

# RESPITE SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR CARERS: PERSPECTIVES OF KEY STAKEHOLDERS

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# DECLARATION

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# Table of Contents

<b>Declaration .....</b>	<b>iii</b>
<b>List of Tables.....</b>	<b>x</b>
<b>List of Figures .....</b>	<b>xi</b>
<b>Acknowledgements .....</b>	<b>xii</b>
<b>Thesis Abstract .....</b>	<b>xiii</b>
<b>1 General Introduction.....</b>	<b>1</b>
1.1 Chapter Introduction .....	2
1.2 Characterising Dementia.....	3
1.3 Dementia Causes, Prevalence and Incidence.....	5
1.4 The Cost Implications of Dementia .....	7
1.5 The Role of Informal Carers .....	8
1.6 ‘Respite’ and Respite Services .....	10
1.7 The Use of Respite Services .....	12
1.8 The Effectiveness of Respite Services .....	13
1.8.1 Systematic Reviews of Effectiveness .....	13
1.8.2 Recent Effectiveness Studies.....	16
1.9 International and National Dementia Care Policy .....	19
1.10 The Significance of this Research .....	21
1.11 Thesis Aim and Objectives .....	22
1.12 Thesis Structure .....	23
<b>2 Methodological Approach.....</b>	<b>26</b>
2.1 Chapter Introduction .....	27
2.2 Theoretical Underpinnings .....	27
2.2.1 Person-Centred Care Theory .....	27
2.2.2 Critical Appraisals of Person-Centred Care Theory.....	29
2.3 Philosophical Underpinnings .....	33
2.3.1 The Paradigm Wars .....	33
2.3.2 Pragmatism .....	34
2.4 The Qualitative Approach.....	35
2.5 Qualitative Interviews: People with Dementia .....	37
2.6 Reflexivity .....	41
2.7 Ethical Considerations .....	43
2.8 Chapter Conclusion.....	45

<b>3</b>	<b>Defining ‘respite’ in dementia: A systematic review and evolutionary concept analysis .....</b>	<b>48</b>
3.1	Abstract.....	49
3.2	Chapter Introduction .....	50
3.3	Background.....	50
3.4	Methods .....	51
3.4.1	Search Strategy .....	52
3.4.2	Search Terms .....	52
3.4.3	Study Selection.....	52
3.4.4	Data Extraction and Analysis .....	55
3.5	Results.....	55
3.5.1	Surrogate Terms and Related Concepts .....	55
3.5.2	Attributes .....	57
3.5.3	Antecedents .....	58
3.5.4	Consequences .....	66
3.5.5	Concept Definition .....	67
3.6	Discussion.....	68
3.6.1	‘Respite’ in Other Related Contexts.....	68
3.6.2	‘Respite’ and Person-Centred Care: Irreconcilable Concepts? .....	70
3.7	Chapter Conclusion.....	71
<b>4</b>	<b>A qualitative systematic review and meta-ethnography of stakeholders’ experiences of respite services for people with dementia.....</b>	<b>75</b>
4.1	Abstract.....	76
4.2	Chapter Introduction .....	77
4.3	Background.....	77
4.4	Methods .....	78
4.4.1	Search Strategy .....	78
4.4.2	Search Terms .....	79
4.4.3	Data Collection and Quality Appraisal.....	79
4.4.4	Data Analysis and Synthesis .....	80
4.5	Results.....	82
4.5.1	Characteristics of Included Studies .....	82
4.5.2	Quality Assessment .....	82
4.5.3	Translation.....	83
4.5.4	Synthesis.....	97

4.6	Discussion.....	99
4.6.1	Developing Respite Services: Implementing Person-Centred Care....	99
4.6.2	‘Respite’ Service Development – What’s in a Name? .....	100
4.6.3	Strengths and Limitations.....	101
4.7	Chapter Conclusion.....	102
<b>5</b>	<b>Perspectives on accessing respite services for dementia in Ireland: A qualitative study with multiple key stakeholders .....</b>	<b>105</b>
5.1	Abstract.....	106
5.2	Chapter Introduction .....	107
5.3	Background.....	107
5.4	Research Design and Methods.....	108
5.4.1	Recruitment/Sampling.....	108
5.4.2	Data Collection.....	109
5.4.3	Interviewing Approach.....	110
5.4.4	Data Management & Analysis.....	110
5.4.5	Ethical Approval.....	112
5.5	Findings .....	113
5.5.1	Service Acceptability.....	114
5.5.2	Navigational Knowledge and Skills .....	116
5.5.3	Constructing and Adjudicating Respite Need .....	117
5.6	Discussion.....	119
5.6.1	Strengths and Limitations.....	124
5.7	Chapter Conclusion.....	125
<b>6</b>	<b>Multiple stakeholder perspectives on respite service provision for people with dementia in Ireland: A Qualitative Study .....</b>	<b>126</b>
6.1	Abstract.....	127
6.2	Chapter Introduction .....	128
6.3	Background.....	128
6.4	Methods .....	129
6.4.1	Study Design .....	129
6.4.2	Sampling, Recruitment & Data Collection.....	129
6.5	Results.....	130
6.5.1	Phases of Transition .....	130
6.5.2	Person-Centred Respite Care.....	133
6.5.3	Reforming ‘Respite’ .....	136

6.6	Discussion.....	139
6.6.1	Strengths and Limitations.....	143
6.7	Chapter Conclusion.....	144
<b>7</b>	<b>Perspectives of people with dementia on respite and day services in Ireland: A qualitative interview study.....</b>	<b>147</b>
7.1	Abstract.....	148
7.2	Chapter Introduction .....	149
7.3	Background.....	149
7.4	Methods .....	150
7.4.1	Study Design .....	150
7.4.2	Recruitment & Sampling.....	151
7.4.3	Data Collection.....	152
7.4.4	Approach to Interviewing.....	153
7.4.5	Data Management & Analysis.....	153
7.4.6	Ethical Approval.....	154
7.5	Findings .....	155
7.5.1	Acceptability of Service Characteristics .....	155
7.5.2	Meaningful Activity .....	157
7.5.3	Personhood .....	159
7.5.4	Narrative Citizenship.....	160
7.6	Discussion.....	162
7.6.1	Strengths and Limitations.....	168
7.7	Chapter Conclusion.....	169
<b>8</b>	<b>General Discussion .....</b>	<b>170</b>
8.1	Review of Main Findings .....	171
8.2	Mobilising Service Reform.....	177
8.3	Practice Implications.....	187
8.4	Policy Implications .....	188
8.5	Contributions to the Literature.....	190
8.6	Limitations and Challenges .....	192
8.7	Research Translation and Impact.....	197
8.8	Thesis Conclusions .....	199
	<b>References .....</b>	<b>201</b>
	<b>Appendices .....</b>	<b>230</b>
	Appendix A: Kitwood's five categories of human psychosocial needs .....	231



Appendix B: ‘Malignant social psychology’ as outlined by Kitwood (1997).....	232
Appendix C: ‘Positive person work’ as outlined by Kitwood (1997) .....	233
Appendix D: The ENTREQ reporting guidelines (Chapter 4) .....	234
Appendix E: Characteristics of included studies (Chapter 4) .....	237
Appendix F: Third-order interpretations (Chapter 4) .....	244
Appendix G: The COREQ reporting guidelines .....	247
Appendix H: Institutional ethical approval .....	251
Appendix I: Study information leaflet.....	252
Appendix J: Visual informed consent for people with dementia .....	253
Appendix K: Written informed consent for people with dementia .....	260
Appendix L: Informed consent for family/informal carers .....	263
Appendix M: Informed consent for providers, policy-makers/academics .....	265
Appendix N: Interview schedule for people with dementia.....	267
Appendix O: Interview schedule for family/informal carers .....	268
Appendix P: Interview schedule for providers, policy-makers/academics .....	269
Appendix Q: Policy brief.....	271

# LIST OF TABLES

Table 2.1 The dominant research paradigms and their characteristics.....	34
Table 2.2 Interview excerpt.....	38
Table 3.1 Key questions to ask during core analysis phase .....	51
Table 3.2 Inclusion and exclusion criteria guiding the systematic search .....	53
Table 3.3 Surrogate terms and concepts related to respite .....	56
Table 4.1 Inclusion and exclusion criteria guiding study selection.....	78
Table 4.2 Key steps involved in conducting the data synthesis .....	81
Table 4.3 Quality assessment of the included studies .....	85
Table 5.1 Examples of initial and final codes .....	112
Table 5.2 Characteristics of the participants in each stakeholder group and their experience of using, providing and/or planning respite services .....	113
Table 5.3 Demographic information relating to the people with dementia and their care arrangements .....	114
Table 6.1 Basic interview topics .....	130
Table 7.1 Interviewees' demographic information .....	152
Table 8.1 A model of restorative care for dementia dyads.....	186
Table 8.2. List of oral presentations .....	197
Table 8.3. List of poster presentations.....	198

# LIST OF FIGURES

Figure 3.1 Flow chart detailing the study selection process..... 54

Figure 3.2 The role of health and social care services in facilitating respite as an  
outcome ..... 67

Figure 4.1 PRISMA flow chart of study selection process ..... 83

Figure 4.2 Conceptual model of the synthesized stakeholders’ perspectives on respite  
service development and actions that would facilitate implementation success ..... 98

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# THESIS ABSTRACT

**Author:** Emma O' Shea

**Thesis Title:** Respite Services for People with Dementia and their Carers: Perspectives of Key Stakeholders

**Introduction:** Respite services are intended to provide a temporary break in caregiving for carers. The international evidence for the effectiveness and acceptability of respite services is mixed in relation to dementia. Non-carer stakeholders have been under-represented in the existing literature, especially people with dementia. This thesis explores the perspectives of multiple stakeholders on respite services for dementia, with a view to informing service development in the Irish context.

**Methods:** The overarching approach is pragmatic, qualitative and guided by Kitwood's theory of 'person-centred care'. Firstly, a concept analysis of 'respite' was conducted. Secondly, a qualitative systematic literature review was undertaken, synthesizing key stakeholders' perspectives on respite services. Finally, semi-structured interviews were conducted with multiple stakeholders, including carers/people with dementia (n=15) and respite service providers/policy-makers/academics (n=20) regarding their perspectives on respite services in Ireland.

**Findings:** The term 'respite' encompasses only the carer's experience and is discordant with the principles of person-centred care. Negotiating timely access to respite services is challenging, due to under/inequitable provision, poor sign-posting, and the ambiguous legitimacy of respite needs in a biomedical-oriented health system. People with dementia sometimes experience malignant social psychologies which diminish personhood. This is partially due to deficit-based constructions of dementia and the task-focused care approach in respite settings. Many stakeholders advocate a move towards a social model of respite, with a 1) homecare orientation and 2) the capacity to support personhood for people with dementia, along with carer support.

**Conclusions:** 'Restorative care' is presented as alternative nomenclature to 'respite', to signify an aim of restoring psychosocial wellbeing for dyads. Collaborative partnership across government departments is necessary to actualise a paradigm shift towards a social model of provision. Staff require education focused on 1) identifying and addressing psychosocial needs for dyads, and 2) supporting personhood in people with dementia. Strengths, limitations and implications are discussed.



# **1 GENERAL INTRODUCTION**

## **1.1 Chapter Introduction**

The studies presented in this thesis have been conducted to better understand key stakeholders' experiences of respite services for people with dementia and their carers, and their perspectives on potential service development. This first chapter is an introduction to this research topic, setting this thesis in the context of existing literature. It hones in on the following key issues:

- 'Dementia', what it is and how it is characterised;
- The causes, prevalence and incidence of dementia;
- The cost of dementia care;
- The role and experience of family/informal carers in supporting people with dementia;
- The nature and characteristics of respite services;
- Critical issues relating to respite service use and provision, e.g. availability, access, and service acceptability, uptake and effectiveness;
- International and national dementia care policy.

The significance of the research is also presented, followed by a statement of the aim and objectives, as well as a summary of the subsequent chapters contained in this thesis.

This research was made possible by funding and education provided through the Health Research Board's Structured Population Health and Health Services Research (SPHeRE) PhD programme (grant number: SPHeRE/2013/1). The first year of this four year programme was taught and included six modules focused on health research in a broad sense (e.g. Health Economics, Research Methods, Perspectives on Population Health and Health Service Research, Health Informatics and Statistics, Health Systems, Policy and Management, Protocol Development and Systematic Reviewing). While this structured PhD programme was not specifically focused on dementia research, I was able to tailor my learning to my chosen area, through assignments, funding to attend external specialist dementia workshops/masterclasses,



and through a national (University College Cork) and an international placement (University of Bangor) in dementia research centres. Additionally, SPHeRE funded my attendance at national and international gerontology and dementia conferences.

I initially chose the topic area for this PhD based on my experience working as an Assistant Psychologist, across two separate dementia services. It was clear from my conversations with carers of people with dementia, that they felt an absence of accessible and acceptable supports, especially respite services. After in-depth discussion with my supervisors and an initial review of the literature, I identified a number of significant knowledge gaps in relation to respite service access and provision, across stakeholder perspectives. This research endeavoured to address these gaps, to better understand areas for respite service development in Ireland.

## **1.2 Characterising Dementia**

Dementia has been characterised from both biomedical and biopsychosocial perspectives. These perspectives have disparate effects in terms of how they influence the planning and delivery of dementia care, and the experience of dementia care for people with dementia and their carers.

Firstly, in relation to the biomedical construction, dementia is often described as an umbrella term for a range of neurodegenerative disorders, which have diverse causes, and many overlapping clinical symptoms. These disorders lead to progressive cognitive decline in relation to memory/recall, increasing levels of confusion and disorientation, impaired executive functioning, personality changes, and gradual loss of speech and language. As the condition progresses, a decline in functional ability also occurs, and many people will experience behavioural and psychological symptoms (agitation, aggression, psychosis, apathy, anxiety, depression etc.) over the course of the condition. Such symptoms tend to occur when an individual with dementia can no longer communicate his/her needs to those around them and/or the person becomes distressed. Dementia can have a particularly unpredictable disease trajectory, compared to other conditions such as cancer, and this can complicate prognostication and planning. However, for clinical purposes dementia is sometimes categorised into three stages (i.e. ‘mild’, ‘moderate’ or ‘advanced’), which serve as approximate markers of disease progression, based on symptom severity.

The term ‘dementia’ comes from the Latin ‘de’ (out of) and ‘mens’ (mind). In recent years there has been a question around whether the term ‘dementia’ has stigmatising or pejorative connotations. The Diagnostic and Statistical Manual of Mental Disorders (DSM) V (American Psychiatric Association, 2013) now advocates the nomenclature, ‘major neurocognitive disorder’, followed by ‘dementia’ in parentheses (Sachdev et al., 2014). While I recognise the position that dementia may be considered a potentially stigmatising term by some, for the purposes of clarity in this thesis, I will continue to use the conventional diagnostic terminology of ‘dementia’. The DSM-V diagnostic criteria for dementia indicate that:

- 1) there must be evidence of significant decline from a previous level of performance, in one or more cognitive domains, based on subjective informant and/or self-reported concerns, as well as more objective evidence of impaired cognition (e.g. from standardised neuropsychological testing),
- 2) there is a significant negative effect of the cognitive deficit on the person’s functional ability and
- 3) conditions, such as delirium and other mental disorders (e.g. schizophrenia, major depressive disorder) must be ruled out before a dementia diagnosis is assigned (American Psychiatric Association, 2013).

The above characterisation of dementia is clearly grounded in a biomedical frame of reference, which is helpful for diagnostic purposes and for facilitating research into prevention and cure. However, dementia has also been characterised from a psychosocial perspective. This perspective developed from the pioneering work of Tom Kitwood (1997). According to Kitwood, the symptoms associated with dementia cannot be explained entirely by the neuropathology of the dementia condition. He argues that the experiences of the person with dementia, and their interactions with their environment and the people around them, influence their experience, cognition, and thus their behavioural presentation. In this way, the biomedical perspective, on its own, is too limiting when it comes to informing the interpersonal aspects of dementia care delivery, which is central to the topic at hand. For the purposes of this thesis, I acknowledge the utility and necessity of both of these perspectives on dementia, and will draw upon them in different ways as appropriate to the context, in line with a more holistic, biopsychosocial perspective.

### 1.3 Dementia Causes, Prevalence and Incidence

There are many types of dementia, including, but not limited to, vascular dementia, dementia with Lewy bodies, mixed dementia, frontotemporal dementia, parkinsonian dementia and Alzheimer's disease. Alzheimer's disease has been described as the most common cause and is said to account for 60-80% of all dementia cases (Alzheimer's Association, 2018). However, a 2019 paper published in *Brain*, by Nelson et al. (2019) has identified a new cause of dementia, 'limbic-predominant age-related TDP-43 Encephalopathy' (LATE), which up until now, has typically been mistaken for AD. The authors state that up to one-third of Alzheimer's diagnoses in older adults may actually be LATE. The risk factors for dementia include age, female sex, family history, diabetes, midlife hypertension, mid-life obesity, smoking, depression, hyperlipidaemia, low educational attainment and physical inactivity (Barnes and Yaffe, 2011; Norton et al., 2014; van der Flier and Scheltens, 2005; Baumgart et al., 2015; Deckers et al., 2015). While age is the greatest risk factor, it should be noted that dementia is not intrinsic to the ageing process (Livingston et al., 2017).

Regarding dementia prevalence (i.e. the proportion of the population that has dementia in a given time period), Prince et al. (2015) determined that there are approximately 46 million people worldwide living with dementia. They predict that this will rise to 131.5 million by the year 2050. These estimates are based on the assumption that the age-specific prevalence will remain stable over time, and that population ageing will be the main driver of the projected increases. These authors also report that the number of people with dementia is set to rise even more sharply in low and middle-income countries than in Western countries (Europe and the Americas). In 2015, 58% of all people with dementia were living in low and middle income countries, and this is set to rise to 63% by 2030 and 68% by the year 2050. To date, there have been no epidemiological studies conducted in Ireland to give population-based estimates of the prevalence of dementia. However, estimates of the prevalence of dementia have been calculated using the 2016 population census data, to which the EuroCoDe and EURODEM prevalence rates were applied (Shea et al., 2017). These estimates indicate that there are approximately 55,000 people with dementia in Ireland. In line with trends in other western high-income countries, this is expected to increase by 3.6% annually, such that by 2036, the number of people

with dementia will have doubled, and by 2046, it will have trebled, to approximately 158,000.

While the prevalence of dementia is on the rise, there is a growing body of evidence indicating that the incidence of dementia within certain age categories has been falling in recent decades, in high-income countries (Prince et al., 2016; Matthews et al., 2016; Satizabal et al., 2016; Roehr et al., 2018; Wu et al., 2017). Dementia incidence refers to the rate of new cases diagnosed in a given period of time. In the UK, Matthews et al. (2016) reported a drop of 20% in the incidence of age-specific dementia in those aged 65 or older, across two decades, up to 2011. However, Prince et al. (2016) in a review of the literature on dementia incidence, warned that there are methodological limitations to the current body of evidence, and the heterogeneity across study designs means that we should not attempt to draw definitive conclusions about incidence trends. They indicate that further research, in the form of nationally representative population cohort surveys, must be conducted. Such multiple wave surveys must track prevalence, incidence and mortality over time, in defined populations, and they must have consistent designs, for cross-study comparative interpretations of trends. Prince et al. (2016) also note that where change trends are found, researchers must consider these changes statistically in light of any compositional changes in the demographics of the population (e.g. based on birth and mortality rates etc.) and any changes in risk factor exposure (e.g. obesity, education etc.).

Considering variations in risk exposure is particularly important in light of the Lancet paper by Norton et al. (2014) which estimates that approximately one-third of Alzheimer's disease cases worldwide might be attributable to potentially modifiable risk factors (including educational attainment, diabetes, midlife hypertension, midlife obesity, smoking, depression and physical activity). In conclusion, Prince et al. (2016) state that the best available evidence indicates that the age-specific prevalence of dementia is unlikely to decrease, even if the incidence of dementia does, due to population ageing. Therefore, effective public health action and the development of capacity in health and social care services must continue to be seen as urgent priorities globally.

## **1.4 The Cost Implications of Dementia**

Given the forecasted upward trends in dementia prevalence, it has been noted that dementia may be the greatest challenge globally for health and social care financing, planning and provision in the 21<sup>st</sup> century (Livingston et al., 2017). Dementia is often indicated as a costly condition in terms of health and social care provision and has significant formal and informal care costs associated with it. Global estimates in a recent analysis indicate that dementia care cost US\$ 818 billion in 2015, representing an increase of 35% since 2010 (Wimo et al., 2017).

In Ireland, dementia is estimated to cost approximately €1.69 billion annually (Connolly et al., 2014). The evidence suggests that the cost of care increases as dementia progresses, which is largely attributable to the more frequent use of formal health and social care services, and the need for admission to long-stay residential care in the later stages (Jönsson et al., 2006). This is reflective of the situation in Ireland, where 43% of the cost of dementia is attributable to residential care (Connolly et al., 2014). The Irish data also reveals that almost half (48%) of the cost of dementia is attributable to the opportunity cost of informal care provided by family and friends in the community, highlighting the extent of our reliance on informal carers in Ireland. This is in line with findings by Reed et al. (2017) and Farré et al. (2016), which indicate that the opportunity cost of informal/family caring is the main contributor to the societal cost of dementia.

It is likely that the provision of the appropriate supports for carers of community-dwelling people with dementia would have the potential to reduce these societal costs significantly. The results of a recent Irish study by Carter et al. (2019) looked at resource utilization regarding formal, informal and private care, in order to analyse the cost of care for people living at home, but on the boundary or margins of long-term residential care. The findings indicate that the average weekly cost of community-based care (including intensive homecare packages), funded through public expenditure, is cheaper than residential care alternatives, especially public long-stay residential care (€872 versus €1526 per week). Including housing and personal consumption costs in this analysis raised the cost of community-based care, but it remained less expensive than residential care. However, the authors note that family carers provide the bulk of informal care, and that when the opportunity cost associated with informal care is considered (e.g. loss of family carers from the

workforce), this raises the average cost of community-based care by €593 per week. The authors indicate that this differential could be seen as the price that people are willing to pay to support homecare over residential care, which is the stated preference of people with dementia, and a prominent policy objective.

In the absence of increased resource allocation to develop service capacity for people with dementia and their carers, it is unclear how the health care system in Ireland will deal with the projected large-scale growth in demand for formal dementia supports for dyads in the coming years.

## **1.5 The Role of Informal Carers**

The best available evidence suggests that over 60% of people with dementia in Ireland are living in the community (Cahill et al., 2012). Given the projected total number of people with dementia noted above (approx. 55,000), this would indicate that about 35,000 people with dementia are community-dwelling at present, most of whom rely on some level of support from family and other informal carers, to avoid institutionalisation. O' Shea et al. (2017) reported that, through extrapolating the findings from the Enhancing Care in Alzheimer's Disease (ECAD) study (Gillespie et al., 2013), there are approximately 60,000 informal carers supporting people with dementia to continue living in the community. There are many positive aspects to the experience of caregiving from carers' perspectives, including feeling a sense of reciprocity, discovering personal strengths, building self-efficacy, developing better coping strategies (e.g. seeking social support), and feeling closer to the person with dementia (Peacock et al., 2010). Carers who experience positive feelings about their caring role tend to experience significantly lower levels of depression and 'burden' and report greater self-rated health (Cohen et al., 2002).

However, caring for a person with dementia can also be highly challenging, particularly as the condition progresses (Reed et al., 2014). Caring for someone with dementia is significantly associated with higher stress levels, poorer quality of life, sleep problems, higher absenteeism at work, and a range of poorer psychological (depression, anxiety) and physical (more comorbid conditions, higher levels of pain) health outcomes, than those observed in non-dementia carers (Pinquart and Sörensen, 2005; Goren et al., 2016). There is a considerable body of work looking at the factors that influence 'burden' and strain in carers of people with dementia.

‘Carer burden’ is often characterised as a construct comprising 1) objective burden, i.e. the practical care of the person with dementia such as supervision and helping with daily tasks, and 2) subjective burden, i.e. the personal strain perceived by the carer (Brodaty et al., 2014). The term ‘burden’ is considered contentious by many however, despite its widespread use, given that it is often used in a way that is stigmatising to people with dementia. It can imply that people with dementia are the burden, as opposed to implying that the situation is burdensome.

The factors that predict carer strain/‘burden’ in the literature include: being a female, spousal and/or live-in carer; having a lack of family support; experiencing additional stressful life events; having poor physical health; poorer dyad relationship quality; lower levels of carer self-esteem; the presence of ‘behavioural and psychological symptoms’; and lower functional ability in the person with dementia (Brodaty and Donkin, 2009; Campbell et al., 2008; Alvira et al., 2015; Kim et al., 2012; Conde-Sala et al., 2014; Pillemer et al., 2018). Furthermore, research by Reed et al. (2014) highlights that the predictors of carer ‘burden’ are different for spousal carers and adult offspring carers. While impaired functional ability was independently associated with greater ‘burden’ in both offspring and spousal carers, offspring ‘burden’ was additionally associated with living with the person, the person living in an urban location, and the person having fallen in the past three months. For spousal carers, female sex, older age, and more years of education were associated with higher levels of ‘burden’.

The finding that the level of strain experienced by carers of people with dementia is high is unsurprising given the levels of unmet support needs reported by carers. Data from a US survey comparing carers of people with dementia (n=208) to carers of older adults without dementia (n=625), indicates that carers of people with dementia report significantly higher levels of unmet service and support needs, across a number of domains (Li, 2012). This is in line with qualitative data indicating that carers of people with dementia experience high levels of unmet need for support, including a break from caregiving (Tatangelo et al., 2018). Importantly, Tatangelo et al. (2018) reported that spousal and offspring carers’ needs tend to differ, in that spousal carers desire time for themselves for socialising and leisure activities, while offspring carers needed a break to tend to other areas of their life they felt they were neglecting as a result of caring for the person with dementia, e.g. caring for their own

young children and attending to their work responsibilities. A scoping review by Morrisby et al. (2018) focusing on the needs of people with dementia and their carers, and the responsiveness of community services to those needs, found gaps in relation to the provision of support, particularly in terms of respite. In line with this, a recent qualitative study indicated that one of the key barriers to sustaining the caregiving role, and facilitating ‘age-in-place’, is the absence of formal supports and services to alleviate carer strain (Thoma-Lürken et al., 2018).

Institutionalisation is not considered a desirable option where it is not absolutely necessary, for people who prefer to live in the community, given that quality of life is often diminished among people with dementia in long-stay residential care (Barca et al., 2011; Olsen et al., 2016). Institutionalisation is also associated with a two-fold increase in mortality risk for people with dementia, even after controlling for health status on admission (Aneshensel et al., 2000). On the other hand, delaying institutionalisation is associated with a reduced risk of mortality in a sample of 258 people with Alzheimer’s disease (McClendon et al., 2006). Along with the evidence of poorer outcomes for people with dementia upon institutionalisation, it is also the stated preference of many older adults to remain living in the community for as long as possible (Kasper et al., 2018). Meeting carers’ support needs is central to ensuring that the caregiving role is sustainable over time, and that admission to a residential care home for the person with dementia is delayed for as long as possible. This is important because carer ‘burden’ is one of the strongest significant predictors of deciding to place, and actual placement of, people with dementia in long-stay residential care (Vandepitte et al., 2018; Gaugler et al., 2009; Toot et al., 2017; Cepoiu-Martin et al., 2016; Gallagher et al., 2011).

## **1.6 ‘Respite’ and Respite Services**

In light of the evidence on the often highly taxing nature of caregiving, the WHO’s Global Action Plan on the public health response to dementia (WHO, 2017) states that one of the key priority areas must be ‘supporting carers of people with dementia’. One of the most commonly provided formal services for supporting carers are respite services. Respite services are provided under the assumption that they can reduce carer strain and improve the quality of the caregiving relationship,



thereby potentially delaying institutionalisation for the person with dementia (Maayan et al., 2014).

‘Respite’ is commonly defined as the provision of a temporary break in caregiving activities for the carer (Maayan et al., 2014). However, in recent years, there has been growing debate around the meaning and nature of the term ‘respite’ in the literature (Evans, 2013a; Chappell et al., 2001). Specifically, there is much deliberation about what the term ‘respite’ means, what the aims of respite services are, who the clients of respite services are (just the carer, or the person with dementia too), and what the desired outcomes of respite service use should be. This debate is timely given the paradigmatic shift from custodial, towards more community-based, person-centred models of dementia care. It is also timely, given findings, including those from a recent study by Black et al. (2019), which indicate that the majority of the unmet needs of community-dwelling people with dementia (N=646) are non-medical in nature. Similarly, a scoping review by Morrisby et al. (2018) concluded that the most commonly identified unmet needs for people with dementia were associated with meaningful activity and social engagement. The authors of both of these studies note that this points to a lack of functional support and meaningful engagement for people with dementia, and a lack of respite support and psycho-education for carers.

There are numerous models of respite within and across healthcare systems which vary by setting, provider, scheduling, duration, geographical availability, approach to care and cost. In terms of setting, respite is traditionally provided in a residential care home or community hospital setting with a one- or two-week duration; however, day services and in-home domiciliary care services can also constitute respite services; these too can provide a break in caregiving, and can do so on a more frequent and ongoing basis in the community (Maayan et al., 2014). Respite can be scheduled or unscheduled (‘emergency respite’) and can be day time only, or overnight, at different durations. We don’t have national data on the availability of respite services for people with dementia in Ireland. However, in the ‘Creating Excellence in Dementia Care’ report (Cahill et al., 2012), the authors anecdotally reported that the most common forms of respite care for people with dementia and their carers in Ireland are (i) day service (ii) residential and (iii) in-home models. Importantly, however, the authors of this report advise that while in-home models of respite exist

in Ireland, they are mainly only available if they are purchased out-of-pocket by families, through private domiciliary care providers.

In other countries, such as the UK and Australia, respite services models have started to become more diversified. Newer alternative models of respite are marked by greater flexibility and responsiveness. These include host family day/overnight respite, social outings in the community, ‘dementia friends’/‘buddies’ initiatives, intergenerational engagement (in day services or the community), farm-based day services, residential respite in a non-institutional setting (e.g. ‘cottage’ respite) and personalised home care (Shanley, 2006; Ibsen et al., 2018; Gresham et al., 2018; Arksey and Bamford, 2007; Vecchio et al., 2018). In Ireland, GENIO (a non-profit organisation) implemented and evaluated flexible respite models in the home and the community, for 3,299 people with dementia and their carers. A report on the four GENIO projects (2012-2015) which were focused on flexible respite supports, indicated these models had high client acceptability, and yielded a wide range of positive outcomes for people with dementia and carers, particularly in relation to quality of life and well-being (O’ Shea and Monaghan, 2015). However, since the €4.9 million GENIO funding ended, these alternative respite support programmes have severely dwindled, and were never scaled up in Ireland.

## **1.7 The Use of Respite Services**

Despite respite being one of the most common support needs reported by carers of people with dementia, the use of respite services by this group has been relatively low (Neville et al., 2015). In an Australian study by Phillipson et al. (2013), despite reporting an unmet need for respite services, 44% of dementia carers surveyed were not utilising day services and 60% were not using residential respite services. Similarly, in the ‘RightTimePlaceCare’ study which included data from eight European countries, both respite and day services were underused across the countries by people with dementia and carers, despite being widely available (Lethin et al., 2016). In particular, day services were under-used in England, Estonia, Germany, Spain, and Sweden, while residential respite services were especially under-used in Estonia, Sweden, and England. This is in line with the findings of other studies, which also report that formal respite and support services are not being accessed as much as the stated need for them is being expressed (Brodaty et al.,

2005; Phillipson et al., 2013; Robinson et al., 2005). This calls into question factors such as respite service availability, appropriateness, access and acceptability, which are central to subject matter of this thesis.

A literature review by Neville et al. (2015) identified that a lack of knowledge on the part of carers regarding the availability of respite services in their locality, as well as misinformation about respite services, are significant barriers to respite service uptake. The authors also note that some carers were reluctant to acknowledge their own need for a break and/or accept formal support. Finally, the authors reported that there are significant client-service fit issues, which impede respite service use for some carers, e.g. regarding transport provision, the approach to dementia care and the perceived effects of service use on the person with dementia and the carers themselves. Corroborating some of these findings, other authors have reported reasons for the non-use of services including, a lack of knowledge about available services, poor service acceptability, the belief that respite care is not yet necessary, as well as refusal of the person to attend respite services (Brodaty et al., 2005; Phillipson et al., 2014; Stockwell-Smith et al., 2010).

The most recent review of respite service use, by Leocadie et al. (2018) corroborated the above findings. They further indicated that carer characteristics (e.g. being a spousal carer), carer beliefs about caring as a family/spousal ‘duty’, and/or carers perceiving that the change in routine and environment associated with out-of-home respite is detrimental to the person with dementia, impedes respite use. Other barriers include living in a large urban area, being geographically removed from respite services, and lack of respite service flexibility. On the other hand, Leocadie et al. (2018) reported that respite service use is more likely when there is good client-service communication and perceived client-service fit, and when carers perceive that service use is of benefit to the person with dementia.

## **1.8 The Effectiveness of Respite Services**

### ***1.8.1 Systematic Reviews of Effectiveness***

The issue of effectiveness has been addressed in two quantitative systematic reviews, both of which have indicated that the evidence is mixed across service models, and that further research is required to draw definitive conclusions (Maayan et al., 2014;

Vandepitte et al., 2016). Maayan et al. (2014) updated a Cochrane review of the evidence on the effectiveness of respite for people with dementia and their carers. Their search returned just four randomised control trials (N=753), where the respite intervention was compared to a control group, with the exception of one study, which compared respite to polarity therapy (a form of touch therapy that applies pressure on 'energy points' to encourage physical relaxation). Non-randomised designs, studies not exclusively focused on dementia, and studies without a control group were excluded. Due to high levels of heterogeneity across the intervention characteristics (e.g. hours of care received), duration of follow-up, the outcomes measured and control group composition, pooling of the data was not feasible. Furthermore, the authors note that there were substantial methodological limitations (e.g. small sample size, short duration, lack of participant and personnel blinding, lack of allocation concealment, and lack of outcome assessment blinding), leading them to deem the studies 'very low quality'. The three trials that compared respite care to no respite care found no evidence of any benefit of respite care for people with dementia or for their carers on any outcome measure, including institutionalisation and carer 'burden'. The study comparing respite care to polarity therapy found that polarity therapy decreased carer perceived stress, but respite care did not. Furthermore, there was no statistically significant difference between polarity therapy and respite care for other measures of psychological health and other carer outcomes.

It is worth noting that only one study reported on outcomes for people with dementia (Lawton et al., 1989). The authors conclude that it is not possible to say, based on the existing evidence whether respite is effective or not. The lack of significant findings regarding respite effectiveness could be because respite does not improve outcomes, or could be because the studies were low quality and under-powered to detect significant effects, that exist in reality. Furthermore, it is worth noting that these randomised control trials are dated and likely not reflective of current practice; the largest study by Lawton et al. (1989, N=632), which comprised the majority of the participants included in this analysis, was conducted two decades ago.

