

Appendix 5.3 Further analysis for the Meta-Regression

This appendix provides detail of the further analysis undertaken to support the meta-regression.

Part 1: Assessment of distribution of continuous variables for the meta-regression

This section provides a breakdown of the analysis of the distribution of the continuous variables selected for the meta-regression.

A: Assessment of effect size for normality

Firstly, in order to support the meta-regression the distribution of the effect size variable was assessed. As presented in Tables 5.3.1 and 5.3.2, this analysis found that the effect size variable was normally distributed and there were no transformations that would improve its distribution.

<p>| Table 5.3.1: Effect size Skewness/Kurtosis tests for Normality |
|-----------------|----------|-------------|-------------|---------------|----------|</p>
<table>
<thead>
<tr>
<th>Variable</th>
<th>Obs</th>
<th>Pr(Skewness)</th>
<th>Pr(Kurtosis)</th>
<th>adj chi2(2)</th>
<th>Prob&gt;chi2</th>
</tr>
</thead>
<tbody>
<tr>
<td>eff</td>
<td>54</td>
<td>0.0611</td>
<td>0.1182</td>
<td>5.66</td>
<td>0.0591</td>
</tr>
</tbody>
</table>
### Table 5.3.2: Effect size transformations

<table>
<thead>
<tr>
<th>Transformation</th>
<th>Formula</th>
<th>Chi2(2)</th>
<th>P(chi2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>cubic</td>
<td>eff^3</td>
<td>60.53</td>
<td>0.000</td>
</tr>
<tr>
<td>square</td>
<td>eff^2</td>
<td>43.15</td>
<td>0.000</td>
</tr>
<tr>
<td>identity</td>
<td>eff</td>
<td>5.66</td>
<td>0.059</td>
</tr>
<tr>
<td>square root</td>
<td>sqrt(eff)</td>
<td>. .</td>
<td></td>
</tr>
<tr>
<td>log</td>
<td>log(eff)</td>
<td>. .</td>
<td></td>
</tr>
<tr>
<td>1/(square root)</td>
<td>1/sqrt(eff)</td>
<td>. .</td>
<td></td>
</tr>
<tr>
<td>inverse</td>
<td>1/eff</td>
<td>28.14</td>
<td>0.00</td>
</tr>
<tr>
<td>1/square</td>
<td>1/(eff^2)</td>
<td>45.8</td>
<td>0.00</td>
</tr>
<tr>
<td>1/cubic</td>
<td>1/(eff^3)</td>
<td>52.53</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**B: Year of publication**

The sensitivity analysis grouped studies by decade in which studies were published. However, to have year of publication in the meta-regression as a continuous variable, instead of decade in which studies were published, it was first necessary to assess that the variable was normally distributed. As presented in tables 5.3.3 and 5.3.4, the analysis found that year of publication as a continuous score was normally distributed and that no transformation improved the distribution substantially.

#### Table 5.3.3: Year of Publication Skewness/Kurtosis tests for Normality

<table>
<thead>
<tr>
<th>Variable</th>
<th>Obs</th>
<th>Pr(Skewness)</th>
<th>Pr(Kurtosis)</th>
<th>adj chi2(2)</th>
<th>Prob&gt;chi2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year</td>
<td>54</td>
<td>0.0792</td>
<td>0.3427</td>
<td>4.14</td>
<td>0.1263</td>
</tr>
</tbody>
</table>

#### Table 5.3.4: Year of Publication transformations

<table>
<thead>
<tr>
<th>Transformation</th>
<th>Formula</th>
<th>Chi2(2)</th>
<th>P(chi2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>cubic</td>
<td>Year^3</td>
<td>4.12</td>
<td>0.128</td>
</tr>
<tr>
<td>square</td>
<td>Year^2</td>
<td>4.13</td>
<td>0.127</td>
</tr>
<tr>
<td>identity</td>
<td>Year</td>
<td>4.14</td>
<td>0.126</td>
</tr>
<tr>
<td>square root</td>
<td>sqrt(Year)</td>
<td>4.14</td>
<td>0.126</td>
</tr>
<tr>
<td>log</td>
<td>log(Year)</td>
<td>4.15</td>
<td>0.126</td>
</tr>
<tr>
<td>1/(square root)</td>
<td>1/sqrt(Year)</td>
<td>4.16</td>
<td>0.125</td>
</tr>
<tr>
<td>inverse</td>
<td>1/Year</td>
<td>4.17</td>
<td>0.125</td>
</tr>
<tr>
<td>1/square</td>
<td>1/(Year^2)</td>
<td>4.18</td>
<td>0.124</td>
</tr>
<tr>
<td>1/cubic</td>
<td>1/(Year^3)</td>
<td>4.2</td>
<td>0.123</td>
</tr>
</tbody>
</table>

**C: Study size**

As with year of publication, study size was assessed in the sensitivity analysis by grouping studies. Studies were grouped by tertile. However, to have the variable as a continuous score (not grouped) in the meta-regression it was necessary to first assess the normality of the variable, as shown in table 5.3.5 and 5.3.6 below.
Table 5.3.5: Study size Skewness/Kurtosis tests for Normality

<table>
<thead>
<tr>
<th>Variable</th>
<th>Obs</th>
<th>Pr(Skewness)</th>
<th>Pr(Kurtosis)</th>
<th>adj chi2(2)</th>
<th>Prob&gt;chi2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size</td>
<td>54</td>
<td>0.0000</td>
<td>0.0000</td>
<td>.</td>
<td>0.0000</td>
</tr>
</tbody>
</table>

Table 5.3.6: Study size transformations

<table>
<thead>
<tr>
<th>Transformation</th>
<th>Formula</th>
<th>Chi2(2)</th>
<th>P(chi2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>cubic</td>
<td>sample~e^3</td>
<td>.</td>
<td>0.000</td>
</tr>
<tr>
<td>square</td>
<td>sample~e^2</td>
<td>.</td>
<td>0.000</td>
</tr>
<tr>
<td>identity</td>
<td>sample~e</td>
<td>.</td>
<td>0.000</td>
</tr>
<tr>
<td>square root</td>
<td>sqrt(sample~e)</td>
<td>72.09</td>
<td>0.000</td>
</tr>
<tr>
<td>log</td>
<td>log(sample~e)</td>
<td>21.64</td>
<td>0.000</td>
</tr>
<tr>
<td>1/(square root)</td>
<td>1/sqrt(sample~e)</td>
<td>7.67</td>
<td>0.022</td>
</tr>
<tr>
<td>inverse</td>
<td>1/sample~e</td>
<td>32.52</td>
<td>0.000</td>
</tr>
<tr>
<td>1/square</td>
<td>1/(sample~e^2)</td>
<td>64.22</td>
<td>0.000</td>
</tr>
<tr>
<td>1/cubic</td>
<td>1/(sample~e^3)</td>
<td>0</td>
<td>0.000</td>
</tr>
</tbody>
</table>

This analysis suggested the variable was not normally distributed and that no transformation would improve the distribution of the variable. As the largest study sample was substantially larger than the next largest study it was treated as an outlier and truncated. Therefore study size was analysed in a number of ways in the meta-regression. This was in tertiles and as a continuous variable, with and without truncation. As presented in tables 5.3.7-5.3.9, whether study size was analysed in tertiles or continuous variable in all cases less heterogeneity was explained than expected by chance.

Meta-regression of study size in tertiles

In table 5.3.7 study size is categorised to compare the medium sized and largest sized studies to smallest sized studies (as the reference category).
Table 5.3.7: Meta-regression with study size in tertiles

<table>
<thead>
<tr>
<th>Study characteristic</th>
<th>Coefficient (SE)</th>
<th>95% CI</th>
<th>Covariate P Value</th>
<th>Joint test for all covariates P Value</th>
<th>Heterogeneity τ²</th>
<th>Proportion of between-study variance explained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medium sized studies</td>
<td>-0.094 (0.076)</td>
<td>-0.246 - 0.059</td>
<td>0.223</td>
<td>0.215</td>
<td>0.014</td>
<td>-12.34</td>
</tr>
<tr>
<td>Largest studies</td>
<td>-0.124 (.070)</td>
<td>-0.265 - 0.016</td>
<td>0.081</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Meta-regression of study size as a continuous variable:

Table 5.3.8: Meta-regression with study size in tertiles

<table>
<thead>
<tr>
<th>Study characteristic</th>
<th>Coefficient (SE)</th>
<th>95% CI</th>
<th>Covariate P Value</th>
<th>Joint test for all covariates P Value</th>
<th>Heterogeneity τ²</th>
<th>Proportion of between-study variance explained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size</td>
<td>-4.90 (1.70)</td>
<td>-3.890 – 2.910</td>
<td>0.774</td>
<td>0.774</td>
<td>0.013</td>
<td>-9.02</td>
</tr>
</tbody>
</table>

Meta-regression of study size as a continuous variable truncated:

Table 5.3.9: Meta-regression with study size in tertiles

<table>
<thead>
<tr>
<th>Study characteristic</th>
<th>Coefficient (SE)</th>
<th>95% CI</th>
<th>Covariate P Value</th>
<th>Joint test for all covariates P Value</th>
<th>Heterogeneity τ²</th>
<th>Proportion of between-study variance explained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size2</td>
<td>-3.99 (0.000)</td>
<td>-0.000 – 0.000</td>
<td>0.802</td>
<td>0.802</td>
<td>0.013</td>
<td>-9.50</td>
</tr>
</tbody>
</table>

D: Quality score
The impact of study quality on effect estimates was assessed in the sensitivity analysis by quartiles of the Crowe Critical Appraisal Tool (CCAT) percentage scores. To analyse study quality as a continuous variable in the meta-regression it was necessary to first assess the normality of the variable. As presented in table 5.3.10, this analysis found the variable was normally distributed.
Table 5.3.10: Quality score Skewness/Kurtosis tests for Normality

<table>
<thead>
<tr>
<th>Variable</th>
<th>Obs</th>
<th>Pr(Skewness)</th>
<th>Pr(Kurtosis)</th>
<th>adj chi2(2)</th>
<th>Prob&gt;chi2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality_Pe~2</td>
<td>54</td>
<td>0.1027</td>
<td>0.7854</td>
<td>2.8800</td>
<td>0.2367</td>
</tr>
</tbody>
</table>

Table 5.3.11: Quality score transformations

<table>
<thead>
<tr>
<th>Transformation</th>
<th>Formula</th>
<th>Chi2(2)</th>
<th>P(chi2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>cubic</td>
<td>Qualit~2^3</td>
<td>13.9</td>
<td>0.001</td>
</tr>
<tr>
<td>square</td>
<td>Qualit~2^2</td>
<td>7.84</td>
<td>0.020</td>
</tr>
<tr>
<td>identity</td>
<td>Qualit~2</td>
<td>2.88</td>
<td>0.237</td>
</tr>
<tr>
<td>square root</td>
<td>sqrt(Qualit~2)</td>
<td>0.83</td>
<td>0.660</td>
</tr>
<tr>
<td>log</td>
<td>log(Qualit~2)</td>
<td>0.05</td>
<td>0.975</td>
</tr>
<tr>
<td>1/(square root)</td>
<td>1/sqrt(Qualit~2)</td>
<td>2.59</td>
<td>0.273</td>
</tr>
<tr>
<td>inverse</td>
<td>1/Qualit~2</td>
<td>8.25</td>
<td>0.016</td>
</tr>
<tr>
<td>1/square</td>
<td>1/(Qualit~2^2)</td>
<td>23.85</td>
<td>0.000</td>
</tr>
<tr>
<td>1/cubic</td>
<td>1/(Qualit~2^3)</td>
<td>39.55</td>
<td>0.000</td>
</tr>
</tbody>
</table>

In analysis of potential transformations of a variable, it is most appropriate to choose the transformation with the lowest chi-square (315). As shown in table 5.3.11, the analysis of transformations of the variable suggested that logging the variable improves the normality. Therefore a new logged variable was created.

**Part 2: Method of calculation of between-study variance (τ²)**
Sharp describes alternative methods for estimation of between-study variance (τ²) in Stata (222). The default method is the restricted maximum likelihood method; alternatives are the empirical Bayes and method of moments calculation. Sharp advises that the basis of using the empirical Bayes method is less clear, so advises that this method should be used with caution (222). There is no established guidance on which is the most appropriate of the alternative methods. Each study level characteristic was examined individually with each method, as presented in tables 5.3.12 – 5.3.14 below. As the restricted maximum likelihood method is the default method and is the most conservative method this method was chosen in the final analysis of the meta-regression for the thesis.
<table>
<thead>
<tr>
<th>Study characteristic</th>
<th>Coefficient (SE)</th>
<th>95% CI</th>
<th>Covariate P Value</th>
<th>Joint test for all covariates P Value</th>
<th>Heterogeneity $\tau^2$</th>
<th>Proportion of between-study variance explained</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of publication</td>
<td>-0.012 (0.003)</td>
<td>-0.018 - -0.006</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.009</td>
<td>29.65%</td>
</tr>
<tr>
<td>Adjusted</td>
<td>-0.120 (0.047)</td>
<td>-0.215 - -0.025</td>
<td>0.014</td>
<td>0.014</td>
<td>0.009</td>
<td>24.54%</td>
</tr>
<tr>
<td>Study size</td>
<td>-0.000 (0.000)</td>
<td>-0.000 - 0.000</td>
<td>0.802</td>
<td>0.802</td>
<td>0.014</td>
<td>-9.50%</td>
</tr>
<tr>
<td>Study quality (CCAT %)</td>
<td>-0.134 (0.093)</td>
<td>-0.321 - -0.053</td>
<td>0.157</td>
<td>0.157</td>
<td>0.014</td>
<td>-8.97%</td>
</tr>
<tr>
<td>Outcome</td>
<td>0.063 (0.053)</td>
<td>-0.043 - 0.169</td>
<td>0.235</td>
<td>0.235</td>
<td>0.013</td>
<td>-5.30%</td>
</tr>
<tr>
<td>Measure - depression</td>
<td>-0.143 (0.084)</td>
<td>-0.311 - 0.025</td>
<td>0.093</td>
<td>0.463</td>
<td>0.014</td>
<td>-9.87%</td>
</tr>
<tr>
<td>Measure - burden</td>
<td>-0.050 (0.067)</td>
<td>-0.185 - 0.084</td>
<td>0.456</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measure - distress</td>
<td>-0.118 (0.096)</td>
<td>-0.310 - 0.075</td>
<td>0.226</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measure - strain</td>
<td>-0.082 (0.179)</td>
<td>-0.442 - 0.278</td>
<td>0.650</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up for 1-2 years</td>
<td>-0.030 (0.070)</td>
<td>-0.172 - 0.112</td>
<td>0.674</td>
<td>-513</td>
<td>0.017</td>
<td>-11.38%</td>
</tr>
<tr>
<td>Follow-up or over 2 years</td>
<td>-0.090 (0.077)</td>
<td>-0.246 - 0.066</td>
<td>0.252</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Study characteristic</td>
<td>Coefficient (SE)</td>
<td>95% CI</td>
<td>Covariate P Value</td>
<td>Joint test for all covariates P Value</td>
<td>Heterogeneity $\tau^2$</td>
<td>Proportion of between-study variance explained</td>
</tr>
<tr>
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</tr>
<tr>
<td>Year of publication</td>
<td>0.118 (0.003)</td>
<td>-0.018 - 0.006</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.007</td>
<td>46.37%</td>
</tr>
<tr>
<td>Adjusted</td>
<td>-0.121 (0.048)</td>
<td>-0.219 - 0.024</td>
<td>0.015</td>
<td>0.015</td>
<td>0.011</td>
<td>20.88%</td>
</tr>
<tr>
<td>Study size</td>
<td>-0.000 (0.000)</td>
<td>-0.000 - 0.000</td>
<td>0.793</td>
<td>0.793</td>
<td>0.014</td>
<td>-4.33%</td>
</tr>
<tr>
<td>Study quality (CCAT %)</td>
<td>-0.134 (0.093)</td>
<td>-0.321 - 0.053</td>
<td>0.157</td>
<td>0.157</td>
<td>0.014</td>
<td>-8.97%</td>
</tr>
<tr>
<td>Outcome</td>
<td>0.063 (0.053)</td>
<td>-0.042 - 0.169</td>
<td>0.235</td>
<td>0.235</td>
<td>0.013</td>
<td>1.99%</td>
</tr>
<tr>
<td>Measure - depression</td>
<td>-0.143 (0.084)</td>
<td>-0.311 - 0.025</td>
<td>0.093</td>
<td>0.463</td>
<td>0.014</td>
<td>-9.87%</td>
</tr>
<tr>
<td>Measure - burden</td>
<td>-0.050 (0.067)</td>
<td>-0.185 - 0.084</td>
<td>0.456</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Measure - distress</td>
<td>-0.118 (0.096)</td>
<td>-0.310 - 0.075</td>
<td>0.226</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measure - strain</td>
<td>-0.082 (0.179)</td>
<td>-0.442 - 0.278</td>
<td>0.650</td>
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<td></td>
</tr>
<tr>
<td>Follow-up for 1-2 years</td>
<td>-0.030 (0.070)</td>
<td>-0.172 - 0.112</td>
<td>0.674</td>
<td>-0.513</td>
<td>-0.017</td>
<td>-11.38%</td>
</tr>
<tr>
<td>Follow-up or over 2 years</td>
<td>-0.090 (0.077)</td>
<td>-0.246 - 0.066</td>
<td>0.252</td>
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<tr>
<td>Study characteristic</td>
<td>Coefficient (SE)</td>
<td>95% CI</td>
<td>Covariate P Value</td>
<td>Joint test for all covariates P Value</td>
<td>Heterogeneity $\tau^2$</td>
<td>Proportion of between-study variance explained</td>
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</tr>
<tr>
<td>Year of publication</td>
<td>-0.012 (0.003)</td>
<td>-0.018 - -0.006</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.009</td>
<td>29.65%</td>
</tr>
<tr>
<td>Adjusted</td>
<td>-0.120 (0.047)</td>
<td>-0.215 - -0.025</td>
<td>0.014</td>
<td>0.014</td>
<td>0.009</td>
<td>24.54%</td>
</tr>
<tr>
<td>Study size</td>
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<td>-0.000 - 0.000</td>
<td>0.005</td>
<td>0.005</td>
<td>0.000</td>
<td>39.61%</td>
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<td>Study quality (CCAT %)</td>
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<td>0.157</td>
<td>0.014</td>
<td>-8.97%</td>
</tr>
<tr>
<td>Outcome</td>
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<td>-0.043 - 0.169</td>
<td>0.235</td>
<td>0.235</td>
<td>0.013</td>
<td>-5.30%</td>
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<tr>
<td>Measure - depression</td>
<td>-0.143 (0.084)</td>
<td>-0.171 - 0.058</td>
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<td>0.463</td>
<td>0.014</td>
<td>-9.87%</td>
</tr>
<tr>
<td>Measure - burden</td>
<td>-0.050 (0.067)</td>
<td>-0.100 - 0.098</td>
<td>0.456</td>
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<tr>
<td>Measure - distress</td>
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<td>-0.140 - 0.094</td>
<td>0.226</td>
<td></td>
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<td></td>
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<tr>
<td>Measure - strain</td>
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<td>-0.406 - 0.485</td>
<td>0.650</td>
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</tr>
<tr>
<td>Follow-up for 1-2 years</td>
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<td>-0.172 - 0.112</td>
<td>0.674</td>
<td></td>
<td>-0.513</td>
<td>-11.38%</td>
</tr>
<tr>
<td>Follow-up or over 2 years</td>
<td>-0.090 (0.077)</td>
<td>-0.246 - 0.066</td>
<td>0.252</td>
<td></td>
<td>-0.017</td>
<td></td>
</tr>
</tbody>
</table>
Part 3: Weighted scatter plots of year of publication and study quality

Weighted scatter plots were developed to support the interpretation of the meta-regression analysis. In the first of these scatter plots, the year in which studies were published were plotted on the x-axis and the SMD on the y-axis (Figure 5.3.1). The size of the marker reflects the relative weight of the study. As presented in Figure 5.3.2, the same was also done for study quality with CCAT percentage scores.

Figure 5.3.1 Scatter plot year of publication and SMD
As can be seen in Figures 5.3.1 and 5.3.2 the variation in study size is so extreme that the weighting scheme to show weights for smaller studies causes weights for larger studies to be so large they overlap the other studies. The presentation of the plot was altered a few times to not have the larger studies overlap the smaller studies, but this was not possible. Hence the bubble plot with the meta-regression has been presented in this thesis (it is also presented below in Figure 5.3.3 for ease of reference). The bubble plot graphs the fitted line together with circles representing the estimates for each study. The size of the circles depends on the weight of the study in the fitted random-effects meta-regression model.
Figure 5.3.3 Bubble plot of fitted regression line.
### Appendix 5.4 Repeat publications

#### Repeat publications from the same dataset

<table>
<thead>
<tr>
<th>Author</th>
<th>Year of publication</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mausbach et al.(316)</td>
<td>2004</td>
<td>Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers</td>
</tr>
<tr>
<td>de Vugt et al.(317)</td>
<td>2005</td>
<td>A prospective study of the effects of behavioural symptoms on the institutionalization of patients with dementia</td>
</tr>
<tr>
<td>Benoit et al.(318)</td>
<td>2005</td>
<td>One-year longitudinal evaluation of neuropsychiatric symptoms in Alzheimer’s disease. The REAL.FR study</td>
</tr>
<tr>
<td>Cohen-Mansfield and Wirtz.(319)</td>
<td>2009</td>
<td>The reasons for nursing home entry in an adult day care population: Caregiver reports versus regression results</td>
</tr>
<tr>
<td>Cohen-Mansfield and Wirtz.(320)</td>
<td>2011</td>
<td>Predictors of entry to the nursing home: does length of follow-up matter?</td>
</tr>
<tr>
<td>Gaugler et al.(321)</td>
<td>2000</td>
<td>Predictors of institutionalization of cognitively impaired elders: Family help and the timing of placement</td>
</tr>
<tr>
<td>Gaugler et al.(28)</td>
<td>2003</td>
<td>Caregiving and institutionalization of cognitively impaired older people: utilizing dynamic predictors of change</td>
</tr>
<tr>
<td>Gaugler et al.(322)</td>
<td>2005</td>
<td>The Effects of Duration of Caregiving on Institutionalization</td>
</tr>
<tr>
<td>Nikzad-Terhune et al.(323)</td>
<td>2010</td>
<td>Do trajectories of at-home dementia caregiving account for burden after nursing home placement? A growth curve analysis</td>
</tr>
<tr>
<td>Gaugler et al.(324)</td>
<td>2005</td>
<td>The longitudinal effects of early behavior problems in the dementia caregiving career</td>
</tr>
<tr>
<td>Gaugler et al.(76)</td>
<td>2006</td>
<td>Predictors of institutionalization in Latinos with dementia</td>
</tr>
<tr>
<td>Gaugler et al.(325)</td>
<td>2004</td>
<td>Predictors of Nursing Home Placement in African Americans with Dementia</td>
</tr>
<tr>
<td>Balardy et al.(92)</td>
<td>2005</td>
<td>Predictive factors of emergency hospitalisation in Alzheimer’s patients: Results of one-year follow-up in the REAL.FR cohort</td>
</tr>
<tr>
<td>Rolland et al.(326)</td>
<td>2007</td>
<td>Wandering behavior and Alzheimer disease. The REAL.FR prospective study</td>
</tr>
<tr>
<td>Winslow and Carter.(327)</td>
<td>1999</td>
<td>Patterns of burden in wives who care for husbands with dementia</td>
</tr>
<tr>
<td>Yaffe et al.(14)</td>
<td>2002</td>
<td>Patient and caregiver characteristics and nursing home placement in patients with dementia</td>
</tr>
<tr>
<td>Belle et al.(328)</td>
<td>2006</td>
<td>Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial</td>
</tr>
<tr>
<td>Dröes et al.(329)</td>
<td>2004</td>
<td>Effect of Meeting Centres Support Program on feelings of competence of family carers and delay of institutionalization of people with dementia</td>
</tr>
<tr>
<td>Gaugler et al.(101)</td>
<td>2005</td>
<td>Early community-based service utilization and its effects on institutionalization in dementia caregiving</td>
</tr>
<tr>
<td>Kuzuya et al.(330)</td>
<td>2012</td>
<td>Day-care service use is a risk factor for long-term care placement in community-dwelling dependent elderly</td>
</tr>
<tr>
<td>Mittelman et al.(331)</td>
<td>1993</td>
<td>An intervention that delays institutionalization of Alzheimer’s disease patients: Treatment of spouse-caregivers</td>
</tr>
<tr>
<td>Hirdes et al.(332)</td>
<td>2008</td>
<td>The Method for Assigning Priority Levels (MAPLe): A new decision-support system for allocating home care resources</td>
</tr>
<tr>
<td>Authors and Year</td>
<td>Date</td>
<td>Summary</td>
</tr>
<tr>
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</tr>
<tr>
<td>Gaugler et al. (333)</td>
<td>2010</td>
<td>The effects of incident and persistent behavioral problems on change in caregiver burden and nursing home admission of persons with dementia</td>
</tr>
<tr>
<td>Morales-Asencio et al. (334)</td>
<td>2008</td>
<td>Effectiveness of a nurse-led case management home care model in Primary Health Care. A quasi-experimental, controlled, multi-centre study</td>
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<tr>
<td>Montgomery and Kosloski (335)</td>
<td>1994</td>
<td>A longitudinal analysis of nursing home placement for dependent elders cared for by spouses vs adult children</td>
</tr>
<tr>
<td>Brodaty and Gresham (165)</td>
<td>1989</td>
<td>Effect of a training programme to reduce stress in carers of patients with dementia</td>
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</tbody>
</table>
## Appendix 5.5 Characteristics of studies where adequate data was not available