More recently, Vandepitte et al. (2016) conducted a systematic review of studies focusing on the effects of respite for people with dementia and their carers.

However, unlike the review by Maayan et al. (2014), both randomised and non-randomised designs were included in the analysis. The decision to broaden the scope of the review to include non-randomised designs was sensible, given that randomisation to respite conditions, while possible, is highly infeasible, and in some cases, unethical (Zarit et al., 2017). Therefore, Vandepitte et al. (2016) included randomized controlled trials, quasi-experimental studies, pre-test post-test studies without a control group, and cohort studies focused on respite for community-dwelling people with dementia in their review. Studies were only included if they assessed outcomes for carers, care recipients, and/or healthcare resource use.

Seventeen papers were included in the final review. In relation to study quality, the authors report that five studies evidenced ‘strong’ methodological quality, nine were of ‘medium’ quality, and three were of ‘weak’ quality. The results, while mixed, indicate that there are some potential benefits from day service use for carers (reduced ‘burden’ and stress) and people with dementia (reduced behavioural symptoms, improved sleep quality) across some indices, but not on others (e.g. quality of life, wellbeing, cognitive or functional status of the person with dementia). Day service use was also associated with an accelerated time to institutionalisation, which the authors indicate might be due to how service use is typically initiated when the dementia has already progressed significantly. In relation to residential respite, there is no evidence of reduced carer ‘burden’ or psychological distress. In fact, one study reported distress and burden actually significantly *increased* after a period of temporary residential respite (Neville and Byrne, 2008). One study, however, did find that carer sleep quality improved during the residential respite episode, but this was not sustained post-discharge (Lee et al., 2007). For people with dementia, residential respite was found to have a negative effect on sleep quality for the duration of the respite episode; this returned to baseline when the recipient returned home (Lee et al., 2007). These findings indicate that the upheaval and disorientation associated with residential respite may preclude benefits for dyads. However, day services seem to have some potential for improving dyad outcomes. There was not enough evidence on in-home models of respite to draw conclusions regarding its effectiveness. The authors advise that further research is required on home-based models.

### ***1.8.2 Recent Effectiveness Studies***

A number of studies have been published since the systematic review by Vandepitte et al. (2016) was conducted, focusing on the effects of day services, and residential and in-home respite for people with dementia and/or carers. Regarding day services, positive effects have been reported for people with dementia in relation to self-reported stress (Williams et al., 2016), and self-reported quality of life; albeit this was only significant for those with the lowest level of awareness/insight regarding their dementia, and proxy-rated quality of life did not increase (Rokstad et al., 2017a). A study by Logsdon et al. (2016) evaluated participant and carer outcomes of a specialized dementia day services programme (staff ratio 1:4; all staff have dementia training; access to a range of allied health services; specialised activities; dyad involvement in care planning; carer support component). In total, 162 people with dementia attended this programme, while 25 comparison dyads were also recruited, who did not have access to day services in their area. No significant differences were found between the groups at three months. However, at six months, people with dementia in the intervention group evidenced significant reductions in 'depressive behaviour', and carers reported significantly lower levels of distress related to behavioural problems, compared to the control group.

However, in a number of other studies, no significant positive effects of day service use have been found. Williams et al. (2016) reported that no improvements were found in people with dementia in relation to mood or anxiety at one- or three-month follow-up. Rokstad et al. (2018) found that nursing home admission was not only *not* delayed at 24-month follow-up for dementia-specific day service users (compared to non-users), but service users were actually *more* likely to be admitted to a nursing home at follow-up, in line with the findings reported by Vandepitte et al. (2016) above. Rokstad et al. (2018) caution that this finding does not necessarily indicate that day service use accelerates institutionalisation, and note that admission to a nursing home seems to be influenced by a complex mix of personal and functional characteristics in people with dementia and carers. Furthermore, the authors highlight that there were more people with moderate or advanced dementia in the intervention group (23%) than in the comparison group (10%). Therefore, it is likely that the carers of the people in the intervention group may have initiated service use

because they were already experiencing higher levels of psychological stress than carers of people in the non-use group.

The only recent study focusing on the effectiveness of residential respite for people with dementia is by Gresham et al. (2018), which was conducted in Australia. Ninety dyads were recruited to participate in the 'Going to Stay at Home' program, as part of a single arm pre-post study design. While the intervention is designated as residential respite, instead of delivering care in an institutional setting, dyads go to stay in a cottage-style, home-like setting. In this model, there is no prolonged dyad separation (carer sleeps with the person with dementia at night in a bedroom with a private bathroom). There is a programme of interventions and activities for both the person with dementia (e.g. tailored leisure activities, physical exercise, outings, cognitive stimulation, and reminiscence therapy) and the carer (e.g. didactic sessions, small-group discussion, modelling of skills, and role-play) separately during the day, and there are joint social activities for all in the evenings. At 12-month follow-up carer depression and 'burden' were unchanged, however carers' levels of unmet need, and behavioural symptoms in persons with dementia, did decrease significantly. Furthermore, the authors compared the intervention group to a group of people with dementia who had been admitted to routine residential respite care in a care home, and there was a marked reduction in institutionalisation at 12-month follow-up for the intervention group ( $p < 0.001$ ). It is important to note that because the comparison group was recruited retrospectively through an audit process, the authors have no way of knowing if the comparison group members' characteristics are equivalent to those of the intervention group. Therefore, extraneous variables may be influencing the difference in institutionalisation rates between groups. Nonetheless, this study indicates that non-institutional overnight respite in a home-like setting, without prolonged dyad separation, and which is focused on meeting the needs of both members of the dyad, may have the potential to delay institutionalisation. However, further research is needed on alternative models of respite.

Only one study has been conducted to date in relation to in-home respite for people with dementia and carers (Vandepitte et al., 2019). This prospectively investigates the effectiveness of in-home respite ( $n=99$  dyads), compared to 'dementia care as usual' ( $n=99$  dyads [propensity score matching performed]), using a quasi-

experimental design. The intervention was a 24-hour in-home respite care program (called 'Baluchonnage'), which was provided alongside their usual dementia care. The duration of the programme is five days, during which carers were relieved of all care duties, while a trained employee assumed responsibility for the care of the person with dementia. The authors indicate that all daily habits/activities and resource use remained unchanged for the person with dementia in the intervention arm, to promote normalcy and continuity. Regarding the control group, 'care as usual' was defined as the use of any 'medical, psychological, and other health and social services, and other supportive initiatives, such as support groups' available to community-dwelling people with dementia and carers. Both groups had data collected at baseline and at six-month follow-up in relation to their background characteristics (socio-demographics, clinical data, and resource use of the patient). Data were also collected on a range of outcomes measures including carer 'self-perceived burden', 'desire to institutionalise the patient', 'health-related quality of life', and 'behavioural problems in the dementia patients' (in terms of frequency and impact). Follow-up assessments measuring these outcome variables were conducted 14-15 days after the intervention, and at six- and twelve-months. The results indicated that at the two-week follow-up, the intervention group reported a significantly lower desire to institutionalize the person with dementia, lower role strain and a lower burden on social and family life, compared to the control group. At six-month follow-up the intervention group had a significantly lower desire to institutionalise the person with dementia compared to the control group, however no other significant differences between groups were detected at six or 12 months.

There are some limitations of this study on in-home respite (Vandepitte et al., 2019) which indicate the results should be considered with some caution. For example, while the minimum duration of the in-home respite intervention was five days, the maximum number of days that a dyad received the intervention for was 17 days, and intervention duration, which likely would have a significant effect on outcomes, was not controlled for in the statistical analysis. Secondly, the authors did not reach the intended sample size, based on their power calculations and selection-bias risk calculations. They only reached 73% of the intended sample size of 100 dyads in each study arm at six-month follow up. This indicates that the analyses were underpowered and, therefore, at a greater risk of type II error. In this way, it is



possible that this study was not powered to detect significant differences between groups, even if they do exist in reality. Thirdly, as is typical in this area, this study did not consider any outcomes for people with dementia, from the perspectives of people with dementia. Nonetheless, this study was the first of its kind to investigate the effectiveness of in-home respite care for carers of people with dementia using a quasi-experimental design, and the results do indicate that this model may have potential to improve carer outcomes, in the short-term (up to two-weeks post-intervention), and at six-month follow-up.

## **1.9 International and National Dementia Care Policy**

At the World Health Assembly in 2017, the World Health Organisation (WHO, 2017) released the ‘Global Action Plan’, a nine year strategy for guiding the public health response to dementia prevention, management, support and care. Within the plan, there are seven areas that the World health organisation has set out as priority areas for action, grounded in rights-based principles linked to the UN Convention on the Rights of Persons with Disabilities. These priority areas include: (i) dementia as a public health priority; (ii) dementia awareness and friendliness; (iii) dementia risk reduction; (iv) diagnosis, treatment and care; (v) support for dementia carers; (vi) information systems for dementia; and (vii) dementia research and innovation. Many countries internationally have developed their own dementia strategies, and indeed some countries, including Norway, France, Scotland and Australia, have now created successive (i.e. second and third) dementia strategies (O’ Shea et al., 2017a). In these strategies and plans, it is clear that there is a shift globally, at least in terms of policy, towards a human rights-based approach to dementia care (Kelly and Innes, 2013; O’ Shea et al., 2017a). Common themes across dementia strategies internationally include: raising dementia awareness, reducing levels of stigma, establishing and improving support services, assessing dementia prevalence/incidence, improving the quality of dementia care, providing high quality dementia education and training, and addressing issues around availability and access to diagnostic services (Chow et al., 2018).

In Ireland, the National Dementia Strategy was launched in 2014 (Department of Health, 2014). Prior to this strategy, no specific government-backed policy for dementia had been developed in Ireland. However, the issue of shifting towards

community-based models of care, to enable ageing-in-place for older adults more generally, has been a policy aim in Ireland since the 1960s with the publication of *The Care of the Aged* report (Inter-Departmental Committee on the Care of the Aged, 1968). The dementia strategy was originally planned by the Irish government in 2011, but designated as a ‘no cost’ endeavour, in light of the economic austerity at that time. Fortuitously, over €33 million of charitable investment was donated to Ireland from The Atlantic Philanthropies between 2011 and 2016, to fund (i) the development of dementia care services and supports, and (ii) the building of partnerships across the range of key stakeholders in Ireland (Carney and O’Shea, 2018).

The overall primary aim of the Irish National Dementia strategy is “*to improve dementia care so that people with dementia can live well for as long as possible, can ultimately die with comfort and dignity, and can have services and supports delivered in the best way possible*” (p. 8). Priority actions outlined in the strategy include improvements in relation to: (i) dementia awareness and public understanding, (ii) timely diagnosis and intervention, (iii) the provision of integrated services, supports and care for people with dementia and their carers, (iv) training and education, and (v) leadership. In relation to the development of integrated services and supports specifically, the strategy indicates that there should be a commitment to identifying gaps in existing support and service provision. It also specifies that areas for action should be prioritised in terms of unmet need to determine the urgency of service development, or where necessary, service reconfiguration. A second objective in relation to this action area is that the Health Service Executive (HSE) will “consider how best to configure resources currently invested in home care packages and respite care, so as to facilitate people with dementia to continue living in their own homes/communities for as long as possible and to improve the supports available for carers” (p. 15). Finally, the strategy promises that the HSE will “ensure that information on how to access advocacy services, voluntary organisations and other support services is routinely given to people with dementia and their families/ carers” (p. 15).

‘Respite’ is mentioned just four times in the body of the text of the Irish National Dementia Strategy (2014), but there is a clear underlying assumption that ‘respite’ services are effective, and support ‘ageing-in-place’. It is stated in the strategy that

respite has “an important part to play in supporting people with dementia to remain viably and safely in their own homes for longer” (p. 25). However, as outlined above, the scientific evidence does not entirely support the validity of this assumption regarding current service provision for people with dementia; particularly in relation to residential respite service models, which can lead to adverse outcomes for people with dementia. This goes against World Health Organisation (2017) guidance on action plan/strategy development, which indicates that the provision of services should be guided by evidence for their effectiveness. In another mention of ‘respite’ (p. 22), the strategy does somewhat qualify this assumption by indicating that respite services which are “responsive and tailored to the needs of the person with dementia, as well as the carer, can make a vital contribution to achieving the best possible outcomes for all”. However, it is known from the Creating Excellence in Dementia Care report (Cahill et al., 2012), which informed the development of the strategy, that respite services in Ireland are underprovided and “lack the flexibility and specificity to address the fluctuating needs of many people with dementia” (p. 89).

## **1.10 The Significance of this Research**

My goal in undertaking this research is to make an original and valuable contribution to literature and practice on the topic of respite services and their development, in relation to people with dementia and their carers. It is clear, based on the research outlined above, that the issue of adequately and appropriately supporting carers of people with dementia must be prioritised if we are going to be able to address the primary objective of our dementia strategy, i.e. to support ‘ageing-in-place’. This is timely now more than ever, particularly in light of the projected upward trends regarding dementia prevalence, and the evidence which indicates that there are significantly higher levels of unmet support needs in dementia carers, compared to carers of people without dementia. It is also clear, from the international literature, that there are a considerable number of problems with current respite service provision, in relation to availability, access, and service acceptability, which can impede service use, even when dyad support needs are high. Additionally, the quantitative research investigating the effectiveness of respite services shows that while day services sometimes benefit dyads, there is no evidence in terms of client

outcomes to support the provision of residential models of respite in institutional settings.

Given that the majority of the international qualitative research on respite and respite services has been conducted from the perspectives of carers, there are considerable gaps in our knowledge about other stakeholder perspectives (e.g. people with dementia, respite service providers, primary care providers, policymakers, academics) on respite services. There are also significant gaps in knowledge regarding how we can develop respite services in a way that is feasible, sustainable, effective, and importantly, acceptable to prospective clients. While it is clear that there are problems with respite service provision, we do not currently have data from multiple user and provider perspectives, which would enable the development of respite services that are consistent with clients' needs and preferences. Furthermore, we do not know the potential challenges and barriers to actualising such service development. By incorporating perspectives from multiple stakeholder groups, it is possible to speak to clients' experiences, as well as to the system-, organisational- and frontline-level factors that influence respite service provision and development in the context of dementia. Furthermore, it makes it possible to wed these viewpoints together to try to understand a reasonable and feasible path forward, regarding the provision of acceptable and effective respite services.

In Ireland, there is a complete dearth of research on respite services for dementia, even from carers' perspectives. Given the between- and within-country heterogeneity in respite service provision, and the lack of convergence on the concept of 'respite' in the international research, it is important to gain an understanding of the meaning and value of 'respite', and the acceptability of the range of respite services for carers and people with dementia, in the Irish context specifically. This information is critically important to addressing a number of objectives outlined in the Irish National Dementia Strategy (Department of Health, 2014), i.e. to develop the range of carer supports, and to provide formal care and support for people with dementia.

## **1.11 Thesis Aim and Objectives**

The overall aim of this thesis is to gain a rich understanding of i) multiple stakeholders' perspectives on current respite service provision, as it relates to

dementia, and ii) how these services can be developed, in a way that is consistent with the principles of ‘person-centred care’ (see chapter two).

The specific objectives of the thesis are as follows:

1. To explore the concept of ‘respite’ as it relates to dementia, and to consider this concept in the context of person-centred dementia care.
2. To synthesize the international qualitative evidence on the range of key stakeholders’ experiences of respite services and their perspectives on respite service development.
3. To explore key stakeholders’ perspectives on respite service access for people with dementia and their carers in the Irish context.
4. To explore key stakeholders’ perspectives on current respite service provision, with a view to informing policy formulation and service development in the Irish context.
5. To specifically include the views of people with dementia in objectives 3&4.

## **1.12 Thesis Structure**

Each of the five objectives above are addressed in the five research papers that comprise chapters 3-7 (four published, one unpublished). These chapters are preceded by an outline of the over-arching methodological approach, and followed by a general discussion chapter. The structure of the rest of this thesis is summarised below:

**Chapter 2** outlines the methodological approach adopted in this thesis. This chapter looks at the overall theoretical approach employed, as well as the philosophical underpinnings which shaped the qualitative methodology. The final sections of this chapter provide additional detail on reflexivity, the minutiae of the qualitative interviewing process regarding people with dementia and ethical considerations for including people with dementia in qualitative interview research. The methods for each study are outlined individually in the ensuing five research chapters (3-7).

In order to better understand 1) the meaning of ‘respite’ and 2) the experiences of key stakeholders in relation to respite service provision, in the context of dementia, two systematic reviews were conducted:

**Chapter 3** is a concept analysis of ‘respite’, which explores what ‘respite’ means in relation to dementia. The chapter also considers the utility of the term, in the context of the dominant care paradigm, ‘person-centred care’. The published paper comprising this chapter is entitled, “Respite in dementia: An evolutionary concept analysis”.

**Chapter 4** is a qualitative systematic review and meta-ethnography focused on key stakeholders’ experiences of respite services for people with dementia, in the published literature. The published paper comprising this chapter is entitled, “Key stakeholders’ experiences of respite services for people with dementia and their perspectives on respite service development: A qualitative systematic review”.

The findings of the above literature reviews indicated that 1) non-carer perspectives on respite are lacking, especially those of people with dementia, and 2) that there are considerable issues relating to service access, and service and care provision. Furthermore, there is a complete dearth of research on respite for dementia in the Irish context. Therefore, a primary qualitative study was designed and undertaken to explore issues relating to respite service access and provision in Ireland. Multiple key stakeholder groups (N=35) were recruited, including people with dementia. The following chapters relate to the data collected as part of this qualitative study:

**Chapter 5** outlines a primary qualitative study of multiple stakeholder perspectives on respite service access in the Irish context. The published paper comprising this chapter is entitled: “Multiple Stakeholders’ Perspectives on Respite Service Access for People with Dementia and their Carers”.

**Chapter 6** is also based on multiple stakeholders’ perspectives, but focuses specifically on issues relating to current respite service and care provision, in the Irish context, with a view to informing policy and service development. This manuscript is currently unpublished. The working title is “Multiple Stakeholders’

Perspectives on Respite Service Development for Dementia in the Irish context: A Qualitative Study”.

**Chapter 7** hones in on the experiences and perspectives of people with dementia specifically, as they relate to residential respite and day services. This focus was considered important, given the theoretical orientation of this thesis (person-centred care theory), the richness of the data, and the omission of the voices of people with dementia from the existing literature on respite. The published paper comprising this chapter is entitled, “The perspectives of people with dementia on day and respite services: A qualitative interview study”.

Finally, **Chapter 8** contains a review, synthesis and discussion of the main findings of this thesis. The methodological strengths and limitations are considered, as well as the implications of the findings in terms of policy, practice and research. The final conclusions of this thesis are then outlined.

## **2 METHODOLOGICAL APPROACH**



## 2.1 Chapter Introduction

This chapter outlines the overall methodological approach employed for this thesis. The theoretical perspective employed on dementia care practice will be discussed, namely person-centred care. Subsequently, I explain and justify the philosophical position of pragmatism, and discuss this in relation to ontology, epistemology and methodology. The individual methods of each research study in this thesis will not be included in this chapter; they are outlined in the five chapters that follow.

However, the approach taken to meaningfully including people with dementia in the primary qualitative research study is outlined in detail here. Finally, issues relating to reflexivity and ethical considerations are addressed.

## 2.2 Theoretical Underpinnings

### 2.2.1 *Person-Centred Care Theory*

The research presented in this thesis is underpinned by Tom Kitwood's theory of 'person-centred' dementia care, arguably the principal dementia care paradigm of our time. The origins of the term 'person-centred' lie in the works of the prominent psychotherapist Carl Rogers, circa the 1960s. This was picked up in the context of dementia by Kitwood in the 1990s (Kitwood, 1997; Kitwood and Bredin, 1992). Kitwood felt that the prevailing biomedical or 'standard' model of care, which focuses almost exclusively on physical deficit and disease, was failing people with dementia by disregarding their psychosocial needs.

The notion of 'person-centred' care is often used synonymously and interchangeably with the notion of high quality care and/or individualised care (Brooker, 2003; Manthorpe and Samsi, 2016). It can be a difficult concept to grasp because it is abstract and multifaceted and can, therefore, take on different meanings to different people both within and across health and social care settings (Brooker, 2003). At the core of the person-centred dementia care philosophy, according to (Kitwood, 1997, p. 8), is the concept of 'personhood'. He defined personhood as: *'the standing or status that is bestowed upon one human being by others, in the context of relationships and social being. It implies recognition, respect and trust'*.

Using this definition, Kitwood explains how personhood can be supported through respectful and dignity-promoting interpersonal interactions which support the

identity and selfhood of the person. This approach is about getting to know the person, their life story, their personal preferences, any concerns they might have, and their goals, in a way that facilitates the building of trust. In this way, relationships built on authentic personhood-supporting interactions are the bedrock of a person-centred approach to dementia care.

Kitwood (1997) argued that people with dementia in health and social care settings are more likely to have their personhood diminished, than supported. Consequently, he argues, people with dementia sometimes present with behaviours that are a side effect of their interpersonal treatment by staff, and/or the characteristics of the clinical environment in which this occurs. He posited that this is not because staff intentionally undermine personhood, but because they misunderstand the personhood status of people with dementia and lack knowledge about the importance of identifying and meeting their psychosocial needs. He posits that this is largely because the biomedical model of training for healthcare professionals typically has a more insular focus, i.e. detecting and addressing physical symptoms and needs.

Kitwood (1997) outlined five categories of psychosocial needs that humans experience, which when met, contribute to an experience of ‘love’. These needs are: Comfort; Attachment; Inclusion; Occupation and Identity (see appendix A for definitions of these needs). According to Kitwood, when any of these needs go unmet, wellbeing is diminished. He felt these universal human needs often go unmet for people with dementia in health and social care settings.

Another concept that Kitwood introduced was ‘malignant social psychology’. This relates to the specific behaviours of people (e.g. health and social care staff) in response to people with dementia and their needs, which can serve to undermine and damage their personhood and self-esteem. Kitwood was clear on his belief that this treatment is not usually out of malice, but stems from a biomedical construction of dementia which is primarily concerned with deficit, decline and loss, both cognitively and functionally. This type of construction can lead staff to mistakenly assume that the behaviours of people with dementia become less meaningful as the condition progresses. In turn, this influences how staff treat and communicate with people with dementia, and can lead to malignant social psychologies. Kitwood outlined 17 malignant social psychologies in his 1997 work *Dementia Reconsidered* (see appendix B). Kitwood (1997) also outlined 12 types of interpersonal

interactions that can serve to support the personhood of someone with dementia, by meeting their most basic psychosocial and relational needs (see appendix C).

Interactions of this kind, grounded in an acknowledgement of, and genuine respect for, the personhood of people with dementia, form the basis of person-centred care.

Kitwood argued that such 'positive person work' validates personhood, and serves to increase the well-being, self-esteem and social confidence of people with dementia.

### ***2.2.2 Critical Appraisals of Person-Centred Care Theory***

While Kitwood established a relational basis for person-centred care in dementia, which propelled a paradigm shift, it has not been without criticism. Several prominent authors have pointed out that there are limitations to Kitwood's theory. Firstly, a number of authors agree that 'personhood' is somewhat limited in its ability to help staff operationalise the idea of a person-centred care approach in everyday practice (Sabat, 2001; Kelly, 2010; Brooker, 2003). Some argue that the notion of 'selfhood', as outlined by Sabat and Harré (1992) in relation to dementia, is preferable, as a somewhat more germane and less contentious concept. The self, Sabat and Harré argue, has three elements: Self-1, the singular self or 'I'; self-2, physical/mental attributes of a person and their beliefs about those attributes; self-3, the publicly presented persona, which is constructed in collaboration with other people.

As with personhood, 'selfhood' is also considered to be socially constructed, in that it can be reinforced, or damaged, relationally. However, with selfhood, the focus is more specifically on recognising and engaging with different forms of self-expression (e.g. verbal, physical, visual, artistic) in an authentic, empathic way. The crux of this approach is that it asks that we take the 'intentional stance' when it comes to interacting with people with dementia (Sabat and Harré, 1994). The 'intentional stance' is a concept borrowed from the work of the philosopher Daniel Dennett (1987). It refers to the assumption that behaviour is meaning-driven in people with dementia, not inherently pathological or purposeless. This positive positioning of people with dementia as semiotic beings, improves interpersonal relationships, and ultimately serves to reinforce selfhood and improve wellbeing in people with dementia (Sabat and Harré, 1992; Sabat, 2001).

Dawn Brooker (2003) also noted that Kitwood's notion of personhood is difficult for staff to operationalise, and that the necessary emphasis on relationship can get lost in translation. For this reason, Brooker (2003) outlined the VIPS definition of person-centred care, comprised of four key operational components which have a clear relational basis. These are: a value base which assumes the unconditional value of all human lives; an individualised approach which emphasises, recognises and validates the uniqueness of the person; seeking to understand the experience and perspective of the person with dementia; and providing a supportive social environment. Brooker (2003) asserts that these are the necessary components of person-centred dementia care.

Another issue that many academics point out, is that 'personhood' is too narrowly focused on the immediate social environment, and doesn't account for the influence of wider socio-cultural and political factors on dementia care (Bartlett and O'Connor, 2007; Innes, 2009; Baldwin and Capstick, 2007). Closely related to this, is the criticism that 'personhood', as something that is 'bestowed upon' a person with dementia by others, positions people with dementia as passive beings, and overlooks the issue of agency (Higgs and Gilleard, 2016; Baldwin and Capstick, 2007; Kelly, 2010). In response to this, a number of authors began arguing, from a political, human rights perspective, for the added value of the concept of 'citizenship', given that it positions people with dementia as active agents in their own lives and communities, with rights and responsibilities. Crucially, it also considers the influence of macro-level factors on dementia care provision and delivery, in a way that person-centred theory does not (Bartlett and O'Connor, 2007; Kelly and Innes, 2013; Cahill, 2018).

The argument that person-centred care theory positions people with dementia as passive beings and doesn't acknowledge that they have agency, arguably lacks validity. It is, however, an easy argument to make if one is relying solely on the definition of 'personhood' outlined in 'Dementia Reconsidered' (Kitwood, 1997), that personhood is something that is 'bestowed on' people with dementia by other people. I contend that Kitwood was using this framing of personhood as a call to arms for those without dementia, and asking them to take responsibility for their role, interpersonally, in shaping their experiences. When the text of 'Dementia Reconsidered' is examined as a whole, it is clear that person-centred care theory is

not as unaware of the importance of agency as some maintain. Kitwood goes into great detail to explain how personhood can be both damaged and supported, through malignant social psychology and positive person work, respectively. If one looks to the components of malignant social psychology and positive person work, it is clear that Kitwood not only acknowledges the agency of people with dementia, but feels strongly about the issue of supporting the narrative, behavioural and creative agency of people with dementia in everyday dementia care practice (e.g. see the positive person work definitions he outlined in relation to ‘collaboration’, ‘negotiation’, ‘play’, ‘validation’, ‘facilitation’, and ‘giving’, in appendix C). In this way, a thorough reading of Kitwood’s work, beyond the summaries, and the definition of ‘personhood’, challenges the view that he conceived of people with dementia as passive, or without agency. However, the socio-cultural and political arguments that Kitwood’s work did not account for any of the macro-level factors that influence dementia care provision is valid, and will be addressed further below.

Higgs and Gilleard (2016) go even further in their criticism of Kitwood’s use of the term ‘personhood’ and question the utility of this concept in relation to person-centred dementia care. They outline ‘personhood’ as both i) metaphysical identity, and ii) a moral status, and assert that Kitwood’s characterisation of personhood confuses these two philosophical stances, confounding the constitution of personhood with the conditions for its existence. In their view, this allows Kitwood to avoid the hard problem of operationally defining the necessary and sufficient components of personhood, meaning that ‘personhood’, as he defines it, is not falsifiable under the scientific method. They argue that it is not sensible to place “such a confused and confusing concept as personhood at the centre of any set of organisational practices of care” (Higgs and Gilleard, 2016, p. 774).

The argument that Kitwood was ‘confounding’ meta-physical and moral philosophies when it comes to personhood has some validity. He did, at different points in ‘Dementia Reconsidered’, position personhood in both moral and meta-physical terms. Ultimately, he chose to characterise personhood relationally, as a moral standing that can be realised through interpersonal processes, which encompasses positive person work, and eliminates malignant social psychologies. While it is true that there is considerable debate about the nature of personhood, and what constitutes it, it should be noted that this debate has existed for centuries

(contributors include Locke, Hume, Descartes, Kant, Buber). The theory of person-centred care, which is fundamentally about having a genuine moral concern for all other human beings, and behaving accordingly, should not be eclipsed by this perhaps everlasting philosophical debate about the nature of personhood. While the concept of personhood, as outlined by Kitwood might not be testable, he felt strongly that an empirical basis must be established for person-centred care, to prioritise the most effective elements of the approach. He advised that observational and ecological approaches are more appropriate for evaluating the effects of person-centred care, given that it may not be feasible to assess the effectiveness of person-centred care, using a randomised control trial approach.

In terms of the effectiveness of person-centred care, the evidence was synthesized in a recent systematic review and meta-analysis by Kim and Park (2017). The study included intervention studies employing both randomised and non-randomised designs. Nineteen studies were included (N=3,985). The majority (17/19) were based in long-term care settings and two were based in participants' homes. Pooling of the data indicated that person-centred care significantly reduces 'agitation', 'neuropsychiatric symptoms', and 'depression' and improves quality of life for people with dementia.

In sum, while there are limitations to Kitwood's work, I argue that almost all the developments in relation to dementia care theory since Kitwood's work, start with, or draw from, the strength of the core principles of his theory. As a social psychologist, Kitwood was somewhat bound by his disciplinary lens, to focus more specifically on the individual-level, and on the role of relationship in mediating the experiences of people with dementia. The fact that his theory of person-centred care is not all-encompassing, and does not represent macro-level factors, does not invalidate its strengths.

For the purpose of this thesis, I will employ the theory of person-centred care as a guiding framework in relation to conceptualising dementia care in respite services. However, in recognition of some of the valid limitations outlined above, I will also incorporate Sabat's lessons, regarding the importance of social positioning and taking 'the intentional stance' in interpersonal interactions. This will serve as my *modus operandi*, methodically, when it comes to communicating with people with dementia, to elicit their perspectives on respite service provision. Furthermore, I will

supplement Kitwood's theory, by considering, as appropriate, the macro-level factors influencing respite service planning, provision and use.

## **2.3 Philosophical Underpinnings**

All researchers make certain, often implicit, assumptions about the nature of reality (ontology) and what is knowable through the research process (epistemology). These assumptions form a worldview which underpins their methodological approach. The philosopher Thomas Kuhn (Kuhn, 1962) referred to these types of worldviews as 'paradigms'.

### **2.3.1 *The Paradigm Wars***

At present, there are three overarching, dominant research paradigms: post-positivist, constructivist and pragmatic (see table 2.1 for characteristics of these paradigms). The first two paradigms are often seen as fundamentally-opposing. Authors including Howe (1988) and Johnson and Onwuegbuzie (2004) have referred to the ideological tensions between purists of these two worldviews as the 'paradigm wars'. The rise of the latter paradigm, pragmatism, is characterised by some as a response to the paradigm wars, as will be outlined below.

The post-positivist paradigm was deeply influenced by the philosopher of science, Karl Popper, as well as other philosophers, including Durkheim and Locke (Creswell, 2009). It is rooted in empiricism, which assumes that there is one single reality, which is knowable through objective quantitative measurement, if we can reject the theory-derived null hypothesis (Popper, 1969). This has been the dominant research paradigm historically, and some still see it as the paradigm against which all others are compared and critiqued (Denzin and Lincoln, 2011). In contrast, constructivism assumes that there can be multiple realities, which are to some degree socially constructed, and so can be subjectively explored and interpreted by researchers, through engaging with qualitative research methods. This paradigm started to gain traction and credibility in the latter years of the twentieth century, to the dismay of many post-positivists (Creswell, 2009). Those who ascribe to constructivism are concerned with meaning-making and the significance of phenomena, as opposed to objective quantitative measurement.

**Table 2.1 The dominant research paradigms and their characteristics**

<b>Post-positivism</b>	<b>Constructivism</b>	<b>Pragmatism</b>
Deterministic Typically quantitative Reductionist Empirical observation Quantitative measurement Theory verification	Open-ended Typically qualitative Social construction Multiple meanings Theory generation	Problem-centred Typically pluralistic Practice oriented Not wedded to a philosophy

(Adapted from Creswell, 2009)

### **2.3.2 Pragmatism**

A third paradigm, pragmatism, became popular partially in response to the disruption of the paradigm wars. Pragmatism stems from the thinking of Peirce in the late 1800s. It was then developed on significantly by Dewey in the early 20<sup>th</sup> century, and more recently in works by Rorty (1982), Cherryholmes (1992) and Morgan (2014). Pragmatism can be characterised as a worldview that is practical and problem-centred, and not committed to any one ontological or epistemological position (Creswell, 2009). In this way, researchers adopting a pragmatist approach are not preoccupied with in-depth philosophical debates, because we can never know the ‘true’ answers to such questions (Morgan, 2014). Instead, pragmatists are more focused on identifying and adopting the most appropriate method(s) to answer their research question(s) (Johnson and Onwuegbuzie, 2004). Morgan (2014) emphasises that while pragmatism has become closely linked with mixed-methods research, they are not co-dependent, and pragmatism can be the guiding philosophy for any research method.

An important issue, which Morgan (2014) points out is not often addressed in discussions on pragmatism, is that while pragmatists don’t believe in the value of debating philosophical issues, this does not mean that they are blank slates, ontologically. Pragmatists tend to believe that there is an external world independent of the researcher’s mind, but that the researcher’s perception of this world is always coloured by their experiences, values and beliefs (Morgan, 2014; Creswell, 2009; Cherryholmes, 1992). Broadly, this pragmatic ontological perspective is in line with



the ontological underpinnings of ‘subtle realism’ (Duncan and Nicol, 2004), i.e. that the researcher’s perspective is influenced by his or her own position and experience in the social world, however, phenomena do exist independent of the researcher’s mind (Hammersley, 1995; Hammersley, 1992).

As someone who has engaged with and has seen the value of both quantitative and qualitative research methods over the course of my research career thus far, I feel that pragmatism reflects my worldview, in relation to the following assumptions:

- 1) That the research process should be malleable and tailored to the research question(s), to achieve the desired knowledge outcomes;
- 2) That there is an objective reality, but it is coloured by how we perceive and interpret it.

Moreover, the biopsychosocial standpoint I outlined in chapter one, regarding my understanding of dementia, is in line with the ontological underpinnings of pragmatism. While dementia is a neurodegenerative medical condition which has observable and measurable causes and effects, I also believe that the social and environmental context can have a significant effect on the perceptions and experiences of people with dementia (as per Kitwood’s work relating to the importance of person-centred care). Thus, my understanding of dementia is consistent with the theoretical and philosophical assumptions underlying the methodological approach in this thesis.

## **2.4 The Qualitative Approach**

A qualitative approach was employed throughout this thesis. The specific design, sampling, recruitment, data collection and data analysis procedures, as well as the ethical considerations of each individual study comprising this thesis, will be outlined in the five chapters that follow (3-7). However, in this section, some additional information is presented in relation to 1) the over-arching research approach, and 2) the qualitative approach employed to provide primary data on the Irish context.