<table>
<thead>
<tr>
<th>Author; country</th>
<th>Year of publication</th>
<th>Research design</th>
<th>Study population; % male care recipients</th>
<th>Sample size: baseline; follow-up</th>
<th>Exposure measure</th>
<th>Outcome measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arai et al. (336); Japan</td>
<td>2001</td>
<td>1 year cohort</td>
<td>Certifiably registered disabled elderly who lived at home with their caregivers. % men not provided</td>
<td>70; 65</td>
<td>CES-D and Zarit Burden Interview</td>
<td>Discontinued caring.</td>
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<tr>
<td>D’Souza et al. (337); United States</td>
<td>2009</td>
<td>4 year cohort</td>
<td>Individuals enrolled in the Michigan Home and Community-Based Services (HCBS) waiver program for elderly and disabled adults and their carers. 27%</td>
<td>108,914; 108,914</td>
<td>Caregiver burden was defined as indication on either of two variables from the target MDS-HC: “primary caregiver expresses feelings of distress, anger, or depression” or “a caregiver is unable to continue in caretaking activities.”</td>
<td>Emergency room (ER) use, hospitalisation and permanent nursing home placement</td>
</tr>
<tr>
<td>Froelich, et al. (338); 12 European countries</td>
<td>2009</td>
<td>2 year cohort</td>
<td>Dementia dyads. 37.5%</td>
<td>2,288; 1,382</td>
<td>Zarit burden interview. Distress as part of the NPI-D</td>
<td>Admission to permanent institutionalisation</td>
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<tr>
<td>Hooley et al. (94); Canada</td>
<td>2005</td>
<td>6 month cohort</td>
<td>Outpatients attending the Heart Function Clinic at a large tertiary care hospital and their carers. 72%</td>
<td>50; 50</td>
<td>Zarit burden interview</td>
<td>Hospitalisation</td>
</tr>
<tr>
<td>Okura et al. (339); United States</td>
<td>2011</td>
<td>5 year cohort</td>
<td>Mix dementia and non-dementia dyads. % men not provided</td>
<td>453; 453</td>
<td>Distress with the NPI-D</td>
<td>Nursing Home Placement</td>
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<tr>
<td>Schur D, Whitlatch CJ (340); United States;</td>
<td>2003</td>
<td>6 month non-randomised intervention</td>
<td>Elders with mental and or physical impairments and their carers. 45%</td>
<td>127; 127</td>
<td>Carer stress measured with the Revised version of the Memory and Behaviour Problems Checklist. Depression measured with the abridged version of the CES-D.</td>
<td>Institutionalisation</td>
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<tr>
<td>Andren S, Elmstahl S (341);</td>
<td>2008</td>
<td>5 year non randomised intervention</td>
<td>Dementia dyads. 23%</td>
<td>192; 192</td>
<td>Burden with the caregiver burden scale (342).</td>
<td>Nursing Home Placement</td>
</tr>
<tr>
<td>Country</td>
<td>Study Information</td>
<td>Study Duration</td>
<td>Outcome Measures</td>
<td>Additional Information</td>
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<td>Sweden</td>
<td>Cho et al. (343); United States</td>
<td>2009</td>
<td>Dementia dyads. 0%</td>
<td>Depression with CES-D.</td>
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<td>Non-randomised intervention study</td>
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<td>McMillan et al. (344); United States</td>
<td>2013</td>
<td>Community dwelling adults with heart disease and an identified family caregiver. 65%</td>
<td>Carer stress with MSAS-HF. Depression measure with the depression subscale from the Profile of Mood States (POMS).</td>
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<td>5 week</td>
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<td>Hospitalisation and Emergency Room visits</td>
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<td></td>
<td>Menn et al. (345); United States</td>
<td>2012</td>
<td>Dementia dyads. 33%</td>
<td>Burden Scale for Family Caregivers (BSFC).</td>
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<tr>
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<td>4 year RCT</td>
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<td>Nursing Home Placement</td>
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<td>Morales-Asencio et al. (346); Spain</td>
<td>2009</td>
<td>Community dwelling Patients and caregivers who initiated a Home Care Programme. 42%</td>
<td>Zarit burden interview</td>
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<td>Thomas R. (347); Canada</td>
<td>2007</td>
<td>Community dwelling people 75 or over living in their own homes not receiving formal home care, able to identify an informal caregiver. 32%</td>
<td>Zarit burden interview</td>
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<td>Institutionalisation</td>
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<td>Callahan et al. (348); United States</td>
<td>2006</td>
<td>Alzheimer’s disease dyads. Usual care % men: 73%. Intervention % men: 61%</td>
<td>Stress with the NPI-D</td>
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<td>Challis D et al. (349); UK</td>
<td>2004</td>
<td>Non-dementia dyads. Usual care: 28%. Intervention: 26%</td>
<td>Stress and burden with the Social Behaviour Assessment Schedule modified for use with carers of older people.</td>
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<tr>
<td></td>
<td>Crotty, M. et al. (350); Australia</td>
<td>2008</td>
<td>Hospitalised patients referred for ambulatory rehabilitation. 48%</td>
<td>Carer stress with Carer Strain Index</td>
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<td>6 month RCT</td>
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<td>Hospital readmission and transfer to residential care</td>
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<tr>
<td></td>
<td>Forster A, et al. (351); UK</td>
<td>2009</td>
<td>Patients with a disabling stroke and their carers. Usual care: 48%. Intervention: 43%</td>
<td>Carer stress with the general health questionnaire and strain with carer strain index.</td>
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<td></td>
<td>Montgomery RJ, Borgatta EF. (352);</td>
<td>1989</td>
<td>Impaired elderly persons and caregivers. 33%</td>
<td>Burden with nine-item scale developed by Montgomery et al. (353)</td>
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<td>20 month RCT</td>
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<td>Nursing home placement</td>
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<tr>
<td>United States</td>
<td>1990</td>
<td>12 month quasi-experimental intervention</td>
<td>Caregivers and frail elderly discharged from hospital. 39%</td>
<td>191; 112</td>
<td>Stress with General Health Questionnaire</td>
<td>Hospital and nursing home days</td>
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<tr>
<td>Oktay JS, Volland PJ, et al.</td>
<td>United States</td>
<td>2013</td>
<td>2 year RCT</td>
<td>Mix dementia and non-dementia dyads. Usual care: 70%. Intervention: 63%.</td>
<td>135; 113</td>
<td>Zung’s depression scale</td>
</tr>
<tr>
<td>Rynanen OP, et al.</td>
<td>Finland</td>
<td>2010</td>
<td>2 year non-randomised intervention</td>
<td>Mix dementia and non-dementia dyads. Usual care: 48.8%. Intervention: 48.8%</td>
<td>164; 164</td>
<td>Zarit burden interview</td>
</tr>
<tr>
<td>Stewart M, et al.</td>
<td>Canada</td>
<td>2007</td>
<td>2 year RCT</td>
<td>Dementia dyads. 33%</td>
<td>82; 25</td>
<td>Stress measured with the Relative Stress Scale</td>
</tr>
<tr>
<td>Tibaldi V, et al.</td>
<td>Italy</td>
<td>2004</td>
<td>3 year quasi-experimental intervention</td>
<td>Frail elderly living in a semi-urban community. Intervention: 30%. Control: 34%</td>
<td>482; 218</td>
<td>Zarit burden interview</td>
</tr>
<tr>
<td>Vellas B, et al.</td>
<td>11 European countries</td>
<td>2012</td>
<td>2 year cohort</td>
<td>Alzheimer’s disease dyads. 35%</td>
<td>1306; 797</td>
<td>Zarit burden interview</td>
</tr>
<tr>
<td>Vincent C, et al.</td>
<td>Canada</td>
<td>2006</td>
<td>9 month cohort</td>
<td>Frail elderly living at home and their carers. 8%</td>
<td>38; 38</td>
<td>Caregiver burden scale (342)</td>
</tr>
<tr>
<td>Whitlatch CJ, et al.</td>
<td>United States</td>
<td>1995</td>
<td>1 year quasi-experimental intervention</td>
<td>Dementia dyads. % men not provided</td>
<td>132; 90</td>
<td>Burden measured with subscales of the Zarit burden interview</td>
</tr>
<tr>
<td>Lim WK, et al.</td>
<td>Australia</td>
<td>2003</td>
<td>6 month RCT</td>
<td>Patients aged 65 years and over who required community services after discharge and their carer. Intervention: 40%. Control: 43%.</td>
<td>654; 598</td>
<td>Caregiver strain index</td>
</tr>
<tr>
<td>Lindpaintner LS, et al.</td>
<td>Switzerland</td>
<td>2013</td>
<td>1 month RCT</td>
<td>Community-dwelling patients at high risk for adverse medicine events who showed additional evidence of vulnerability and their carers. 43%</td>
<td>60; 60</td>
<td>Caregiver strain index</td>
</tr>
<tr>
<td>Reference</td>
<td>Year</td>
<td>Study Type</td>
<td>Study Description</td>
<td>Sample Size</td>
<td>Outcome Measure</td>
<td>Outcome Type</td>
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<tr>
<td>Kalra L, et al. (364); UK</td>
<td>2004</td>
<td>1 year RCT</td>
<td>Stroke patients and their caregivers. 53%</td>
<td>300; 268</td>
<td>Caregiver strain index</td>
<td>Institutionalisation</td>
</tr>
<tr>
<td>Mohide E, et al. (365); Canada</td>
<td>1990</td>
<td>6 month RCT</td>
<td>Dementia dyads. Intervention: 30%. Control: 27%</td>
<td>60; 42</td>
<td>Depression with CES-D</td>
<td>Institutionalisation</td>
</tr>
<tr>
<td>Weinberger M, et al. (366); United States</td>
<td>1993</td>
<td>6 month RCT</td>
<td>Dementia dyads. Intervention: 35%. Control: 41%</td>
<td>264; 227</td>
<td>Assessed carer stress but does not detail how this was measured</td>
<td>Hospital admission and admission to nursing home</td>
</tr>
<tr>
<td>Wilkinson et al. (367); UK</td>
<td>1997</td>
<td>5 year cohort</td>
<td>Stroke patients and their caregivers. 53%</td>
<td>291; 106</td>
<td>Caregiver strain index</td>
<td>Institutionalisation</td>
</tr>
<tr>
<td>Hughes SL, et al. (368); United States</td>
<td>2000</td>
<td>1 year RCT</td>
<td>Disabled elderly and their carers. Intervention: 97%. Control: 96%</td>
<td>1966; 667</td>
<td>Burden with scale developed by Montgomery et al. (353)</td>
<td>Hospital readmission</td>
</tr>
<tr>
<td>Jette et al. (369); United States</td>
<td>1995</td>
<td>6 year cohort</td>
<td>Disabled elderly and their carers. 23%</td>
<td>634; 586</td>
<td>Burden with measures developed for the study. Three measures used: 1. Impact on personal time and physical health; 2. Impact on family relationships; and 3. Impact on decision to work and/or work schedule.</td>
<td>Nursing Home Entry</td>
</tr>
<tr>
<td>Tsuji et al. (370); United States</td>
<td>1995</td>
<td>5 year chart review</td>
<td>Frail older patients receiving formal home care services and their carers. % men not provided</td>
<td>334; 334</td>
<td>Stress due to caregiving (not clear if this was a composite measure)</td>
<td>Nursing Home Placement</td>
</tr>
<tr>
<td>Gilley et al. (371); United States</td>
<td>2005</td>
<td>3 year cohort</td>
<td>Alzheimer’s Disease dyads. 32%</td>
<td>396; 396</td>
<td>Perceived burden measured with the 10-item subjective caregiving burden scale (372).</td>
<td>Institutionalisation</td>
</tr>
<tr>
<td>Aneshensel et al. (373); United States</td>
<td>1993</td>
<td>2 year cohort</td>
<td>Dementia dyads. % men not provided</td>
<td>555; 494</td>
<td>Measured stress based on Pearlin’s model. Primary stressors: cognitive status of care recipient; problematic behaviour; ADLs and IADLs; role overload; relational deprivation; and patient resistance to help. Secondary stressors: family conflict; conflicting demands of job and</td>
<td>Institutionalisation</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Duration</td>
<td>Group</td>
<td>Burden Measure</td>
<td>Outcome</td>
<td></td>
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<tr>
<td>McCann et al. (2005)</td>
<td>2005</td>
<td>4 year intervention</td>
<td>Alzheimer's Disease dyads</td>
<td>32%</td>
<td>298, 298</td>
<td>Perceived burden measured with the 10-item subjective caregiving burden scale (372).</td>
</tr>
<tr>
<td>Kurasawa et al. (2012)</td>
<td>2012</td>
<td>2 year cohort</td>
<td>Disabled elderly and their carers</td>
<td>35%</td>
<td>133, 90</td>
<td>Burden with the Zarit burden interview. Depression with CES-D.</td>
</tr>
</tbody>
</table>
### Appendix 5.6 Characteristics of included studies