While there are many different characterisations and definitions of qualitative research, it typically aims to describe and understand phenomena through exploring participants' experiences, attitudes, opinions, behaviours and social interactions, and the contexts in which they occur (Creswell, 2009; Tashakkori and Teddlie, 2010). Overall, an inductive qualitative approach was adopted, i.e. a bottom-up process of collecting data, which can serve to generate new knowledge and theory. This was a practical decision, driven by the research questions, as opposed to any affinity for the specifics of qualitative research or inductive, bottom-up inquiry.

The research questions were constructed based on deficits in respite service provision observed in the existing literature, and conversations that I have had with carers and people with dementia while working as an assistant psychologist. While the focus of this research was on the personal experiences of stakeholders, it was specifically as they related to respite services and their development, as opposed to delving deep into their internal psychological processes in a more idiographic manner, akin to phenomenological inquiry. In line with the pragmatist philosophy guiding this research, the intention throughout was to balance the endeavour of obtaining rich, detailed and nuanced data about personal experiences regarding respite services, with the endeavour to collect data that is tangible and implementable.

For the purposes of the primary qualitative study, a semi-structured interview design was chosen, as opposed to focus groups, for a number of reasons. Firstly, with focus groups, there is a danger that more dominant individuals will set and arbitrate the range and tone of the narrative; taking this approach was not worth that risk. Examples of potential power dynamics might include carers speaking for people with dementia, carers and/or people with dementia not feeling comfortable challenging healthcare professionals' perspectives, and healthcare professionals not wanting to be honest about their perspectives in the presence of colleagues or management. Another issue with focus groups, is they require that 6-10 participants can gather at the same time, for up to two hours, in the same room. Even if separate focus groups were conducted for each stakeholder group, it would likely still be very challenging to reconcile the participants' busy and varied schedules and commitments.

Adopting a semi-structured one-on-one interview approach, while more time-consuming, allowed for in-depth exploration of a wide range of topics relating to each participant's experiences of respite services in a more private and empathic space, without value judgements or disagreements from other stakeholders. This was especially important in relation to people with dementia. Using a semi-structured interview design was considered less cognitively taxing than a focus group setting, where multiple perspectives and topics may be being expressed at any one time. This individual interview approach meant the researcher and the person with dementia could work closely together to make meaning of the experiences of the person with dementia. The approach to interviewing people with dementia specifically is outlined in greater depth below. Finally, it must be acknowledged that there is arguably more space for the interviewer to influence the research process in individual interviews, compared to focus group settings. Therefore, reflexivity is discussed in section 2.6 below.

## **2.5 Qualitative Interviews: People with Dementia**

An empathetic approach was employed for all stakeholder interviews. This approach holds that empathic inquiry, listening and responding can disarm participants of preconceived power dynamics, and facilitate a deeper understanding of participants' viewpoints (Josselson, 2013) (Fontana and Prokos, 2007). This approach is detailed in later chapters. However, in addition, with people with dementia, the 'intentional stance' (Sabat and Harré, 1992; Sabat and Harré, 1994) was also consciously employed. As outlined above, taking the intentional stance is about operating from the assumption that the behaviour of people with dementia is meaning-driven and context-bound, even if difficult to interpret initially. Interpretation was facilitated by collecting information about the person from the family carer and/or respite staff ahead of the interview (e.g. biographical history), as well as information about their life now, including their communication style. People with dementia were also given opportunities to correct or confirm my understanding of their perspective.

An excerpt (see table 2.2) from one of the interviews with people with dementia is depicted below as a case study, to illustrate the intentional stance in practice.

**Table 2.2 Interview excerpt**

PP: I began to say at home last night... I asked myself questions too... how do I feel about this experience... do I feel rejected? and the answer is yes... do I feel that I didn't... that my opinion was not worth taking... the answer is yes... and I didn't find it easy to get over it... I'm still suffering inwardly a bit... you can see that...

I: from feeling disregarded?

PP: yes, they raise expectations... I don't know how they did this... but they didn't check me out and see what did I want...

I: would you say that is typical of your experience here?

PP: in a sense it wasn't a once off... the very fact that we had to intervene from Geneva and create a course... what country are you going to... the middle east... what do they like... how do you know they like it... when did you last ask them?

I: yes, that applies in the Middle East and here too [pointing at the table, in the day service]?

PP: It does, it helped us back to square once before... But nobody asks the right questions here... Therefore, the class are all losing out on an opportunity of learning from us...

I: Nobody 'surveys' you here, as you said

PP: Yes, they should build in a question and answer session and force people to give opinions before during and after... but it isn't easy to educate people to do that... they are not normally able to do that of their own accord... or they think because they are the headmasters [*people in charge, power issue*] that they shouldn't be asking us questions about simple stuff like chips.

I: You think that those in charge think they're above that?

PP: Oh yeah, there were two staff one day who decided to teach me a lesson I was asking too many questions... and eh... I could move my seat... they were movable... so I could move it but not a certain distance because they threatened to block me... and that in a sense is threatening to block my ideas.

I: mmm...

PP: and that turned out nasty... I got so annoyed with her... do you see this stick here? I used this with both of them [staff members]. I turned it on one of them...one of them was as bad as the other... I mean I didn't ever think it would come to that.

I: You were frustrated because they didn't want to know your 'ideas'...

PP: Very, very frustrated... and it was all because of the movement of seats... and they wanted to inch me and keep me away from the headquarters..."

'PP' = participant; 'I' = interviewer

In this excerpt, the interviewee is describing his experience of how he is treated in day services and the fallout from that, in terms of his personhood and self-esteem. However, the relevance of some of this discourse to the overall narrative was only clear to me at some points throughout the interview, because of in-depth conversations with his wife and the day service manager about him and his life. These conversations gave me context to understand that some of the terminology he was using concerning other contexts, from previous life experiences, was being employed by him now to disclose his experience of day services. In other words, statements that I might otherwise have interpreted as irrelevant to my research question took on a different significance.

This man was a professor of marketing, who has been an educator and an author, and has led teams working with foreign nations on marketing campaigns to improve the public image of certain goods/services. Much of his language throughout the interview employed terminology that would have been germane to the context of his professional life, e.g. *"the very fact that we had to intervene from Geneva and create a course - what do they like, how do you know they like it, when did you last ask them?"* and *"nobody asks the right questions here... Therefore, they are all losing out on an opportunity of learning from us"*.

However, it became clear that this narrative was a tool he was using to communicate his experience of the day service. Validation that some of the apparently irrelevant language and anecdotes were in fact relevant to his experience of day services came about in both implicit and explicit ways. Explicitly, for example, I would ask questions like 'is that is the same here' (e.g. "yes, that applies in the Middle East? And here too?" [Pointing at the table, situated in the day service]), and he would confirm or refute verbally or behaviourally. More implicitly, there were nuances in

this language that indicated he was referring to his experience of the day service, although not using the applicable contextual language. After referring to the ‘intervening from Geneva’ scenario, he talks about how nobody asks the right questions ‘*here*’. Other times, he would refer to the management as ‘headmasters’ and the building as their ‘headquarters’, but would point or direct me to look at the day service manager or indicate that the headquarters is the building being referred to, by pointing down.

By taking the intentional stance, I was able to co-construct a rich narrative regarding some of his interpersonal experiences with staff (some of which his wife had already corroborated, or alluded to), which left him feeling deprived of narrative agency.

This eventually led to him disclosing a scenario involving a disagreement between him and staff members over the positioning of a chair, after which he lashed out physically. However, by assuming that there was intention on his part in the ‘chair moving’ scenario, it became clear to me that this was not a dementia-related behaviour as the day service manager had positioned it, but a symptom of frustration and distress at how staff hadn’t attempted to understand his motivation. He felt like they were “blocking his ideas” and in the moment, he became vexed and lashed out at a healthcare assistant with his walking stick. This is something that disturbs him, because it is clear that he doesn’t view himself as someone who is violent (“I didn’t ever think it would come to that”). His tone and facial expressions indicated that he still carries guilt about this.

My interpretation at this point was that, not only was his narrative agency diminished in this scenario, but his self-concept and self-esteem were also damaged by how he reacted to this mistreatment. The power of this type of ‘malignant social psychology’, in this way, cannot be understated, because not only does the person suffer how they feel they have been mistreated, but they can also suffer how they react to such mistreatment, especially if it is not in line with their self-concept. I fed back to him my interpretation, that what happened with the stick was out of frustration at being ignored (“*You were frustrated because they didn’t want to know your ‘ideas’*”), and this empathic response, led him to elaborate on his perspective, by identifying the power dynamics that he perceives are at play within the service. He inferred that this type of behaviour from staff is an instrument of disempowerment,

used to minimise disruption to the service and/or system (i.e. *“they wanted to inch me and keep me away from the headquarters...”*).

This approach highlights the value of purposefully assuming intentionality, personhood and agency in people with dementia in interpersonal interactions, and listening and responding accordingly, with curiosity and empathy.

## **2.6 Reflexivity**

Reflexivity can be defined as “thoughtful, self-aware analysis of the intersubjective dynamics between the researcher and the researched. In particular, critical self-reflection regarding the ways in which the researchers’ social background, assumptions, positioning and behaviours impact the research process”, is central to reflexive research practices (Finlay and Gough, 2008, p. ix). In this section I will communicate from a more personal position, using the first person pronoun, to detail some of the insights that I have gathered about the research process, and my role in that. The approach that I took to reflexive practice in my research was three-pronged, incorporating personal introspection, as well as intersubjective and collaborative reflexive practices.

Firstly, I view reflexivity as necessarily an introspective process, in line with my epistemological affinity with pragmatism. If there is an objective reality, but it can only be filtered and perceived through the minds of the researcher, then introspective reflexivity becomes an extremely important endeavour. Early on in the research process, at the point where the research questions were being formulated, my supervisor encouraged me to think about my personal interest in the topic, my assumptions about the topic, and how my own characteristics and preconceptions might influence the research process. Having had both personal and professional experience of people with dementia, family carers and respite services, I was not approaching this research as a blank canvas. The research questions I was interested in, stemmed from conversations I have had, and observations I had made over a number of years about the lack of availability and acceptability of respite services, especially in rural areas.

Secondly, I came to see reflexivity as having a substantial intersubjective element in relation to data collection and analysis, since meaning is co-constructed. This view of reflexivity is in line with the empathetic approach adopted for the semi-structured

interviews. The empathetic approach requires immediate intersubjective reflection on the part of the researcher, given that empathic listening, processing and responding must occur in the moment. Other ways in which I tried to incorporate intersubjective reflexivity during the interview process, were 1) inviting participants to reflect on their own overt perspectives and 2) probing to expose potential implicit assumptions, indicated through the use of certain types of discourse (e.g., “you refer to people with dementia as ‘Alzheimer’s people’, can you tell me why you chose those words”, or “you used the term ‘person-centred care’ a number of times - what does that mean to you in relation to people with dementia?”). Sometimes my line of questioning could be gently challenging, if the rapport was good, e.g. “you said residential respite is ‘detrimental’ for people with dementia and that you wouldn’t even put an animal in there – do you believe it is ‘detrimental’ for *everyone* with dementia?” Sometimes, instead, I would name the use of the devil’s advocate position (e.g. “Let’s play devil’s advocate - one could argue that implementing person-centred care doesn’t *only* come down to resources– what is your take on that?”). Often, but not always, when such invitations to reflect on alternate viewpoints were extended to participants, it allowed for deeper engagement with their perspectives. Intersubjective reflexivity was also vital in the data analysis stage. It helped me understand why missed or wasted opportunities for co-constructing meaning occurred. For example, sometimes when trying to formulate an ‘empathic’ response, I ironically missed opportunities for authentic connection in the moment. I came to realise that it was important to try to remain grounded and present. Additionally, I recognised early on, that I had a tendency to try to fill silences. I realised that in giving in to this impulse, my behaviour was squashing potential opportunities for deeper reflection on the part of the interviewee. I began to use silence as a tool to create space for interviewees to reflect, as appropriate to the context.

Finally, in terms of the third aspect comprising my approach to reflexivity, I also engaged a great deal in collaborative reflexive practice with my thesis supervisors. This type of collaboration allowed me to engage with some of the more hidden assumptions and attitudes that were influencing my meaning-making throughout the data analysis and synthesis process. A prime example of the value of collaborative reflexivity, is how my supervisor helped me to realise that, given my own personal



perspective on how respite services require development (as outlined above), I had a tendency to hone in a bit more on accounts of respite services which problematized current provision. Once I became aware of this, I knew I had to make an active effort to be more receptive to, and curious about, the positive aspects of participants' experiences regarding respite services throughout the research process.

## **2.7 Ethical Considerations**

Special attention was given to the ethical considerations relating to the inclusion of people with dementia in this research. Ethical approval to interview people with dementia (along with other key stakeholder groups) was granted by the Dublin City University Research Ethics Committee (appendix H).

Historically, people with dementia have been omitted from research due to questions around the issue of their 'capacity' to give their informed consent to participate, and/or to provide meaningful and valid data. 'Capacity' in this context is a legal concept, which indicates that 'informed consent' can only be given when potential participants understand and appreciate the conditions and possible implications of a study. Furthermore, the person must be able to clearly demonstrate their understanding, and how that informs their decision-making around the choice to give their consent to participate, to researchers. This capacity-led approach to consent has led to a systematic marginalisation of the experiences of people with dementia from the body of literature on dementia care (Dewing, 2002; 2007; 2008).

In light of the shift towards a biopsychosocial understanding of dementia in recent years, this exclusionary approach has been exposed as being damaging to knowledge production in dementia care research. Furthermore, there is now an acknowledgement that the blanket omission of people with dementia from research on the basis of 'capacity' infringes on the rights of people with dementia to have their experiences feed into the findings and conclusions of research that may have implications for the future care of people with dementia. Of course, it is also true that including people with dementia in research raises the issue of risk and harm. Putting in place measures to minimise the likelihood of harm for people with dementia engaged in the research process should always be paramount, regardless of how the issue of consent is approached. This will be addressed further below.

For the purposes of this study, Dewing's (2007; 2008) 'process consent' method was employed, as an alternative to the capacity approach to written informed consent. This was employed in addition to standard proxy consent from the family/informal carer. The process method facilitates the inclusion of people with dementia with mild and moderate dementia, not just those who can clearly demonstrate 'capacity' for informed consent. The process method is typically characterised as a continuous, ongoing evaluation of the person's inclination to continue engaging in the interview process, as determined through their behaviour, affect, body language, facial expressions and vocal communications. This approach is complex and requires much preparation and reflexivity on the part of the researcher, to ensure that the wellbeing of the person with dementia is protected throughout the research process. In this way, the process consent method can be considered a person-centred approach to ethically including people with dementia in research.

Dewing (2007; 2008) has outlined the process consent method as having a number of key components. Firstly, the researcher must consult someone who knows the person with dementia well, who can provide details about the life, personality, communication style, strengths, interests, concerns/fears of the person, and can disclose any topics or lines of questioning which should be avoided to minimise the risk of distress. Regarding distress, for example, a very important consideration relates to understanding the person's awareness and/or acceptance of their dementia diagnosis; accidentally disclosing a diagnosis of dementia to a person who does not know of, or does not accept the diagnosis, could cause significant distress and harm to the wellbeing of a participant. Subsequently, the initial willingness of the person to engage with the interviewing process must then be assessed, after a brief explanation of the research is given in a way that is digestible to the person. Here both written and visual consent forms were employed (appendices J, K), however people with dementia were not excluded on the basis of not being able to complete the forms. If it is clear that the person is willing and happy to participate, the issue of consent is continuously reappraised by the researcher throughout the interview process. Any signs of distress, distraction or disinterest should be taken as an indication that the person may no longer be happy to participate, and this should be probed. If the person cannot be re-engaged in a way that they seem comfortable with, the interview should be drawn to a close. Finally, the person should be given brief

feedback, asked if they want other information or support, and thanked for their contribution.

In this research, all of the interviews with people with dementia ended on the basis of following the process method of consent, i.e. when the person with dementia communicated (typically indirectly or non-verbally) that they would prefer to no longer engage in the interview process. No participant became distressed, but many became disinterested or distracted (e.g. asking more than once about when lunch would be served) in a way that suggested that continuing to try and re-engage them would not be respectful of the person's wishes at that time. This typically occurred somewhere between 20 and 40 minutes into the interview process.

## **2.8 Chapter Conclusion**

In this chapter, the broad methodological approach, as well as the theoretical and philosophical assumptions which informed the primary qualitative research contained in this thesis, were outlined in detail. This included a discussion of the merits and criticisms of Kitwood's theory of 'person-centred' dementia care and the concept of personhood. The pragmatic, qualitative approach underpinning this research was also outlined and justified. Finally, key methodological issues, which could not be addressed in the published papers due to restrictions in journal word counts, were considered, i.e. the approach to interviewing people with dementia, and issues relating to reflexivity and ethical considerations.

The next chapter will outline a literature review focused on analysing the concept of 'respite', to better understand what this means in relation to dementia respite service provision. The findings are contextualised in light of the principles of person-centred dementia care theory.

## Declaration of Authorship

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Title of PhD by Publication Thesis	Respite Services for People with Dementia and their Carers: Perspectives of Key Stakeholders
Section 2: Paper details	
Title of co-authored paper included in the thesis under examination	Respite in Dementia: An Evolutionary Concept Analysis
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This paper is one of	4 co-authored papers to be submitted as part of the PhD by publication thesis submitted for examination
Section 3: Candidate's contribution to the paper	
Provide details below of the nature and extent of your contribution to the paper (include both your intellectual and practical contributions) and your overall contribution in percentage terms:	
I conceived of the idea together with my primary supervisor. I conducted the systematic literature search and the concept analysis. I also interpreted the findings and then drafted and submitted the manuscript. I estimate that my contribution was 80%.	
Where a paper has joint or multiple authors, list the names of all other authors who	

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#### Section 4: Signature and Validation


I confirm that the following statements are true:

the information I have provided in this form is correct

this paper is based on research undertaken during my candidature at DCU

Signature of PhD Candidate:  Date: 04/10/2019

I confirm that the information provided by the candidate is correct:

Signature of Principal Supervisor:  Date: 04/10/2019

In some cases, it may be appropriate for verification to be given by both the principal supervisor and the lead/corresponding author of the work (where the lead/corresponding author of the work is not the candidate or the principal supervisor):

Signature of Lead/Corresponding Author N/A

### **3 DEFINING ‘RESPITE’ IN DEMENTIA: A SYSTEMATIC REVIEW AND EVOLUTIONARY CONCEPT ANALYSIS**

The work presented in this chapter has been published as:

O’ Shea, E., Timmons, S., O’ Shea, E., Fox, S., and Irving, K. (2017) ‘Respite in dementia: an evolutionary concept analysis’, *Dementia*, 18(4), pp. 1446–1465. DOI: 10.1177/1471301217715325.

### 3.1 Abstract

**Aim:** There is a lack of conceptual clarity around ‘respite’ as it relates to people with dementia and their carers. This study provides clarification on the use and meaning of the term and considers the concept in relation to the dominant care paradigm in dementia, i.e. person-centred care.

**Methods:** Rodgers (1989) evolutionary concept analysis framework was employed. A systematic search was conducted of the PubMed/MedLine, Embase, Cinahl, PsychInfo, Scopus, Web of Science, and Cochrane databases (1980 – 2016, English) with fixed search terms relating to ‘respite’ and ‘dementia’. Papers with primary qualitative data and literature reviews were included. This search was supplemented with snowballing techniques (back/forward searching, generic search engines). Data was analysed thematically, through an iterative process of constant comparison.

**Results:** Respite is understood both as a service that provides a physical break for the carer and as a psychological outcome, i.e. a mental break for the carer, which can be facilitated by formal services, under certain conditions. The conceptual model outlines how client factors (dyadic relations, recognising/accepting need, carer psychosocial issues, restorative occupation, and stigma) and service factors (model/characteristics, care quality, staff expertise, meaningful occupation for people with dementia and communication and support), interact to influence a respite outcome. The key antecedent for a positive respite experience is that the carer perceives that mutual benefit is garnered by the dyad from service use.

**Conclusion:** The term respite can be interpreted as both a service and an outcome. However, it is clear that ‘respite’, as currently understood, acknowledges the relational experience of the carer only. It is, therefore, potentially damaging to the planning and delivery of person-centred dementia care. We suggest ‘restorative care’ as potential alternative nomenclature to respite care, thereby highlighting the importance of providing mutual, personalised health and social care services that serve to enhance care relationships rather than diminish them.

## **3.2 Chapter Introduction**

There is a lack of conceptual clarity around ‘respite’ as it relates to people with dementia and their carers. Therefore, the initial task of the thesis was to provide clarification on the use and meaning of the term and to consider the concept in relation to the dominant dementia care paradigm, i.e. person-centred care.

## **3.3 Background**

Respite care is one of the most common services that people with dementia attend. ‘Respite services’ generally are delivered with a view to ‘providing a temporary break in caregiving for the carer’, in order to reduce ‘stress’ and ‘burden’ for carers of people with dementia (Maayan et al., 2014). Multiple models exist, including residential, in-home, and day services, and therefore, services can differ in terms of provider, location, duration and frequency of care.

It has been noted that the term ‘respite’ is shrouded by uncertainty and conceptual disagreement (Evans, 2013b; Evans, 2013a). As a result, research in the area of ‘respite’ has been stifled by heterogeneous conceptualisations and descriptions of what respite is, who it is for, what it entails, and what it should achieve for the service user(s) (Evans, 2013b; Evans, 2013a; Shaw et al., 2009). As researchers and academics, we have a responsibility to build the evidence base of a given area on well-developed and clear concepts that are understood by all to have approximately the same meaning (Weaver and Mitcham, 2008). This is particularly important in relation to concepts that will guide the planning, development and delivery of services providing dementia care over the coming years, as more and more people are diagnosed.

This chapter aims to contribute to this effort, by establishing what ‘respite’ means as a concept, from the perspectives of key stakeholders in dementia, across a range of health disciplines, in both the conceptual and empirical literature. The meaning of ‘respite’ will subsequently be considered and appraised within the context of the dominant contemporary dementia care paradigm – person-centred care. The basic principles of the person-centred care approach include that formal carers demonstrate, in their interactions with people with dementia, that they i) value and respect them as individuals with their own experiences and perspectives, ii)



demonstrate and communicate empathy and understanding for their experience, and iii) encourage independence and social engagement for the person with dementia (Brooker, 2003; McCormack, 2004; Edvardsson et al., 2008; Doyle and Rubinstein, 2013). In recent years, there has been a call for all dementia-based services to adopt more ‘person-centred’, holistic and individualized approaches to care, thereby counteracting the biomedical and custodial models of care which can often serve to undermine the ‘personhood’ of people with dementia (Kitwood, 1997).

### 3.4 Methods

Rodger’s evolutionary method of concept analysis (Rodgers, 1989; Rodgers, 2000) was employed to guide this analysis. The objective of this inductive approach is not only to provide a level of clarification around a concept, but importantly, to also establish a basis for the future development of the concept (Rodgers, 2000). The strength of the approach is that it is systematic and can usefully assist researchers to i) clarify, ii) describe and iii) explain concepts by analysing how a chosen concept has been used within and across health disciplines and contexts (Toftagen and Fagerstrøm, 2010).

Toftagen and Fagerstrøm (2010) also propose a number of key questions that researchers should consider when they engage with the core analysis phase of this method in relation to five areas (see Table 3.1):

**Table 3.1 Key questions to ask during the core analysis phase**

<b>Surrogate terms</b>	Do other words say the same thing as, or have something in common with respite?
<b>Attributes</b>	What are the characteristics of respite?
<b>Antecedents</b>	Which events or phenomena have been associated with respite in the past?
<b>Examples</b>	Are concrete examples of respite described in the data material?
<b>Consequences</b>	What happens after or as a result of respite?

These steps will provide the framework to guide this analysis of the concept of respite, based on conceptual and empirical literature, with particular reference to people with dementia and their carers.

### ***3.4.1 Search Strategy***

A search was conducted of the PubMed/MedLine, Embase, Cinahl, PsychInfo, Scopus, Web of Science, and the Cochrane databases (date parameters 1980 – 2016). The search strategy aimed to identify all peer-reviewed literature relating to respite as a concept in relation to dementia. Google and Google Scholar were also searched to locate any further unindexed peer-reviewed literature. A hand search of the reference lists of the relevant studies, and of other relevant literature reviews and concept analyses, was also conducted as a ‘back search’, while the ‘cited by’ function of Google Scholar was used to ‘forward search’ for articles that have cited the included studies, and have relevance to the present research question.

### ***3.4.2 Search Terms***

MeSH headings are the US National Library of Medicine's controlled thesaurus of terms used to organise the MEDLINE/PubMed databases. The Cochrane Library and the CINAHL database also use MeSH headings. The following MeSH headings were used in the search strings: Respite Care (MeSH)\*, Day Care, Medical (MeSH)\*, Dementia (MeSH)\*, Alzheimer disease (MeSH)\*

**The full list of search terms, in Boolean operators, were:**

‘Dementia **OR** Alzheimer disease **OR** Alzheimer’s **OR** cognitive impairment **OR** older adults **OR** frail elderly’

**AND**

‘Respite care **OR** respite **OR** day care **OR** day-care **OR** residential respite **OR** in-home respite **OR** in home respite’

### ***3.4.3 Study Selection***

While the aim was to take a broad and inclusive approach to conceptualising respite, with particular reference to dementia, there were criteria guiding study selection,

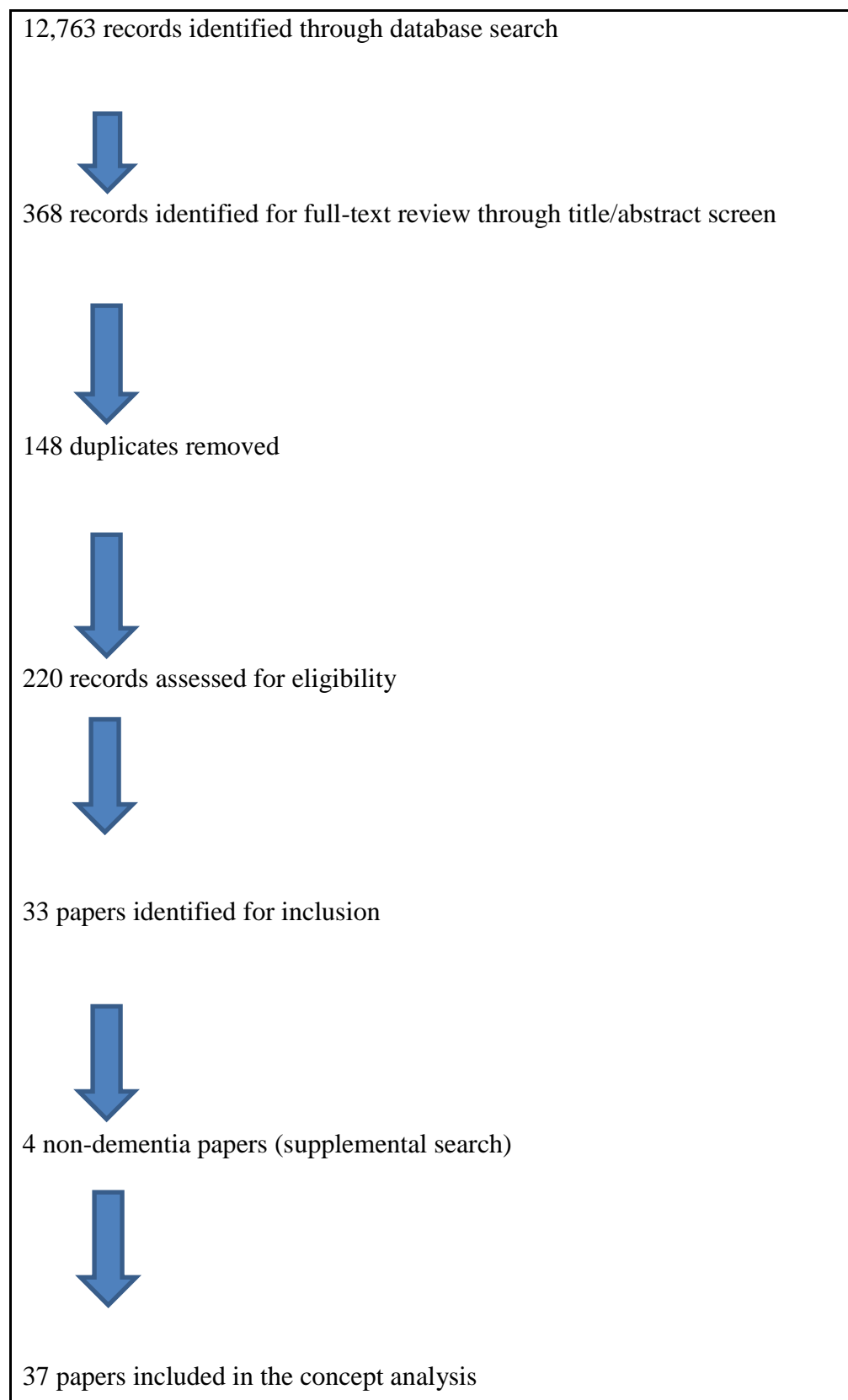
which were required to narrow down the literature and identify relevant papers (see Table 3.2).

There is a focus on respite as it relates to dementia for this study, as evidenced by the systematic element of the search. However, we sought to supplement the systematic search with snowballing techniques (backwards and forwards searching) and the use of generic search engines, to identify seminal papers focused on the concept of respite, but not necessarily on dementia (see figure 3.1 for flow chart). Our rationale for doing this is that there is much to be learned from other areas (e.g. intellectual disability, older adults), in terms of the contextual factors that influence the concept of respite.

**Table 3.2 Inclusion and exclusion criteria guiding the systematic search**

<b><u>Inclusion criteria</u></b>
<ul style="list-style-type: none"><li>▪ Peer-reviewed articles focused on dementia and carers of people with dementia</li><li>▪ Articles that present a clear definition of ‘respite’</li><li>▪ Articles presenting a theoretical framework or discussion of the concept of ‘respite’</li><li>▪ Qualitative research studies that investigate the meaning of respite</li><li>▪ Reviews and discussion papers meeting other inclusion criteria</li></ul>
<b><u>Exclusion criteria</u></b>
<ul style="list-style-type: none"><li>▪ Books/book chapters/commentaries/editorials/dissertations</li><li>▪ Non-peer reviewed articles</li><li>▪ Articles not in English</li><li>▪ Articles that do not include 1) a definition or 2) a conceptual framework and/or discussion involving respite</li></ul>

**Figure 3.1 Flow chart detailing the study selection process**



After reviewing the titles and abstracts of papers identified in the systematic search to assess eligibility, 220 papers were considered eligible for full-text review. Of these, 33 were considered to meet the criteria for inclusion, independently by two reviewers. A further four papers (Chappell et al., 2001; Evans, 2013a; Hanson et al., 1999; Whitmore, 2017) were identified from the supplemental literature search on Google and Google Scholar. The final sample consisted of 37 papers.

#### **3.4.4 Data Extraction and Analysis**

Each of the included articles was read in full and analysed for any data relevant to surrogate terms, attributes, antecedents, examples and consequences. A coding framework was developed based on the questions outlined by Tofthagen and Fagerstrøm (2010) to assist with conducting this core analysis phase (see table 3.1 above), and information about the year of publication, the methods used and the discipline of the first author was also recorded. The framework and its comprising codes were subsequently reviewed for recurring themes and patterns in relation to respite. Through an iterative process of constant comparison to identify similarities and differences across studies, categories were identified in relation to respite, with a particular focus placed on how this relates to dementia. A matrix was created to check each identified category against each included study to determine presence or absence of the category and to record how the category manifests in relation to respite.

### **3.5 Results**

#### **3.5.1 Surrogate Terms and Related Concepts**

Identifying surrogate terms (words used interchangeably to express a concept) and related concepts are central to understanding the concept under scrutiny (see table 3.3) (Rodgers, 2000). The most common surrogate terms for respite in relation to dementia fall into two clusters in the literature, and these indicate respite as either i) a service or ii) an outcome. While discussion of surrogate terms and concepts related to respite is beyond the scope of this paper, they have shaped the analysis and will be referred to later.

**Table 3.3 Surrogate terms and concepts related to respite**

<b>1. Surrogate Terms</b>					
<b>A. Respite as a service</b>	in-home services	day care services	residential services	crisis services	emergency care
	domiciliary care	formal services	community care	professional care	temporary care
	in-hospital care	intermittent care	sitter services	support services	overnight care
	weekend care	substitute care	relief services		
<b>B. Respite as a carer outcome</b>	temporary relief	time out	rest	short-term break	taking leave
	time away	down time	extended break	emotional rest	free time
	freedom	escape	getting out	getting away	mental break
	psychological relief	mental disengagement	private time	space	
<b>2. Related Concepts</b>					
	burden	strain	coping	burnout	stress
	depression	anxiety	quality of life	wellbeing	carer support

### **3.5.2 Attributes**

For Rodgers (2000), the identification of the attributes of the concept enables the comprehension of the core definition/characterisation of the concept. This analysis will describe the ongoing evolution of the term ‘respite’, as it relates to dementia, and how respite has been primarily characterised over the years as a health and social care service, but more recently also, as an outcome for the carer, which can be facilitated through service use.

Since the 1980s, there has been a growing emphasis on the ‘strain’ and ‘burden’ that informal carers of people with dementia, the ‘hidden victims’, experience as a result of caregiving (Abramson, 2009; Woods, 2001). The provision of ‘respite services’ has been widely advocated as an intervention to reduce carer strain. ‘Respite services’ are most commonly defined as ‘services that provide a temporary break in caregiving for the carer’ (Maayan et al., 2014). The assumption in providing ‘respite care’ is that a physical break from caregiving will serve to reduce ‘burden’ and increase the carer’s capacity to care, ultimately delaying institutionalisation for the person with dementia (Maayan et al., 2014; Vandepitte et al., 2016). However, there are two key problems regarding the conceptualisation of respite as a service: 1) there is high service non-use and attrition, despite high stated need for ‘respite’ (Donath et al., 2009; Parahoo et al., 2002; Phillipson et al., 2014) and 2) there is mixed evidence for the effectiveness of ‘respite services’ across service models (see outcomes below).

Qualitative studies have been conducted across disciplines including psychology, nursing, health services research, occupational therapy, social work and medicine to understand carers’ experiences of and perspectives on ‘respite services’ in relation to dementia since the mid 1990’s (Kirkley et al., 2011; Cotrell, 1996; McGrath et al., 2000; Beisecker et al., 1996). Findings from these studies have indicated that the characterisation of respite as a service is often inconsistent with the meaning of respite for the service users. While carers also refer to ‘respite services’, they tend to conceptualise ‘respite’, for themselves, as a psychological break from caregiving (McGrath et al., 2000; Teitelman and Watts, 2005; Teitelman and Watts, 2004; Watts and Teitelman, 2005; Strang, 2001; Strang and Haughey, 1998), which can be facilitated by service use under certain conditions (see antecedents below).