<table>
<thead>
<tr>
<th>Characteristics of included studies</th>
<th>Author; country; year of publication</th>
<th>Research design</th>
<th>Study population care recipient % men</th>
<th>Sample size: baseline follow-up</th>
<th>Exposure measure</th>
<th>Outcome measure</th>
<th>Quality score</th>
<th>statistical results</th>
<th>Adjusted or unadjusted</th>
</tr>
</thead>
</table>
| Bakker et al. (376); the Netherlands; 2013 | 2 year cohort | Dementia dyads. 55% | 328; 328 | Neuropsychiatric Inventory Distress scale (NPI-D). | Institutionalisation | 73% | Cox proportional Hazard Model - Caregiver distress (NPI-D): Hazard Ratio= 1.011; CI 0.975 - 1.048; p=.559. | Adjusted for young vs late onset dementia; carer age; carer sex; spousal carer; advanced dementia; diagnosis (Alzheimer’s dementia, front temporal dementia, mixed/vascular dementia, other dementias); neuropsychiatric symptoms (hyperactivity, psychosis, mood, apathy); caregiver distress (NPI-D); caregiver sense of competence (SSCQ); time from symptom onset at inclusion; interaction group with dementia severity; interaction group with apathy score.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design/Location</th>
<th>Sample Size</th>
<th>Follow-up</th>
<th>Dementia Group</th>
<th>Measure</th>
<th>Carer Measure</th>
<th>Long-term Outcomes</th>
<th>Adjusted for</th>
</tr>
</thead>
<tbody>
<tr>
<td>Banerjee et al. (2003)</td>
<td>UK; 1 year cohort</td>
<td>100; 69</td>
<td></td>
<td>Dementia dyads. % men not provided</td>
<td>Zarit Burden Interview</td>
<td>Institutionalisation</td>
<td>30%</td>
<td>Logistic regression: carer burden (ZBI) Odds Ratio=1.02; CI 0.96-1.08; p=0.542.</td>
</tr>
<tr>
<td>Bannister et al. (1998)</td>
<td>UK; 1 year cohort</td>
<td>124; 116</td>
<td></td>
<td>Dementia dyads. 27%</td>
<td>Carer depression assessed using the GMS schedule</td>
<td>Residential or nursing home care</td>
<td>48%</td>
<td>Carer RDC depression: admitted 5 (20%); not admitted 26 (29%); OR=0.6; CI 0.2-1.8.</td>
</tr>
<tr>
<td>Bond et al. (2002)</td>
<td>Australia; 2 year cohort</td>
<td>163; 158</td>
<td></td>
<td>Dementia dyads. % men continued receiving care: 50%; discontinued receiving care 64%</td>
<td>Geriatric Depression Scale</td>
<td>Yielding care to permanent supported accommodation</td>
<td>50%</td>
<td>Carer geriatric depression scale score was significantly different in those continuing to care (M=8.8; SD=6.2) compared to those yielding to care (M=11.2; SD=6.4; p&lt;.05)</td>
</tr>
<tr>
<td>Brodaty et al. (1993)</td>
<td>Australia; 5 year controlled intervention study</td>
<td>91; 91</td>
<td></td>
<td>Dementia dyads. 51%</td>
<td>Stress measured with General Health Questionnaire</td>
<td>Actual nursing home placement</td>
<td>40%</td>
<td>Impairment on GHQ (carer stress) was significant predictor of placement. Cox regression coefficient (HR)=−0.0511 SE+/−0.0204; p&lt;.05</td>
</tr>
<tr>
<td>Study</td>
<td>Cohort Type</td>
<td>Subjects</td>
<td>Interview</td>
<td>Placement</td>
<td>Carer Satisfaction with Telephone Contacts</td>
<td>Study Details</td>
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<tr>
<td>Brown et al. (66); United States; 1990</td>
<td>1 year cohort</td>
<td>Subjects of the geriatric assessment programme of the University of Nebraska Medical Centre. 30%</td>
<td>Zarit Burden Interview.</td>
<td>Nursing home placement</td>
<td>55% T-test of caregiver burden at initial visit (M and SEM) for individuals whose CR was admitted to a nursing home (n=27; M=40.8; SEM=40.4-30.8) compared to those where no placement took place (n=82; M=20.8; SEM=30.0-20.6; p&lt;.01).</td>
<td>Unadjusted</td>
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<tr>
<td>Camden et al. (78); UK; 2011</td>
<td>1 year cohort</td>
<td>Dementia dyads. 85%</td>
<td>Zarit Burden Interview. Carer anxiety with anxiety subscale of HADS.</td>
<td>Living in 24-hr care</td>
<td>83% ZBI: Cox regression for admission to 24-hour care, burden score: B=0.022; SE=0.020; Wald=1.297; DF=1; P=0.255; Hazard Ratio=1.023. HADS: Cox regression for admission to 24-hour care, carer anxiety score: B=-0.037; SE=0.063; Wald=0.352; DF=1; P=0.553; Hazard Ratio=0.964</td>
<td>Adjusted for negative vs positive reason for caring; neutral vs positive reason; carer gender; carer age; care recipient gender; care recipient age; child of care recipient; NPI score; ADL score; MMSE score; burden score; carer anxiety score.</td>
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<tr>
<td>Chuang et al. (95); Taiwan; 2005</td>
<td>1 month cohort</td>
<td>Stroke patients. % men readmission: 25%; % men non-readmission</td>
<td>Carer burden index.</td>
<td>Readmission to hospital within 1 month</td>
<td>85% Chi square for differences between burden groups =9.32; p&lt;.01.</td>
<td>Unadjusted</td>
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<tr>
<td>Study</td>
<td>Cohort Duration</td>
<td>Study Design</td>
<td>caregiver burden measure</td>
<td>Institutionalisation</td>
<td>Carer burden results</td>
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<tr>
<td>Cohen et al. (67); Canada; 1993</td>
<td>18 month cohort</td>
<td>Dementia dyads. % men not provided</td>
<td>Zarit Burden Interview.</td>
<td>Institutionalisation 50%</td>
<td>Carers who placed their dependent at 18 months reported higher levels of burden [f (1,132) =4.37; p&lt;.05] Unadjusted</td>
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<tr>
<td>Cohen-Mansfield and Wirtz (68); United States; 2007</td>
<td>3 year cohort</td>
<td>Adult day care participant ≤34%</td>
<td>Zarit Burden Interview.</td>
<td>Any nursing home admission 65%</td>
<td>Bivariate analysis with cox regression: caregiver burden risk ratio =1.91; p=.001; CI 1.29-2.82. Unadjusted</td>
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<tr>
<td>Colerick and George (380); United States; 1986</td>
<td>1 year cohort</td>
<td>Alzheimer's Disease dyads. % men not provided</td>
<td>Stress measured with Langer 22-item screening scale (381).</td>
<td>Institutionalisation 45%</td>
<td>Stress symptoms for those who continued home caregiving: M=8.75; those who became institutionalised: M=9.41. Unadjusted</td>
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<tr>
<td>Deimling et al. (79); United States; 1985</td>
<td>6 month cohort</td>
<td>Families living with and caring for an older relative. % men not provided</td>
<td>Stress effects with composite measured created for study. Zung depression scale.</td>
<td>Institutionalisation 43%</td>
<td>Carer’s stress scores of those who institutionalised the care recipient (M=8.38) were not significantly different from those who did not (M=6.61; F=3.222;p=ns). Carer’s depression scores of those who institutionalised the care recipient (M=49.01) were not significantly different from those who did not (M=48.32; F=0.076;p=ns). Unadjusted</td>
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<tr>
<td>Drame et al. (64); France; 2013</td>
<td>6 month cohort</td>
<td>Patients aged 75 and over hospitalised via the Emergency Department. 35%</td>
<td>Zarit Burden Interview.</td>
<td>Nursing home was defined as any type of residential care establishment or long-term care hospital unit 95%</td>
<td>Caregiver burden HR=2.61; 95 CI=1.67-4.06; p&lt;0.001. Unadjusted</td>
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<tr>
<td>Fisher, Lieberman. (142); United States; 1999</td>
<td>2 year cohort</td>
<td>Alzheimer’s Disease dyads. 46%</td>
<td>Carer strain 11-item scale developed by Niedereche and Fruge (382).</td>
<td>Nursing home placement 50%</td>
<td>No significant difference was found between those who placed their care recipient in a nursing home (n=79; carer strain M=22.7; SD=5.2) and those who didn't (n=85; Unadjusted</td>
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<tr>
<td>Study</td>
<td>Time</td>
<td>Sample Description</td>
<td>Measure</td>
<td>Outcome</td>
<td>Statistic</td>
<td>Adjustments</td>
<td>Notes</td>
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<tr>
<td>Gaugler et al. (60); United States; 2005</td>
<td>3 year cohort</td>
<td>Dementia dyads. 40%</td>
<td>Zarit burden Interview</td>
<td>Long term nursing home placement</td>
<td>60%</td>
<td>Odds ratio for burden =1.02; 95CI=1.01-1.03.</td>
<td>Unadjusted</td>
<td></td>
</tr>
<tr>
<td>Haupt, Kurz. (383); UK; 1993</td>
<td>1 year cohort</td>
<td>Alzheimer’s Disease dyads. 25%</td>
<td>Items of the Zarit burden interview were used.</td>
<td>Nursing home placement</td>
<td>40%</td>
<td>No significance was found between carer burden scores in those who did not institutionalise (M=2.8; SD=1.0) and those who did (M=3.3; SD 0.9; F=3.12) institutionalise their care recipient</td>
<td>Unadjusted</td>
<td></td>
</tr>
<tr>
<td>Hebert et al. (69); Canada; 2001</td>
<td>5 year cohort</td>
<td>Dementia dyads. % men not provided</td>
<td>Zarit burden Interview. Depression with CES-D</td>
<td>Both NHP and Acute care admission longer than 3 months.</td>
<td>63%</td>
<td>Severe carer burden was found to be significantly associated with a shorter time for institutionalisation controlling for ADL rating only HR=1.77; 95CI=1.28-2.44. Carer depression was found to be significantly associated with a shorter time for institutionalisation controlling for ADL rating only HR=1.04; 95 CI=1.01-1.07.</td>
<td>Adjusted for ADL rating only</td>
<td></td>
</tr>
<tr>
<td>Kodama et al. (384); Japan; 2009</td>
<td>2 year cohort</td>
<td>Caregivers of self-care-dependent elderly. 35%</td>
<td>Depression with CES-D</td>
<td>Institutionalisation</td>
<td>50%</td>
<td>Carers in a good relationship whose care recipient was admitted to a nursing home (n=54) had a mean CESD score of 5.8 (SD=3.6). Carers who continued caring (n=411) had a mean CESD score of 5.4(SD=3.4).</td>
<td>Unadjusted</td>
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<tr>
<td>Kramer. (385); United States; 2000</td>
<td>1 year cohort</td>
<td>Dementia dyads. % men not provided</td>
<td>Burden with Memory and Behaviour Problem checklist. Depression with CES-D</td>
<td>Institutionalisation</td>
<td>48%</td>
<td>Significance difference between carers stress scores in those who did not institutionalise (M=18.98) and those who did (M=25.00; T=-2.23; p=.05). No significance difference found between carers depression scores in those who did not institutionalise (M=13.65) and</td>
<td>Unadjusted</td>
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</tbody>
</table>
Kuzuya et al. (87); Japan; 2011
3 year cohort
Community dwelling elderly with some degree of physical or mental impairment . 36%
1067; 935
Zarit burden Interview.
Hospitalisation
63%
Mean burden scores for those who continued home care was 27.26 (SD=17.12), while those whose CR was admitted to a nursing home was 30.46 (SD=16.9)
Unadjusted

Lieberman, Kramer.(386); United States; 1991
1 year cohort
Dementia dyads. 36%
321; 321
Caregiver stress assessed by the presence or absence of the number of reported family problems associated with caregiving (e.g. financial, psychological and social).
Institutionalisation
43%
Stress of carers whose care recipient was institutionalised (M=1.9; SD=1.4) was significantly higher than those who remained in the community (M=1.4; SD=1.2; beta=.18; t=2.9; p=.00).
Unadjusted

Molloy et al.(80); Canada; 1999
3 year cohort
Dementia dyads. 43%
30; 30
Zarit burden Interview.
Institutionalisation
60%
Burden score was not predictive of institutionalisation (OR=1.02; p=.625).
Unadjusted

Nygaard HA.(387); United States; 1991
1 year cohort
Dementia dyads. % men not provided
46; 46
Strain measured on a scale developed for study.
Admitted to a nursing home
50%
No significance found in strain between those admitted (Median=7; range=2-10) and those not admitted (Median=6, range=1-10; Kruskal Wallis=0.12; p=0.7)
Unadjusted

Ohwaki et al.(81); Japan; 2009
1 year cohort
Elderly people living in the community eligible for care under long-term
244; 244
Zarit burden Interview.
Placement was to both nursing home and hospital admission.
58%
There was no significant difference found in burden levels between those who continued home care and those who did not (p=0.91).
Unadjusted
| Study | Cohort Duration | Sample Description | Carer Depression | Institutionalisation | Carer Depression HR | 95% CI | Adjusted vs Baseline
|-------|-----------------|-------------------|------------------|---------------------|--------------------|------|-------------------
| Oura et al. (388); Japan; 2006 | 5 year cohort | Frail elderly receiving in-home care. 43% | Carer depression with CES-D. | Institutionalisation | 35% | Carer depression HR=1.32; 95CI=0.49-3.56. | Adjust for CR characteristics: gender; age; dementia; dementia with behavioural disturbance; Carer characteristics: Gender; age; depression; consulted with a doctor about their own health; spouse; daughter-in-law; Care setting: family member helped with caregiving; able to go out without accompanying the elderly.
| Philp et al. (70); UK; 1997 | 2 year cohort | Dementia dyads. 2% People with Dementia a: 114; 103 | Carer stress assessed by asking the carer to rate their overall level of stress using a 3-category response ('a lot', 'some', and 'hardly and/none'). Institutionalisation was defined entry to residential or nursing home on a permanent basis; or a long-stay bed in a geriatric or psychiatric hospital | 48% | Carer stress was significantly associated with institutionalisation (to both hospital and NH) p=0.020. | Unadjusted
| Pot et al. (71); the Netherlands; 2001 | 1 year cohort | Dementia dyads. 30% | Perceived stress measured with the 'Self-Perceived Pressure from Informal Care' questionnaire (SPPIC) (389). Admission to either a residential home or a nursing home. | 65% | There was a significant difference in stress between those whose care recipient remained at home (M=4.53; SD not provided) and those whose care recipient was institutionalised (M=5.52; SD not provided; t= -2.24; p<0.05). No | Unadjusted
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Cohort</th>
<th>Sample Size</th>
<th>Measure</th>
<th>Outcome</th>
<th>Outcome Description</th>
<th>Significance</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>Pruchno et al. (1990)</td>
<td>1990</td>
<td>1 year cohort</td>
<td>315; 220</td>
<td>Burden with a measure derived for the study</td>
<td>Institutionalisation</td>
<td>43%</td>
<td>Significant differences in burden were found between carers whose CR remained in the community (M=32.75) and those who were institutionalised (M=35.85; t=2.86; p=&lt;.01). Significant differences in depression were found between carers whose CR remained in the community (M=14.93) and those who were institutionalised (M=20.16; t=3.16; p=&lt;.001).</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Rongve et al. (2013)</td>
<td>2013</td>
<td>6 year cohort</td>
<td>189; 165</td>
<td>Carer distress with the Relative’s Stress Score (390).</td>
<td>Permanent or alternating residing in nursing homes or home for the elderly</td>
<td>80%</td>
<td>Higher carer distress (HR=1.03; 95CI=1.01-1.05) predicted faster admission to a nursing home.</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Schulz et al. (2004)</td>
<td>2004</td>
<td>18 month RCT</td>
<td>1222; 1177</td>
<td>Carer stress assessed with the Revised Memory and Behaviour Problem Checklist (RMBPC) (392).</td>
<td>Institutionalisation</td>
<td>63%</td>
<td>Caregivers reporting greater burden were more likely to institutionalise their relative HR=1.02; 95CI=1.01-1.03; P=&lt;.001</td>
<td>Adjusted for carer race; RMBPC; MMSE; and positive aspects of caregiving.</td>
</tr>
<tr>
<td>Schwarz, Elman (2003)</td>
<td>2003</td>
<td>3 month cohort</td>
<td>156; 128</td>
<td>Perceived stress measured with the Perceived Stress Scale (281). Depression measured with the CES-D.</td>
<td>Hospital readmission</td>
<td>60%</td>
<td>No significant differences were found in stress scores between those re-admitted to hospital (M=16.18; SD=8.3) and not those re-admitted (M=16.75; SD=9.2; p=.55). No significant differences were found in depression scores between those re-admitted to hospital (M=10.87; SD=8.5) and not re-admitted (M=11.86; SD=9.1; p=.86).</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Study</td>
<td>Country and Year</td>
<td>Cohort Duration</td>
<td>Population</td>
<td>Measure of Burden</td>
<td>Measure of Burden</td>
<td>Institutionalisation</td>
<td>Results</td>
<td></td>
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<tr>
<td>Shugarman et al.(162); United States; 2002</td>
<td>3 month cohort</td>
<td>Home Care Support participant s. 30%</td>
<td>527; 527</td>
<td>Burden measured with items from the MDS-HC (393).</td>
<td>Hospital readmission</td>
<td>60%</td>
<td>Burdened carers= 106; non-burdened carers=421; burdened carers whose recipient was admitted=17; non-burdened carers whose recipient was admitted=67.</td>
<td></td>
</tr>
<tr>
<td>Soto et al.(82); France; 2006</td>
<td>1 year cohort</td>
<td>Alzheimer’s Disease dyads. % men not provided</td>
<td>455; 455</td>
<td>Zarit burden Interview.</td>
<td>Institutionalisation</td>
<td>58%</td>
<td>The OR for those with moderate Zarit score was OR=1.21; 95 CI=0.46-3.16; p=0.693.</td>
<td></td>
</tr>
<tr>
<td>Spillman, Long.(54); United States; 2009</td>
<td>2 year cohort</td>
<td>Older people aged 65+ with chronic disabilities with an established caregiving arrangement. 32%</td>
<td>1006; 1006</td>
<td>Carer’s reports of frequent recipient behaviour problems and of experiencing strain from providing care along with the overall level of stress the caregiver reports experiencing from caregiving responsibilities.</td>
<td>Nursing home entry considered admissions to nursing homes for episodes of care that last at least 60 days</td>
<td>48%</td>
<td>Stressed carers=191; non-stressed carers=815; stressed carers whose recipient was admitted=33; non-stressed carers whose recipient was admitted=98</td>
<td></td>
</tr>
<tr>
<td>Spruytte et al.(394); Belgium; 2001</td>
<td>9 month cohort</td>
<td>Dementia dyads. 31%</td>
<td>144; 109</td>
<td>Self-Perceived Pressure from Informal Care (389).</td>
<td>Institutionalisation</td>
<td>68%</td>
<td>Author emailed data 21.8.14</td>
<td></td>
</tr>
<tr>
<td>Stevens et al.(223); United States; 2004</td>
<td>2 year cohort</td>
<td>Dementia dyads. 29%</td>
<td>215; 215</td>
<td>Burden with Memory and Behaviour Problem Checklist. Depression with CES-D.</td>
<td>Nursing home placement</td>
<td>60%</td>
<td>Carer stressfulness appraisal of memory and behaviour problems demonstrated significant influence on time to placement: HR=1.544, chi square=4.527; p=.033. CESD did not demonstrate significant influence on time to placement: HR=1.005, chi square =0.17; p=.68.</td>
<td></td>
</tr>
<tr>
<td>Strain et al.(151); Canada; 2003</td>
<td>5 year cohort</td>
<td>Older adults diagnosed with cognitive</td>
<td>123; 123</td>
<td>Zarit burden Interview.</td>
<td>Institutionalisation</td>
<td>65%</td>
<td>Carer burden in high risk: OR=1.03 95CI=0.93-1.14. Medium risk, OR=1.03 95CI=0.96-1.10. Low-risk: OR=1.04 95CI=0.97-1.11.</td>
<td></td>
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</table>