The temporary physical break provided by ‘respite services’ is not sufficient to facilitate respite for the carer under this conceptualisation; a mental break must also be experienced (Teitelman and Watts, 2005; Strang, 2001; Strang and Haughey, 1998). This has important implications for service provision in relation to dementia, and indicates that the characterisation of respite as a service only, is not only inconsistent with service user conceptualisations, it may be partially accountable for the mixed evidence in relation to service user outcomes and the underuse of formal services for the purpose of respite. It must be noted that, to our knowledge, the meaning of respite has not been explored from the perspectives of people with dementia to date.

### **3.5.3 Antecedents**

According to Rodgers (2000), antecedents refer to those things which have been previously associated with the concept. The antecedents fall into two distinct, but inter-related categories, i.e. client factors and service factors, each of which contain elements that can enhance or inhibit the respite experience for carers.

#### **1. Client factors**

Here, the term ‘client’ refers to the service users, i.e. the person with dementia and the carer. This analysis has identified five client factors that impact upon the carer’s ability to experience a mental break through service use: 1) Dyadic relations, 2) recognising and accepting need, 3) carer psychosocial factors, 4) restorative occupation, and 5) stigma.

#### **Dyadic Relations**

A clear pattern in the qualitative research indicates the significance of the dyadic relationship and how aspects of this can be an emotional barrier in the carer’s ability to experience respite. Carers commonly reported feelings of ‘guilt’ in relation to service use for the purpose of respite (Parahoo et al., 2002; Cotrell, 1996; Myren et al., 2013; Upton and Reed, 2005; Tretteteig et al., 2017). Negative feelings around service use are amplified for the carer when the person with dementia indicates that they do not accept the service or that they refuse to attend, which can lead to conflict in the dyad, and despair and frustration in the carer (Robinson et al., 2012). Carers can feel that service use is a ‘betrayal’ and an ‘abandonment’ of the person with



dementia, because they are not fulfilling the caregiving role to which they 'committed' (Strang and Haughey, 1999; Cotrell, 1996; de la Cuesta-Benjumea, 2010; Phillipson and Jones, 2011b). This feeling was particularly common for spousal and female carers and people over 70 years (Phillipson et al., 2014; Cotrell, 1996; Tretteteig et al., 2017; Tretteteig et al., 2016; Strang, 2001; Upton and Reed, 2005). This commitment to care has been reported by some spouses, despite poor quality relations ('longstanding lovelessness') prior to the onset of the dementia, as it is seen as their 'duty' or 'job' (Upton and Reed, 2005). The duration of the caregiving relationship is also significant and can impact carers' readiness to acknowledge their need for a mental break (Strang and Haughey, 1998; Gottlieb and Johnson, 2000). Finally, some carers also saw service use or the need for 'respite', as a 'signal' that this was the beginning of the person with dementia being 'taken away' from them, i.e. institutionalised (Parahoo et al., 2002; Cotrell, 1996). According to Robinson et al. (2012), carers noted that in their experience, 'promoting feelings of safety and security' for the person with dementia, and addressing their 'fears' around service use, served to foster greater acceptance and willingness to attend. From these findings, it is clear that relational factors differentially affect emotions and beliefs regarding the meaning of respite, which can preclude a positive respite experience for the carer.

### **Recognising and Accepting Need**

The carer's recognition and acceptance of the need for a break is an important factor in service use and achieving a respite experience (Cotrell, 1996; de la Cuesta-Benjumea, 2010; Neville et al., 2015; O'Connell et al., 2012; Parahoo et al., 2002; Phillipson and Jones, 2012; Upton and Reed, 2005; Donath et al., 2009). According to Strang and Haughey (1998, 1999) and Strang (2000a), the first key step to achieving a mental break from caregiving is recognising the need, followed by a process of the carer accepting the need and ultimately granting 'self-permission' to come out of carer role temporarily. A number of carers spoke to how it was important to have other people (i.e. 'social referents') positively reinforce the idea that a break was necessary for them, to accept their need for respite (Phillipson and Jones, 2011b; de la Cuesta-Benjumea, 2010). Perception of need could also be negatively influenced by others, e.g. family members believing care should be delivered only by family, not formal services (Parahoo et al., 2002). Positive

reinforcement regarding need can be garnered from staff within services (Phillipson and Jones, 2012). Alternatively, services can negatively influence the carer's process of accepting the need for respite, particularly when care quality is perceived to be poor (Gilmour, 2002).

### **Carer Psychosocial factors**

Carers can experience a range of personal psychological and social barriers to respite. Upton and Reed (2005) reported that there can be a relinquishment of the self and personal identity, as the carer struggles to cope with the demands of the caregiving role. The ability to 'get out' of the caregiving 'sphere of existence' and into their own individual world (Strang and Haughey, 1998; Strang, 2000a; Strang, 2001), can be impacted upon by carers' coping strategies (Watts and Teitelman, 2005; Gottlieb and Johnson, 2000; Strang and Haughey, 1998), identity issues (Strang and Haughey, 1998; Strang, 2000a; Strang, 2000b), social support resources (Strang and Haughey, 1998; Teitelman and Watts, 2004; Watts and Teitelman, 2005), negative beliefs and affect (e.g. equating service use with failure to cope (Phillipson and Jones, 2012), believing no service could substitute for them (Phillipson and Jones, 2011b; Phillipson and Jones, 2011a; Beisecker et al., 1996) and personality factors and predispositions (Watts and Teitelman, 2005). Carers also experience anxiety around temporarily relinquishing control and decision-making power regarding the care of the person with dementia (Phillipson and Jones, 2011b). While these psychosocial factors are individual to each carer, they are interrelated with dyadic relational and attachment factors and the perception of need (Strang, 2001; Strang and Haughey, 1998), as well as service factors (see below). Services have a substantial role to play in supporting carers to overcome these barriers and achieve a mental break.

### **Restorative Occupation for the Carer**

Restorative occupation, according to Watts and Teitelman (2005), is essential to achieving a respite experience during service use, and increasing caregiving capacity. A 'beat the clock' feeling has been reported by carers in relation to using services for the purpose of respite (Teitelman and Watts, 2004; Watts and Teitelman, 2005). Carers focus on completing as many tasks as possible while the person with dementia is under the care of formal services (Watts and Teitelman, 2005; Phillipson

and Jones, 2011a), sometimes precluding ‘any real sense of respite’. This intended ‘respite’ time, in reality, is mostly used for ‘urgent’ functional activities and ‘chores’ (e.g. shopping, housework) (Parahoo et al., 2002), and/or meeting other family members’ needs (e.g. adult children carers, who have children and spouses of their own) (Parahoo et al., 2002; Phillipson and Jones, 2012). In this way, the break from caregiving that services provide is often not used for leisure or recreation (Parahoo et al., 2002; Teitelman and Watts, 2004; Upton and Reed, 2005), but for catching up with functional tasks that have been neglected as a consequence of the demands of caregiving. Watts and Teitelman (2005) state that it is important that carers engage in ‘absorbing activities’ (i.e. activities which provide a psychological distraction from caregiving concerns), as these activities are central to ‘renewal’ and ‘mental clarity’.

### **Perceived Stigma**

According to a review by Robinson et al. (2012), stigma is a key issue in terms of respite for people with dementia. Carers note that ‘leaving home comforts’ can make the person with dementia feel unsafe and increases the ‘potential for embarrassment’. It can also increase levels of anxiety around how others will perceive them in light of their dementia-related symptoms. Public stigma has been reported towards people with dementia, causing carers to ‘conceal’ the person, to protect them from social rejection (in Robinson et al., 2012). Carer self-stigma has been reported in relation to service use (Hochgraeber et al., 2015). This may be a particular issue for female carers, who feel they may be judged for not fulfilling their gender role regarding the ‘obligation’ to provide informal care (de la Cuesta-Benjumea, 2010; Strang, 2001). Finally, in a 2014 review by Phillipson and colleagues, the authors described a large cross-sectional study by Montoro-Rodriguez et al. (2003), where higher levels of carer stigma were significantly associated with greater use of ‘in-home respite’. This relationship was not statistically significant for carer stigma and ‘adult day care’, which may indicate that in-home services are more acceptable to carers who experience stigma. The stigma variable in this study was a composite of four items which together indicate that the ‘stigma’ referred to carers’ own embarrassment/discomfort relating to the behaviour of their relative. While stigma is an important and multifaceted factor which can impact ‘respite service’ use, it is not clear from the literature how it relates to respite as an outcome.

## **2. Service factors**

Along with the above client factors, four key service factors that impact the carer's ability to experience a mental break have been identified and are outlined below: 1) the service model and characteristics, 2) care quality and staff expertise, 3) meaningful occupation for the person with dementia, and 4) communication and support.

### **Service Model & Characteristics**

The 'respite service' model and characteristics are also significant in terms of the carer's willingness to use services and ability to experience a mental break.

Mixed carer preferences have been reported in relation to in-home and day service models (Cotrell, 1996; O'Connell et al., 2012). Factors influencing a carer preference for day services include 'dementia stage' (Cotrell, 1996) and the nature of the care relationship (co-residing adult children 'overwhelmingly' favour day services, unlike spouses who prefer in-home models [Cotrell, 1996]). Factors influencing a preference for in-home models include the physical environment (less 'clinical' and 'institutional' than other models) (Holm and Ziguras, 2003) and the smaller staff-client ratio compared to day services (Holm and Ziguras, 2003). The acceptability of the model to the person with dementia also influences carer use and preference (Cotrell, 1996; Strang and Haughey, 1998). Residential/overnight models were the least preferred (Cotrell, 1996; Phillipson and Jones, 2011b) and are often seen as a 'last resort' with a view to delaying institutionalisation (Phillipson and Jones, 2011b). People with dementia have reported a preference for in-home models as there is more continuity and opportunity to develop relationships (Holm and Ziguras, 2003). Day services have been found to be particularly unacceptable to older males with dementia and those with early onset dementia (Phillipson and Jones, 2012; Parahoo et al., 2002).

There were two important themes relating to respite service characteristics, across models, which influenced the acceptability of the service from carers' perspectives. Carers have called for services to be more flexible and responsive in terms of meeting the dyad's needs, e.g. regarding availability, opening hours, duration, activities, transport and meals (Beisecker et al., 1996; Holm and Ziguras, 2003; Kirkley et al., 2011; O'Connell et al., 2012; Phillipson and Jones, 2011a; Tretteteig

et al., 2017; Tretteteig et al., 2016; Tang et al., 2011). Continuity was also vital, in relation to both care and staffing (Cotrell, 1996; Hochgraeber et al., 2015; Holm and Ziguras, 2003; Kirkley et al., 2011; Parahoo et al., 2002; Phillipson and Jones, 2011a), particularly as the condition progresses (O' Connell et al., 2012).

### **Care Quality and Staff Expertise**

Dementia care quality was a prime concern for carers. Absence of trust in the quality of care provided by a service for the person with dementia is a crucial barrier to a positive respite experience (Beisecker et al., 1996; Cotrell, 1996; de la Cuesta-Benjumea, 2010; McGrath et al., 2000; O' Connell et al., 2012; Phillipson and Jones, 2011b; Strang, 2001; Strang and Haughey, 1998; Tretteteig et al., 2016). Perceived poor care quality indicates that service use is not mutually beneficial for the dyad, precluding a mental break for the carer (de la Cuesta-Benjumea, 2010; Hochgraeber et al., 2015; McGrath et al., 2000; Phillipson and Jones, 2012). Staff approaches to, and expertise in, dementia care were central to carers' perceptions of care quality (Beisecker et al., 1996; Cotrell, 1996; Tretteteig et al., 2016) and influence carers' ability to experience respite (Beisecker et al., 1996; Donath et al., 2009). Staff should be 'kind' and 'empathic' in their approach (Beisecker et al., 1996; O' Connell et al., 2012), demonstrate 'respect' for the person with dementia, and get to know and understand them as people (de la Cuesta-Benjumea, 2010; Donath et al., 2009; O' Connell et al., 2012; Parahoo et al., 2002). Carers attribute poor outcomes for the person with dementia, in part, to a lack of appropriate training in dementia care for the staff (Cotrell, 1996; Hochgraeber et al., 2015; Phillipson and Jones, 2011a; Phillipson et al., 2014). Respite service managers emphasised the importance of recruiting 'the right staff' and supporting them appropriately, with supervision and peer meetings, to deliver person-centred care (Kirkley et al., 2011). This was considered challenging however, given the substantial barriers (e.g. resource constraints, pay levels, staff knowledge and skills, leadership style) service managers face in implementing organisational cultural change in 'respite services', which were originally designed with only carers in mind.

## **Meaningful Occupation**

An important way in which carers can perceive mutual benefit from service use is when the service engages the person with dementia in meaningful activity (Donath et al., 2009; Holm and Ziguras, 2003; McGrath et al., 2000; Myren et al., 2013; O'Connell et al., 2012; Parahoo et al., 2002; Phillipson and Jones, 2011a; Tretteteig et al., 2016). Meaningful activity/occupation means different things to different carers, e.g. physical exercise and games (Donath et al., 2009), tailored activities that the person with dementia enjoys (Holm and Ziguras, 2003; O'Connell et al., 2012), 'stimulating' activities (Beisecker et al., 1996), an opportunity for social interaction (McGrath et al., 2000) and/or the promotion of personal abilities (Hochgraeber et al., 2015; McGrath et al., 2000; Myren et al., 2013; Parahoo et al., 2002). However, regardless of the activity, it was clear from these studies that it was not acceptable from the carers' perspectives for people with dementia to just be 'kept busy' (Hochgraeber et al., 2015). Holm and Ziguras (2003) outlined how services providing meaningful activity can be more acceptable to people with dementia. Phillipson and Jones (2011a) reported this is also true for the carer, and can boost their confidence in the service as an acceptable substitute. Carers believe that people with dementia benefit from being engaged in 'positive occupation' that recognises their skills, abilities and capacity, as this enhances their 'personhood' and 'sense of self' (Phillipson and Jones, 2012). When positive occupation for the person with dementia is observed, carers are more likely to perceive mutual benefit and achieve a respite experience.

## **Communication & Support**

Carers have highlighted the importance of service-dyad interactions, in terms of communication, support and information, for perceiving benefit from service use (Donath et al., 2009; Gilmour, 2002; O'Connell et al., 2012; Phillipson and Jones, 2011a; Tretteteig et al., 2017). Poor service-dyad and within-service staff communication negatively impact carers' perceptions of the quality of care and the safety of the person with dementia (O'Connell et al., 2012). Phillipson and Jones (2011a) reported that carers felt services could support them better if staff made an effort to engage with them about the person, their care needs, and the dyad's existing care routine. Carers feel that services are a worthy substitute when they demonstrate

an intimate knowledge of the person with dementia, as this is a key element of family care (de la Cuesta-Benjumea, 2010). Gilmour (2002) states that for a service to be acceptable, staff must relocate themselves in ‘non-traditional’ and ‘secondary’ supporting care roles, where the clients direct the care and the staff support and deliver this. There must be an ongoing dialogue between the dyad and the service, which fosters a triadic partnership based on understanding and trust. This may be the cornerstone of facilitating a positive respite experience for carers. Services should also design and deliver ‘context-specific interventions’ for the carer, which are tailored to their individual relational, psychosocial and practical needs, to facilitate them in achieving a ‘legitimate’ break from caregiving (de la Cuesta-Benjumea, 2010; de la Cuesta-Benjumea, 2011).

### **Mutuality: The Key Antecedent?**

It seems likely that the client and service factors outlined above interact differentially to influence the respite outcome for each dyad. However, mutuality may be the overarching prerequisite for carers in relation to achieving a respite experience. Here, we posit, in line with the findings of other authors, that not only must the carer believe that they can benefit from service use, the carer must also perceive that the person with dementia is satisfied with and benefitting from service use, before they can allow themselves to experience respite (Holm and Ziguras, 2003; McGrath et al., 2000; O’Connell et al., 2012; Phillipson and Jones, 2012; Robinson et al., 2012). In this way, service use must be perceived as *mutually beneficial* by the carer, if the carer is to achieve a mental break (Holm and Ziguras, 2003; McGrath et al., 2000). The need for perceived mutual benefit can be understood as a need for the carer to trust that the service is at least an adequate substitute, in order to limit the relational and psychosocial barriers to accepting the need for a respite experience. The respite service must also have strong person-centred origins and attributes if the carer is to believe that it is an adequate substitute.

While the centrality of the person with dementia is very clear for carers in the papers outlined above, it must be noted that the perspectives and experiences of people with dementia themselves have been largely neglected to date in relation to the respite literature. This is important and will be considered further in the discussion section of this chapter.

### **3.5.4 Consequences**

Consequences, according to Rodgers (2000), are themes or outcomes that arise from the concept. Two recent systematic reviews of the effectiveness literature in relation to ‘respite services’ for people with dementia and their carers have been conducted by Maayan et al. (2014) and Vandepitte et al. (2016). These reviews indicate that the evidence for the effectiveness of ‘respite services’ across service models, for a range of outcomes, including institutionalization and carer burden, is largely mixed (Maayan et al., 2014; Vandepitte et al., 2016). There is evidence to suggest that day services are effective in relation to ‘reducing carer burden’ and ‘dementia-related behaviours’. However, adverse outcomes including ‘increased carer burden and distress’ have been reported in relation to residential respite services. Furthermore, day service use was associated with accelerated nursing home placement (Vandepitte et al., 2016).

The qualitative findings regarding outcomes in relation to ‘respite service’ use are also mixed. Some carers reported improved coping and emotional regulation (Beisecker et al., 1996; Cotrell, 1996) and a perceived increased capacity to care for longer (Beisecker et al., 1996; Phillipson and Jones, 2012). Day services are considered beneficial for people with dementia by their carers in terms of social interaction, cognitive stimulation, quality of life, self-esteem and enjoyment. They can also allow the carer to maintain employment (Beisecker et al., 1996; Phillipson and Jones, 2012). However, carers also report negative outcomes of respite service use, including functional decline, broken teeth, pressure ulcers, malnutrition, weight loss, reduced mobility and deterioration in dyad relations (Cotrell, 1996; O’Connell et al., 2012; Phillipson and Jones, 2011b).

While the mixed results regarding the effectiveness of service use have been attributed to heterogeneity in service models and characteristics, as well as in research designs (Maayan et al., 2014; Vandepitte et al., 2016), it is probable that the traditional conceptualisation of respite as a service, is partially accountable. It is more likely that service user outcomes are influenced by whether or not carers actually experience a restorative mental break while using services (Strang, 2000a; Strang and Haughey, 1998). To date, there is an absence of research defining the desired or anticipated outcomes of a mental break for the carer, or evaluating the



association between mental breaks and outcomes for the dyad. In practice, it seems important that services that aim to facilitate respite strive to understand what each individual dyad values in terms of outcomes, and determine how best these could be achieved.

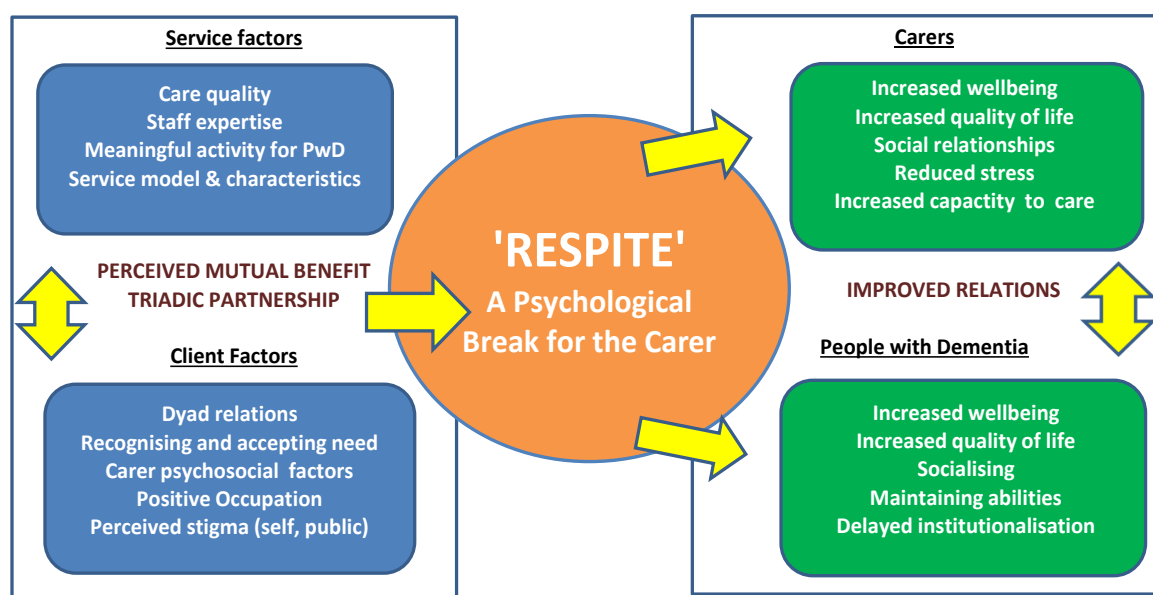
### 3.5.5 Concept Definition

Based on the analysis of the attributes, antecedents and outcomes of ‘respite’, it seems that, from the perspective of carers of people with dementia, ‘respite’ is more usefully conceptualised as:

*A psychological outcome of a mental break for carers, which can be facilitated by the use of formal health and social care services under certain conditions, when the carer perceives that service use is necessary and mutually beneficial for the dyad.*

A conceptual model of respite, as it relates to dementia, is outlined in figure 3.2. This model depicts the range of interconnected client and service factors (outlined above), which influence the carer’s ability to achieve a respite experience through service use, as well as the potential outcomes associated with respite under this conceptualisation, again from the carer perspective.

**Figure 3.2 The role of health and social care services in facilitating respite as an outcome**



### **3.6 Discussion**

This aim of this paper was to establish a level of conceptual clarification around respite in dementia, from the perspectives of key stakeholders, as they are found in the literature, across health disciplines. An ancillary aim of this paper was to consider the concept in the context of the person-centred care paradigm, which will be further deliberated below.

Respite is still characterised, as it has been historically, as a service. However, in more recent years it is coming to be understood from the carer's perspective, i.e. as a psychological outcome, a mental break for carers. The achievement of such a mental break through the use of formal services, can be influenced by a range of complex and interconnected (i) client (dyadic relations, recognising and accepting need, carer psychosocial factors, restorative occupation and stigma) and (ii) service (service model and characteristics, care quality and staff expertise, meaningful occupation, and communication and support) 'antecedents'. The key antecedent underlying the achievement of a positive respite experience for the carer is that the carer perceives that 'mutual benefit' is being garnered from service use, such that the person with dementia is safe and well, is satisfied with the service and is engaged in meaningful occupation/activity, during this break in caregiving. It is also important for the carer, that the care is underpinned by the principles of personhood, i.e. that the person is treated with empathy, dignity and respect, is meaningfully included in decision-making, and that the strengths, interests and skills of the person with dementia are nurtured. From the carer perspective, communication and information are key to fostering trust in the service and the quality of care. Communication is also vital to nurturing a triadic partnership, and enables the carer to trust that the service is indeed mutually beneficial for the individuals comprising the dyad. This is essential to facilitating a meaningful respite experience for the carer.

#### ***3.6.1 'Respite' in Other Related Contexts***

These findings have some parallels as well as dissimilarities with concept analyses of respite, which are not focused specifically on dementia, but other related contexts, e.g. older adults; intellectual disability (Chappell et al., 2001; Evans, 2013a; Hanson et al., 1999; Whitmore, 2017).

Hanson et al. (1999) considered the concept of ‘respite care’, as opposed to just the term ‘respite’ in relation to older adults. This analysis is slightly more limited in scope than the present analysis, in that consideration of the term ‘respite care’ delineates respite as a service from the outset. However, even under this characterisation, the authors concluded that, in relation to older adults generally, ‘the concept of ‘respite care’ has to be broadened to encompass the needs of family carers for education, information and support’, somewhat intimating the present point that effective communication, information and support are important service factors in relation to respite. Similar to Hanson et al. (1999), Whitmore (2017) also explored the concept of ‘respite care’, but in relation to children with special healthcare needs, unsurprisingly also characterising it as a service ‘providing carers with temporary relief from their responsibilities of caregiving’. However, Whitmore (2017) does acknowledge that an ‘adequate break’ for the carer has to be more than the physical break from caregiving which the ‘service’ perspective generally intimates. Awareness of the need for respite services, acceptance of the use of respite services, the service characteristics and the quality of respite care are key to improved outcomes, e.g. ‘decreased caregiver stress’ and ‘improved family quality of life’.

Evans (2013a) explored ‘respite’ as a concept in relation to older adults generally. However, he characterised respite as a ‘complex intervention’, which on the surface, is more in line with characterising respite as a service, than as an outcome. However, this is less passive than the basic ‘service’ characterisation as it indicates, similar to the argument in this analysis that the service must actively and purposefully interact and intervene with the clients. In this way, merely taking custody of the person with dementia and facilitating a physical break for the carer is not sufficient. Evans (2013a) concluded that the concept of respite consisted of three distinct attributes, i.e. partnership (relationship with service), service (characteristics, assistance and engagement) and outcomes (for the carer and care-recipient). These attributes, correspond with some of the present findings, e.g. service-dyad communication/partnership, the role of service characteristics, the care quality and approach, and the need for a focus on outcomes for people with dementia as well as carers.

The findings that most closely align with those reported here are from Chappell et al. (2001) in their seminal study on the meaning of respite, which involved in-depth

interviews and focus groups with 294 carers of older adults, including people with dementia. None of the carers, according to the authors, ‘spoke of their experience of respite in relation to service provision’. The authors concluded that respite should be reconsidered as an outcome, in line with the carers’ perspectives on the meaning of the term, as opposed to a service, and that policy and practice in this area should be based on evidence, informed by the voice of the service user.

### ***3.6.2 ‘Respite’ and Person-Centred Care: Irreconcilable Concepts?***

It is clear from the findings of this analysis, and the findings of previous concept analyses that the care-recipient and their experiences and perspectives are not generally considered in relation to the term ‘respite’.

‘Respite’ is laden with ambiguous meaning that serves to create an imbalance of power in relation to the caregiving relationship, falling almost exclusively on the side of the carer. From the ‘related terms’ section above (table 3.3), it is clear that concepts related to ‘respite’ are fundamentally connected to the carer’s experience of providing care to the person with dementia, and more often than not, represent their experience of the relationship in a negative light (e.g. ‘burden’, ‘strain’, ‘depression’, ‘stress’, ‘burnout’, ‘anxiety’, ‘coping’, ‘carer support’). This narrative tends to omit the experience and perspective of the person with dementia in the caregiving relationship.

This omission of the person with dementia is problematic for the conceptualisation of respite as an outcome, given that in order for carers to realise a respite experience through service use, they are clear that the person with dementia and their wellbeing, must be the foremost consideration. Given that the term ‘respite’ does not encompass the experience of the person with dementia, it is inherently limited in its ability to guide the design and planning of services and care in such a way that can facilitate carers to achieve a respite experience, and certainly is not consistent with a person-centred approach to health and social care service delivery for people with dementia. Therefore, it seems logical that the term ‘respite’ cannot sensibly be employed going forward, without us knowingly neglecting the experience of the person with dementia.

There is a need for a new term that connotes, and indeed embraces, the perspective and experience of the carer *and* the person with dementia in relation to the use of health and social care services which provide a break in the caregiving relationship. Clearly, this term must indicate that the care provided by formal services should have a dual focus of (i) facilitating and supporting a respite experience for the carer (as defined and outlined above) and (ii) engaging the person with dementia in occupation and activity that is meaningful and beneficial, from their own perspective.

We propose ‘restorative care’ as a useful alternative to describe the process whereby people with dementia and their family carers mutually benefit from the experience. This term acknowledges the intricate interdependence involved in the dyadic attachment relationship and suggests the central role that services could play in delivering tailored, personalised interventions and supports to both dyad members in a way that is acceptable to them, and that satisfies individual and dyadic needs. It is through adherence to person-centred values that services can deliver the outcomes that matter, to both sides of the care relationship.

We postulate that the employment of this term, ‘restorative care’, may be useful for offsetting the limitations that conceptualising respite (either as a service *or* an outcome) as being only for the carer, has put on the aptitude and capacity of formal services to recognise and meet the individual needs of the carer and the person with dementia. Services must re-evaluate their goals in relation to providing ‘respite’ and consider that care should be delivered in line with person-centred values.

### **3.7 Chapter Conclusion**

This analysis has indicated that ‘respite’ in relation to dementia is still largely conceptualised as it has been historically understood, i.e. as a service that relieves ‘burden’ and reduces the strains and stresses of caring, for carers. However, there has been a shift towards viewing respite as a psychological outcome for carers, which can be facilitated through the use of formal health and social care services, if the carer perceives that mutual benefit will be obtained from the care provided. That can only be achieved if such care is rooted within personhood and puts the person with dementia at the centre of decision-making. Mutuality depends on the direct engagement of the person with dementia in the process of care. ‘Respite’, as a

concept, is not fit for purpose in this respect and is irreconcilable with the person-centred care paradigm.

‘Restorative care’ is an alternative to respite that encompasses the perspectives of both the carer and the person with dementia in relation the use of health and social care services. The use of this term would be helpful for service providers in reimagining, recalibrating and reorganising services to reflect the needs and preferences of people and their carers. Future research must explore the perspectives of people with dementia specifically, as well as carers and other key stakeholders (e.g. service providers, healthcare professionals), in relation to service use for the purpose of restorative care. This is necessary to determine what acceptable, appropriate and effective restorative care would look like.

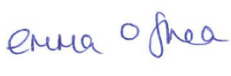
With this clearer understanding of the meaning and implications of the term ‘respite’, the next chapter goes on to systematically review and synthesize the existing qualitative literature regarding the experiences and perspectives of key stakeholders in relation to respite services for dementia.

## Declaration of Authorship

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Title of co-authored paper included in the thesis under examination	Key stakeholders' experiences of respite services for people with dementia and their perspectives on respite service development: A qualitative systematic review.
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This paper is one of	<input type="text" value="4"/> co-authored papers to be submitted as part of the PhD by publication thesis submitted for examination
Section 3: Candidate's contribution to the paper	
Provide details below of the nature and extent of your contribution to the paper (include both your intellectual and practical contributions) and your overall contribution in percentage terms:	
I conceived of the idea together with my primary supervisor. I conducted the systematic literature review and the meta-ethnography. I also interpreted the findings and then drafted and submitted the manuscript. I estimate that my contribution was 80%.	
Where a paper has joint or multiple authors, list the names of all other authors who contributed to the work (this can be appended in a separate document, where necessary):  Prof. Kate Irving; Dr. Suzanne Timmons; Prof. Eamon O' Shea; Dr. Siobhan Fox	
Section 4: Signature and Validation	
I confirm that the following statements are true:	

the information I have provided in this form is correct

this paper is based on research undertaken during my candidature at DCU

Signature of PhD Candidate: 

Date: 04/10/2019

I confirm that the information provided by the candidate is correct:

Signature of Principal Supervisor: 

Date: 04/10/2019

In some cases, it may be appropriate for verification to be given by both the principal supervisor and the lead/corresponding author of the work (where the lead/corresponding author of the work is not the candidate or the principal supervisor):

Signature of Lead/Corresponding Author N/A



## **4 A QUALITATIVE SYSTEMATIC REVIEW AND META- ETHNOGRAPHY OF STAKEHOLDERS' EXPERIENCES OF RESPITE SERVICES FOR PEOPLE WITH DEMENTIA**

The work presented in this chapter has been published as:

O' Shea, E., Timmons, S., O' Shea, E., Fox, S., and Irving, K. (2017) 'Key stakeholders' experiences of respite services for people with dementia and their perspectives on respite service development: a qualitative systematic review', *BMC Geriatrics*, 17(1), p. 282. doi: 10.1186/s12877-017-0676-0.

## 4.1 Abstract

**Background:** Respite services provide a break in the caregiving relationship for people with dementia and their carers, however they are often under-utilised and service acceptability can be low. This study aims to understand key stakeholders' experiences of respite services for people with dementia and their carers.

**Methods:** A systematic search was conducted of the PubMed/Medline, Embase, CINAHL, PsychInfo, Scopus, Web of Science, and Cochrane Library databases (1980 – 2016, English) with fixed search terms relating to 'respite' and 'dementia', following PRISMA guidelines. Noblit and Hare's approach to meta-ethnography was employed.

**Results:** In total, 23 papers were reviewed, describing 20 independent samples across 12 countries. The views of 889 participants were synthesized (mostly carers', n=690). Five key concepts were identified and outlined, i.e. 1) the transition to service use 2) expanding organisational capacity 3) dementia care quality 4) building a collaborative care partnership and 5) dyad restoration. There was broad agreement around the key areas for service development across stakeholder groups (flexible and responsive person-centred care, meaningful activity for people with dementia, enhanced client-service communication and informational support). However, there was clear divergence in stakeholder perspectives around the barriers to the implementation of such developments. Organisational tension was evident between frontline staff and management in respite services, hindering the cultural change necessary to facilitate service development in line with client preferences.

**Conclusion:** Respite services must surmount internal organisational barriers to change, and cultivate a collaborative, solution-focused care culture, which acknowledges the centrality of the dyad and their care preferences. Future research should explore the development of alternative/modified community respite service models, which have greater capacity to be responsive to the needs of each individual dyad. The perspectives of people with dementia must be included in research in this area going forward.

## **4.2 Chapter Introduction**

This chapter is comprised of a qualitative systematic review and meta-ethnography of multiple stakeholders' perspectives on respite services in the context of dementia. It synthesizes and interprets the findings of the existing qualitative literature, and was instrumental in informing the direction and the design of the primary qualitative study conducted for the purposes of this thesis, in the Irish context (the findings of which are outlined in later chapters).

## **4.3 Background**

'Respite' services are often cited as an essential model of carer support, which can delay or prevent institutionalisation for the person with dementia, by providing a temporary break in caregiving for the carer (Maayan et al., 2014). Respite models include residential care, day services and in-home care, and services can differ considerably across a range of parameters including: provider; setting; duration; and the quality and components of care. Carers' service needs may differ on a number of broad life circumstances (Stirling et al., 2010), including age, cohabiting, carer health status, other dependents, the nature of their relationship to the person with dementia and their employment status. However, there is evidence that along with access and availability issues, and psychosocial barriers to attendance, there is a significant lack of client trust in existing respite services and the quality of dementia care provided (Shaw et al., 2009; Phillipson et al., 2013). These findings indicate that respite services may not always provide care that is acceptable to its clients (i.e. people with dementia and carers).

To date there has not been a systematic review of the qualitative literature which can inform respite service development in relation to dementia. Therefore, in order to understand how we can feasibly develop respite services, the research question guiding this review was: What are key stakeholders' experiences of respite services, and their perspectives on service development, in relation to dementia? It is important to consider the perspectives of the range of key stakeholders (clients [i.e. people with dementia, carers], respite service staff and management, other healthcare professionals with a stake in respite services, policy makers) and to marry these together, to understand not only how respite services should be developed in line

with client preferences, but also the factors that might influence the implementation of such developments in complex health and social care systems.

## 4.4 Methods

The review followed the Centre of Reviews and Dissemination guidelines for conducting systematic reviews in healthcare and is reported in line with the ‘enhancing transparency in reporting the synthesis of qualitative research’ (ENTREQ) statement (see appendix D for completed checklist) (Tong et al., 2007). In line with Noblit and Hare’s (1988) approach to meta-ethnography, the first step was to clearly state the specific research question. The second step was to determine the inclusion/exclusion criteria (see table 4.1) and devise a search strategy to identify studies which can speak to the research question.

**Table 4.1 Inclusion and exclusion criteria guiding study selection**

<b><u>Inclusion criteria</u></b>
<p>Primary qualitative studies focused on respite services in dementia.</p> <p>Mixed methods research with a distinct, clearly reported qualitative element.</p> <p>Studies with descriptions of the data collection and analysis procedures.</p> <p>Studies employing surveys will be included if they collect qualitative data relating to the research question (and meet other inclusion criteria).</p> <p>Study participants with dementia must be community-dwelling.</p> <p>Studies published in English, in peer-reviewed journals.</p>
<b><u>Exclusion criteria</u></b>
<p>Quantitative studies with no qualitative element.</p> <p>Qualitative studies which do not include the perspectives of key stakeholders, e.g. studies employing observational techniques only.</p> <p>Studies that include or are focused on older adults generally (not just people with dementia) and/or their carers.</p> <p>Studies which are not peer-reviewed, e.g. reports, theses.</p> <p>Studies not reported in English.</p>

### 4.4.1 Search Strategy

A search was conducted of the PubMed/Medline, Embase, CINAHL, PsychInfo, Scopus, Web of Science, and the Cochrane Library databases (date parameters 1980 – 2016). The search strategy aimed to identify all peer-reviewed literature relating to

the research question. Google and Google Scholar were also searched to locate any unindexed peer-reviewed literature relevant to the research question. A hand search of the reference lists of the included studies, and of other relevant reviews, was also conducted as a ‘back search’, while the ‘cited by’ function of Google Scholar was used to ‘forward search’ for articles that have cited the included studies, and have relevance to the present research question.

#### ***4.4.2 Search Terms***

MeSH headings are the US National Library of Medicine's controlled thesaurus of terms used to organise the MEDLINE/PubMed databases. The Cochrane Library and the CINAHL database also use MeSH headings. The following MeSH headings were used in the search strings: Respite Care (MeSH)\*, Day Care, Medical (MeSH)\*, Dementia (MeSH)\*, Alzheimer’s disease (MeSH)\*

The full list of search terms, in Boolean operators, were:

‘Dementia **OR** Alzheimer’s disease **OR** Alzheimer’s **OR** cognitive impairment **OR** older adults **OR** frail elderly’

**AND**

‘Respite care **OR** respite **OR** day care **OR** day-care **OR** residential respite **OR** in-home respite **OR** in home respite’.

#### ***4.4.3 Data Collection and Quality Appraisal***

Two authors independently screened abstracts and full-texts, and subsequently reviewed eligible full-text articles for inclusion, based on the above inclusion/exclusion criteria. Where articles were rejected, reasons for rejection were recorded and are outlined in the PRISMA flow chart (figure 4.1). Data items extracted include information about the publication (date, authors, country, study aim(s)), study eligibility (design, methods, and analysis), respite model, participant characteristics, and raw data (in the form of themes and/or quotations). The data were managed using NVivo 11. The quality of the studies was assessed using the Evaluation Tool for Qualitative Studies (ETQS) (Long and Godfrey, 2004). This tool was employed with a view to assessing the validity, robustness and transparency of

each study. According to Hannes et al. (Hannes et al., 2010), the ETQS is preferable to the widely-used CASP tool (CASP, 2006), as it provides more detailed instructions on how to interpret the evaluation criteria. It contains the following overarching sections, each with a template of key questions to guide the appraisal: phenomenon studied and context issues; ethics; data collection, analysis and researcher bias; and policy and practice implications (Long and Godfrey, 2004). The quality assessment was conducted independently by two authors (EOS, SF). The quality assessment was not used to exclude studies in this review, given that the findings reflect the quality of the written report, rather than the actual research process in many cases (Atkins et al., 2008; France et al., 2014).

#### ***4.4.4 Data Analysis and Synthesis***

The analysis and synthesis were guided by Noblit and Hare's meta-ethnography approach (Noblit and Hare, 1988), and informed by recent methodological papers on this evolving approach by France et al. (2014) and Toye et al. (2014). Meta-ethnography is a form of interpretative synthesis that can be used in the reviewing and evaluation of qualitative research studies (Noblit and Hare, 1988). This method was chosen as it moves past the simple summarising of primary data. It is used as an inductive method which serves to compare, translate and integrate concepts across studies, while also attempting to preserve the context and interpretive properties of the primary data (Atkins et al., 2008; Dixon-Woods et al., 2005). This method is often used to create new theories, or develop upon existing ones (Toye et al., 2014). It is increasingly being employed in health research, in particular in relation to patients' experiences of illness and care (Atkins et al., 2008).

Initially, papers were read and re-read to identify information on the study context. Subsequently, the 'results' and 'discussion' sections of the included studies were coded inductively for meaning, as they related to the research question. Codes were attached to meaningful segments, as opposed to strict line-by-line coding. A second researcher (SF) independently coded over 20% of papers (5/23) for quality assurance purposes; differences were settled through discussion.

These codes and the corresponding raw data were then compared, using (i) reciprocal translation (recognising reoccurring themes/concepts across studies) and (ii) refutational translation (recognising themes/concepts that are dissimilar across

studies, but cannot be explained by contextual factors). A constant comparison approach was employed to achieve this. Included studies were considered in chronological order by date of publication, and the codes and concepts in each subsequent study were compared against those in all the studies that preceded it. This continued through an iterative process until no new translations could be made.

In terms of the data synthesis, the focus of our ‘third order’ construct-building (i.e. our interpretations), was based largely on marrying the ‘second order’ constructs (the original authors interpretations of the primary data), with our interpretations of first order constructs (participant raw data), all while bearing the original study context in mind. The synthesis of the present findings led to 23 final translations (see appendix F), which informed the final line of argument and the conceptual model (see figure 4.2). NVivo11 was used to organise and manage the data, codes and concepts during the initial translation stage. However, the final translations (and the corresponding data and concepts) were extracted and synthesized using a matrix in Microsoft Excel. The synthesis was conducted by EoS and KI, in consultation with the other co-authors. The seven sequential steps that were followed in relation to the data synthesis element of this meta-ethnography are summarised in table 4.2.

**Table 4.2 Key steps involved in conducting the data synthesis**

Step	Process
1	Active reading of the studies to understand the context, to appraise study quality and to extract relevant data.
2	Themes were identified in the ‘results’ and ‘discussion’ sections of papers from i) participant raw data (first order constructs) and ii) the authors’ interpretations of this (second order constructs), and coded for meaning in relation to the research question.
3	Second order constructs and the assigned codes were compared and contrasted within and across studies in NVivo11.
4	Overall key concepts were identified and extracted to excel to be outlined in a matrix.
5	The relationship between i) each study and ii) each key concept was examined, with the original context of each in mind.
6	Studies were ‘translated’ into one another. The similarities/differences identified enabled the development of a conceptual model.
7	Active re-reading of the original studies was conducted to verify the appropriateness of the synthesis, prior to write-up.

## 4.5 Results

A total of 12,763 records were identified through the database search (see figure 4.1 for flow-chart). After the title/abstract screening process, and removal of duplicates (N=148), 216 full texts were reviewed. We excluded 194 records at this stage. One further paper was identified through a forward hand-search of the 22 included papers. Thus, we included 23 papers in total.

### 4.5.1 *Characteristics of Included Studies*

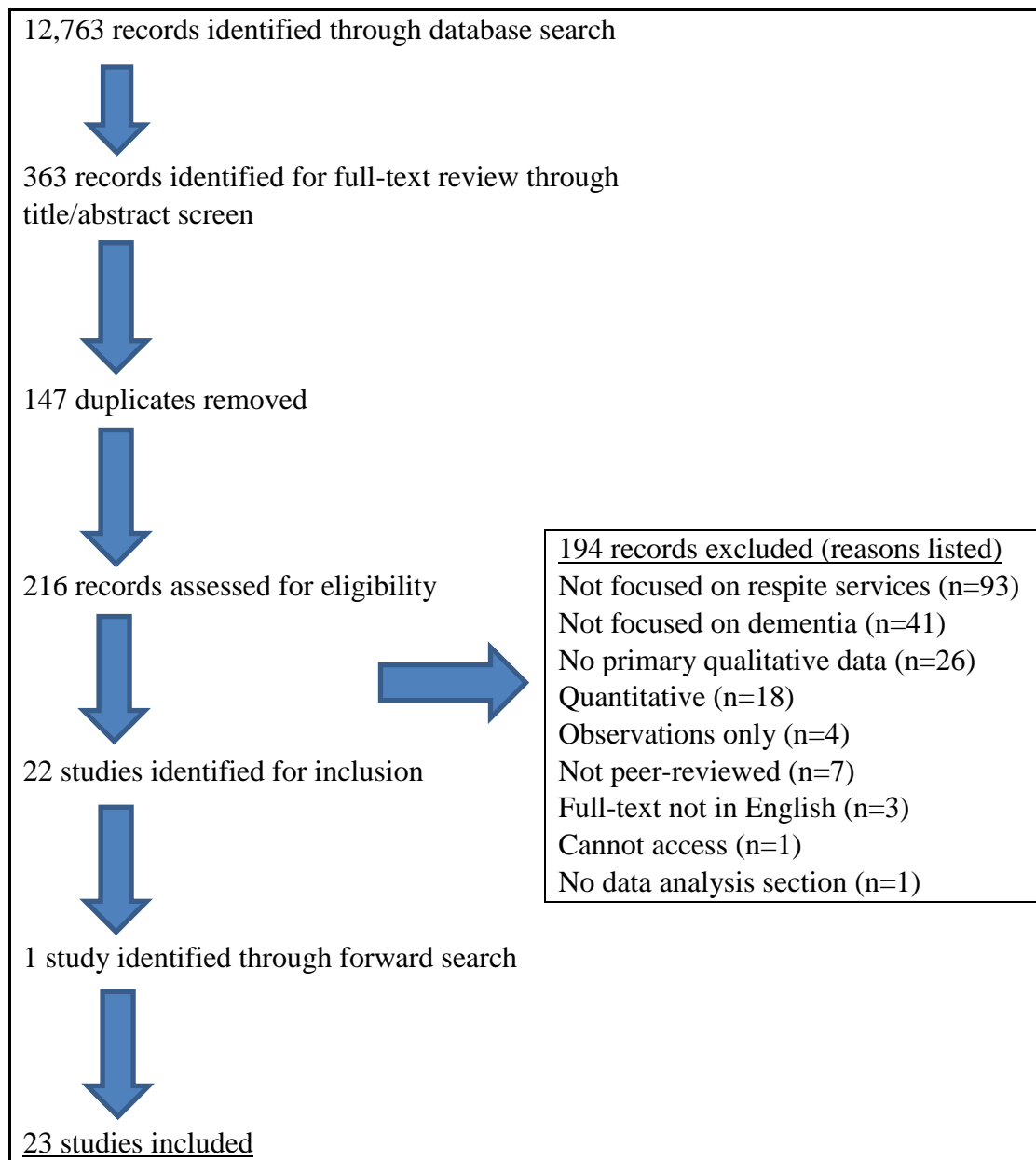
In total 23 papers were reviewed, describing 20 independent samples (17 entirely qualitative studies, three mixed methods studies). The views of 388 participants were synthesized from the 17 independent qualitative studies, including 13 people with dementia, 224 carers, 44 ‘care providers’, 34 ‘frontline staff’, 53 ‘managers’, 12 ‘volunteers’, six ‘academic/policy-makers’, and two ‘independent consultants’. Of the three unique mixed methods (four papers) studies reviewed, the perspectives of a further 466 carers (open-ended survey responses), 18 ‘frontline staff’ (semi-structured interviews) and 17 ‘managers’ (semi-structured interviews) were synthesized. The studies were conducted across 12 countries, spanning four continents (see appendix E for details on the study characteristics).

### 4.5.2 *Quality Assessment*

The summary of the quality assessment conducted using the ETQS is illustrated in table 4.3. Overall, ten studies were considered ‘medium-high’, ten studies ‘medium’, and three were ‘low-medium’ quality, in terms of methodological reporting transparency. No articles were excluded on the basis of the quality assessment.



**Figure 4.1 PRISMA flow chart of study selection process**



#### 4.5.3 Translation

This analysis has highlighted five key concepts, comprised of 12 subthemes that outline the experiences of key stakeholders in dementia in relation to respite services, and their perspectives on respite service development. The overarching concepts are presented in the following order (not indicative of concept salience):

1. Transitioning to service use
2. Expanding Organisational Capacity

3. Dementia Care Quality
4. Building a Collaborative Care Partnership
5. Dyad Restoration

Both first order (raw primary data, i.e. direct participant quotations) and second order interpretations (study authors' interpretations of the primary data) are employed to support the analysis below. First order interpretations are indicated in italicised quotations, while second order interpretations are indicated by non-italicised quotations. The final synthesis of the concepts from the range of stakeholder viewpoints presented below, led to the development of a model (figure 4.2) which illustrates 1) the crucial areas identified for improvement across respite service models, as they relate to people with dementia, and 2) the perceived barriers and facilitators to implementing these developments, primarily from the perspectives of clients (almost entirely carers' views), and respite service staff and management.

**Table 4.3 Quality assessment of the included studies**

First author, year	Phenomena under study	Theoretical framework/ orientation	Setting	Sampling / Recruitment	Depth / Breadth of Perspective	Ethics	Data collection	Data Analysis	Positionality/ Reflexivity	Policy/ Practice Implications	Quality Assessment
Brataas, 2010	√	√	√	√	√	√	√	√	X	√	Medium-High
Cahill, 2003	√	√	√	X	√	X	X	X	X	√	Low-Medium
de Jong, 2009	√	√	√	√	√	√	√	√	X	√	Medium-High
Donath, 2009	√	√	√	X	X	√	√	X	X	√	Medium
Donath, 2011	√	√	√	X	X	√	√	X	X	√	Medium
Gilmour, 2002	√	√	√	X	√	√	√	X	X	√	Medium
Gústafsdóttir, 2014	√	√	√	√	√	√	X	X	X	X	Medium
Hochgraeber, 2015	√	√	√	√	√	√	X	√	X	√	Medium-High
Holm, 2003	√	X	√	X	√	X	X	X	X	√	Low-Medium
Huang, 2016	√	√	√	√	√	√	√	√	X	√	Medium-High
Jansen, 2009	√	√	√	√	√	√	√	√	X	√	Medium-High
Kirkley, 2011	√	√	√	√	√	√	√	√	X	√	Medium-High
McGrath, 2000	√	√	√	√	X	X	√	√	X	√	Medium
O'Connell, 2012	√	√	√	√	X	√	√	X	X	√	Medium
Parahoo, 2002	√	√	√	√	√	X	X	X	X	√	Medium
Perry, 2001	√	√	√	√	X	X	√	X	X	√	Medium
Phillipson, 2011(IH)	√	√	√	√	√	√	√	√	X	√	Medium-High
Phillipson, 2011(RR)	√	√	√	√	√	√	√	√	X	√	Medium-High
Phillipson, 2012(DC)	√	√	√	√	√	√	√	√	X	√	Medium-High
Robinson, 2012	√	√	√	√	√	√	√	√	X	√	Medium-High
Strang, 2000	√	√	√	X	√	X	√	X	X	√	Low-Medium
Upton, 2005	√	√	√	X	√	√	X	X	X	√	Medium
Woolrych, 2013	√	√	√	√	√	X	√	X	X	√	Medium

X = Not Clear/Not Methodologically Sound; √ = Clear/Methodologically Sound

Quality assessment categories: Low-Medium = 6≥X, Medium 3-5X, Medium-High 2≤X

## Transitioning to Service Use

### *Timely Access to Services*

Accessing respite services was considered challenging for carers across a number of studies, both from the perspectives of carers (O'Connell et al., 2012; Robinson et al., 2012; Gústafsdóttir, 2014; Phillipson and Jones, 2011b; Phillipson and Jones, 2011a; Phillipson and Jones, 2012) and service providers (Jansen et al., 2009; Hochgraeber et al., 2015). The availability of appropriate services was generally deemed poor by carers: *“There are different levels of care but nothing is quick ... and there are not many places when you are actually faced with trying to find one to use”* (Phillipson and Jones, 2011b). Carers noted that availability was often poor even in what they considered “emergency situations” (Phillipson and Jones, 2011b; Phillipson and Jones, 2011a). This indicates a possible disparity between client and service views of what constitutes an ‘emergency’, influenced by the poor availability of respite services: *“...if I rang today and said I needed someone today because I’m going to the hospital...they’d say no we don’t have anyone”* (Phillipson and Jones, 2011a).

Carers experienced significant difficulties navigating the health and social care system, particularly in terms of identifying personnel who could connect them to available respite services and help them to identify their support needs (Robinson et al., 2012). Providers agree that the process of gaining access should be more transparent, and suggest that minimising bureaucracy and assigning a “central point of contact” to assist families would be beneficial (Jansen et al., 2009; Hochgraeber et al., 2015). Providers therefore see the service access problem to be rooted primarily in the under-resourcing and the infrastructural inadequacies of the system. They note, for example, that carers frequently present at hospitals to gain access to services as they reach crisis point, having failed to traverse the fragmented system (Jansen et al., 2009). However, some healthcare providers admitted some personal culpability at the service level, indicating that even they, staff working within the system, have a “lack of knowledge about the available services” (Hochgraeber et al., 2015).

While cost sharing did not feature as a major concern for carers, some carers do reference cost as a barrier to respite service use (O'Connell et al., 2012; Huang et al., 2016). Service providers agree that cost sharing sometimes acts as a barrier to

access, particularly for residential respite services (Jansen et al., 2009). However, other providers believe that reducing user costs would undermine the value of services for stakeholders and might ultimately adversely affect public perception of care quality (Hochgraeber et al., 2015).

A particularly common access concern for carers was the provision of safe and reliable transportation to and from community-based services (O'Connell et al., 2012; Phillipson and Jones, 2012; Hochgraeber et al., 2015; Holm and Ziguas, 2003; de Jong and Boersma, 2009; Brataas et al., 2010): *“the fact that they were able to provide transport to the centre and home again...without that it all would have been too hard”* (Phillipson and Jones, 2012). Despite the centrality of transport for carers, some service providers deemed this to be extremely resource-heavy, and therefore, not always feasible (Jansen et al., 2009; Cahill et al., 2003): *“You have to get them there in a reasonable time; however, the costs to take them there may prevent that”* (Jansen et al., 2009).

#### *Service Acceptability and Negotiating Service Refusal*

Carers describe a ‘settling in’ process whereby services are gradually introduced in an effort to make the person with dementia feel safe and secure in the midst of a significant care transition (Robinson et al., 2012; Parahoo et al., 2002). During this “trial and error” period, carers focus on appraising the service-client fit (Robinson et al., 2012), in terms of disruption to routine (O'Connell et al., 2012; Gústafsdóttir, 2014; Parahoo et al., 2002), personality factors (e.g. introverted vs. extraverted, (Huang et al., 2016)), sex (e.g. day services are less unacceptable to some men) (Phillipson and Jones, 2012), early versus later onset dementia (e.g. day services as unacceptable for early onset) (Phillipson and Jones, 2012; Parahoo et al., 2002), dementia ‘stage’ (Huang et al., 2016), staff ability to manage complex behavioural needs (Phillipson and Jones, 2011b; Phillipson and Jones, 2012; McGrath et al., 2000) and the service model (Parahoo et al., 2002; McGrath et al., 2000), with a view to assessing the initial acceptability of the service.

Carers report that service refusal on the part of the person with dementia can be a significant relational obstacle in the transition to service use (Robinson et al., 2012; Phillipson and Jones, 2011b; Phillipson and Jones, 2011a; Huang et al., 2016) and considerably adds to carer strain, sometimes making service use “more trouble than

it's worth" (Phillipson and Jones, 2011a). Some carers have suggested that this refusal is impacted upon by factors including stigma and fear of social evaluation (Robinson et al., 2012; Huang et al., 2016), (e.g. others "*thinking he's a dill*" (Robinson et al., 2012)). Carers' responses to service refusal were diverse, spanning from acceptance and acquiescence, to frustration and despair (Robinson et al., 2012; Phillipson and Jones, 2012; Huang et al., 2016; Upton and Reed, 2005). Other carers endured the initial conflict and persisted with service use regardless (Robinson et al., 2012; Phillipson and Jones, 2012). Carer suggestions for negotiating service refusal were around reassurance and "promoting feelings of safety and security" and "not giving up" (Robinson et al., 2012), as well as explaining the potential benefits of service use to the person with dementia (McGrath et al., 2000). Regarding the perspectives of people with dementia who use day services, initial ambivalence and reluctance in relation to service use diminished when they were made to feel secure about their "cognitive losses", and came to trust that the staff were predictable and reliable (Brataas et al., 2010). Providers' perspectives on the potential role of services in mediating service refusal are not clear. However, providers do acknowledge the potential role stigma has in dementia respite service non-use, believing that the stigma is in relation to service use itself and that the solution to this lies in improving the public image of respite care (Hochgraeber et al., 2015).

#### *Carers' Negative Beliefs about Service Use*

The transition to service use can also sometimes be complicated by carers' negative beliefs about service use, and their concerns about the safety of, and the outcomes for, the person with dementia (Phillipson and Jones, 2011b; Phillipson and Jones, 2012; Upton and Reed, 2005; Gilmour, 2002). Carers worried that service use would ultimately cause deterioration in the person with dementia, thus intensifying carer strain (Phillipson and Jones, 2011b; Upton and Reed, 2005; Gilmour, 2002): "*He might be a lot worse mightn't he? ... So I mean there's not much point in that is there, if I'm going to suffer afterwards*" (Upton and Reed, 2005). Additionally, for carers service use was synonymous with failure to cope (Phillipson and Jones, 2012), and/or to fulfil their duty to care (Phillipson and Jones, 2011a), leading to feelings of guilt (Phillipson and Jones, 2011b; Huang et al., 2016; Upton and Reed, 2005), particularly for spousal carers. Carers also felt that it signalled that the need for permanent placement in long-term care was imminent (Phillipson and Jones, 2011b;

Parahoo et al., 2002). However, carers sometimes had no choice but to overcome such beliefs about service use, as their need for support became insurmountable (Phillipson and Jones, 2012): *“I couldn’t allow that thought to stay with me because I knew I had to survive, I had to have help.”*

Furthermore, carers sometimes either don’t perceive, or accept, their own need for a break (Phillipson and Jones, 2011b; Huang et al., 2016; Parahoo et al., 2002).

However, as the dementia condition progresses and their coping resources deplete, they are forced to recognise this need (Phillipson and Jones, 2011b; Phillipson and Jones, 2012; Parahoo et al., 2002; Strang, 2000a). In particular, children of people with dementia may be forced to acknowledge this need sooner than spousal carers, because of a range of other responsibilities consistent with their life stage, including being in employment and raising their own children (Parahoo et al., 2002). Social, familial and professional (healthcare professionals) ‘referents’ can serve to reinforce and validate the legitimacy of the carer’s need for a break (Phillipson and Jones, 2011b; Phillipson and Jones, 2012; Jansen et al., 2009; Upton and Reed, 2005; Strang, 2000a): *“...they [day centre staff] helped me realise that it was normal to need a break”* (Phillipson and Jones, 2012). Conversely, other family members can potentially complicate the primary carer’s belief about the need for service use (Phillipson and Jones, 2011b; Huang et al., 2016; Parahoo et al., 2002), particularly if their cultural values favour family-managed care (Parahoo et al., 2002; Huang et al., 2016). Notably, service providers did not reference this aspect of the transition to service use.

## **Expanding Organisational Capacity**

### *Resources & Infrastructure*

According to care providers, one of the key barriers to respite service development and improved care quality is human and fiscal under-resourcing (Cahill et al., 2003; Jansen et al., 2009; Kirkley et al., 2011): *“If we had more money, more time, and more staff, that’s the only way I think we could make it more person-centred”* (Kirkley et al., 2011). Service providers feel that a lack of resources is preventing them providing good quality care (Gilmour, 2002; Jansen et al., 2009; O’Connell et al., 2012). In terms of infrastructure, service providers state that the lack of appropriate and acceptable community and in-home services for people with

dementia impedes the achievement of respite for some carers: *“I don’t always think that the respite options match the respite needs”* (Jansen et al., 2009).

Both carers and providers have indicated that the design of the built environment of respite services should be non-institutional, safe and serve to enhance the wellbeing of the person with dementia (Cahill et al., 2003; Holm and Ziguras, 2003; Huang et al., 2016; O’Connell et al., 2012; Phillipson and Jones, 2012; Woolrych and Sixsmith, 2013). Providers note that design features including inadequate space, orientation cues, and lighting and heating can increase behavioural and psychological symptoms in people with dementia (Cahill et al., 2003), while unsuitable facilities (e.g. confined shower space, poor water supply, no handrails) can impact patient safety and staff strain (Cahill et al., 2003; Woolrych and Sixsmith, 2013). Some providers had ideas for improving the built environment, but believed that such improvements hinged on receiving increased funding (Cahill et al., 2003).

#### *Clinical Governance*

Both service providers and carers highlight governance issues in respite service planning and delivery (Cahill et al., 2003; de Jong and Boersma, 2009; O’Connell et al., 2012; Phillipson and Jones, 2012; Woolrych and Sixsmith, 2013). For example, some models of respite (e.g. in-home) may require more regulation, safeguarding and monitoring to ensure high quality care provision and staff performance (de Jong and Boersma, 2009; Holm and Ziguras, 2003). Service providers note that the lack of training requirements for staff, particularly for in-home care, impacts care quality and continued service use: *“We rarely get people who understand both dementia and have personal care skills...and sometimes when people do come in they’re not trained, and they don’t do a good job, and they make it worse so the clients don’t use home care”* (Jansen et al., 2009). Along with improved training, measures should be implemented to increase staff accountability and responsiveness at service level (de Jong and Boersma, 2009). Some authors also argue that additional international and national guidance is needed to inform the delivery of ‘best practice’ dementia respite for healthcare professionals (Cahill et al., 2003; O’Connell et al., 2012; Phillipson and Jones, 2012).

Continuity of care is an essential issue in relation to respite services (de Jong and Boersma, 2009; Gilmour, 2002; Hochgraeber et al., 2015; Holm and Ziguras, 2003;



Jansen et al., 2009; Parahoo et al., 2002; Phillipson and Jones, 2011a; Woolrych and Sixsmith, 2013), and can influence access, length of stay and the capacity of the service to deliver individualised care (Woolrych and Sixsmith, 2013). Management hold that “service co-ordination necessitates ongoing cooperation and communication between formal carers across all domains of care” to foster effective cross-organisational working. However, frontline staff indicate that, from their perspective, “bed-blocking” is one of the key barriers to continuity, and that this must be rectified at the systems-level (Woolrych and Sixsmith, 2013). Poor care co-ordination can also affect the client’s perspective of the utility of the service; carers want evidence of collaboration between all professionals involved in the care of the person with dementia (de Jong and Boersma, 2009; Holm and Ziguras, 2003; O’Connell et al., 2012; Parahoo et al., 2002).

#### *Facilitating Organisational Change*

Fostering organisational change in respite services is a challenging task for service managers, particularly in relation to implementing person-centred care (Kirkley et al., 2011; Woolrych and Sixsmith, 2013). Part of the role of management is to foster the “natural potential of staff” in terms of implementing this approach (Kirkley et al., 2011). Staff must feel supported psychosocially and professionally (Hochgraeber et al., 2015; Kirkley et al., 2011; Woolrych and Sixsmith, 2013), and in terms of their dementia education/training needs (Jansen et al., 2009; Kirkley et al., 2011), in order to provide person-centred care. However, managers often feel powerless to lead on cultural change (Kirkley et al., 2011; Woolrych and Sixsmith, 2013): “...*you just have to pray they [staff resistant to change] take early retirement*” (Kirkley et al., 2011). Interestingly, managers themselves were “not always aware of their own training needs”, making it difficult for them to lead on such change (Kirkley et al., 2011).

Flexibility and responsiveness in care provision is one of the main developments that both frontline staff and carers deem important across respite service models (Cahill et al., 2003; de Jong and Boersma, 2009; Hochgraeber et al., 2015; Huang et al., 2016; O’Connell et al., 2012; Phillipson and Jones, 2011a; Woolrych and Sixsmith, 2013). However, staff discuss the barriers to this in relation to organisational bureaucracy (“*hitting brick walls everywhere you turn*”), and how the absence of decision-making autonomy, and “risk-averse” managerial culture sometimes leaves

staff feeling demoralised, powerless and incapable of implementing service improvement initiatives (Kirkley et al., 2011; Woolrych and Sixsmith, 2013). Conversely, carers discuss this primarily in relation to dementia care quality and the staff approach to dementia care, which will now be outlined below.

## **Dementia Care Quality**

### *The Care Approach*

Carers were clear that they expected staff within respite services to deliver individualised care that demonstrates affection, friendliness, empathy and respect towards people with dementia (Donath et al., 2011; Gilmour, 2002; Huang et al., 2016; O'Connell et al., 2012; Parahoo et al., 2002; Phillipson and Jones, 2011a; Robinson et al., 2012), while also maintaining their 'professional dimension' (Gilmour, 2002; Phillipson and Jones, 2011a). For some carers, good quality care was about treating the person with dementia "*like a human being*" (Phillipson and Jones, 2011a), while for others it was more than this; it was about taking a more personalised approach that considers the "uniqueness" and "individual needs" of each person (Huang et al., 2016; Parahoo et al., 2002; Robinson et al., 2012). An example of a satisfactory approach to care was concisely summarised by one daughter: "*They sent someone who was wonderful with mum, she totally got it. She attended to mum's physical needs...but also in talking with her about her life ... engaging with her*" (Phillipson and Jones, 2011a). People with dementia also expressed an appreciation for "caring" staff (Holm and Ziguras, 2003) that "displayed attitudes of goodness, understanding and respect" (Brataas et al., 2010).

Person-centred care was also important for service providers, with some evidence of staff discussing people with dementia and their care in a manner consistent with personhood concepts and ideals (Cahill et al., 2003; Hochgraeber et al., 2015; Holm and Ziguras, 2003; Kirkley et al., 2011). However, the practice of person-centred care can be challenging and, more often than not, services superficially label their care 'person-centred' without actually delivering this in practice (Kirkley et al., 2011), indicating that there is ambiguity around the meaning of what person-centred care is for some providers. For frontline staff, this more personalised approach to care requires dementia-specific training, while others believe that it would be

facilitated by improved integration of services at the organisational level (Woolrych and Sixsmith, 2013).

### *Care Components*

While both carers and care providers noted that assistance with personal care, activities of daily living and medication monitoring were important care components (Jansen et al., 2009; McGrath et al., 2000; Phillipson and Jones, 2011a), the most valued care component in terms of service development from the carer and provider perspective, was engaging the person with dementia in ‘meaningful’ activity (Cahill et al., 2003; de Jong and Boersma, 2009; Donath et al., 2011; Donath et al., 2009; Hochgraeber et al., 2015; Holm and Ziguras, 2003; O’Connell et al., 2012; Parahoo et al., 2002; Perry and Bontinen, 2001; Phillipson and Jones, 2011a; Strang, 2000a). Carer perspectives differed around what constitutes ‘meaningful’ activity for people with dementia (de Jong and Boersma, 2009).

Some carers valued physical activities, e.g. walking (de Jong and Boersma, 2009; Donath et al., 2011; Donath et al., 2009; Hochgraeber et al., 2015; Phillipson and Jones, 2011a; Strang, 2000a) and/or therapeutic and rehabilitative activities (e.g. directed at speech, cognition, reading, the arts) (de Jong and Boersma, 2009; Hochgraeber et al., 2015; Perry and Bontinen, 2001; Phillipson and Jones, 2011a; Strang, 2000a), while carers in one study believed activities should not be imposed on the person with dementia (de Jong and Boersma, 2009): *“Of course you have a day program and everything but, but if the man doesn’t want to do anything, then let him”*. For some carers, ‘meaningful’ activity was whatever the person with dementia deemed enjoyable (Holm and Ziguras, 2003; O’Connell et al., 2012). Therefore, while some carers prefer a prescribed activity programme that may maximise health outcomes and enhance functional abilities, other carers valued a tailored person-centric approach (de Jong and Boersma, 2009; Holm and Ziguras, 2003; O’Connell et al., 2012; Parahoo et al., 2002) to ‘meaningful activity’ that engages the person with dementia and makes them feel “worthwhile” (Phillipson and Jones, 2012). For people with dementia, activities that gave them a sense of “belonging” were considered important and “promote a good mood” (Brataas et al., 2010). However, according to providers, because physical care (e.g. “continence care” and “bathing”) is hugely time-intensive, especially as the dementia condition progresses, staff are

often limited in the time available to deliver non-physical care components (Jansen et al., 2009).

## **Building a Collaborative Care Partnership**

### *Empathic Client-Service Communication*

For carers, the development of trusting care relationships between the dyad and the service was underpinned by empathic communication with and about the person with dementia and their care (de Jong and Boersma, 2009; Gilmour, 2002; Gústafsdóttir, 2014; O' Connell et al., 2012; Phillipson and Jones, 2011a; Robinson et al., 2012). Perceived poor communication with services makes it difficult for carers to relinquish the carer role and achieve a positive respite experience (Gilmour, 2002) and carers believe this leads to adverse outcomes (Gilmour, 2002; O' Connell et al., 2012). Amongst carers who were satisfied with care quality, it was evident that they felt that their views had been solicited and valued (de Jong and Boersma, 2009; Gilmour, 2002; Gústafsdóttir, 2014; Robinson et al., 2012). Trust in care quality was amplified when carers felt that staff were asking “*the right questions*” about the person with dementia and their care (Gilmour, 2002), and when staff were seen to be developing a positive relationship with the person with dementia (Phillipson and Jones, 2011a). A designated point of contact was considered a substantial benefit in terms of dyad-service communication by carers and frontline respite staff (de Jong and Boersma, 2009; Hochgraeber et al., 2015; Robinson et al., 2012). There is minimal research from the perspective of the person with dementia, but people with dementia valued being included in care decisions (e.g. regarding activities) and reported that they valued listening, and being listened to, by staff (Brataas et al., 2010).

From the staff perspective, communication is also considered essential for relationship-building (Jansen et al., 2009; Woolrych and Sixsmith, 2013): “*Once they get to know you, they start to trust you. Communication is the big thing*” (Woolrych and Sixsmith, 2013). However, the development of a trusting client-service care relationship requires a dedicated time commitment which staff feel must be better supported at the organisational level (Woolrych and Sixsmith, 2013), again highlighting the resource issue. Furthermore, service providers noted that client-service communication regarding care should be collaborative, not directive, and

staff should seek to understand the carer's perspective on meeting the care needs of the person with dementia (Gilmour, 2002; Jansen et al., 2009).