Unadjusted
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Cohort</th>
<th>Impairment or Dementia Dyads</th>
<th>Distress with CES-D</th>
<th>Hospitalisation</th>
<th>Odds Ratio for CES-D</th>
<th>95% CIs</th>
<th>Unadjusted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thorpe et al. (96); United States; 2010</td>
<td>1 year cohort</td>
<td>Dementia dyads. 49% men not provided</td>
<td>1186; 1186</td>
<td>Distress with CES-D.</td>
<td>68%</td>
<td>Odds Ratio for CES-D=1.01</td>
<td>95% CIs=0.98-1.04.</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Voisin et al. (90); France; 2010</td>
<td>2 year cohort</td>
<td>Dementia dyads. 30%</td>
<td>686; 686</td>
<td>Zarit Burden Interview.</td>
<td>Hospitalisation</td>
<td>58%</td>
<td>Carer burden score RR=1.016; 95% CI=1.008-1.025; p=.0002</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Washio et al. (395); Japan; 2002</td>
<td>6 month cohort</td>
<td>Caregivers and the disabled elderly. 40%</td>
<td>48; 48</td>
<td>Depression with CES-D.</td>
<td>Admission to long term care institution</td>
<td>50%</td>
<td>Derived numbers for 2x2 table from article</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Whitlatch et al. (74); United States; 1999</td>
<td>2 year cohort</td>
<td>Alzheimer’s Disease dyads. 35% men not provided</td>
<td>926; 926</td>
<td>Zarit burden Interview. Depression with CES-D.</td>
<td>Institutionalisation</td>
<td>55%</td>
<td>Carer burden at baseline was significantly higher for those carers who placed the care recipient (M=19.2) than those who did not (18.0; t=6.92; p&lt;.01). Carer depression at baseline was significantly higher for those carers who placed the care recipient (M=22.3) than those who did not (20.2; t=6.93; p&lt;.01).</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Young et al. (396); United States; 1998</td>
<td>18 month cohort</td>
<td>Alzheimer’s Disease dyads. 35%</td>
<td>575; 426</td>
<td>Burden measured by 6 item scale developed by the author.</td>
<td>Institutionalisation</td>
<td>50%</td>
<td>Mean burden scores for those who continued home care (n=261) was 18.8, while those whose CR was admitted to a nursing home (n=165) was 21.7.</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Zarit, Todd, Zarit (75); United States; 1986</td>
<td>2 year cohort</td>
<td>Dementia dyads. 64% men not provided</td>
<td>64; 43</td>
<td>Zarit burden Interview.</td>
<td>Institutionalisation</td>
<td>48%</td>
<td>Initial burden scores were significantly higher for those carer who placed their spouse in a nursing home (M=43.54) than those who did not (M=33.59; t=2.23; p&lt;.05).</td>
<td>Unadjusted</td>
</tr>
<tr>
<td>Study</td>
<td>Sample Size</td>
<td>Study Design</td>
<td>Baseline Characteristics</td>
<td>Measure of Carer Distress</td>
<td>Measure of Institution</td>
<td>Outcome</td>
<td>Results</td>
<td>Adjustments</td>
</tr>
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<tr>
<td>Gruneir et al. (397); Canada; 2013</td>
<td>71303; 71303</td>
<td>1 year cohort</td>
<td>Carer distress with measure from InterRAI HC assessment (393).</td>
<td>Admission to acute care</td>
<td>88%</td>
<td>Results obtained on email</td>
<td>Unadjusted</td>
<td></td>
</tr>
<tr>
<td>Baumgarten et al. (398); Canada; 1994</td>
<td>86; 86</td>
<td>1 year cohort</td>
<td>Depression with the CES-D.</td>
<td>Institutionalisation</td>
<td>53%</td>
<td>Mean CES-D scores for those whose care recipient was institutionalised = 15.8 (SD not provided) and those not institutionalised = 15.5 (SD not provided).</td>
<td>Unadjusted</td>
<td></td>
</tr>
<tr>
<td>Mittelman et al. (83); United States; 2006</td>
<td>406; 406</td>
<td>18 year RCT</td>
<td>Zarit burden Interview. Depression with geriatric depression scale.</td>
<td>Nursing home placement</td>
<td>53%</td>
<td>The carer burden HR = 1.009; 95CI=0.996-1.021; p=0.1759. The carer depression HR = 1.016; 95CI=0.988-1.044; p=0.2791. Adjusted for group (intervention vs control); carer gender; carer age; patient age; patient income; year of study entry; global deterioration scale; carer physical health; patient physical health; satisfaction with support network; frequency of memory and behaviour problems; reaction to memory and behaviour problems; depressive symptoms and carer burden.</td>
<td>Adjusted for group (intervention vs control); carer gender; carer age; patient age; patient income; year of study entry; global deterioration scale; carer physical health; patient physical health; satisfaction with support network; frequency of memory and behaviour problems; reaction to memory and behaviour problems; depressive symptoms and carer burden.</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Type</td>
<td>Design</td>
<td>Dyad Composition</td>
<td>Measures</td>
<td>Interventions</td>
<td>Methodology</td>
<td>Results</td>
<td>Adjustments</td>
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<tr>
<td>Spijker et al. (399); Netherlands; 2011</td>
<td>12 month RCT</td>
<td>Suspected Dementia dyads. %men in control=36%; % men intervention=30%</td>
<td>295; 262</td>
<td>Carer depression CES-D.</td>
<td>Institutionalisation in long-term care facilities.</td>
<td>80% Log regression, carer depression OR=1.05; 95% CI=1.01-1.09; p=0.01.</td>
<td>Adjusted for group assignment (intervention vs control); gender; living arrangement; severity of dementia; sense of competence; behavioural problems; carer depressive symptoms; group assignment x sense of competence; gender x living arrangement</td>
<td></td>
</tr>
<tr>
<td>Joling et al. (400); The Netherlands; 2012</td>
<td>18 month RCT</td>
<td>Dementia dyads. 67%</td>
<td>Control group: 96; 95</td>
<td>Neuropsychiatric Inventory Questionnaire (NPI-Q) distress score. Depression measured with CES-D.</td>
<td>Institutionalisation</td>
<td>78% Results obtained by email.</td>
<td>Unadjusted</td>
<td></td>
</tr>
<tr>
<td>Phung et al. (401); Denmark; 2013</td>
<td>3 year RCT</td>
<td>Alzheimer's Disease dyads. 45%</td>
<td>Control group: 167; 167</td>
<td>Depression measured with Geriatric depression scale.</td>
<td>Nursing home placement</td>
<td>80% Results obtained by email.</td>
<td>Unadjusted</td>
<td></td>
</tr>
<tr>
<td>Wai Tong, Lee. (402); China; 2011</td>
<td>18 month RCT</td>
<td>Dementia dyads. 56%</td>
<td>Control group: 46; 45</td>
<td>Family Caregiving Burden Inventory (FCBI).</td>
<td>Institutionalisation</td>
<td>93% Results obtained by email.</td>
<td>Unadjusted</td>
<td></td>
</tr>
<tr>
<td>Wang, Chien. (403); China; 2011</td>
<td>7 month RCT</td>
<td>Dementia dyads. 54%</td>
<td>Control group: 40; 40</td>
<td>Family Caregiving Burden Inventory (FCBI).</td>
<td>Institutionalisation</td>
<td>80% Burdened carers= 20; non-burdened carers=19; burdened carers whose recipient was admitted=13; non-burdened carers whose recipient was admitted=8</td>
<td>Unadjusted</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Duration</td>
<td>Design</td>
<td>Dementia dyads, % men not provided</td>
<td>Control group</td>
<td>Outcome</td>
<td>Placement</td>
<td>%</td>
<td>Notes</td>
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<tr>
<td>Droes et al. (224); The Netherlands; 2006</td>
<td>18 month non-randomized pre and post-test design</td>
<td></td>
<td></td>
<td>Control group: 34; 18</td>
<td>General Health Questionnaire (GHQ-28).</td>
<td>Nursing home placement</td>
<td>50%</td>
<td>Author replied with data 1.9.14</td>
</tr>
<tr>
<td>Kurz et al. (404); Austria, Switzerland and Germany; 2010</td>
<td>15 month RCT</td>
<td>Alzheimer’s Disease dyads. 32%</td>
<td>Control group: 132; 106</td>
<td>Montgomery-Asberg Depression Scale.</td>
<td>Permanent nursing home placement</td>
<td>73%</td>
<td>Author replied with data 17.10.14</td>
<td>Unadjusted</td>
</tr>
</tbody>
</table>
Appendix 6.1 Participant inclusion criteria for Study 2

Healthcare professionals and carer support NGOs identified carers that met the following inclusion criteria. The PhD scholar also asked a number of screening questions when first meeting with the carer in order to ensure the carer meets the inclusion criteria. Data was sought from carers that meet the following criteria:

- Identify as being the primary carer of an older person (aged 65 and over);
- The care recipient did not require acute or critical care at the time of recruitment;
- The care recipient was or had been in the last 6 months ordinarily a community-dwelling resident (i.e., not a resident of a nursing home or other residential care home);
- The carer had started the process of applying for long-term care for the care recipient or undergone the process in the previous six months;
- The decision to apply for long-term care had been made for a period of at least 3 weeks;
- The carer was involved in the decision to transfer the care recipient to a long-term care facility;
- The carer had been the primary carer for at least three months;
- The carer was over the age of 18;
- The carer was able to converse in and understand English;
- The carer did not have evident cognitive impairment as advised by the gatekeeper; and
- The carer was willing to participate in the study.

Data was sought from healthcare professionals that met the following criteria:

- Part of a community-based or hospital-based healthcare professional group that are key in the decision to transfer an older care recipient to long-term care, namely: Public Health Nursing, Community Registered General Nursing, General Practice, Social Work, Occupational Therapy, Psychology and Geriatrics.
- The professional was involved in the decision-making process to transfer older care recipients to long-term care for at least three months;
- The professional was willing to participate in the study; and
- The PhD Scholar did not personally know the professional.
Appendix 6.2 Ethical approval letter

Royal College of Surgeons in Ireland
The Research Ethics Committee
121 St. Stephens Green, Dublin 2, Ireland.
Tel: +353 1 4022205 Email: recadmin@rcsi.ie

Dr David Smith, Acting Chair
Dr Niamh Clarke, Convener
26th May 2015

Ms Nora-Ann Donnelly
Department of Psychology
Beaux Lane House,
Lower Mercer Street,
Dublin 2

Ethics Reference No: REC1057

Project Title: Caregiving and long-term care: A qualitative study with healthcare professionals.