### *Meeting Carer's Informational Support Needs*

Carers also value informational support and advice from staff within services in terms of developing their understanding of dementia, improving the quality of care that they can provide at home, and their own capacity to cope in the carer role (de Jong and Boersma, 2009; Parahoo et al., 2002; Phillipson and Jones, 2011a). Carers want information about managing behavioural and psychological symptoms, as well as on safety issues, e.g. "falling, handling drugs, the danger of gas stoves, and arranging aids and adaptations to the home" (de Jong and Boersma, 2009). One carer noted that the in-home service he received would have been more supportive, if he had been given much-wanted advice and education in relation to dementia care: "*I would really like, not just a well-trained caregiver, but an external adviser. I am the only person that looks after my wife most of the time, and it would be invaluable to be able to say to that person, if they had the knowledge, well you know, how do you think she is doing, what do you think her needs are ... do you think we are meeting her needs?*" (Phillipson and Jones, 2011a).

## **Dyad Restoration**

### *Mutual benefit*

Some carers conceptualise respite, not just as a service, but as an experience and/or an outcome, i.e. a restorative psychological and physical break from caregiving, which they can achieve when they perceive that both sides of the dyad benefit mutually from service use (McGrath et al., 2000; Perry and Bontinen, 2001; Strang, 2000a). For carers, a number of service and client (psychosocial, occupational) factors impact upon the benefit they experience from service use. In terms of service factors, the length/duration of the respite episode and the perceived quality of care are important (O'Connell et al., 2012; Parahoo et al., 2002; Phillipson and Jones, 2011a; Strang, 2000a). There is divergence in findings around carer preferences for the timing and duration of respite care (McGrath et al., 2000; Strang, 2000a; Upton and Reed, 2005). Some carers prefer frequent, shorter intervals (e.g. day services, in-home models) which facilitate them in keeping on top of chores, while others prefer longer intervals (i.e. residential/ overnight models) as they feel this extended block

of time better allows for revitalisation (Strang, 2000a). Regarding care quality, it was important that the carer trusted that the person with dementia was being appropriately cared for (Gilmour, 2002; Gústafsdóttir, 2014; Phillipson and Jones, 2011a). Perceiving that the person with dementia was safe and satisfied, allowed carers to relinquish the caregiving role temporarily (Gilmour, 2002) and alleviated carer guilt in relation to ‘abandoning’ the person with dementia (McGrath et al., 2000; O’ Connell et al., 2012; Phillipson and Jones, 2011a). Carer restoration was, in part, determined by how carers chose to occupy their time during service use (McGrath et al., 2000; Parahoo et al., 2002; Perry and Bontinen, 2001; Phillipson and Jones, 2012; Strang, 2000a; Upton and Reed, 2005). Ideally, this should be with absorbing activities (e.g. socialising, hobbies) and not just urgent or menial errands (McGrath et al., 2000; Perry and Bontinen, 2001; Strang, 2000a; Upton and Reed, 2005). A number of study authors concluded the need for services to deliver individualised interventions to informal carers, to help them to overcome the psychosocial and relational barriers to achieving a respite experience (McGrath et al., 2000; Phillipson and Jones, 2011a; Robinson et al., 2012; Upton and Reed, 2005).

### *The Post-Respite Evaluation*

After service use, carers continually evaluate the benefits of service use for the person with dementia, to determine the utility of the service for dyad restoration. This is assessed through observing the stated satisfaction/dissatisfaction of the person with dementia, across respite models (Gilmour, 2002; Gústafsdóttir, 2014; Holm and Ziguras, 2003; O’ Connell et al., 2012; Perry and Bontinen, 2001; Strang, 2000a) and monitoring the post-respite outcomes for the person with dementia (Gilmour, 2002; O’ Connell et al., 2012; Perry and Bontinen, 2001; Phillipson and Jones, 2011b; Strang, 2000a; Upton and Reed, 2005). Where poor outcomes were evident, carers were reluctant to use the service again, particularly in relation to residential respite: “...after two weeks she stopped walking, lost hair from being left in bed all day. ...It was very upsetting to my wife and she certainly slipped back in her health. I don’t know if I could use this again” (O’ Connell et al., 2012). For those carers that were satisfied that service use was mutually beneficial, carers perceived psychosocial, functional and cognitive gains (de Jong and Boersma, 2009; McGrath et al., 2000; O’ Connell et al., 2012; Perry and Bontinen, 2001; Phillipson and Jones,

2012; Robinson et al., 2012). Finally, for people with dementia, a beneficial day service experience was described as something that increased their self-worth, happiness and energy levels (Brataas et al., 2010).

#### **4.5.4 *Synthesis***

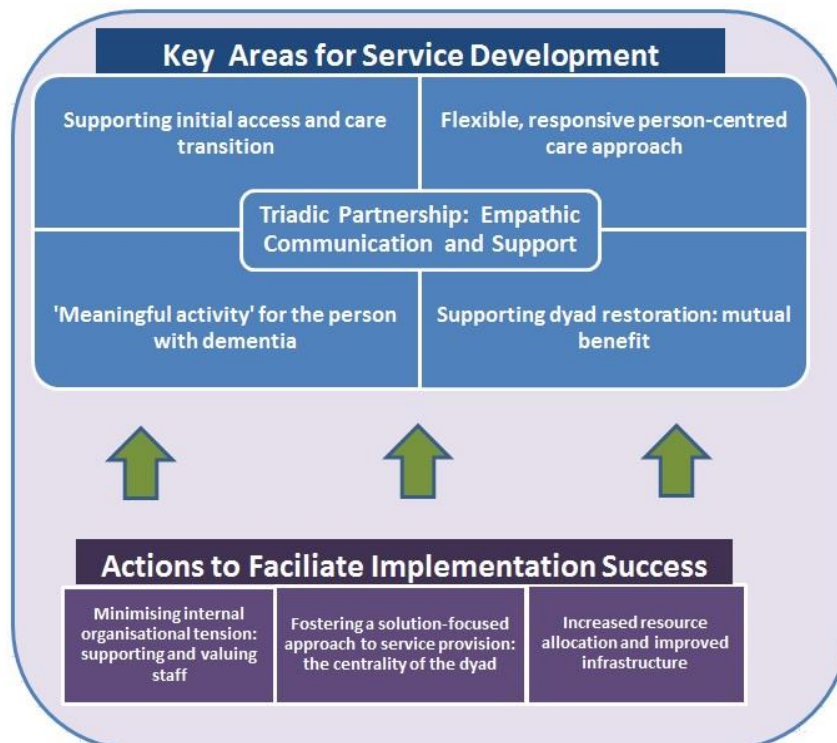
Each of the five concepts in this study was linked with a number of third order interpretations: Transitioning to Service Use (n=6), Expanding Organisational Capacity (n=6), Dementia Care Quality (n=3), Building a Collaborative Care Partnership (n=5) and Dyad Restoration (n=3) (see appendix F). The third order interpretations were synthesized to develop a line of argument (see figure 4.2 for conceptual model) in relation to key stakeholders' experiences of respite services and their perspectives on service development. This line of argument will now be outlined.

There was broad agreement across the range of stakeholders regarding the key areas for respite service development. There was a consensus around improving access and better supporting the transition to service use, as well as providing more flexible and responsive person-centred care and meaningful activity. There was strong support for ensuring that both sides of the dyad benefit from service use. For carers, their ability to achieve a restorative respite experience is largely dependent on the perception that the service recognises the centrality of the person with dementia and their care needs, and that staff within the service are willing to partner and collaborate with the dyad to understand these needs. Carers indicate that effective client-service care collaboration is underpinned by empathic communication and validation. Building and developing this type of supportive care partnership serves to reassure the carer about the service-client fit in terms of the care approach and components. Ultimately, it is this that facilitates carers in achieving a restorative physical and psychological break from caregiving through service use.

However, the findings also indicate that there are divergences among client, staff and management perspectives on the key barriers and facilitators to implementing such respite service developments. Carers predominantly locate their preferences regarding service development at the service-level, in terms of what frontline staff can do to improve respite service provision (care approach, communication, informational support etc.). However, there is some discordance between staff and

management perspectives on implementation barriers. Staff tend to believe that service development is largely dependent on building organisational capacity at the systems-level (e.g. increased resources and improved infrastructure). Staff also point out that the risk-averse and bureaucratic managerial culture does not support them to implement developments at the frontline. However, staff don't seem to acknowledge their role, relationally, in improving the care experience for clients. While management also acknowledge the need for expanded capacity at the systems-level, they also perceive staff reluctance to engage with cultural change as a substantial barrier to service development at the service-level. This within-service mismatch in perspectives serves to immobilise development initiatives. It is important that services focus on fostering an organisational culture that is collaborative, values staff, and supports them educationally and psychosocially to enact change, in line with client preferences.

**Figure 4.2 Conceptual model of the synthesized stakeholders' perspectives on respite service development and actions that would facilitate implementation success**





## 4.6 Discussion

This is the first study, to our knowledge, to systematically review and synthesize the qualitative literature on key stakeholders' experiences of respite services, as they relate to people with dementia, with a view to informing service development. The findings underline a number of areas for improvement, including: improved access and transition; flexible and responsive person-centred dementia care; 'meaningful activity' for the person with dementia; empathic client-service communication; and restorative care for both sides of the dyad. However, the findings indicate that implementing such developments is an extremely complex undertaking and one that may require a multi-faceted implementation approach, underpinned by wider organisational cultural change and increased resource allocation.

### *4.6.1 Developing Respite Services: Implementing Person-Centred Care*

The majority of studies reviewed here recognised the importance of person-centred dementia care in respite services. However, many barriers to its delivery were clear, across the range of stakeholders. It is clear that organisational cultural change is perhaps the most important consideration here in terms of understanding how we can implement such developments in respite services, in line with client needs and preferences.

Dupuis et al. (2016), describe a culture change initiative, Partnerships in Dementia Care (PiDC), which is being rolled out in long-term care settings in Canada, and which is informed by the integrated theoretical and philosophical underpinnings of a number of approaches to culture change. It is possible that PiDC could be a useful framework to conceptualise how more bottom-up implementation approaches could be successful and sustainable in respite services that currently are at a stalemate in terms of shifting the care culture towards a more person-centred care approach, in line with client preferences. The fact that the PiDC initiative advocates for a 'bottom up' implementation approach is important in relation to the findings of this synthesis, which indicates that the top-down approaches often employed in respite services (in which organisational values and attitudes in relation to dementia care are imposed upon frontline staff, often in the absence of the necessary supports and education) do not work well, and may be at least partially accountable for the organisational tension evidenced in this review.

Bottom-up approaches such as PiDC advocate for a more relational basis to culture change, and this seems important on at least two levels based on the present findings, i.e. within-service relations, and client-service relations. The principles of this framework highlight the importance of adopting a relationship-based approach through collective decision-making, valuing abilities, respecting others, accountability and shared responsibility, and focusing on ‘the process’ (which is primarily about empathic communication within and between all stakeholders, ongoing reflection and open dialogue). In terms of applying this framework, the authors note that the partnerships framework can be conceptualised as being about i) ‘working collaboratively’, ii) ‘thinking and doing differently’ and iii) ‘re-imagining new possibilities’, in relation to dementia care. Including the voice of the person with dementia and their carer in this process is absolutely crucial to imagining any new possibilities.

#### ***4.6.2 ‘Respite’ Service Development – What’s in a Name?***

According to cultural change initiatives, such as the PiDC framework outlined above, ‘thinking and doing differently’, and ‘reimagining new possibilities’ are central modes of change. In relation to respite services, the term ‘respite’ which currently guides the planning, organisation and delivery of services aiming to provide a break in caregiving for the carer, is arguably not a useful term when considered in the context of person-centred dementia care (O’ Shea et al., 2017c). This is because the baggage associated with ‘respite’ indicates that it is a term which only speaks to the experiences and perspectives of the carer in terms of the dyadic relationship and service use. The term is loaded with meaning that cannot speak to the experiences of the person with dementia, and is therefore discordant with the principles of person-centred dementia care. We must consider re-imagining the terminology used to describe the aims of what are currently known as ‘respite’ services, to ensure that the nomenclature guiding service and care delivery is consistent with the principles of person-centred dementia care. This reimagining may also help respite staff and management in developing a shared vision of the purpose of their work, i.e. to facilitate improved outcomes for carers *and* people with dementia.

While any new nomenclature is up for debate, one possible re-imagination of the term ‘respite care’ is ‘restorative care’ (as outlined in chapter 3), which has more potential to highlight the importance of providing mutually-beneficial, personalised health and social care services that serve to enhance care relationships (O’ Shea et al., 2017c). The weakness of the current literature in eliciting and articulating the view of the person with dementia is a cause of some concern and needs to be addressed urgently.

#### ***4.6.3 Strengths and Limitations***

Measures were put in place to maximise the quality of this review, including practicing reflexivity, employing two independent reviewers, and adhering to the PROSPERO protocol (registration number: CRD42016050191). This study was conducted by an experienced multidisciplinary team (geriatric medicine, nursing, economic, social policy, psychology) with expertise in qualitative approaches. Consequently, we believe that the conceptual model (figure 4.2), synthesizing stakeholders’ perspectives on service development, provides the reader with a rich third-order interpretation of how improvements can be implemented in respite services. Another strength of this review was the number and diversity of stakeholders (family/informal carers, people with dementia, frontline staff, service managers etc.) and countries (12 countries, across four continents [Europe, Asia, Australia/Oceania, and North America]) included. The inclusion of multiple perspectives allows for a more holistic view of the topic of respite service development, including the factors that might influence implementation.

Nonetheless, the primary limitation, potentially affecting the validity of this review, if not the whole research community, is the absence of people with dementia in the primary studies. There were just 13 identifiable people with dementia represented here out of 889 stakeholders across 23 studies. Another limiting factor is that the findings of this review are based on studies published only in English, and studies conducted primarily in western countries. Therefore, the findings may not represent countries with different cultures, models of respite provision, and/or low-middle income countries. The methodological quality of some of the studies included in this review was marred by a lack of transparency regarding the characteristics of the respite services, sampling, recruitment and data collection and analysis techniques.

Future research in this area must comply with published reporting guidelines to ameliorate these issues.

## **4.7 Chapter Conclusion**

This review has found that key stakeholders are in broad agreement about a number of key developments which are necessary across service models, to improve respite care for people with dementia. These include improved access and transition; flexible and responsive person-centred dementia care; ‘meaningful activity’ for the person with dementia; empathic client-service communication; and restorative care for both sides of the dyad. However, divergent stakeholder perspectives about implementing such developments highlight that organisational cultural change is an extremely complex process, requiring a multi-faceted, relational, and bottom-up approach for successful and sustainable implementation. Future research should explore the development of alternative/modified respite service models, which have greater capacity to be flexible and responsive to the needs of each individual dyad, focusing especially on the provision of ‘restorative care’, as highlighted in Chapter 3.

The findings of the literature reviews outlined in chapters 3 and 4 have indicated that non-carer perspectives on ‘respite’ and respite services are lacking, especially those of people with dementia. These reviews also highlighted that, from carers’ and to a lesser extent, service providers’ perspectives, there are considerable issues relating to two broad areas in particular: i) respite service access, and ii) respite service (and care) provision. However, there is a dearth of research on respite in the Irish context. The next chapter engages directly with multiple stakeholders in the Irish context, to explore their perspectives on the first key issue listed, i.e. respite service access.

## Declaration of Authorship

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Section 2: Paper details	
Title of co-authored paper included in the thesis under examination	Multiple Stakeholders' Perspectives on Respite Service Access for People with Dementia and their Carers
Publication Status	Published
ISSN and link to URL (where available)	ISSN: 1758-5341 URL: <a href="https://academic.oup.com/gerontologist/article/59/5/e490/531683/">https://academic.oup.com/gerontologist/article/59/5/e490/531683/</a>
This paper is one of	4 co-authored papers to be submitted as part of the PhD by publication thesis submitted for examination
Section 3: Candidate's contribution to the paper	
Provide details below of the nature and extent of your contribution to the paper (include both your intellectual and practical contributions) and your overall contribution in percentage terms:	
I conceived of the idea together with my primary supervisor. I designed the interview schedules, recruited participants and conducted all of the interviews. I transcribed, coded and analysed the data using a thematic analysis. I interpreted the findings and then drafted and submitted the manuscript. I estimate that my contribution was 80%.	
Where a paper has joint or multiple authors, list the names of all other authors who contributed to the work (this can be appended in a separate document, where necessary):	
Prof. Kate Irving; Dr. Suzanne Timmons; Prof. Eamon O' Shea	
Section 4: Signature and Validation	

I confirm that the following statements are true:

the information I have provided in this form is correct

this paper is based on research undertaken during my candidature at DCU

Signature of PhD Candidate:



Date: 04/10/2019

I confirm that the information provided by the candidate is correct:

Signature of Principal Supervisor:



Date: 04/10/2019

In some cases, it may be appropriate for verification to be given by both the principal supervisor and the lead/corresponding author of the work (where the lead/corresponding author of the work is not the candidate or the principal supervisor):

Signature of Lead/Corresponding Author: N/A

## **5 PERSPECTIVES ON ACCESSING RESPITE SERVICES FOR DEMENTIA IN IRELAND: A QUALITATIVE STUDY WITH MULTIPLE KEY STAKEHOLDERS**

The work presented in this chapter has been published as:

O' Shea, E., Timmons, S., O' Shea, E., and Irving, K. (2019) 'Multiple stakeholders' perspectives on respite service access for people with dementia and their carers', *The Gerontologist*, 59(5), e490–e500. doi:10.1093/geront/gnz095.

## 5.1 Abstract

**Introduction:** People with dementia and carers do not always access respite services in a timely manner, or in some cases, at all. While carers' perspectives on respite access have been explored, other stakeholder perspectives, especially providers and people with dementia, are under-represented in the existing literature. The aim of this study was to synthesise multiple stakeholders' perspectives, including people with dementia, on accessing respite services in the context of dementia.

**Methods:** Purposive sampling was employed. Semi-structured interviews were conducted with 35 key stakeholders, including people with dementia (n=6), carers (n=9), respite front-line staff (n= 4), respite managers (n=8), primary care professionals (n=3) and policy-makers/academics (n=5). The process of consent is outlined. Data were interpreted inductively using thematic analysis. Reflexivity was considered throughout the research process.

**Results:** Three themes ('Service Acceptability'; 'Navigational Knowledge and Skills'; 'Constructing and Adjudicating Respite Need') were identified that relate to how access to respite services is negotiated between service providers and dyads.

**Discussion:** A number of the findings support previous research. Novel findings relating to the access negotiation process include 1) the ambiguous legitimacy of respite needs, in a system configured to deliver a biomedical model of care and which considers non-medical care as a family responsibility, and 2) the constraining effects of disparate conceptualisations of 'respite' between carers and providers. Future research should interrogate the appropriate boundaries of public responsibility in relation to respite service planning/delivery for dementia, with particular reference to client preferences for community and in-home provision.



## **5.2 Chapter Introduction**

The literature reviews in chapters three and four highlight that respite service access can be complex and challenging, especially from carers' perspectives. However, the reviews also highlight that non-carer viewpoints have been under-represented in the literature to date. This study explores multiple stakeholder perspectives on respite service access in the Irish context, for the first time.

## **5.3 Background**

One of the most common means of attempting to tackle carer strain in the context of dementia, is providing timely access to respite services, either outside or inside the home (Maayan et al., 2014). While we don't have national data on the precise characteristics of the range of respite service models in Ireland, the most commonly available respite services are residential respite, day services, and in-home models (Cahill et al., 2012). Informal carers in Ireland are entitled to an annual state-funded 'carer support' grant of €1700 (as of June 2018) if they meet certain criteria, as well as up to 30 nights of care in a residential respite facility annually, often taken in two, two-week blocks. Access to respite services is usually facilitated by primary care providers, i.e. general practitioners (GPs) and/or public health nurses (PHNs).

However, it is clear from the international literature that accessing formal supports, including respite, can be particularly challenging for community-dwelling people with dementia and their carers (Phillipson et al., 2014; Donnelly et al., 2017; Stephan et al., 2018; Macleod et al., 2017; O' Shea et al., 2017b; Oliveira et al., 2019).

Furthermore, the timeliness of respite service access for dementia dyads can be problematic. This is important given that the point in time when dyads access support can have implications for the sustainability of the carer role (Stephan et al., 2018).

Some of the barriers to accessing formal supports and services, such as respite, include inadequate carer knowledge about the availability of supports and an inability to navigate the healthcare system (Stephan et al., 2018; Phillipson et al., 2014), inadequate primary care professionals' knowledge and signposting abilities (Stephan et al., 2018; Hochgraeber et al., 2015), lack of services (Mansfield et al., 2018; Stephan et al., 2018), the costs associated with service use (Stephan et al., 2018), carer perceptions regarding their own need for help (Stephan et al., 2018;

Leocadie et al., 2018), carer guilt around ‘abandoning’ the person/their duties (Macleod et al., 2017; Leocadie et al., 2018), resistance and service refusal by the person with dementia (Macleod et al., 2017; Stephan et al., 2018), concerns about care quality (Macleod et al., 2017; Leocadie et al., 2018), and a carer belief that respite use indicates failure in relation to their own ability to provide care (Macleod et al., 2017; Stephan et al., 2018). Conversely, facilitators of respite service access include having a central point of contact (Stephan et al., 2018; Leocadie et al., 2018), transport to and from services (Hochgraeber et al., 2015), a belief on the part of carers that breaks will help them to care for longer (Macleod et al., 2017), and a perception that service use is not just for the carer, i.e. that the person with dementia will have unmet needs addressed also (Leocadie et al., 2018).

However, the majority of the existing literature to date on accessing formal services, and especially research focused on respite services, has been from carers’ perspectives (Stephan et al., 2018). Including other stakeholder perspectives is necessary to give us a deeper understanding of the access process as regards respite services for dementia. Therefore, this chapter aims to understand and synthesize multiple key stakeholder perspectives on accessing respite services for dementia, in the Irish context. By integrating multiple stakeholder views on respite care, it should be possible to get a more holistic and integrated perspective on patterns of access.

## **5.4 Research Design and Methods**

Qualitative semi-structured interviews were conducted in the Republic of Ireland between July 2017 and March 2018. This study is presented according to the Consolidated Criteria for Reporting Qualitative Research (COREQ, see appendix G) (Tong et al., 2007). The research presented in this chapter was conducted as part of a wider qualitative semi-structured interview study conducted in the Republic of Ireland between July 2017 and March 2018, which focused on key stakeholders’ perspectives on respite services and their development more broadly.

### **5.4.1 Recruitment/Sampling**

Purposive sampling was employed across stakeholder groups including people with dementia, informal/family carers, respite service providers (front-line staff and management), primary care providers (PHNs and GPs) and academics/policymakers.

This was with a view to capturing a spread of characteristics across stakeholder types (e.g. male/female; rural/urban; respite model; management/frontline; dementia type; spousal/child carer, as applicable). Regarding service providers, the researcher approached management in two residential respite services (one rural, one urban), four day services (three urban, one rural) and three private domiciliary care services (serving urban and rural areas) for permission to interview management and staff within those services. All agreed, except for one day-service. PHNs, GPs, academics and policy-makers from across the country were contacted directly by email/phone. All of those contacted agreed to participate. People with dementia and carers were recruited through participating day/residential services, as well as through a PHN. The nurse managers in participating respite services were key research gatekeepers for granting us access to people with dementia and carers for inclusion in this study. It is not clear how many service users were approached by these gatekeepers, or how many people refused them. The researcher was contacted by gatekeepers only when service users expressed interest in the study; all who expressed interest ultimately participated. Regarding people with dementia and carers, a recorded formal diagnosis of dementia was required for inclusion and participants had to be community-dwelling respite service users. One person with early onset dementia in this study was not a current user of respite services. However, she was previously a service user in her capacity as a carer for her mother who had dementia. For the other stakeholder groups, they had to be currently working with/caring for people with dementia, organising/managing care, and/or involved in dementia policy-making. Some stakeholders occupied multiple roles, e.g. respite service provider *and* carer. Participants occupying multiple stakeholder roles were asked what they would like their primary designation to be. They are reported accordingly.

#### **5.4.2 Data Collection**

Cross-sectional semi-structured interview data were collected in-person for all participants. Service providers', academics' and policymakers' interviews ranged from 60-180 minutes. Interviews with carers and people with dementia ranged from 20-65 minutes. All participants were interviewed alone, with the exception of one person with dementia, who wanted their daughter present. The researcher spoke to the informal carer prior to the interview to understand key aspects of the person's

biographical history, as well as information about their life now, to facilitate communication and interpretation throughout the interviews, and to help build familiarity and rapport with the person. Following piloting, semi-structured interview schedules were finalised for each stakeholder group (see appendices N-P). Key topic areas were access, availability, acceptability/fit, equity issues, health systems factor, provider factors, and client/dyad factors. This schedule was used flexibly across stakeholder groups and the focus of the questions was tailored so that they made sense to each participant given their circumstances and cognitive ability.

While participants were given an option, all ultimately agreed to have their interviews digitally recorded using an Olympus VN-750 audio-recording device. This device does not have a password-protection function, so the data was immediately transferred to a hard drive for secure storage and deleted from the device.

#### **5.4.3 Interviewing Approach**

An empathetic interviewing approach was employed (Fontana and Prokos, 2007). This fits with the subtle realist approach, because it aims to elicit participants' true narratives, as known to them at the time of the interview. Empathic inquiry, listening and responding can disarm participants of preconceived power dynamics, and facilitate a deeper understanding of participants' viewpoints (Josselson, 2013). This approach does not mean interviewees cannot be challenged, but does call for interviewers to earn the right to challenge, by first effectively demonstrating an understanding of the interviewees' perspectives (e.g. through summarising, paraphrasing, and mirroring their narrative back to them, to give them a chance to clarify and/or explain their position in more depth). Validation was sought from each participant throughout, and again near the close of the interview.

#### **5.4.4 Data Management & Analysis**

To uphold confidentiality, the audio and written data files were assigned anonymised codes and saved to an encrypted, password-protected hard-drive. Data was also backed-up online using 'Google Drive' and the university server, which is backed-up daily. Personally identifiable information was removed from all data by EmOS, the only team member who had access to the codes. Other team members only had access to completely anonymised transcriptions of the data.

Inductive thematic analysis was employed, as described by Braun and Clarke (2006). The data were transcribed verbatim by EmOS. The transcripts were read closely before the coding process began and initial memos were made. NVivo 11 was used to support coding and data management. Initially, a subsection (7/35 [20%]) of the transcripts were coded using an inductive, bottom-up approach. Labels were applied to meaningful segments of the data, to develop a set of codes to apply to all subsequent transcripts. As the codes were applied to the remaining transcripts, several iterations of coding were necessary, where codes were added or revised to reflect new learning and more nuanced understanding of the data, as it relates to the research question. Examples of coding, including initial codes, and the final codes used to inform category development, are outlined in table 5.1.

Codes were subsequently grouped into potential categories and interrogated for meaning to arrive at cohesive themes. Particular attention was paid to identifying positive and negative cases, within and across stakeholder groups. The goal was to move beyond identifying simple semantic themes, where engagement with the data occurs only on a surface level. We have tried to derive latent themes, by interpreting the patterns in the data, and considering them in light of their potential significance, broader meaning and implications. Patterns in the data were discussed with other team members to understand the underlying assumptions and ideas, in order to make sense of them in a way that facilitated cohesive collation. To encourage reflexivity, thoughts and experiences in relation to data collection and analysis were recorded and brought to meetings with senior members of the research team throughout the research process. The purpose of these meetings was to challenge the assumptions being made by the primary researcher, to support her in becoming aware of the values/beliefs underlying her interpretations.

**Table 5.1 Examples of initial and final codes**

<b>Data segment</b>	<b>Examples of initial code(s)</b>	<b>Final code(s)</b>
“there are fewer residential services in rural areas anyway... and then the amount of respite beds in those services might be even less because a lot of those services are full up with residents... it’s far more difficult in rural areas, whereas in the cities there are so many respite places available... well, a lot more at least”	Availability  Rural versus urban	Inequitable provision
“We need someone, one person, who can direct you on where to go to meet your needs... The PHN should be able to tell you all that because that is their job, but a lot of times they are overworked and they are generalists, so really not every PHN, or GP even, will know everything about supports and information for every health area...”	Sign-posting  Role of PHN <sup>a</sup>  PHN workload  Lack of specialist knowledge	Single point of contact    Primary care capacity
“The system isn’t great either, for instance we have people on our list for respite who might die before the date comes up, but the time isn’t actually reallocated because that’s not been communicated to us from primary care and so we need to offer it out maybe the day before, or even day of, and that’s too short notice for people...”	Wasted resources  Communication	Service fragmentation

a: PHN = Public health nurse

#### **5.4.5 Ethical Approval**

Ethical approval was obtained from Dublin City University Research Ethics Committee (DCUREC/2017/018; see appendix H). For participants without dementia, written informed consent was obtained. Carers of the people with dementia all gave proxy written consent. Written consent through a signature, or a tick in the case of the visual consent forms, was also obtained from people with dementia, where possible. Additionally, the researcher also used the ‘process consent method’ (Dewing, 2007) throughout the interview process. The language, behaviour

and body language of people with dementia were monitored continuously for signs of discontent/distress/apathy. The study information leaflet and stakeholder consent forms can be found in appendices I-M.

## 5.5 Findings

Participant characteristics in relation to sex and respite service use/provision/ planning are outlined for all stakeholder groups in table 5.2.

**Table 5.2 Characteristics of the participants in each stakeholder group and their experience of using, providing and/or planning respite services**

	N	Male	Female	Experience with:		
				<u>Residential</u> <u>Respite</u>	<u>Day</u> <u>Services</u>	<u>In-Home</u> <u>Care</u>
<b>People with dementia</b>	6	3	3	5	5	2
<b>Informal Carers</b>	9	2	7	7	8	7
<b>Respite Managers</b>	8	1	7	4	3	1
<b>Respite Frontline Staff</b>	4	1	3	2	1	1
<b>Primary Care Professionals</b>	3	1	2	3	3	3
<b>Policymakers/Academics</b>	5	2	3	5	5	5

Some further demographic information of note on informal carers: Of the nine carers, three were adult children (two daughters, one son; age range: 38-52), five were spousal carers (three wives, two husbands; age range: 62-89), and one was a family friend (age 76). Table 5.3 outlines further demographic information about the people with dementia, including sex, age, diagnosis, age at diagnosis, severity, marital status, living arrangements, and ethnicity.

**Table 5.3 Demographic information relating to the people with dementia and their care arrangements**

PP	Sex	Age	Age at dx	Diagnosis <sup>a</sup>	Dementia Severity <sup>b</sup>	Marital Status	Living arrangement	Ethnicity
P1	M	80	74	Alzheimer's disease	Mild	Married	Wife, 81; Urban	White Irish
P2	F	66	64	Fronto-temporal	Moderate	Married	Husband, 71; Rural	White Irish
P3	M	80	74	Alzheimer's disease	Moderate	Widowed	Son, 44; Urban	White Irish
P4	F	86	82	Alzheimer's disease	Moderate	Widowed	Friend, 76; Rural	White British
P5	F	58	56	Alzheimer's disease	Mild	Married	Husband, 60; Urban	White Irish
P6	M	74	70	Vascular dementia	Moderate	Divorced	Daughter, 37; Urban	White Irish

a, b: Dementia diagnosis and severity were self-reported by informal carers/respite staff, they were not formally assessed for the purposes of this study.

This analysis has highlighted three salient themes, relating to how respite access is negotiated between healthcare providers, informal carers and people with dementia. These are 'Service Acceptability', 'Navigational Knowledge and Skills' and 'Constructing and Adjudicating Respite Need'. They will be outlined in turn below.

### **5.5.1 Service Acceptability**

Poor acceptability, either perceived or experienced, was a considerable barrier for some people with dementia, and consequently their informal carers, in relation to respite service access. While service providers often tended to characterise service refusal as stubbornness, or a fear-based phase that could be overcome with exposure, in fact, when asked, the people with dementia that were reluctant to use respite services usually had sensible reasons for refusing care. While day services outside the home were acceptable to some (largely because of the social and activity elements, the food, transport and/or the value for money), residential respite generated a poor response across the board from people with dementia. Even the mention of residential respite created tension, both in the actual interviewing process



and with their informal carers. Some people with dementia spoke of the clinical nature of residential respite environments, with one person outlining the “*coldness of it*”, and another lamenting the lack of engagement.

*“It was unbelievable there... I had nothing to do all day only walk around in a circle...I will not be having that again”*

One woman with early onset dementia, who is not currently using any form of respite, indicates that she intends never to use respite services because she feels that she would be “*out of place*” in terms of demographics and interests, but also that staff “*wouldn’t know what to do with me*” in relation to engagement. She was also concerned, as were some informal carers that using the same services as more advanced people with dementia would cause her excessive anxiety about her future:

*“It would make me feel terrible about what is happening to me, and would give me a vision of what might be to come for me in years to come...”*

In the dyadic interview, the topic of attempting to access a second day of day services, and of trying to access residential respite for the first time caused conflict mid-interview, with the person with dementia clearly delineating, in line with some of the other people with dementia, and many informal carers, that he would prefer to be supported in his own home.

*“I can’t see why I have to... ‘you must go to day centre’... I don’t want to... and when there’s so much to do at home... I don’t want that respite... I don’t want to go and stay anywhere... I need to have my own thing here [indicating at home]”*

Informal carers found reluctance and refusal on the part of people with dementia to access out of home respite care difficult to manage, sometimes leading to intense feelings of guilt for having raised the issue. Service providers and policy-makers also noted that service refusal can be a substantial relational barrier to informal carers seeking timely access, but refusal was usually perceived by these stakeholder groups as an attachment-related issue, rather than as a service acceptability problem, as the people with dementia frame it. While a number of informal carers interpreted reluctance as a somewhat natural part of a transition process and indicated that they could work through it, others did not feel that it was worth the conflict and the guilt, especially regarding residential respite, and indicated that they would not pursue access at that point.

### 5.5.2 Navigational Knowledge and Skills

For a minority of informal carers, the timing and ease of access to the range of respite services was satisfactory, and they felt they had a central point of contact (i.e. GP, PHN) that they could turn to for information about services. However, for many informal carers, access was far more protracted and frustrating. Carers indicated, and many providers corroborated, that the complex and fragmented healthcare system is almost unnavigable for carers, who are not aware of the GP/PHN pathway to respite service referral. Furthermore, many carers felt that making contact with the PHN was problematic. PHNs were experienced by some as unresponsive service gatekeepers that unnecessarily complicated, rather than facilitated access. Carers noted that direct (e.g. online) access to information about supports would be preferable in this context.

*“They just have all the information and we can’t get at it until we can get to talk to them... it was very hard to get through to the lady on the phone... I actually rang the number given to me about 30 times and left voice messages but no one bothered to get back to me... I think if they had all the information online then it would be better... I wouldn’t need to waste all that time finding someone to give it to me...”*

Some informal carers also describe later learning that the range of available respite services and supports conveyed to them by the GP and/or PHN was not exhaustive. Some acceptable and appropriate services from informal carers’ perspectives were overlooked, indicating that signposting is not always tailored or comprehensive. Service providers corroborated this perspective, explaining that primary care providers are not always aware of the range of available dementia supports, because of the generalist nature and wide remit of their work.

In the absence of a special interest in dementia, primary care professionals are not typically embedded enough in the dementia care landscape to effectively signpost to respite services. For one GP, the extreme of this scenario can culminate in ‘emergency respite’, crisis ED admissions with a view to accessing community supports, or even care home placement.

*“We struggle to know where services are... I have a network of people around me that I can ring for that information...but that wouldn’t necessarily be typical of GPs... I know colleagues who don’t have access to a community hospital and who*

*don't have links with the Alzheimer Society... I have no doubt that us in primary care, not knowing where all of these services are, contributes to that situation of patients ending up in hospitals EDs, so that they will be discharged with supports, or to a nursing home..."*

### **5.5.3 Constructing and Adjudicating Respite Need**

Another vital issue regarding timely access relates to how respite 'need' is conceptualised and adjudicated differently by informal carers and service providers. PHNs and policy-makers signified how the health system has been configured to be responsive to physical needs primarily. This is demonstrated by how PHNs typically only encounter dementia dyads when a nursing need arises. Indeed, even when contact is made, psychosocial and relational issues which might necessitate formal supports are sometimes purposefully not probed by PHNs, particularly when they have limited supports to offer. Carers indicate that sometimes they felt they even had to plead with healthcare professionals to establish respite candidature.

*"I was so stressed when the doctor rang me and said that physically there's nothing wrong with him so we're thinking of discharging him... I really went off at him and I was nearly begging him saying 'oh my god you don't realise what it's like, I can't keep doing this'... He rang me back an hour later and said, 'actually, you're putting up with a lot at home, leave it with me and we'll get something in place.'"*

Not surprisingly, perhaps, the difficulties in negotiating access to public services have forced some of the informal carers interviewed here, who are able to afford to pay out of pocket, to purchase private in-home respite and day services.

While some respite service providers criticise primary care professionals for not detecting and responding to respite needs early enough, many other service providers and policy-makers locate fault at the systems-level as regards under-provision.

*"When you've come into contact with the PHN, things are probably getting a bit ropery for you, but for their own very good reasons PHNs are very well defended and it's because they have so little to offer in terms of support for those kinds of more psychosocial needs... What can they do about that? When asked about services they say things like 'all I can offer is' and 'this is all I have', because it's true..."*

One carer pointed out, in line with provider and policy-maker perspectives, that this is at least partially because the state has continued to prioritise long-term residential care provision over community-based care in the case of dementia: *"There are no services in the community to keep him here... They went away and organised 'Fair Deal' to support families to get people into nursing homes but they never organised something like that for people to stay at home"*.

In some cases, respite 'need' could be seen as almost inconsequential to service provision. This is demonstrated by widespread inequitable access to such services on at least two levels, from the perspectives of service providers and policy-makers, in terms of how people with medical cards (which creates certain entitlements to free healthcare services) tend to be prioritised over those without, even when their 'needs' are similar, and how there is marked under-provision of respite services in rural areas compared to urban areas. This is further evidenced, according to service providers and policy-makers, by how even within the range of existing provision, under-resourcing and staffing, allied to inadequate training, can result in some respite providers refusing dementia referrals because they don't have the necessary capacity to care for people with dementia.

*"Sometimes when I ring the day centre I am told that it wouldn't be an appropriate referral...but our big bug bear with respite is we have two potential respite facilities available to us in this area but one of them won't take a dementia patient if they are mobile... definitely not if they have challenging behaviour..."*

The way that informal carers conceptualise 'respite', and their own need for it, also influences the access process. Some carers, wives in particular, admit that they were initially reluctant to acknowledge and/or attend to their own respite need, until they were really struggling, because they felt it was their duty to care. Respite providers corroborate this, indicating that many informal carers wait until either the person has substantial physical needs, and/or they are near burnout themselves, to seek access, which providers feel is often *"too late for them to get benefit"*. This indicates that carers internalise the cultural attitude, also held by the state that the primary responsibility for care should fall on the family, unless there are substantial physical needs or there is a crisis situation necessitating professional intervention. In this way, respite use can signify failure to fulfil this perceived duty of care.

This reluctance to seek help is also intricately tied up in, and complicated by, carers' understandings of the term 'respite', and how their perception differs from health professionals'. For informal carers, 'respite' is typically seen as an outcome, a mental and physical break, which can be achieved through service use, but *only* when they trust that the care is person-centred and of high quality (*"it's only good to me when I know that he's looked after"*). However, some providers still tend to frame respite as a break from the "*burden*" of caring for the person, essentially problematizing the person with dementia. This burden-based conceptualisation offered by staff in healthcare encounters can jar with informal carers' perspectives. This makes it exceptionally challenging for carers to legitimise help-seeking for a respite need, because it positions it as a carer-centred venture, and not necessarily one premised on mutual benefit.

*"They can't buy into using respite and those kinds of services unless there is a benefit for the person because it's just all guilt if they don't believe there's something in it for the person...there has been too much emphasis up to this point that the benefit of respite is for the family, for their 'burden', and that is not helping"*

In sum, these findings indicate that negotiating timely access to respite services is a complex interplay between clients and health services, influenced by: 1) anticipated/actual service acceptability, 2) poor primary care knowledge/signposting practices, and 3) how the concepts of 'need' and 'respite' are constructed and adjudicated differentially by informal carers and health care professionals.

## **5.6 Discussion**

This study provides insights into a range of key stakeholder perspectives on how respite access is negotiated between dementia dyads and services. While most of the previous research in this area focuses solely on the perspectives of informal carers, this study adds the perspectives of people with dementia, respite and primary care providers and policy-makers, and marries these perspectives to arrive at some novel insights. A number of findings here corroborate the findings of previous research on access barriers, as outlined in the introduction, e.g. under-provision and poor availability, poor carer knowledge, poor primary care signposting, low acceptability, client reluctance and refusal, carer guilt and refusal to acknowledge their own need for a break, client care quality concerns, and carers' beliefs that respite use equates to

failure. In terms of facilitators, having a central point of contact was perceived to support timely access.

As a result of including a range of key stakeholders, we have also discovered some unique insights relating to how respite access is negotiated, with particular reference to the construction and adjudication of respite need. It is clear from these perspectives that timely access to respite services is hindered in an overarching way by how the health and social care system is configured to provide a biomedical model of care. This model dictates that staff are primarily educated about, and responsive to physical, functional or emergency health needs. Therefore, 'respite' is not always considered a valid need in and of itself, or one for which the state should have to assume responsibility; some informal carers internalise this attitude which impedes help-seeking.

Despite the biopsychosocial model, first outlined by Engel (1977), being widely accepted as the optimal approach to care, it remains hugely challenging to adopt this more holistic approach at a systems- and practice-level. Some suggest that the implementation of a biopsychosocial model is difficult because there is no tangible definition or protocol to guide implementation (Farre and Rapley, 2017). Others attribute this to the difficulty reconciling the flexibility needed for the biopsychosocial approach to be effective, with the necessary focus on technique and method in the biomedical approach, which requires a certain level of "machineness" to be efficient (Gibes, 2014). This tension between the models can be seen to reflect the trade-off between effectiveness and efficiency, and in health systems, efficiency is valued more than effectiveness (Gibes, 2014). This is clear according to Wade and Halligan (2017), in how the biopsychosocial model has had little influence on the larger scale commissioning, organisation, or funding of health and social care services. While we cannot speak directly to the relevance of these findings regarding respite access in other countries, it is unlikely that this issue regarding the adjudication of respite need is unique to the Irish context.

We feel that within these findings regarding the construction and adjudication of respite need, there are two particularly important issues. These relate to, 1) the boundaries of the state's responsibility to identify and meet respite needs for dementia dyads, and 2) the constraints of 'respite' as a concept. These two issues will be now considered in turn, as they relate to respite access.

The concept of need is crucial to the issue of negotiating respite access, based on these findings. Many providers and policy-makers felt that there was enormous under-provision of respite services, especially in rural areas, which left PHNs sometimes unable to even probe dyads' psychosocial and respite needs, because they could not assume responsibility in the absence of appropriate and/or acceptable services. Furthermore, even where services are notionally available, they sometimes don't have the capacity, in terms of staffing and/or staff competency, to admit someone with dementia. Providers note that this is especially true when people with dementia present with "challenging behaviours", leading to problems for dyads that are arguably *most* in need of support. If respite 'need' was really the primary trigger for marshalling service access, then those with behavioural issues, which indicate significant unmet needs in the person, and likely high stress in the informal carer, would be *prioritised* for access, not rejected. In this way, 'need' can seem somewhat extraneous to the issue of access, because respite needs often only earn legitimacy when there are significant physical/functional needs present also. This under- and inequitable- provision, coupled with service impermeability and poor dementia care capacity, exposes the continued dominance of a biomedical approach at the systems-level. Since 'respite' is a psychosocial 'need', it is somehow less legitimate, and the boundaries and scope of the state's responsibility to provide access to care of this nature, are not delineated.

These findings reflect those of a study by Donnelly et al. (2017), in which 38 interviews with carers of people with dementia and healthcare professionals were conducted to explore how inadequacies in the Irish health system can impede aging-in-place. From professionals' perspectives, their ability to provide access to community supports was hindered because of how little they have to offer dyads, as in the present study. The providers specifically underlined that while they do recognise unmet support needs, because of under-resourcing and -provision, they cannot always assume responsibility for such needs. Furthermore, some of the providers also acknowledged, as in this study, that inequity is rife and that access to services is not always based on need, but on factors including geographical location and how loud carers/advocates 'shout'. Our findings reinforce these findings, and indicate that there is a stark policy-practice gap at play here. The under-resourcing of

community supports and services for people with dementia contradicts government policy in Ireland, with regards to the issue of ageing-in-place.

As regards considering what these findings mean for social policy, it might be useful to take a political lens, to understand some of the normative assumptions influencing the access negotiation process. Many authors have noted the detrimental role of neoliberal political ideologies and policies for how care is organised, provided and accessed (McGregor, 2001; Rotarou and Sakellariou, 2017; Sakellariou and Rotarou, 2017; Sevenhuijsen, 2003; Tronto, 2017; Tronto, 1993). The basic premise of neoliberalism is that a market-based approach, with minimal state intervention, is best. What is most valued therefore, is individual and/or familial self-reliance and responsibility (McGregor, 2001; Sakellariou and Rotarou, 2017; Rotarou and Sakellariou, 2017; Sevenhuijsen, 2003; Tronto, 1993; Tronto, 2017). In relation to the effects on care specifically, this has been characterised by ‘a relocation of care from the public to the private’ (Sevenhuijsen, 2003).

Many countries, including Ireland, the United Kingdom, Canada, the United States of America and Australia, have undergone reforms in the structuring and financing of their healthcare systems, in line with neoliberal ideology, since the 1970s and 80s, and more recently again, because of economic austerity measures driven by the 2008 global recession. Such reforms are signified, for example, by spending cuts, down-sizing, deficit-cutting, user-pay fees, and two-tier and for-profit health care (McGregor, 2001). In Ireland, financial cutbacks in the public sector have resulted in some families resorting to private respite care, leading to significant growth in the private market in the past decade (O’ Shea et al., 2017a).

In terms of considering the relevance of this political lens to the issue of respite access, we will now turn to the ‘phases of care’ framework proposed by Fisher and Tronto (1990). The first three phases are of particular relevance. Phases one and two, ‘*caring about*’ and ‘*caring for*’ are interconnected. During phase one, needs should be recognised and given the appropriate attention (i.e. assessment), while phase two refers to the willingness and capacity of services to take responsibility for meeting the identified needs. Some primary care professionals and informal carers here state that an initial problem relating to this is lack of knowledge, and signposting capacity. However, PHNs specifically highlight how being informed is of no use to them in the context of under-provision. Some simply feel that it would be futile to assess for



respite needs in some areas, because of the lack of services. Phase three is ‘*care-giving*’ and relates to delivering care in practice, and having the resources and competency to meet the needs in question. In this study it was clear that this was a secondary road block for respite access; even where services exist in an area, managers might refuse referrals from primary care, and prevent access at that point, because they feel they are not equipped in terms of either staffing or skill mix, to take a person with dementia under their care. In line with the work of Tronto (1993, 2017) we suggest that perhaps the most important issue impeding timely, equitable access to respite in relation to the above three care phases, is the failure to prudently allocate care responsibilities and draw unambiguous boundaries around what will (and will not) be provided by the state. Essentially, this is about creating entitlements for people post-diagnosis, to remove the current uncertainty, and the personal discretion of healthcare professionals in the adjudication of need, which ultimately drives inequity. Creating rights and entitlements is likely to incur additional costs to the taxpayer and the state, but such is the current gap between need and provision, that this may be the only way forward.

We will now turn briefly to a second novel finding of this study, i.e. the issue of what the term ‘respite’ means to different stakeholder groups, and the potentially constraining impact of this on informal carers’ willingness to seek access to supports and services, in a timely manner. It was clear that ‘respite’ can be understood quite differently by carers and providers, and that this mismatch in perspectives on the meaning of respite can make it significantly more difficult for informal carers to seek and accept help labelled as ‘respite’. Most informal carers here conceptualise respite as a psychological break from caring, but many stipulated that this could only be achieved if they felt that the person with dementia is being cared for in a person-centred manner. However, it was clear that many primary care and respite providers did not share this conceptualisation. Some even stated that they explicitly indicate to carers, albeit with the intention of validating the carer’s need for service use, that respite is categorically *not* for the benefit of people with dementia, but for the purpose of relieving them of their ‘burden’; thus implying that the person with dementia is the source of burden. This negative construction of people with dementia, and the insinuation that their well-being is not providers’ central-most concern, makes it difficult for carers to relinquish their perceived duty of care. This

is in line with the findings of chapter three, which highlight that the perception of mutual benefit is a key antecedent for carers in being able to achieve a restorative respite experience.

It is not necessarily true that service providers who understand ‘respite’ in this way always provide poor dementia care. However, the language of respite is value-laden with stigmatising connotations about the person with dementia that providers can be blind to, but informal carers often are not. It is possible that carers experience and understand this type of negative construction of dementia as an implicit indication of how the service will approach the care of the person with dementia, which reduces the likelihood of help-seeking, acting as a barrier to access. It is worth referring to the argument in chapter three, that ‘respite’ as a concept, is discordant with the principles of person-centred dementia care and mutuality, which paradoxically, informal carers must perceive to achieve a meaningful break from caregiving (O’Shea et al., 2017c). In relation to supporting access, ‘restorative care’ might better fit with the principle of mutual benefit for the dyad than ‘respite care’, given that it does not position the person with dementia in a stigmatising way (i.e. as something that a break is needed from). Perhaps such a reframing of the purpose of respite care, would improve the perceived legitimacy of service use for carers.

### ***5.6.1 Strengths and Limitations***

Unlike previous studies in this area, the present study included a wide range and sizeable number (N=35) of stakeholder perspectives on respite access, including people with dementia. We employed purposive sampling, with a view to capturing a spread of characteristics (e.g. male/female; rural/urban; respite model; management/frontline; dementia type; spousal/child carer). However, some limitations must be noted. We encountered gatekeeper issues in recruitment which made access to people with dementia difficult. It is possible, given that this was part of a larger study on stakeholders’ perspectives on respite services that the service providers, who acted as gatekeepers in terms of recruitment for this study, chose people with dementia and carers that they felt would reflect their services in a more positive light. A second issue worth noting here is that we interviewed clients who have used/are using at least one model of respite. Therefore, this data may not reflect the experiences of those who have failed to gain access completely. Finally, the

informal carers and people with dementia here are English-speaking people of Irish or British nationality, so this data cannot account for any additional access barriers that non-English-speaking individuals, non-nationals, and/or those of ethnic minority might encounter in trying to negotiate access to respite services.

## **5.7 Chapter Conclusion**

Negotiating timely access to respite services for people with dementia remains a substantial challenge. In terms of addressing this issue, we need to think about building signposting and needs-identification capacity in primary care, including replacing the term ‘respite’ with non-stigmatising nomenclature. We also need to think about expanding dementia care capacity within services. Many of the issues regarding access rely on us taking more seriously the issue of expanding the boundaries of public responsibility for respite care, with particular reference to home-based respite. The stakeholders here considered this to be an issue driven, at least in part, by the biomedical configuration of the health system, in which the respite needs of informal carers of people with dementia especially have little legitimacy. Perhaps as part of an acknowledgement that people with dementia are citizens, not just patients, we should consider the role of other governmental departments in assuming some responsibility for the non-health related support needs of dementia dyads. Future research should interrogate the issue of the boundaries of care in relation to respite service planning and delivery, with particular reference to client preferences for in-home provision.

As previously noted, the findings in the literature reviews presented in chapter three and chapter four highlighted that, from carers’ and to a lesser extent, service providers’ perspectives, there are considerable issues relating to two broad areas in particular: i) respite service access, and ii) respite service (and care) provision. This chapter took an in-depth look at perspectives on access. The next chapter focuses on the perspectives of these same stakeholders, in relation to current respite service and care provision, with a view to informing service development in the Irish context.

## **6 MULTIPLE STAKEHOLDER PERSPECTIVES ON RESPITE SERVICE PROVISION FOR PEOPLE WITH DEMENTIA IN IRELAND: A QUALITATIVE STUDY**

**O' Shea, E.,** O' Shea, E., Timmons, S., & Irving, K. (2019). Multiple Stakeholder Perspectives on Respite Service for People with Dementia: A Qualitative Study. *Unsubmitted Manuscript.*

## 6.1 Abstract

**Introduction:** Traditional models of respite, particularly those based within residential care settings, are not always effective, and there is evidence that they have low acceptability for some people with dementia and their carers.

**Aim:** To explore key stakeholders' perspectives on respite service provision for people with dementia and their carers in the Irish context, with a view to informing service development.

**Methods:** Purposive sampling was employed. Semi-structured interviews were conducted with 35 key stakeholders, including people with dementia (n=6), carers (n=9), front-line staff (n=7), managers (n=8), policy-makers/academics (n=5). Data were interpreted inductively using thematic analysis, with a focus on latent meaning.

**Results:** Three salient themes were identified ('Phases of Transition', 'Person-centred Respite Care'; and 'Respite Reform'). Three phases of transition are discussed, which rely on appropriate coordination, dyad inclusion in decision-making, empathic communication by respite staff and perceived mutual benefit by carers. Clients describe care resembling a 'person-centred' approach as their ideal, without using that term. However, people with dementia do not always have their personhood supported, and while providers indicate that they deliver 'person-centred care', many demonstrated a poor understanding of the concept and divulged biomedical constructions of dementia. Many stakeholders indicated service reform is necessary. Segregated residential respite in institutional settings has low acceptability and effectiveness. The majority of clients would prefer if resources were re-directed towards flexible community- and home-based supports, including, but not limited to, day services.

**Discussion:** Any reform of respite towards a home/community focus will require a transformation in how dementia is understood and viewed by society. The term respite should be discarded, given that it is pejorative and out-dated. Investment in dementia education and infrastructure is needed to foster a coordinated continuum of supports, within dementia-inclusive and supportive communities. Other implementation factors are discussed.

## **6.2 Chapter Introduction**

The previous chapter focused on the perspectives of multiple stakeholders regarding the issue of respite service access. This chapter will include and integrate multiple stakeholder perspectives on current respite service and care provision for people with dementia and their carers, with a view to understanding potential areas for service development in the Irish context.

## **6.3 Background**

Respite services are intended to provide a temporary break in caregiving for the carer (Maayan et al., 2014). This model of carer support is important, given that caregiving can be a hugely challenging experience, particularly as dementia progresses and the needs of people with dementia become more complex (Ploeg et al., 2019). However, previous research has indicated that there are some problems regarding the effectiveness of respite services for dementia dyads. A Cochrane review found no evidence for the effectiveness of respite for people with dementia, or carers, on any outcome measure, including rates of institutionalisation and carer 'burden' (Maayan et al., 2014). Another systematic review, by Vandepitte et al. (2016), which included non-randomised designs, indicated that while there is some evidence that day services reduce carer 'burden', there is evidence of unexpected adverse outcomes for both the person with dementia (reduced sleep quality) and the carer (increased 'burden', 'distress') from using residential respite services.

Additionally, the qualitative systematic review outlined in chapter four indicated that, according to carers, service acceptability, the approach to dementia care, and the level of service-client communication can be poor. Respite providers' perspectives indicated that building respite service capacity in line with the needs and preferences of clients is challenging, owing to a lack of resources, and the difficulties associated with mobilising culture change in respite settings (Kirkley et al., 2011a). Some key areas for service development that were identified in the meta-ethnography in chapter four include supporting the transition to respite service use (Robinson et al., 2012; Parahoo et al., 2002; McGrath et al., 2000; Huang et al., 2016), improving client-service communication, (Phillipson et al., 2011a,b; Gilmour et al., 2002; O'Connell et al., 2012; Robinson et al., 2012), care quality (O'Connell et al., 2012; Robinson et al., 2012; Phillipson et al., 2011a,b; Huang et al., 2016),

resources and infrastructure (Jansen et al., 2009; Cahill et al., 2003; Kirkley et al., 2011), education/training (Jansen et al., 2009; Kirkley et al., 2011) and the need for services to adopt a dyadic focus (McGrath et al., 2000 ; Strang et al., 2000 ; Perry et al., 2001).

No studies to date have included and integrated multiple stakeholder perspectives on respite services in relation to dementia. Thus, the current study aims to explore multiple stakeholder perspectives on respite service provision for people with dementia and their carers in Ireland, with a view to informing service development. Given the absence of research in the Irish context, the heterogeneity of respite models across countries, and the primacy of carers' perspectives in the international literature overall, this study will be inductive in nature.

## **6.4 Methods**

### ***6.4.1 Study Design***

Qualitative semi-structured interviews were conducted in Ireland between July 2017 and March 2018. This research is underpinned by an inductive approach, and a subtle realist perspective, i.e. that although the researcher's perspective is certainly influenced by his/her own position and experience in the social world, phenomena do exist independently of the researcher's mind and are knowable through the research process (Hammersley, 1995; Hammersley, 1992). Practically, this gave an importance focus on reflexivity throughout the research process. The present study is presented according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) by Tong et al. (2007), with a view to maximising reporting transparency.

### ***6.4.2 Sampling, Recruitment & Data Collection***

The sampling recruitment and data collection processes for this study have been outlined previously. Table 6.1 depicts the main interview topic areas pertaining to this particular study. This schedule was used flexibly both within and across stakeholder groups to ensure relevance to their situation, and to facilitate communication.

**Table 6.1 Basic interview topics**

Purpose of respite services
Meaning of ‘respite’
Clients’ needs
Care quality and components
Client/service communication
Outcomes of service use
Organisational issues
Staff education/training
Clients’ preferences for service provision
Implementing service development
Any other issues

Details relating to the [approach to interviewing](#), [data management and analysis](#) and [ethical considerations](#) have also been previously outlined in detail in chapter 5.

## **6.5 Results**

This analysis has highlighted three salient themes, which will be outlined below: phases of transition; person-centred respite care; and respite reform.

### ***6.5.1 Phases of Transition***

Three discrete phases of transition were evident regarding respite across stakeholder perspectives: 1) precursory, 2) commencement, and 3) homecoming.

In the precursory phase, most carers indicated that reluctance from the person with dementia, and their own guilt and anxiety in relation to separation, are the most challenging respite transition experiences. Regarding residential respite, many carers highlighted that this precursory phase occurs with each upcoming residential respite episode. A number of people with dementia voiced the perspective that out-of-home respite, particularly residential services, was not acceptable to them. This caused dyad conflict initially. In order to mitigate anticipated conflict and alleviate guilt, most of the carers here employed some form of deception around the reason for service use. For example, many carers insisted service use was under doctors’ orders;



they felt that wielding the authority of the medical doctor, as the decision-maker, reduced negative affect and conflict in the dyad.

*“She would say “where are we going”, and I’d say “we’re going to [day service]” and when she cribbed I’d say “you have to go because the GP sent you there” and then it’s ok... It’s a good one really because what he says goes you see, and I didn’t feel too bad then either you know” [family carer]*

For some carers and providers, deception was seen as a harmless means of easing the psychosocial impact of the precursory phase of transition for out-of-home respite care. However, this was a divisive issue and other providers, particularly in residential settings, noted that such untruths can create inconsistencies for people with dementia, whose *“reality is shifting”*, thus exacerbating distress during service use. Some respite providers point out that the use of deception by carers is often necessary, because there is not enough support from primary care professionals in terms of supporting the dyad to prepare psychologically for service use. A popular proposal by providers and policy-makers to improve communication and coordination in this precursory phase was the appointment of a *“single point of contact”* in primary care that has protected time and designated responsibility for signposting and co-ordinating respite services. However, there is no consensus regarding whether this role could feasibly be filled by PHNs, or another novel role, in- or outside the health system.

Regarding the commencement phase, where service initiation occurs, both carers and respite providers spoke to the role of respite services in facilitating transitions. Some carers felt that day services had a positive influence on this commencement phase. On first contact, staff made an effort to welcome them and demonstrated an attentiveness that alleviated carers’ anxieties. However, some carers, particularly wives, reported negative experiences regarding residential respite. Some were made to feel unwelcome and redundant by respite staff, which created overwhelming feelings of anxiety, precluding a respite experience.

*“The staff told me “don’t you be coming in now” and I kind of felt they didn’t want me coming in, that I was a nuisance... but the alternative is I’m sitting at home worrying the whole time... I’m thinking that he’s just staring into space and no one cares about whether he is ok or has someone to talk to...” [family carer]*

On the other hand, two disparate positions were evident amongst service providers. Some primarily attributed poor transition to a lack of ‘readiness’ and ‘poor fit’. The concept of ‘readiness’ is an interesting framing, because this places culpability for any unsuccessful transition on the dyad, indicating flexibility and responsiveness are not central concerns.

*“From the minute they come in some of them are looking for something to find fault with... Like with one woman last week, she was in doing the activities and the family weren’t happy with the activities... Then she was ‘too quiet’ when she wasn’t in with the group, and for me I find that for people coming in for respite, they have to accept it for it to work... So I said to them ‘look, I don’t think you’re ready for it, you’re not at that place’”* [residential respite manager]

Another residential provider corroborated this, indicating that the risk-averse managerial culture dictates that only those who are highly ‘dependent’ and immobile can really make a ‘successful’ respite transition to their dementia-specific unit:

*“A big problem really with referrals, often we find that the person is too good yet to be in the dementia unit and they can’t stay if they are a safety risk, especially if they are mobile... We don’t put respites on other wards, so they have to go home in those scenarios”*

In contrast to these provider perspectives, some day and respite service providers, were adamant, in line with carer perspectives, that they can and do play an active part in easing client transitions by working to build familiarity and trust, thereby *“demystifying the service for them”*, through a client-centred welcoming ritual, with a view to understanding the dyads’ needs and preferences, and building an open and trusting client-service partnership. This is a prerequisite for supporting carers to “let go”.

*“When you try to understand them like their situation and what they worry about and want from it, then you can support the carer to feel better about taking a break and to feel less guilty... It’s actually more important for them to be validated with the reality of the situation so we are honest and transparent... and I say to them ‘we are there 24/7 if they need us’... but carers need to know that we see they are still the main person over their care”* [residential respite manager]

However, some of these providers note that there are cases when it is difficult to obtain the necessary information about the person with dementia from carers to facilitate a smooth transition, because carers sometimes don't have the knowledge or tools to communicate this:

*"It's hard when people don't have the ability to explain themselves... like carers say things like 'oh they're a bit bothered sometimes' but what does that mean? and then they can't identify why or when that happens"*

Finally, in the homecoming phase, both carers and providers indicated that the outcomes of respite service use are a key barometer defining the success of a transition, during and especially in the aftermath of a residential episode, or in the early days of day service use. The observed outcomes for the person with dementia, and for the dyad relationally, ultimately shape willingness to continue service use in the future, for better or worse. While several carers and people with dementia indicated that there were positive outcomes associated with day services that encouraged continued use, difficulties in the homecoming phase were often evident in relation to residential respite according to carers, people with dementia, respite service providers and primary care professionals.

*"What we find is a lot of families are refusing to use [residential] respite because when they have used it in the past and the person has come out more disorientated and worse off, it just sets them back..."* [public health nurse]

### **6.5.2 Person-Centred Respite Care**

All stakeholder groups were concerned with the care approach within respite services. There was considerable divergence within and across stakeholder perspectives around the goals of care, the care components, and the interpersonal approach of staff. Carers and people with dementia described ideal care as consistent with a person-centred approach, although they did not employ that label. Almost all providers used the term "person-centred", however various understandings of the term were evident, which are mediated by how staff implicitly construct dementia.

Carers' experiences of care in day services were primarily positive. They cited kindness and respect for the person with dementia as the most valued elements of care, as well as the provision of meaningful activity, in a social environment.

However, carers reported more negative experiences in residential settings. This was corroborated by some primary care and day service providers, and people with dementia. For carers, in the absence of meaningful, person-centred engagement for the person with dementia, indicating mutual benefit for the dyad, a positive ‘respite’ experience is elusive.

*“I had to say to them, don’t just let him lie in the bed with no one around him... that was my greatest concern about that place that the staff... I didn’t trust them... I’m not sure what the point of this ‘respite’ thing is if they aren’t going to care for him. What good is that to me?”* [family carer]

Regarding people with dementia, some were satisfied with the interpersonal manner of staff and the activities in day services, particularly owing to the social element. However, others did indicate that their personhood has been undermined by staff, in both day and residential respite services, which has made them feel “*not worthwhile*”. A number of people with dementia felt that their agency is sometimes disregarded, and they are not given opportunities to communicate their needs and preferences. One man gave an explicit example of such a scenario, which occurred during a group activity session in a day service, triggering intense feelings of humiliation and frustration that manifested behaviourally, much to his own dismay.

*“There were two staff one day who decided to teach me a lesson... I could move my seat... so I could move it but not a certain distance because they threatened to block me... and that in a sense is threatening to block my ideas... and that turned out nasty... do you see this stick here? I used this with both of them [staff] ...I didn’t ever think it would come to that.”* [person with dementia]

Additionally, most people with dementia here indicated that what they really desire, but don’t often experience in respite services, is to be supported in engaging in purposeful or reciprocal activities. Many reflected on times when they had felt a sense of reciprocity, because they had occupied a valued role, which reinforced their sense of self-worth. However, service providers in this study did not invoke the importance of reciprocity, and the opportunity to add value to the lives of others is not provided in respite services, according to people with dementia.

*“Before, I’d have a lot of people asking me if I’d come over and have a look at this and that in the department... I’d still have a person say to me what do you think? I*

*used to love that actually... they say to me please come over and I'd give them what they need... But it's a thing that I used to do outside of this thing now"* [person with dementia]

Most providers considered their approach as person-centred. However, there were very different understandings of the term across providers. Some demonstrated a refined understanding of this concept as something that is constructed interpersonally, through respectful, dignity- and personhood-promoting interactions. However, others' grasp of the concept was shallow, as evidenced through their discourse. For example, some providers positioned "person-centred care" as just another tick-the-box information-gathering exercise that is "*done and recorded on admission*", to satisfy health authority quality benchmarks. Other providers described 'person-centred' as more of a "*non-pharmacological intervention*" or "*tool*" that can serve to subdue "*disruptive behaviours*". In this context, some providers are practicing the archetypal custodial care model, but superficially labelling it 'person-centred'.

The primary barriers to person-centred care, according to providers, were under-resourcing, and a consequent need to ration care by prioritising "necessary tasks" such as physical needs, especially in residential respite settings.

*"It would be great to have the time to sit down and meet all of these kinds of other needs but when we haven't enough staff it's difficult because we have needs that we really need to attend to like their eating drinking and toileting... We always have to prioritise people who come in with physical needs, it's important at the end of every day that all the necessary tasks and paperwork are done and everyone is safe"*

In this way, staff feel pressure to be maximally efficient, necessitating a tightly routinized approach to their work. Staff note that a major impediment to implementing person-centred care is the use of 'agency staff'. Since agency staff are typically not familiar with the ward/unit routine, their presence can frustrate usual ward staff and force them to forgo "non-essential tasks":

*"Often we'd have people from agencies who just come in and they basically just walk around the place... Whereas if you have the staff that are normally there then you have your routine and you know what each of you are doing... Routine is important, especially with the [low] staffing levels."*

One of the differentiating factors between those providers with sophisticated versus superficial understandings of ‘person-centred care’ became evident through the different discourse they employed in relation to constructing dementia, and the personhood status of people with dementia. Some residential providers in particular seemed to hold primarily biomedical constructions of dementia, which emphasise deficit and decline, and typically assume a progressive nullification of personhood over time. This was often characterised by statements, intended to portray sympathy for families, such as: *“they have lost so much of their loved one”*; *“it’s a kind of death of the person before they pass”*; *“it robs them [the family] of the person while they’re still alive”*. Conversely, those providers (along with many academics/policy-makers) who acknowledged the interpersonal and environmental influences on the experiences and behaviour of people with dementia, tended to be better able to operationalise person-centred care.

### **6.5.3 Reforming ‘Respite’**

While the first two themes were related largely to perspectives concerned with interpersonal and relationship-building factors, this final theme focuses on service acceptability, and outlines how many stakeholders indicate that reform, rather than ‘development’ is necessary.

All stakeholder groups except people with dementia indicated that respite service provision must become more demand-led, outcome-focused and community/home-based. Policy-makers and academics feel that ignoring client preferences is myopic and that we are not capitalising on the resources spent in terms of value, by providing reactive services with mediocre acceptability.

*“With this model we are not at all maximising on returns for the resources put in... What we need to do now is frame a new model...we absolutely need to build up responsive community and in-home supports, but you know, it’s difficult to turn this liner”* [policymaker/academic]

While carers and people with dementia do greatly value some characteristics of day services, (including the continuity, the provision of transport and food, the social setting), carers need more choice and flexibility in the timing and location of supports which some providers, policy-makers and academics also acknowledged, e.g., *“They just want short flexible blocks of support, say in their home...It’s not*

*much to ask*”. A number of carers stated that this would make them feel like the state valued their role, and would better facilitate meaningful respite experiences.

*“Us carers don’t get that acknowledgement... a snippet of time that is just our own and at a time of our choosing... It’s like they are throwing us a bone with day services and respite sometimes...we should be able to have lives outside of being carers and life doesn’t just happen within the confines of typical service hours of 10-4pm... It would really make a big difference in my life if I could choose when I get help...”* [family carer]

Interestingly, a number of residential respite managers and staff indicated that it is a “hassle” and a “nuisance” for them to provide respite services, which diverts resources and attention away from their full-time residents.