Researchers Name (lead applicant): Ms Nora-Ann Donnelly HRB PhD Scholar in Health Services Research, Department of Psychology, RCSI.

Principal investigator on the project (PI): Dr Frank Doyle (Department of Psychology, RCSI).

Other Individuals Involved: Dr Niamh Humphries (Department of Epidemiology, RCSI) and Professor Anne Hickey (Department of Psychology, RCSI).

Dear Ms Donnelly,

Thank you for your Research Ethics Committee (REC) application. We are pleased to advise that ethical approval has been granted by the committee for this study.

This letter provides approval for data collection for the time requested in your application and for an additional 6 months. This is to allow for any unexpected delays in proceeding with data collection. Therefore this research ethics approval will expire on 1st September 2016.

Where data collection is necessary beyond this point, approval for an extension must be sought from the Research Ethics Committee.

This ethical approval is given on the understanding that:

• All personnel listed in the approved application have read, understand and are thoroughly familiar with all aspects of the study.
• Any significant change which occurs in connection with this study and/or which may alter its ethical consideration must be reported immediately to the REC, and an ethical amendment submitted where appropriate.
• Please submit a final report to the REC upon completion of your project.

We wish you all the best with your research.

Yours sincerely,

Niamh Clarke

PP Dr Niamh Clarke (Convener)
Dr David Smith (Acting Chair)
Appendix 6.3 Healthcare professionals' participant information leaflet

Department of Psychology
Division of Population Health Sciences

Contact details: Royal College of Surgeons in Ireland, 123 St Stephens Green, Dublin 2.
Telephone: + 353 1 402 2428 / Fax: +353 1 402 2764
Email: ccaetano@rcsi.ie / Website: www.rcsi.ie

Head of Department: Prof. Anne Hickey  Department Secretary: Ms. Carole Caetano
Academic Staff: Dr. Frank Doyle  Dr. Sally Doherty  Dr. Mary Clarke  Dr Caroline Kelleher  Dr Lisa Mellon

Caregiving and long-term care:
A qualitative study with healthcare professionals and carers

Research Team: Dr Frank Doyle, Ms. Nora-Ann Donnelly, Prof. Anne Hickey and Dr Niamh Humphries

Supervisor: Dr Frank Doyle
Telephone number: (01) 402 2718 (office hours)

Researcher: Ms Nora-Ann Donnelly
Telephone number: (01) 402 2520 (office hours)

You are being invited to take part in a research study. Before you decide whether or not you wish to take part, you should read the information provided below carefully.

You don't have to take part in this study. You can change your mind about taking part in the study any time you like. You don't have to give us a reason. If you want to opt out of the study, you can rest assured it won't affect you in the future.

Why is this study being done?

We are a research group based in the Royal College of Surgeons in Ireland (RCSI) studying the key factors in the transfer an older care recipient to long-term care and the role of carer stress in this process. As the population is aging this information is important in helping healthcare planners and policy-makers to plan for the future.

Who is organising and funding this study?
This study is being conducted by Nora-Ann Donnelly, a PhD scholar based in the Department of Psychology, RCSI. The supervisory team comprises of Dr Frank Doyle, Department of Psychology, RCSI; Professor Anne Hickey, Head of the Department of Psychology, RCSI; and Dr Niamh Humphries, Department of Epidemiology, RCSI. The study is funded by the HRB in Ireland and is being completed to meet the requirement for a PhD in Health Services Research.

**Why am I being asked to take part?**

We are interviewing healthcare professionals that are key figures in the decision to transfer an older care recipient to long-term care. Sharing your experience of the key factors influencing this decision will provide invaluable information in helping us understand admissions to long-term care.

**How will the study be carried out?**

The study will take place between June and December 2015. We anticipate that between 15 to 20 healthcare professionals will be invited to participate in interviews. Once you have agreed to take part Nora-Ann Donnelly will arrange for an interview to take place at a time and location that is convenient for you.

**What will happen to me if I agree to take part?**

The interview will last approximately 30 minutes to 1 hour, depending on your availability. The interview will explore the key factors influencing the decision to transfer an older care recipient to long-term care; and the implications of carer stress on these factors. You will not be contacted for a second interview following the interview.

**Video/and or Audio recordings?**

The interview will be digitally recorded. You will have the opportunity to review the interview transcript at a later date, to add to the transcript or to indicate that a part or the entire transcript not be used. If you wish to avail of this option please let me know at the end of the interview.

**What are the benefits?**

While there are no direct benefits to participation, the study provides an opportunity for you to share your experiences. The majority of research around admission to long-term care focuses on the care recipient. There is a scant degree of research on healthcare professionals’ perspectives, yet healthcare professionals are key figures in this process. Consequently, the research community will hopefully gain invaluable insights and more fully understand the process.

**What are the risks?**

We do not foresee any risks to you from participating in the study. Interviews will be held at a time and place that is convenient for you. You will also have the option to conduct the interview over the phone once written consent has been received.
Is the study confidential?

Yes. The information you provide will be kept confidential. The digital recording of your interview will be transcribed. Once the transcript has been edited the digital file will be destroyed. The transcript will be anonymised (all names and identifying data will be removed). The data generated by this study will be controlled by the research team and will only be discussed by the research team once it is anonymised. All information will be kept securely in line with best practice for data security.

Following completion of the study the results will be published as part of a PhD thesis. The findings may also be used in a number of peer reviewed journal articles. All the data used for these purposes will be anonymised. Should you wish to have a copy of publications arising out of this study please let me know.

Where can I get further information?

If you need any further information now or at any time in the future, please contact:

**Supervisor:**
Dr Frank Doyle  
Department of Psychology  
Royal College of Surgeons in Ireland  
Tel: (01) 402 2718 (office hours)  
Email: FDoyle4@rcsi.ie

**Researcher:**
Ms. Nora-Ann Donnelly  
Department of Psychology  
Royal College of Surgeons in Ireland  
Tel: (01) 402 2520 (office hours)  
Email: noraadonnelly@rcsi.ie

**Thank you very much for taking the time to consider participating in this project.**
Appendix 6.4 Study postcard

**Side 1:**

Caregiving and long-term care: A qualitative study with Healthcare Professionals and Carers

Research Team: Ms Nora-Ann Donnelly¹, Dr Alan Moore², Prof. Anne Hickey¹, Dr Niamh Humphries³ and Dr Frank Doyle¹

¹ Royal College of Surgeons in Ireland

Are you a carer of an older person? Are you and your family in the process of applying for or accessing long-term care?

OR  Are you a healthcare professional involved in supporting families decide on or access long-term care?

We are a research group based in the Royal College of Surgeons in Ireland (RCSI). We would like to invite healthcare professionals and carers of older persons to take part in a research study on caregiving in Ireland and the entry of loved ones to long-term care.

**What is involved?**

The study will involve an interview with you which will last for a maximum of an hour, depending on your availability. The interview will be at a time and place that is most convenient for you. All the information you provide will be made anonymous so it will not be possible to identify you in any way.

**Why is the study important?**

This information will help us better understand the process of caregiving and entry to long-term care in Ireland. As the population is aging this information is important in helping healthcare planners and policy-makers plan for the future.

**Where can I get further information?**

If you would like to take part in this research, or need further information simply contact Nora-Ann Donnelly using the contact details overleaf.

Thank you

**Side 2:**

Caregiving and long-term care: A qualitative study with Healthcare Professionals and Carers

Research Team: Ms Nora-Ann Donnelly¹, Dr Alan Moore², Prof. Anne Hickey¹, Dr Niamh Humphries³ and Dr Frank Doyle³

¹ Royal college of surgeons in ireland

² Jameson hospital Dublin

Are you a carer of an older person? Are you and your family in the process of applying for or accessing long-term care?

OR  Are you a healthcare professional involved in supporting families decide on or access long-term care?

Are you willing to discuss your perspective on caregiving in Ireland and on the entry of loved ones to long-term care?

If you would like to take part in this research, or need further information simply contact Nora-Ann Donnelly using the contact details below.

Nora-Ann Donnelly
Address: Department of Psychology
Royal College of Surgeons in Ireland
Beaux Lane House
Lower Mercer Street
Dublin 2
Tel: (01) 402 2520
Email: noradonnelly@rcsi.ie

Thank you very much for taking the time to consider participating in this research project.
Appendix 6.5 RCSI Press Release

RCSI seeks family carers to participate in research study - Royal College Surgeons in Ireland

Royal College of Surgeons in Ireland Coláiste Róga na hÉireann

Home > News & Events >

RCSI seeks family carers to participate in research study

03 June 2015

Study to capture carer’s voice announced to coincide with National Carers Week

Researchers from RCSI (Royal College of Surgeons in Ireland) are calling on family carers to volunteer to take part in a research study which aims to address the absence of the carer’s voice in health research. The study has been announced to coincide with National Carers Week. The research findings will provide information to healthcare planners and policy-makers in order to better understand carers’ perspectives on caregiving and the process of entry to nursing homes in Ireland.

Family carers are fundamental to community care in Ireland and provide substantial support to loved ones, often providing significant levels of care in quite challenging circumstances. As the population is aging in Ireland, the role of family carers in supporting older populations will become even more important. Yet carers are often invisible in the analysis of the health system and one factors influencing older population’s use of health services, particularly nursing homes. This new study on caregiving in Ireland and entry of loved ones to nursing homes, being carried out by the RCSI research group, aims to address this deficit.

Nora-Ann Donnelly, Department of Psychology, RCSI who is coordinating the research project said: “If you are a family carer of older person and you and your family are in the process of applying for or accessing long-term care for a loved one, the research group would really like to hear from you. The study provides you with an opportunity to have your voice heard. Sharing your perspective and experiences will provide invaluable information in helping to understand caregiving in Ireland and the key factors in admissions to long-term care.”

The study will involve a face to face interview with the carers at a time and place that is convenient for them and will take no more than one hour. All the information provided will be kept confidential and anonymised so it cannot be linked to the participants in any way.

For further information on taking part in the research contact Nora-Ann Donnelly, Department of Psychology, RCSI by email or by phone (01) 402 2520.

National Carers Week, which is taking place this week (5-14th June) and involves many events throughout Ireland to celebrate the immense contribution of family carers.

The RCSI research group includes Nora-Ann Donnelly, Dr Frank Doyle and Prof Anne Holroy, Department of Psychology, RCSI; Dr Niamh Humphreys, Department of Epidemiology, RCSI; and Dr Alan Moore, Department of Obstetrics Medicine, Beaumont Hospital. The study is funded by the Health Research Board in Ireland.

RCSI is among the top 50 most international universities in the world (Times Higher Education University World Rankings, 2014-15). It is a not-for-profit health sciences institution focused on education and research to drive positive change in all areas of human health worldwide. RCSI is headquartered in Dublin and is a recognised College of the National University of Ireland. In 2010, RCSI was granted independent degree awarding status by the State, which enables the College to award degrees alongside its traditional powers to award certificates.

https://www.rcsi.ie/index.jsp?m=1108&p=1008a-0043
Appendix 6.6 Advertised in healthcare websites

Family carers are being asked to take part in a new study which is focusing on what it is like to place a loved one in long-term care. According to researchers from the Royal College of Surgeons in Ireland (RCSI), one of the aims of this study is to address the absence of the carer's voice in health research.

If you are a family carer of an older person and you and your family are in the process of applying for or accessing long-term care for a loved one, the research group would really like to hear from you. The study provides you with an opportunity to have your voice heard. Sharing your perspective and experiences will provide invaluable information in helping to understand caregiving in Ireland and the key factors in admissions to long-term care,” explained research coordinator, Nora-Ann Donnelly.

The RCSI pointed out that family carers are “fundamental to community care in Ireland, providing a huge level of care often in challenging circumstances. Furthermore, as people are now living longer, the population is ageing and the role of carers is becoming even more important.”

http://www.vnhealth.com/

Previous Article:

Next Article:
Appendix 6.7 Centre for Aging Research and Development Ireland (CARDI) Advertisement

As of the 24 September 2015 The Centre for Ageing Research and Development in Ireland (CARDI) became the Ageing Research and Development Division within the Institute of Public Health in Ireland (IPH). This website will remain online but will no longer be updated. To keep up to date with our work please visit the Division of Ageing Research and Development section of the IPH website.

Home > News > RCSI seeks family carers to participate in research study

RCSI seeks family carers to participate in research study

**Theme**  FAMILY, SUPPORT, SOCIAL NETWORKS AND PARTICIPATION, HEALTH & WELL BEING, LIVING ENVIRONMENTS

23rd June 2016

**Region**  Republic of Ireland

**News Source:**
Royal College of Surgeons Ireland (RCSI)

**Link to Article:**
http://www.rcsi.ie/index.jsp

Researchers from RCSI (Royal College of Surgeons in Ireland) are calling on family carers to volunteer to take part in a research study which aims to address the absence of the carer’s voice in health research. The research findings will provide information to healthcare planners and policy-makers in order to better understand carers’ perspectives on caregiving and the process of entry to nursing homes in Ireland.

The study will involve a face-to-face interview with the carers at a time and place that is convenient for them and will take no more than one hour. All the information provided will be kept confidential and anonymised so it cannot be linked to the participants in any way.

For further information on taking part in this research contact Noa-Anne Donnelly, Department of Psychology, RCSI by email or by phone (01) 402 2620.

**Tags:**  RESEARCH STUDY, CAREERS, ROYAL COLLEGE OF SURGEONS IN IRELAND
Carer Participant Information Leaflet

Department of Psychology
Division of Population Health Sciences

Contact details: Royal College of Surgeons in Ireland, 123 St Stephens Green,
Dublin 2.
Telephone: +353 1 402 2428 / Fax: +353 1 402 2764
Email: ccaetano@rcsi.ie / Website: www.rcsi.ie

Head of Department:  Prof. Anne Hickey   Department Secretary:  Ms. Carole Caetano
Academic Staff:  Dr. Frank Doyle  Dr. Sally Doherty  Dr. Mary Clarke  Dr. Caroline Kelleher  Dr Lisa Mellon

Caregiving and long-term care:
A qualitative study with healthcare professionals and carers

Research Team: Dr Frank Doyle, Ms. Nora-Ann Donnelly, Prof. Anne Hickey and Dr Niamh Humphries

Supervisor: Dr Frank Doyle
Telephone number: (01) 402 2718 (office hours)

Researcher: Ms Nora-Ann Donnelly
Telephone number: (01) 402 2520 (office hours)

You are being invited to take part in a research study. Before you decide whether or not you wish to take part, you should read the information provided below carefully.

You don't have to take part in this study. You can change your mind about taking part in the study any time you like. You don't have to give us a reason. If you want to opt out of the study, you can rest assured it won't affect you in the future.

Why is this study being done?

Carers provide a substantial amount of support for older people, yet they are often invisible in the health system. We want to hear from carers themselves about their experiences of caregiving and the decision to transfer their loved one to long-term care. This information will help us better understand the process of entry to long-term care in Ireland. As the population is aging this information is important in helping healthcare planners and policy-makers to plan for the future.
Who is organising and funding this study?

We are a research group based in the Royal College of Surgeons in Ireland (RCSI). This study is being conducted by Nora-Ann Donnelly, a PhD scholar based in the Department of Psychology, RCSI. The supervisory team comprises of Dr Frank Doyle, Senior Lecturer in the Department of Psychology, RCSI, Professor Anne Hickey, Head of the Department of Psychology, RCSI, and Dr Niamh Humphries, Senior Research Fellow, Department of Epidemiology, RCSI. The study is funded by the HRB in Ireland under Grant No. PHD/2007/16 and is being completed to meet the requirement for a PHD in Health Services Research.

Why am I being asked to take part?

We want to hear your perspective on caregiving for an older person in Ireland and on the decision to transfer your loved one to long-term care. Sharing your perspective and experiences will provide invaluable information in helping to understand the key factors in caregiving in Ireland and those contributing to admissions to long-term care.

How will the study be carried out?

The study will take place between June and December 2015. We anticipate that fifteen carers, like you, will be invited to participate in interviews. Once you have agreed to take part Nora-Ann Donnelly will arrange for an interview to take place at a time and location that is convenient for you.

What will happen to me if I agree to take part?

We recognise how precious your time is. So we have planned that the interview will take a maximum of an hour, depending on your availability. The interview will be digitally recorded and will explore your perspectives and experiences of caregiving and what you perceive as the most important factors contributing to your loved one’s entry to long-term care. You will not be contacted for a second interview following the interview.

What are the benefits?

While there are no direct benefits to participation, participating in the study will provide you with an opportunity for your voice to be heard, to share your experiences of caregiving, express what you perceive are the critical factors in the decision to transfer your loved one to long-term care and your insights into this process. By participating in the study, the research community will hopefully more fully understand carers in Ireland. The study will also add to the research around admission to long-term care, contributing to the evidence base so as to support healthcare planners and policy-makers to plan for the future.
What are the risks?

We do not foresee any major risks to you from participating in the study. Interviews will be held at a time and place that is convenient for you. You will also have the option to conduct the interview over the phone once written consent has been received. We understand that as this study will include the factors which lead to your loved one needing to be transferred to long-term care this may highlight difficult experiences. If it is causing you upset, you can choose to stop participating immediately. As part of this leaflet we also have provided a list of carer support services which can be accessed freely should you wish to do so.

Will it cost me anything to take part?

It will not cost you anything to take part. The interview will take place at a time and location that is convenient for you.

Is the study confidential?

Yes. Everything that is discussed in the interview will be confidential. The digital recording of your interview will be transcribed and once the transcript has been edited the transcript will be anonymised (all names and identifying data will be removed) and held securely for 7 years and then destroyed, in line with RCSI policy on data storage. You will have the opportunity, should you wish, to review the interview transcript for clarification, to add to the transcript or to indicate that a part or the entire transcript not be used. If you wish to avail of this option please let me know at the end of the interview. Data will only be discussed or analysed by the research team once it is irrevocably anonymised. As with all research, confidentiality would only ever be broken where people are in situations of extreme and immediate harm. Under these extreme circumstances, the researcher may be obliged to contact the appropriate authorities, but this would be discussed with you further before action is taken. All information will be kept securely, it will be encrypted and password protected, on a computer in line with best practice for data security.

Following completion of the study the results will be published as part of a PhD thesis. It is also envisaged that the findings will be used in a number of peer reviewed journal articles arising from the study. All the data used for these purposes will be anonymised. Should you wish to have a copy of publications arising out of this study please let me know at the end of the interview.

Where can I get further information?

If you have any further questions about the study or if you want to opt out of the study, you can rest assured it won’t affect the quality of treatment you or your loved one receives in the future.

If you need any further information now or at any time in the future, please contact:
Thank you very much for taking the time to consider participating in this project.

Carer support services

The Carers’ Association
Freephone 1800 240 724
Monday to Friday, 9am – 5.30pm
Email: nationalcareline@carersireland.com
Website: www.carersireland.com

Money Advice Budgeting Service (MABS)
Helpline number: 0761 072000
Monday to Friday, 9am – 8pm
Email: helpline@mabs.ie

Caring for Carers Ireland
Telephone: 065 6866515
Monday to Friday 9.30am to 5.00pm
Email: caringforcarers@eircom.net

Senior Helpline
LoCall: 1850 440 444
Seven days a week, 10am-1pm and 7-10pm

Citizen’s Information Centres
LoCall: 1890 777 121
Monday to Friday, 9am-9pm
Website: www.citizensinformation.ie

AWARE
Helpline: 1890 303 302
Seven days a week, 10am–10pm
Email: info@aware.ie
Website: www.aware.ie

The Alzheimer Society of Ireland
National Helpline Freephone 1800 341 341
Monday to Friday, 10am – 4pm
Email: info@alzheimer.ie
Website: www.alzheimer.ie

Active Retirement Ireland
Tel: 01-6792142
Email: fara@eircom.net
Address: Shamrock Chambers, 1-2 Eustace Street, Dublin
Appendix 6.9 Advertised on organisational websites
Appendix 6.10 Seniorcare.ie advertisement

RCSI seeks Family Carers to participate in Research Study

RCSI seeks family carers to participate in research study

Study to capture carer’s voice announced to coincide with National Carers Week

Researchers from RCSI (Royal College of Surgeons in Ireland) are calling on family carers to volunteers to take part in a research study which aims to address the absence of the carer’s voice in health research. The study has been announced to coincide with National Carers Week. The research findings will provide information to healthcare planners and policymakers in order to better understand carers’ perspectives on caregiving and the process of entry to nursing homes in Ireland.

Family carers are fundamental to community care in Ireland and provide substantial support to loved ones, often providing significant levels of care in quite challenging circumstances. As the population is aging in Ireland, the role of family carers in supporting older populations will become even more important. Yet carers are often invisible in the analysis of the health system and on policies influencing older population’s use of health services, particularly nursing homes. This new study on caregiving in Ireland and entry of loved ones to nursing homes, being carried out by the RCSI research group, aims to address this issue.

Nora Ann Donnelly, Department of Psychology, RCSI who is coordinating the research project said: “If you are a family carer of older person and you and your family are in the process of applying for or accessing long-term care for a loved one, the research group would really like to hear from you. The study provides you with an opportunity to have your voice heard. Sharing your perspectives and experiences will provide invaluable information in helping to understand caregiving in Ireland and the key factors in admissions to long-term care.”

The study will involve a face to face interview with the carers at a time and place that is convenient for them and will take no more than one hour. All the information provided will be kept confidential and anonymised so it cannot be linked to the participants in any way.

For further information on taking part in this research contact Nora Ann Donnelly, Department of Psychology, RCSI by email or by phone (01) 402 5350.

National Carers Week which is taking place this week (5-14 June) and involves many events throughout Ireland to celebrate the immense contribution of family carers.

The RCSI research group includes Nora Ann Donnelly, Dr Frank Doyle, and Prof Gene Helary, Department of Psychology, RCSI; Dr Niamh Humphries, Department of Epidemiology, RCSI, and Dr Alan Moore, Department of Geriatric Medicine, Beaumont Hospital. The study is funded by the Health Research Board in Ireland.

RCSI is among the top 50 most international universities in the world (Times Higher Education University World Rankings, 2014-15). It is a not-for-profit health sciences institution focused on education and research to drive positive change in all areas of human health worldwide. RCSI is headquartered in Dublin and is a recognised College of the National University of Ireland. In 2010, RCSI was granted independent degree awarding status by the State, which enables the College to award degrees alongside its traditional powers to award licences.

seniorcare.ie/RCSI_seeks_Family_Carers_to_participate_in_Research_Study.aspx

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Appendix 6.11 Disclosure Protocol

In circumstances where there is cause for concern the following Disclosure Protocol will be followed:

- Participants will be informed on the Participant Information Sheet and verbally at the beginning of the interview that the researcher is obliged to report any disclosures which suggest that a person is at risk of extreme and immediate harm.

- In circumstances where a participant discloses information to suggest that a person is at risk of extreme and immediate harm the researcher will be obliged to follow the Disclosures Protocol as set out by the research team. This will involve:
  1. Discussing the disclosure with the participant and remind him/her what was stated on the Participant Information Sheet and at the start of the interview regarding disclosures; and that action may have to be taken.
  2. In the first instance, the researcher will then discuss the disclosure with the Principal Investigator.
  3. The PI may then decide to convene an emergency meeting with the research team where a decision will be made regarding the action that should be taken i.e. to contact a HSE Senior Case Worker or the Gardaí etc.

- If the researcher considers anyone is in immediate (life-threatening) danger, the Gardaí will be called immediately.

For Participant Information Sheet section ‘Is the study confidential?’
Yes. Everything that is discussed in the interview will be confidential. The digital recording of your interview will be transcribed and once the transcript has been edited the digital file will be destroyed and the transcript will be anonymised (all names and identifying data will be removed). You will have the opportunity, should you wish, to review the interview transcript at a later date for clarification, to add to the transcript or to indicate that a part or the entire transcript not be used. If you wish to avail of this option please let me know at the end of the interview. Data will only be discussed or analysed by the research team once it is irrevocably anonymised. As with all research, confidentiality would only ever be broken where people are in situations of extreme and immediate harm. Under these extreme circumstances, the researcher may be obliged to contact the appropriate authorities (i.e. the Gardaí), but this would be discussed with you further before action is taken. All information will be kept securely, it will be encrypted and password protected, on a computer in line with best practice for data security.

Following completion of the study the results will be published as part of a PhD thesis. It is also envisaged that the findings will be used in a number of
peer reviewed journal articles arising from the study. All the data used for these purposes will be anonymised. Should you wish to have a copy of publications arising out of this study please let me know at the end of the interview.

References for other studies where such a protocol was put in place:

Appendix 6.12 Consent form

Department of Psychology
Division of Population Health Sciences

Contact details: Royal College of Surgeons in Ireland, 123 St Stephens Green, Dublin 2.
Telephone: + 353 1 402 2428 / Fax: +353 1 402 2764
Email: ccaetano@rcsi.ie / Website: www.rcsi.ie

Head of Department: Prof. Anne Hickey    Department Secretary: Ms. Carole Caetano
Academic Staff: Dr. Frank Doyle   Dr. Sally Doherty   Dr. Mary Clarke     Dr Caroline Kelleher    Dr Lisa Mellon

Caregiving and long-term care: A qualitative study with healthcare professionals and carers
Research Team: Dr Frank Doyle, Ms. Nora-Ann Donnelly, Prof. Anne Hickey and Dr Niamh Humphries

I have read and understood the Information Leaflet about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.  

Yes ☐  No ☐

I understand that I don’t have to take part in this study and that I can opt out at any time. I understand that I don’t have to give a reason for opting out and I understand that opting out won’t affect me or my loved one’s future medical care.

Yes ☐  No ☐

I am aware of the potential risks of this research study.

Yes ☐  No ☐

I understand that an audio recording will be made and that I have the right to review and edit any transcripts to which I have contributed.

Yes ☐  No ☐

I have been given a copy of the Information Leaflet and this completed consent form for my records.

Yes ☐  No ☐

Storage and future use of information:

I give permission for material/data to be stored for possible future research related to the current study without further consent being required subject to research ethics committee approval.

Yes ☐  no ☐

I give permission for material/data to be stored for possible future research unrelated to the current study without further consent being required subject to research ethics committee approval.

Yes ☐  no ☐

Participant Name (Block Capitals): __________________________
Participant Signature: __________________________          Date: __________
To be completed by the Principal Investigator or his nominee.

I the undersigned have taken the time to fully explain to the above patient the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Name & Qualifications (Block Capitals): ______________________________

Signature: _______________________________ Date: ___________

2 copies to be made: 1 for participant and 1 for PI.

Appendix 6.13 Interview guide: Healthcare professional

Department of Psychology
Division of Population Health Sciences

Contact details: Royal College of Surgeons in Ireland, 123 St Stephens Green, Dublin 2.
Telephone: + 353 1 402 2428 / Fax: +353 1 402 2764
Email: ccaetano@rcsi.ie / Website: www.rcsi.ie

Head of Department: Prof. Anne Hickey Department Secretary: Ms. Carole Caetano
Academic Staff: Dr. Frank Doyle Dr. Sally Doherty Dr. Mary Clarke Dr Caroline Kelleher Dr Lisa Mellon

Caregiving and long-term care: A qualitative study with healthcare professionals and carers

Research Team: Dr Frank Doyle, Ms. Nora-Ann Donnelly, Prof. Anne Hickey and Dr Niamh Humphries

Background information

- Interviewer to record gender.
- Professional group.
- Can you tell me about your role in the decision to transfer a patient to long-term care?
- How long have you been involved in this decision-making process?

Admission to long-term care

- Tell me about how the decision to transfer an older person to long-term care is made? [Prompts: who is involved in the decision? How is it made?].
• What do you think are the key factors that generally drive the admission to long-term care? [Prompts: care recipient characteristics, carer characteristics and the care-giving situation, wider health service drivers].
• In your experience, which of these factors are the most critical?
• In your experience, do other forms of health service utilisation (social and community care (respite, home help, homecare packages); primary care (GP visit) or acute care (ED visits and/or hospital admission)) delay entry to long-term care?
• I have a quote from the Minister for Health, Leo Varadkar from 17th of February 2015 that I would like to show you to get your reflections on it:
  “More money would also have to be made available for homecare packages, otherwise the” perverse situation “could result where it was easier to get into a nursing home than to go home from hospital.”
  • What do you think about this?
• How do you think the drivers of admissions have changed over-time, if at all? [Prompts: more obvious factors or more subtle - culture around nursing home placement; increases in the availability of beds].

High proportion of admissions to long-term care from acute care

• Data from the Department of Health has shown that, in 2011 and 2012, the highest proportion of admissions to long-stay beds were from acute hospitals. What do you think about this?
• Why do you think the decision to transfer an older person to long-term care is made in acute care? [Who initiates it? Access route to long-term care?].
• What role, if at all, does the carer play in the decision to admit a patient to long-term care?

Carer stress

• What does the terms ‘carer stress ’or ‘carer burden’ mean to you?
• How do you recognise carer stress? How common is it or how frequently do you encounter carer stress?
• What would you attribute carer stress to?
• What implications do you think carer stress has on a carer?
• If a carer appears to be quite stressed or burdened, would this influence your decision regarding long-term care?
• Many researchers believe carer stress predicts entry to long-term care. What do you think?
• As part of my PhD, I did a study on the association between carer stress and subsequent institutionalisation of older care recipients. I found that, while carer stress is significantly associated with subsequent institutionalisation, the size of this effect is negligible. That is, it appears that carer stress is not really a driver for subsequent institutionalisation. How does this relate to your professional experience?

Is there anything else you would like to add before we finish up?
Appendix 6.14 Interview guide: carer

Department of Psychology
Division of Population Health Sciences

Contact details: Royal College of Surgeons in Ireland, 123 St Stephens Green, Dublin 2.
Telephone: +353 1 402 2428 / Fax: +353 1 402 2764
Email: ccaetano@rcsi.ie / Website: www.rcsi.ie

Head of Department: Prof. Anne Hickey    Department Secretary: Ms. Carole Caetano
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Caregiving and long-term care: A qualitative study with healthcare professionals and carers
Research Team: Dr Frank Doyle, Ms. Nora-Ann Donnelly, Prof. Anne Hickey and Dr Niamh Humphries

Background information
- Interviewer record age and sex of carer and care recipient
- Are you married? Do you have children?

Caregiving History
- How long have you been caregiving for __________?
- Can you tell me about a typical day caregiving for __________? [Prompt: hours, tasks, intensity of caregiving; other dependents/employment?]
- How is your own health or wellbeing?

Carer Stress
- How do you find caring for __________? [Positive and not so positive aspects?]  
- How does caring for __________ make you feel? [Positive and not so positive aspects?]
- Do you ever feel stressed as a result of caring for __________? [Prompt: Can you give me an example of a time when you found it stressful?]
  - How does this stress impact on you or your family?
- Do you feel there is anything that can be done to help reduce carer stress? [Prompt: informal and formal supports?]

Carer Support
- Did you ever discuss the caregiving situation with a health professional?
- Do you or have you received services to help care for __________ (homecare package, personal care attendant, home help, respite, public or community health nursing services, day centre)?
- How did you find this? [Positive and not so positive aspects? Implications for long-term care or stress?]
Long term care

- Tell me about the decision to transfer your loved one to long-term care?
- What factors influenced that decision? [Care recipient factors? Carer factors? Family and/or healthcare professionals influence?]
- What would you say was the primary motivation to transfer your loved one to long-term care?
- Had you thought about long-term care for __________ before now? If so, can you tell me about this?

Is there anything else you would like to add about the experience of being a carer?
Appendix 6.15 Thematic analysis: line-by-line coding

An extract from an interview is presented in text box 1 below to illustrate how two codes emerged for one of the sub-themes ‘inequity in service availability’.

Box 1: Example of how two codes emerged for sub-theme ‘inequity in service availability’

“I think the other problem is in the country it depends where you live…When I worked in [names area], in one area I had home help immediately and in the other area, the other side of the road, there was a waiting list…There’s no fairness in the system at all…I worked [names area], we covered everybody for dressings. Wound dressing, regardless of whether you were the Prime Minister, the Bank Manager, you got your dressing done. I came out to this area and they only cover people who have medical cards. So if you were working and you don’t have a medical card you have to go to your GP or back to the clinic and pay for your dressings...There’s no standard across the whole country. It depends on where you live and who the boss is. It’s, there’s a lot more than carer stress going on when people go into a nursing home…it depends on where you live…the other bit is if you shout really loud you get it. That’s the other problem in this country. There’s no priority of need…The people who continually ring and who go on the radio and complain, they get it tomorrow. But the people who actually sit there on the waiting list, sit on the waiting list. Em and that’s not fair either. That’s the way it works. The people who shout loudest, loudest, loudest. Keep ringing, keep complaining, they get moved up and they get seen to a bit earlier.” (Healthcare professional 8)

Once a particular phenomenon was identified codes were merged and themes identified. An example of how the theme ‘insufficient and inequitable community services’ emerged can be seen from the text box above. Here the participant spoke of her experiences of how service availability can vary depending on where a care recipient lives and how much the family advocate to access the service. These experiences, from this extract, fell into two codes. Firstly, the substantial variation in the availability of services between even small geographical areas. Secondly, the lack of transparency in relation to factors influencing waiting times to access services. These codes were grouped into the sub-theme ‘inequity in service availability’.
availability’. This sub-theme then formed part of a larger theme which explored how community care services appear to be insufficient and inequitable.
Appendix 7 Further analysis for Chapter 8

1. Review of the path from age to frailty

As age was not found to be significantly related to frailty in the full original model, removal of this path was reviewed. Figure 1 and Figure 2 present the model with and without the path from age to frailty. As can be seen in Figure 2, without this path, age then relates to cognition which then relates to frailty. The fit statistics were slightly lower in the model without the path from age to frailty (AIC: 3032.751 BIC: 3095.888). However, it was decided to keep the path from age to frailty as this was more theoretically meaningful.

2. Community care influencing caregiving hours

Community care influencing caregiving hours was reviewed (Figure 3 below). In this model, carers had nearly 3.5 times higher odds of providing over 21 hours of care a week if their care recipient was receiving community care. As the qualitative study found that receipt of community care was central to the journey to long-term care.
it was decided to continue to analyse models in which caregiving hours influence receipt of community care.

3. Re-examining the influence of caregiving hours in the model

The influence of caregiving hours was re-examined. Firstly, looking at the direct effect of cognition and frailty on caregiving hours. In this case, caregiving hours would then influence receipt of community care (Figure 4). Should community care influence caregiving hours, the direct effect of caregiving hours on stress and institutional care utilisation was reviewed (Figure 5). As displayed in Figure 4, cognition and frailty did not have a significant direct effect on caregiving hours. Further, caregiving hours did not have a significant direct effect on stress nor on institutional care utilisation (Figure 5). Caregiving hours is the number hours a carer has provided in help to a care recipient in the last month. This is a self-report variable and subject to recall bias. It was included in the model as it is included in the Luppa et al. model as a measure of intensity of caregiving (22). However, it was not found to be related to cognition or frailty, nor to stress or institutional care utilisation. Therefore it was decided to remove this variable as it is not adding much meaning to the model.
4. Frailty and cognition on institutional care utilisation

In the Pearlin et al. and Luppa et al. models ‘primary stressors’ have a direct effect on institutional care use (22, 27). Therefore the direct effect of frailty and cognition on institutional care use was examined. Firstly, in a model in which stress has a direct effect on institutional care use, then in a model in which institutional care use has a direct effect on stress (Figure 6 and Figure 7). As presented in Figure 6, in the model in which stress has a direct effect on institutional care use, neither frailty nor cognition have a significant direct effect on institutional care use. However, in the model in which institutional care use has a direct effect on stress (Figure 7), frailty has a significant direct effect on institutional care use. A recipient had a 61% increased odds of institutional care use per standard deviation increase in frailty (OR 1.61; 95%CIs: 1.51-2.26; p<.01).
Figure 6. Examining the direct effect of cognition and frailty in stress to institutional care utilisation model
(Notes: AIC: 2810.665 BIC: 2870.48. *p<0.05, **p<0.01, ***p<0.001)

Figure 7. Examining the direct effect of cognition and frailty in institutional care utilisation to stress model
(Notes: AIC: 2851.721 BIC: 2911.535. *p<0.05, **p<0.01, ***p<0.001)
5. Examining if coping mediates the effect of stress on institutional care utilisation

According to the theoretical models, coping may mediate the effect of stress on institutional care utilisation (22, 27). There is no direct measure of coping in TILDA. However, there is a question on coping included as part of the Aging Perceptions Questionnaire. Respondents are asked to agree to disagree with the statement ‘as I get older I do not cope as well with problems that arise’. This variable was used as a proxy measure of coping to see if difficulty coping had any direct effect on institutional care utilisation. The variable was recoded to indicate those reporting a difficulty coping compared to those with that did not.

As presented in Figure 8, stress had a significant direct effect on difficulty coping. A carer had nearly three times higher odds of reporting a difficulty coping if they were more stressed (OR: 2.89; 95% CIs: 1.91-4.37). However, difficulty coping did not have a significant direct effect on institutional care use. According to both the Baron and Kenny and Zhao definitions of mediation, these findings suggest that for this sample of carers, coping does not mediate the effect of stress on institutional care utilisation (287, 405). However, as this is a proxy measure of coping it would not be possible to conclude from these findings that coping does not mediate the effect of stress on institutional care use.

Figure 8. Coping after stress
(Notes: AIC: 2970.527 BIC: 3040.31. *p<0.05, **p<0.01, ***p<0.001)

6. Examining if community care mediates the effect of stress on institutional care utilisation

According to the Luppa et al. model, the path between community care and stress is bidirectional (22). This means stress can both mediate the effect of community care on institutional care use and community care can mediate the effect of stress on institutional care use. Therefore, the analysis examined if community care mediates the effect of stress on institutional care use. The direct effect of stress on institutional care use was first tested without community care in the model. In this model, stress appears to have a strong direct effect on institutional care use (OR: 1.56; 95% CIs: 1.12-2.16; p<0.05). However, when community care was then added
to the model this effect reduces (OR: 1.48; 95% CIs: 1.05-2.06; \( p < 0.05 \)) (Figure 9). According to the Baron and Kenny test for mediation, the path between the independent variable (in this case stress) and the presumed mediator (in this case community care) has to be significant (405). However, as displayed in Figure 9, the path between stress and community care was not found to be significant. Furthermore, according to Zhao et al. typology of mediation the indirect effect has to be significant to qualify mediation (287). However, as presented in Table 1 the indirect effect of community care in institutional care use was not found to be significant. This suggests that community care does not mediate the effect of stress on institutional care use.

![Figure 9. Community care as a mediator (AIC: 2754.854 BIC: 2814.668) *p<0.05, **p<0.01, ***p<0.001](image)

### Table 1 Direct effect of stress and indirect effects of community care

<table>
<thead>
<tr>
<th>Effect of Stress and Community Care</th>
<th>Coefficient</th>
<th>95% CI</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct effect of stress on institutional care utilisation without community care in model</td>
<td>0.44</td>
<td>0.12 - 0.77</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Direct effect of stress on institutional care utilisation with community care in model</td>
<td>0.39</td>
<td>0.05 - 0.72</td>
<td>&lt;0.05</td>
</tr>
<tr>
<td>Indirect effect of community care</td>
<td>0.30</td>
<td>-0.09 - 0.69</td>
<td>0.131</td>
</tr>
</tbody>
</table>

### 7. Examination of institutional care and community care use as a mediators on stress

As part of examining stress as an outcome of the journey to long-term care, whether institutional care use acts as a mediator in this process was also examined. As cognition was not found to be associated with stress, cognition was removed from the model. The direct effect of receipt of community care on stress was examined without institutional care use in the model. This was then compared to the model with institutional care use included (Figure 10). As presented in Table 2, receipt of community care continued to have a significant direct effect on stress, though slightly reduced, when institutional care use was included in the model. However the indirect effect of institutional care use was not found to be significant, suggesting institutional care use does not act as a mediator on the effect of receipt.
of community care on the level of stress experienced. Institutional care use was also not found to modify the effect of community care use on stress.

Whether community care use acts as a mediator or moderator of the effect of institutional care use on stress was also examined. As presented in Table 2, institutional care use continued to have a significant, though slightly reduced, effect on stress when community care was included in the model. However, the indirect effect was not found to be significant. The extent that receipt of community care modifies the effect of institutional care use on stress as also examined. However the results suggest that receipt of community care neither mediates nor moderates the effect of institutional care use on stress.

Figure 10. Institutional care use as a mediator (AIC:1542.872 BIC: 1582.748)
*p<0.05, **p<0.01, ***p<0.001

Table 2 Institutional care use and receipt of community care as mediators on stress

<table>
<thead>
<tr>
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<tr>
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<td>0.02-0.73</td>
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<td>Indirect effect through institutional care use</td>
<td>0.13</td>
<td>-0.14-0.39</td>
<td>0.353</td>
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<td>Effect of institutional care use as a moderator of stress</td>
<td>-0.26</td>
<td>-0.96-0.43</td>
<td>0.454</td>
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</table>

<table>
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<th>Coeff.</th>
<th>C.I. (95%)</th>
<th>P-Value</th>
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<tr>
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<td>0.19-0.75</td>
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<td>0.396</td>
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<td>Effect of community care as a moderator of stress</td>
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<td>-0.96-0.43</td>
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