*“When respites come in there can be an awful lot of issues, which takes up an awful lot of time... I know that sounds very, very negative but we have to spend so much time and resources on people that we don’t really know, which takes away from our residents...So we have just four beds now which is manageable”*

*“I suppose we have to think on admission about medication reconciliation for respites, but we have the same routine, the same paper work for a respite admission as we do for our long term patients so it can be a hassle”.*

One policy-maker eloquently pointed to this lack of acceptability regarding residential respite, for many clients and providers:

*“Families aren’t necessarily happy with their experiences of residential respite services and its hassle for providers because it’s so costly to run... it’s like we’re stuck in an unhappy marriage and we’re afraid to name what’s going on... It’s a formula that has been around for a long time and it should be refreshed, definitely.”*

In terms of solutions, policy-makers and some providers suggested developing a coordinated continuum of responsive and engagement-focused home- and community-based supports with capacity for evening, night and weekend provision, along with daytime hours. Others added that future models should add value psychosocially and relationally for the dyad, and should not impose a ‘care’ narrative on them.

Regarding implementing a continuum of community and home-based supports, policy-makers and providers, and even one person with dementia, indicated that funding needs to be aligned with this vision. Some even felt that funds could be directed away from residential services to invest in community services.

*“Why are the government putting all that money into something that really doesn’t help most people? Can’t we use that for homecare? That’s what we want, to be at home and to have the opportunity to be out and about in our own towns and villages, out walking or whatever it is, you know... not shipped off somewhere”* [person with dementia]

Other factors that could potentially influence the reform of respite services according to stakeholders include persuading decision-makers that the state should accept more responsibility for supporting the social health and wellbeing of dementia dyads, and related to this, the absence of legislation and a dedicated funding stream for home-based care. Some providers and policy-makers indicate that the lack of policy and action in relation to home-based respite is largely because *“they [government] do not want to take on this responsibility”*. Many stakeholders indicated that high quality dementia education for staff, family and people in the local community, will be necessary to foster dementia-inclusive and -supportive communities. Additionally, a handful of interviewees specified that the current discourse of ‘respite’ is out-dated and pejorative, indicating that it may be necessary to replace this term if we are going to successfully reform services in line with client preferences.

*“‘Respite’ in itself has interesting philosophical connotations, because respite suggests that...if you’re getting respite from something, it must be hell... that the person must be hell? Words have to mean what they mean and the use of words like ‘respite’, they may be muddying the waters...”* [policymaker/academic]

This rings especially true, in light of the views of some respite providers on the purpose of respite care:

*“I would say ‘respite’ it’s really to do with giving a carer a break... it’s not really to do with the actual individual.”*



## 6.6 Discussion

This study has reported multiple stakeholder perspectives on respite service provision for people with dementia and their carers in the Irish context. Three distinct themes were outlined: ‘phases of transition’, ‘person-centred respite care’, and ‘reforming respite’. While previous research in this area has heavily focused on carers’ perspectives, and to a lesser extent service providers’ perspectives, the viewpoints of people with dementia, policy-makers and academics have also been included, and integrated, in the present study.

Some of the findings here are in line with previous research with carers and service providers, indicating that respite transitions are often challenging, guilt-inducing experiences for carers, especially in the face of poor service acceptability and outright service refusal by some people with dementia (Robinson et al., 2012; Phillipson and Jones, 2011b; Phillipson and Jones, 2011a; Huang et al., 2016; Rokstad et al., 2017b). The findings also corroborate that having a ‘single point of contact’ (Robinson et al., 2012; Hochgraeber et al., 2015) and empathic client-service communication can facilitate transitions (O’Connell et al., 2012; Robinson et al., 2012; Phillipson and Jones, 2011a; Gilmour, 2002b), and that the outcomes of service use feed into carers’ appraisals of the value of continued service use (O’Connell et al., 2012; Robinson et al., 2012; Gilmour, 2002b; Rokstad et al., 2017b).

Similarly, the findings substantiate past reports that carers value a person-centred approach, including facilitating meaningful (i.e. tailored) activity/engagement (O’Connell et al., 2012; Phillipson and Jones, 2011a; Huang et al., 2016; Parahoo et al., 2002; Gilmour, 2002b; Rokstad et al., 2017b), but do not always perceive this to be provided, especially in residential settings (O’Connell et al., 2012). Similarly providers in this study also cite under-resourcing, under-staffing and inadequate support from management as barriers to person-centred respite care (O’Connell et al., 2012; Hochgraeber et al., 2015; Gilmour, 2002b; Kirkley et al., 2011b).

Furthermore, the use of the term ‘person-centred’ to describe care provision, without actually implementing it, has been reported elsewhere in relation to respite services (Kirkley et al., 2011b). Regarding service development, a need for greater flexibility and responsiveness has been reported in other studies (O’Connell et al., 2012; Phillipson and Jones, 2011a; Hochgraeber et al., 2015; Parahoo et al., 2002; Huang et al., 2016).

This study also reveals some novel insights regarding respite service provision in the context of dementia. While the issue of care transitions has had an upsurge in popularity in the dementia care literature in recent years, the focus tends to be on transitions to and from hospital settings, or to long-term residential care and/or hospice/palliative care settings (Fortinsky and Downs, 2014; Hirschman and Hodgson, 2018); respite service transitions are often not considered. In these other occurrences, successful transitions happen in the context of person-centred provision at the systems and service level, i.e. in terms of being coordinated, responsive, and tailored to clients' needs and preferences, through effective service-client communication (Hirschman and Hodgson, 2018). However, it is important to highlight that respite is a special case of transition, because in other transition scenarios (e.g. hospital, residential care, and hospice) carers tend to handover to professionals because they feel they are no longer best placed to meet the persons' care needs. However, with respite, this is not necessarily the case. Many carers still feel they are the principal expert regarding the person's needs, making it challenging for them to handover care, even temporarily.

We found that transitions are especially complicated if 1) service acceptability is low for the person with dementia, 2) the carer feels guilt/anxiety, 3) primary care coordination is poor, 4) the carer has unaddressed concerns about care quality, 5) the carer feels pushed out, and/or 6) the service provider doesn't recognise their own role in facilitating transitions. Transitions are largely contingent on empathic communication, client inclusion in decision-making processes and trust- and partnership-building. Providers need to demonstrate their commitment to providing person-centred dementia care and support, to the carer, so that they can achieve a positive respite experience. Moreover, the issue of transition is intricately linked with the actual observed care approach upon commencing service use. This prominent theme will now be discussed.

There was considerable divergence across stakeholder experiences of the care approach in respite services. Carers and people with dementia were clear about preferring a person-centred approach. While many people with dementia were satisfied with the activities provided in day services, some reported an unmet need for reciprocal engagement. However, providers did not demonstrate an awareness of this. While most providers indicated that a 'person-centred' care approach was

important, many demonstrated a muddled and superficial comprehension of the concept. A biomedical explanatory model of dementia, as characterised by decline, deficit and a progressive corrosion of personhood was evident through snippets of discourse by some providers, even those who earnestly indicated person-centred care was an important service goal. This may imply, in line the work of Sabat (2003, 2006), McParland (2017) and Behuniak (2011), that providers can only understand what ‘person-centred’ respite care is, in ways which are consistent with their core internal assumptions about the personhood status of people with dementia.

Sabat (2003) indicates that a biomedical construction of dementia propels ‘malignant social positioning’ (Sabat, 2003), which denotes how what one person says about and to another, can position them in either positive or negative ways, and affects the persons’ sense of self accordingly. This was evident in the present study in how some people with dementia described having experienced inauthentic, infantilising, condescending, and silencing interpersonal interactions. Sabat (2006) argues that this occurs when people misapprehend the personhood status and the semiotic (i.e. meaning-making) ability of people with dementia. In view of that, it would be useful for staff to be educated to operate off an implicit assumption that people with dementia do retain meaning-making abilities which govern their behaviour, if they are going to be able to support personhood and meaningful engagement. Education and professional support targeted at addressing implicit beliefs and assumptions about dementia may facilitate the fundamental shift as regards the implementation of person-centred approaches to support.

The final theme, ‘reforming respite’, indicates a number of fundamental acceptability-related problems regarding the characteristics of the currently available respite services, which all stakeholder groups addressed to some extent. Carers were clear that the current under-provision and lack of choice regarding home and community-based supports indicates to them that they are not valued by the state. Some providers and policy-makers agreed, noting that the one-size-fits-all approach to respite provision means resources are wasted providing low-acceptability, inflexible and according to best evidence, potentially ineffective services (Vandepitte et al., 2016; Maayan et al., 2014). Many stakeholders, including people with dementia, felt that we need a shift in resource allocation, away from residential respite models, or at least those delivered in institutional settings, and towards a

continuum of personalised home- and community-based respite supports. People with dementia were clear that they want to be more than the cared *for*; they want to be supported to contribute to community and family life. Some residential respite providers also indicated that this service model is a ‘hassle’, which takes time and resources away from their long-term care residents.

It is not necessary to start over in terms of designing demand-led models of respite. Numerous flexible and responsive models premised on mutual dyad benefit exist in the literature, even if they are not specifically designated as respite. These include bespoke one-on-one community- and home-based day, evening, overnight and weekend services, host-home models, holiday respite, cottage respite, group outings, activities and day trips, and special interest groups and clubs (Parahoo et al., 2002; O’ Connell et al., 2012; Cullen and Keogh, 2018). Some more well-delineated models include ‘farm-based day care’/‘green care farms’ (Ibsen et al., 2018; de Bruin et al., 2012), ‘singing for the brain’ (Ward and Parkes, 2017; Osman et al., 2016), the Meeting Centre Support Program (Mangiaracina et al., 2017; Evans et al., 2018) and a range of intergenerational programs with children and teenagers (see Galbraith et al., 2015). It seems that the problem is not that alternative models have not been designed/evaluated, but that the commitment to scaling them up is poor, even when benefit and cost-effectiveness have been demonstrated.

In Ireland, ‘GENIO’ evaluated personalised home-based respite models for dementia, which focused on supporting personhood, autonomy and social connectivity through flexible block hours of tailored engagement and activity for people with dementia and support for their carers (O’ Shea and Monaghan, 2015; Cullen and Keogh, 2018; Cahill et al., 2014). The evaluations showed high client acceptability and lead to significantly improved outcomes for dyads in terms of enhanced personhood and wellbeing for people with dementia, and reduced ‘burden’ and opportunity costs for carers (Cullen and Keogh, 2018; O’ Shea and Monaghan, 2015). GENIO’s findings indicate that providing desegregated respite supports does not warrant a whole new infrastructure, but with the appropriate levels of coordination and dementia education, it is feasible to embed respite-enhancing supports into local clubs, organisations and businesses. While some people with dementia may prefer home-based one-on-one support, others will want to engage in activities in their local community that cater to their strengths, interests and/or need

for reciprocal engagement and occupation. Opportunities for valued roles and meaningful social engagement should be considered across a number of potential activity categories for each person, and in the context of what is available in the local community.

Regarding implementation, some stakeholders believe that persuading decision-makers at Government-level will be challenging, given that it is not feasible to provide randomised control trial evidence of the effectiveness of such a model, over and above existing, traditional models. This has previously been acknowledged in relation to respite service evaluation in the literature (Zarit et al., 2017). Furthermore, multiple stakeholder groups point out that substantial financial investment will be needed to facilitate the expansion of community and home-based supports, and their appropriate staffing (levels/competency), co-ordination and regulation. The term ‘respite’ is also considered a barrier to reform by some, since this term implies that custodial care is sufficient, because the service is intended only for the carer’s benefit. In a recent concept analysis (as presented in chapter 3), it was reported that this is a problem, because positive respite experiences are elusive for carers unless they perceive mutual benefit for the dyad (O’ Shea et al., 2017c). The authors proposed ‘*restorative care*’ as an alternative to ‘respite care’, which is congruent with clients’ preferences, and doesn’t position people with dementia as burdensome.

### **6.6.1 *Strengths and Limitations***

The present study focused on a wide range, and sizeable number (N=35) of stakeholder perspectives, including people with dementia who have been previously under-represented. We used purposive sampling to capture a spread of characteristics within each stakeholder group (e.g. male/female; rural/urban; respite model; management/frontline; dementia type; spousal/child carer). However, we must note that the carers and people with dementia here are all English-speaking people of Irish/British nationality. Therefore, this data cannot account for the experiences of non-English-speaking individuals, non-nationals, and/or those of ethnic minority in relation to this topic. It is worth noting that we encountered gatekeeper issues which made recruiting people with dementia difficult. It is possible that gatekeepers chose people with dementia and carers that they felt would reflect their services in a particular (e.g. more positive) light. It is also possible that gatekeepers only chose

people with dementia that they felt could communicate their perspectives in an articulate way, which means that those who potentially have their narrative agency and personhood supported even less, on a day-to-day basis, may not be represented here.

## **6.7 Chapter Conclusion**

While day services generally are considered acceptable across stakeholder groups, the appropriateness and utility of segregating people with dementia for residential respite in institutional settings is questionable to many stakeholders. Clients would prefer a shift to an integrated, demand-led continuum of personalised community and home-based supports that confer benefits on both people with dementia and their carers. Providers must seek to understand dyads' concerns and perceived support needs, and must validate the primacy of the family carer from the outset, to support care transitions and build trust-based partnerships. Service providers should aim to provide person-centred, strengths-based care for people with dementia, as well as carer support. Implementation factors identified to actualise this vision for support include the need for significant investment and planning, e.g. in terms of funding and payment models, co-ordination, integration, regulation (particularly of home-based respite), staffing levels, and dementia training and education.

Importantly, the views of people with dementia must be central to any reconfiguration of respite services in Ireland. Given, 1) that a 'person-centred' orientation underpins this thesis, and 2) the richness of the qualitative data, it was considered important that the views and experiences of the people with dementia be given an elevated platform. Therefore, the next chapter focuses specifically on this perspective and considers its significance and implications in greater depth than could be achieved in the present chapter.

## Declaration of Authorship

Section 1: Candidate's details	
Candidate's Name	Emma O' Shea
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Title of PhD by Publication Thesis	Respite Services for People with Dementia and their Carers: Perspectives of Key Stakeholders
Section 2: Paper details	
Title of co-authored paper included in the thesis	Perspectives of people with dementia on day and respite services: A qualitative interview study
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This paper is one of	4 co-authored papers to be submitted as part of the PhD by publication thesis submitted for examination
Section 3: Candidate's contribution to the paper	
Provide details below of the nature and extent of your contribution to the paper (include both your intellectual and practical contributions) and your overall contribution in percentage terms:	
I conceived of the idea together with my primary supervisor. I designed the interview schedule, recruited the participants and conducted the interviews. I transcribed, coded and analysed the data using a thematic analysis. I interpreted the findings and then drafted and submitted the manuscript. I estimate that my contribution was 80%.	

Where a paper has joint or multiple authors, list the names of all other authors who contributed to the work (this can be appended in a separate document, where necessary):

Prof. Kate Irving; Dr. Suzanne Timmons; Prof. Eamon O' Shea

#### Section 4: Signature and Validation

I confirm that the following statements are true:

the information I have provided in this form is correct

this paper is based on research undertaken during my candidature at DCU

Signature of PhD Candidate:



Date: 04/10/2019

I confirm that the information provided by the candidate is correct:

Signature of Principal Supervisor:



Date: 04/10/2019

In some cases, it may be appropriate for verification to be given by both the principal supervisor and the lead/corresponding author of the work (where the lead/corresponding author of the work is not the candidate or the principal supervisor):

Signature of Lead/Corresponding Author N/A



## **7 PERSPECTIVES OF PEOPLE WITH DEMENTIA ON RESPITE AND DAY SERVICES IN IRELAND: A QUALITATIVE INTERVIEW STUDY**

The work presented in this chapter has been published as:

**O' Shea, E.** et al. (2019) 'The perspectives of people with dementia on day and respite services: a qualitative interview study', *Ageing & Society*, 1-23. doi: 10.1017/S0144686X1900062X.

## 7.1 Abstract

**Background:** Respite services have traditionally been viewed as services for carers mainly. Perhaps as a result, perspectives of people with dementia have been largely ignored. We consider these perspectives on respite services, and contextualise them in light of Tom Kitwood's (1997) prediction that person-centred dementia care would be adopted only superficially by dementia services.

**Aim:** To explore the perspectives of people with dementia on day and respite services.

**Methods:** Convenience sampling was employed. Semi-structured interviews were conducted with six community-dwelling people with dementia. A thematic analysis was conducted on the data.

**Results:** Four themes were identified: 'Acceptability of Service Characteristics', 'Meaningful Activity', 'Personhood' and 'Narrative Citizenship'. Day services were more acceptable than residential respite, though some people would prefer home-based models, if available. 'Meaningful' engagement must be individually defined. However, purposeful and reciprocal activity was commonly invoked as meaningful. 'Personhood' and 'narrative citizenship' were quintessential markers of quality care; while some people experienced personhood being bestowed upon them, others reported distinct instances of malignant social psychology, discrimination and stigma in interactions with staff in respite services.

**Conclusion:** An implementation gap may still persist regarding person-centred care in some respite services, based on the perspectives of people with dementia. Delivering the vision for care outlined here would require greater flexibility in service provision, more resources and more one-on-one staff-client time. The fundamental shift in thinking required by some staff relies on us supporting them to develop a greater self- and shared cultural-awareness around dementia.

## 7.2 Chapter Introduction

The findings of the concept analysis (chapter three) and the qualitative systematic review and meta-ethnography (chapter four) clearly highlighted the absence of the voices of people with dementia in relation to research on respite and day services. This study hones in on the data pertaining to the perspectives of people with dementia regarding respite services in Ireland, and considers the significance and implications of these findings for policy and practice in greater depth than in chapter six.

## 7.3 Background

People with dementia are not well-represented in the existing literature on respite service provision and development. This is unsurprising, given that the views of people with dementia have long been lacking in relation to the service development literature more generally; carers' perspectives have conventionally been given precedence, because these proxy accounts were seen to be more reliable (Cantley et al., 2005; Pipon-Young et al., 2012; Lloyd et al., 2006; Murphy et al., 2015). The lack of this discourse in itself indicates a lack of citizenship for people with dementia. Their voice is often absent because gatekeepers decide who is, and who is not, suitable to participate in research. The omission of the perspectives of people with dementia from research to date has likely compromised our ability to reform respite services in a way that ensures the personhood and citizenship of people with dementia is supported.

As outlined in chapter two, Kitwood defined a new 'person-centred' dementia care which began a paradigm shift, away from the biomedical perspective on dementia and towards a more holistic perspective on the needs of a person with dementia, over and above their physical needs. He argued that care must meet the psychosocial and 'personhood' needs of people with dementia also, with personhood being defined as something that is both conferred and experienced relationally, i.e. "*a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust...*" (Kitwood, 1997, p. 8).

One of Kitwood's main concerns was that person-centred care, if adopted at all, would only be done so superficially, through the strategic use of discourse and window-dressing. He warned of the potential danger that care practices and culture

would not change accordingly, in a way that could serve to truly support and maintain the personhood of people with dementia in care settings (Kitwood, 1997, p. 133): *“It is conceivable that most of the advances that have been made in recent years might be obliterated, and that the state of affairs in 2010 might be as bad as it was in 1970, except that it would be varnished by eloquent mission statements, and masked by fine buildings and glossy brochures”*.

Therefore, this chapter explores, through the lens of personhood, how people with dementia experience respite and day services, and the care provided to them in these settings. Specifically, I seek to understand if people with dementia feel that their personhood is being supported in these settings. This is imperative, because we can only really know what ‘person-centred’ dementia care should look like in practice, from understanding the perspectives of people with dementia; this is the real test of the validity of Kitwood’s warning about implementation.

## **7.4 Methods**

### **7.4.1 Study Design**

The research presented in this paper was conducted as part of a wider qualitative semi-structured interview study conducted in the Republic of Ireland between July 2017 and March 2018, with a range of key stakeholders (N=35, i.e. people with dementia [n=6], carers [n=9], frontline staff [n=7], managers [n=8] and policymakers/academics [n=5]), on the range of respite services. While the objective of the larger study is to explore and synthesise the perspectives of multiple stakeholders, we felt that given 1) the lack of published data representing the perspectives of people with dementia on this particular topic, and 2) the richness of the present data, it would be valuable to give this perspective a platform of its own.

The research is underpinned by a subtle realist perspective, i.e. that the researcher’s perspective is influenced by his/her own position and experience in the social world; however, phenomena do exist independent of the researcher’s mind, and are knowable through the research process (Hammersley, 1995). This perspective holds that once the researcher is aware of their own position and how it might influence the research process, they can make claims about the validity of their representation, while also recognising that other perspectives on the phenomenon are possible. The

present study is presented in line with the Consolidated Criteria for Reporting Qualitative Research guidelines (COREQ, see appendix G), developed by Tong et al. (2007).

#### ***7.4.2 Recruitment & Sampling***

Six people with dementia were recruited through two day services, a respite service and a public health nurse, using convenience sampling, but with a view to representing a range of socio-demographic characteristics (e.g. male/female, age range, dementia type, urban/rural, spousal/child relationship; see table 7.1 for interviewee characteristics). The nurse managers served as gatekeepers to this population. It is not known how many people with dementia were asked by these gatekeepers to participate in the study, or how many people refused. The researcher was contacted only when a client was interested in hearing more about the study. The only inclusion criterion for the study was a recorded formal diagnosis of dementia. Five of the six people with dementia were using, or have in the past used at least one respite service model. The sixth interviewee had early onset dementia, and had not yet used formal services, but has recent (within previous ten years) experience of caring for her own mother with dementia who used both day services and residential respite services, and wanted to share her unique perspective on respite services as someone with early onset dementia looking toward the need for support in the future. We felt this was relevant because there are diverging perspectives regarding the appropriateness of general services for those with early onset dementia (Keady and Nolan, 1997; Reed et al., 2002). Furthermore, there is evidence, albeit limited, from the perspectives of people with early onset dementia that the perceived acceptability of older adult day services is low (Beattie et al., 2004).

**Table 7.1 Interviewees' demographic information**

Pseudonym	Sex	Age	Age at dx	Diagnosis	Severity	Marital Status	Living arrangement	Ethnicity	Services used*
John	M	80	74	Alzheimer's Disease	Mild	Married	Wife, 81; Urban	White Irish	DS, RR, IH, HH
Anna	F	66	64	Fronto-temporal	Moderate	Married	Husband, 71; Rural	White Irish	DS, RR, IH, HH
Adam	M	80	74	Alzheimer's disease	Moderate	Widowed	Son, 44; Urban	White Irish	DS, RR, HH
Cora	F	86	82	Alzheimer's disease	Moderate	Widowed	Friend, 76; Rural	White British	DS, RR, HH
Noelle	F	58	56	Alzheimer's disease	Mild	Married	Husband, 60; Urban	White Irish	None
Bill	M	74	70	Vascular dementia	Moderate	Divorced	Daughter, 37; Urban	White Irish	DS, RR, HH

\*DS=day services, RR=residential respite, IH=in-home/domiciliary services, HH=home help

#### **7.4.3 Data Collection**

Following piloting and modification, a semi-structured interview schedule was developed for use based on the existing literature in this area (see appendix N). This schedule was used flexibly and people with dementia were encouraged to continue with whatever narratives were meaningful to them, through prompts, based on the questions they were asked in relation to respite services. The interviews were recorded using a digital audio recording device (Olympus, VN-750). Field notes were made after each interview.

Cross-sectional interview data was collected face-to-face for all participants by EmOS, a female PhD researcher, with no prior relationship with interviewees. Interviews ranged from 20-65 minutes in duration. Just one interview took place in a participant's home, and he requested that his daughter be present. The other five took place within the service through which the interviewee had been recruited; these participants were interviewed alone. With a view to maximising interviewee responses, the researcher spoke to the primary carer prior to the interview to

understand key aspects of the person's biographical history (family life, occupation, hobbies/interests), as well as information about their life now, including their interests and skills, to facilitate communication and interpretation throughout the interviews, and to help build familiarity and rapport with the person (Murphy et al. (2015).

#### ***7.4.4 Approach to Interviewing***

The interviewer took a postmodern, empathetic approach to interviewing participants (Fontana and Prokos, 2007) which does not hold neutrality or detachment as a goal. Interviewers adopting this approach position themselves as advocates and partners in the study, who aim to use the results to advocate for changes in policy and practice (Fontana and Prokos, 2007). EmOS explained her reasons for conducting the research, and why the topic was important to her. Genuine empathic inquiry and responding is key and can facilitate a disarming of any preconceived power dynamics, leading to a deeper understanding of the perspectives of participants (Josselson, 2013).

This was achieved here through 1) asking open, interviewee-centred questions, 2) taking the 'intentional stance' as described in detail in chapter two, and 3) responding empathically and in flexible ways to interviewee responses (e.g. through summarising, paraphrasing, and mirroring their narrative back to them, to check understanding), using all available knowledge about the person to provide context. Transcripts were not returned to participants; however, validation was sought from each participant throughout the interview, and again near the close of the interview to ensure that they felt they had been given sufficient opportunity to disclose their perspectives to their satisfaction. The interviewees were each thanked and it was made clear to them that they had made a valuable contribution to the research by sharing their personal experiences and perspectives, as advised in Murphy et al. (2015).

#### ***7.4.5 Data Management & Analysis***

Directly after the interviews, the audio files were saved to an encrypted, password-protected hard-drive under an assigned code, to ensure that confidentiality and

anonymity were upheld. Data were stored and managed using the NVivo 11 programme.

Inductive thematic analysis was employed for this analysis, as described by Braun and Clarke (2006). The data were transcribed verbatim by EmOS from digital audio recordings, and information which might make interviewees personally identifiable was removed to preserve anonymity. The transcripts were read and reread to gain familiarity with the data, before the coding process began. At this point, initial memos were made to begin the audit trail.

NVivo 11 was used to support the coding process and manage the data for analysis. EmOS coded all six transcripts and met regularly with a senior member of the team (KI) not involved in the interviewing process, to discuss the codes and the potential themes. This was to ensure rigour through triangulation, to challenge my assumptions and to encourage a high degree of reflexivity throughout the analytic process. Codes were compared and contrasted iteratively, and were explored and compiled to form cohesive, rich and well-defined themes. In relation to data saturation, here defined as ‘the point in coding when you find that no new codes occur in the data’ (Urquhart, 2012, p. 194), saturation was reached. At the final iterations of the coding process, no new or anomalous codes were being identified that didn’t fit within working categories. Particular attention was paid to identifying positive and negative cases in relation to each theme.

#### **7.4.6 Ethical Approval**

Ethical approval for the study was obtained from Dublin City University Research Ethics Committee (DCUREC/2017/018, see appendix H). Potential participants met with the researcher, and were given study information (appendix I) as well as either visual or written consent forms (see appendices J and K), where consent could be given. The family carers of the people with dementia all gave proxy written consent. Even though either, or both, proxy and self-consent was obtained, the researcher also used the ‘process consent method’ (Dewing, 2007) throughout the interview process. Accordingly, the language, behaviour and body language of the person with dementia was monitored continuously for signs that they were no longer happy to participate, and in that event, the interview was brought to a conclusion.



## 7.5 Findings

The analysis revealed four major themes which will be discussed below:

- 1) Acceptability of Service Characteristics;
- 2) Meaningful Activity;
- 3) Personhood;
- 4) Narrative Citizenship.

### 7.5.1 *Acceptability of Service Characteristics*

For a number of interviewees, attending day services was enjoyable, convenient in terms of food and transport, and good value for money:

*“It’s very nice... I really like it here” [Anna]*

*“For €12 it’s well worth it... we get our coffee and tea and a bun in the morning and then we get our lunch and a dessert and coffee or tea after that... and we get a bus... I think it’s terrific and I’d love to come more often but I can’t because of the waiting list... [Cora]*

However, for some other interviewees, including Noelle, a 58-year-old with early onset dementia, neither day services nor residential respite models are acceptable. She believes that these services are designed for older adults, a group she doesn’t fit into. She maintains that staff would not be capable of meeting her needs as a younger woman with dementia. Furthermore, she is concerned that by attending day services or residential respite, she would inevitably witness people who are far more advanced in their dementia, which would cause her undue stress and anxiety about her future:

*“It would make me feel terrible about what is happening to me, and would give me a vision of what might be to come for me in years to come and I do not want to fear what might be even more by seeing all that...” [Noelle]*

With residential respite in particular, Noelle feels that the “back and forth and upheaval” of it would be “*traumatic*” for her, a belief that was borne out of her personal experience of caring for her mother with dementia in recent years.

These more negative sentiments about residential respite were also echoed by Bill and John, who having experienced residential respite admissions, now refuse to use this service model. John cited an unsavoury “coldness” to the environment as a core reason for his negative attitude. Both Bill and Noelle indicated that they would prefer to receive respite support in their own homes:

*“I can’t see why I have to... ‘you must go to day centre’... I don’t want to... and when there’s so much to do at home... I don’t want that respite... I don’t want to go and stay anywhere... I need to have my own thing here [indicating at home, interview conducted in his sitting room]” [Bill]*

*“Well I would want someone to come to the house maybe, and help me to bake and do washing and maybe we could go for a walk with the dogs...” [Noelle]*

For some interviewees, social engagement was important, and indeed was the main appeal of using services outside of the home:

*“I do, I like chatting to people... no matter what happens if you have social contact it’s very, very good... I get on very well with everybody... Coming here cheers me up and it gets me out of the house and I’m meeting people all the time different types of people... We must have a laugh, if we don’t have a laugh we have nothing... and we have many laughs here” [Adam]*

However, the level or type of engagement was unsatisfactory to some. John, Bill and Anna felt at times that they could not meaningfully socially engage those around them, particularly those who are less able to communicate verbally. Here, John notes how he carries this dissatisfaction home to his wife.

*“I do [like coming here] if I can learn from them but some people don’t speak much... I find that silence is deafening sometimes... I would like something a bit more discerning and be surrounded by people who can say we didn’t like this or that today... I come home and say to my wife I tried to talk to four or five different people at the table and they don’t say anything so I find myself complaining to her at home about the quality of the course [day service]”*

### 7.5.2 *Meaningful Activity*

For all interviewees, how their time is occupied in respite care was important to them.

John reported his dissatisfaction with a recent residential respite stay in terms of the lack of activity or engagement that he experienced over the course of the week:

*“It was unbelievable there... I had nothing to do all day only walk around in a circle...”*

However, the experience of activity and engagement in day services was more positive overall. Adam and Cora were both satisfied with the level and type of engagement they experienced in their respective day services. For them, ‘meaningful’ engagement was largely about having something to participate in socially or creatively, as a group. In this way, activities such as bingo, painting and dance were seen as enjoyable ways to feel a part of something bigger, which for Adam, is *“a good way to pass away the time”*. While participation and being part of a group defines ‘meaningful’ engagement/activity to some, others place more value on activities that stimulate their personal values and interests. Anna spoke repeatedly about the importance of being “kept busy”. Interestingly, when asked if she is ‘kept busy’ at the day service she attends, she said that she is not kept busy in the way that she would like (i.e. gardening, embroidery, making curtains, cleaning). This indicates the importance of staff exploring what is meaningful for each individual person.

A number of interviewees further defined what ‘meaningful’ engagement meant to them, beyond occupation, participation and catering to personal interests. John, Cora, Bill, Adam and Noelle all spoke about being engaged in way that gave them a sense of *purpose*. This was not a common experience for them in either day services or residential respite, but many of them, in the context of being asked about what they want from service use, reflected on times when they previously felt purpose in their lives. Bill, who worked as a horticulturist before his diagnosis, described how it used to feel to have others ask for his help and expertise, and to feel a sense of reciprocity. He is not asked to share his knowledge at the day service, despite there being a garden that clients have access to:

*“Before I’d have a lot of people asking me if I’d come over and have a look at this and that in the department... I’d still have a person say to me what do you think? I used to love that actually... there are a lot of people out there actually and they would go around and they say to me please come over and I’d give them what they need... but it’s a thing that I used to do outside of the thing now...”*

Similarly, when John was asked what he would like to get out of service use, he went on to describe a time when he was able to contribute professionally in such a way that helped economies in the Middle East, and how he went on to write a book about it, so that others may learn from his experience and expertise:

*“Ten years earlier the markets in the middle east laid up. They were drawing blanks where they used to make money... they thought how can we do this... and then we said our piece [him and his team from Ireland] and they more or less agreed with us then... and they discovered weaknesses... we helped them discover why... I wrote a book about it afterwards... I decided I should leave something behind in terms of the literature...”*

While Bill and John described how they felt purpose based on what they could offer to others professionally, Adam and Noelle, recalled finding purpose through caring for their children, as this gave them a valued role, and an increased sense of self-worth:

*“I just love when they come home from school and [names] from college at the weekends and I feed them all up and I send them away again with enough food for a small army and I know they love that and I just feel... am I feel that they need me as their mom... but I also kind of... when I cook and bake for them I feel like I’m not just some useless, helpless person that they feel sorry for... like I matter and you know I can do something for them still...” [Noelle]*

When Noelle looks ahead to needing more support as her dementia progresses, she links this with her need to “feel useful”, which is something she did not see staff attempt to do when her mother was using day services.

### 7.5.3 Personhood

It was greatly important to interviewees that they were treated with kindness, care and understanding by staff. For two people, Adam and Cora, this was their experience of staff in day services.

*“Oh they are very, very nice people and it’s nice to be nice... it costs us nothing”*  
[Adam]

*“The people all the staff are terrific... The two boss ladies are fantastic, very kind and careful and helpful...”* [Cora]

However, this was far-removed from the experiences of the others. One man explained how the way he is spoken to sometimes by staff makes him feel “*not worthwhile counting*” and “*not a person*”, which is a clear statement of him experiencing damage to his personhood and self-esteem. He describes reflecting on the effects of this type of treatment when he returns home from his day service, where he ruminates on negative interactions with staff, deepening his feelings of rejection and further eroding his personhood:

*“I began to say at home last night, ‘how do I feel about this experience...? Do I feel rejected?’ ... And the answer is yes... Do I feel that I didn’t... that my opinion was not worth taking? The answer is yes...”* [John]

John goes on to clarify that not all staff fail to treat him as ‘*a person*’. Some staff are nice sometimes, but his sense is that this can be somewhat “*superficial*”, and that there is a lack of authenticity or genuineness to some of their interactions with him. He experiences this as a lack of respect:

*“They’re not even trying to meet the needs of the customer... They’re leading everyone up/down the pathway... It needs to be more sincere, but it’s not at all... There’s no real respect, it’s like I don’t matter...”*

Noelle also had a negative experience of staff in respite and day services, in terms of how her mother was treated. She felt that her mother’s dignity was compromised in these services because staff saw her as “*less than*”, compared to people without dementia, and she refuses to endure this treatment when it comes to her eventually needing more support:

*“I would honestly rather sit at home on my own than go somewhere and be made to feel helpless and senile and like I am less than other people... No way in the world will I ever do that... I think staff could do with understanding that I want to be seen and understood and treated the same as they would treat their sisters and their friends and anyone else in the world who doesn't have this thing [dementia] ...I don't want to be made to feel different...”*

Her hopes for respite service development in this respect is that she would like homecare, provided by staff who see and respect her as a whole and complex person with many identities, roles and strengths. She does not want a service that infantilises her, or otherwise wears away her personhood and sense of self.

*“I want that carer to have the cop on to know that I am still a person...I pray to God that they wouldn't treat me like a child or like I'm less than an adult woman, a mother, a wife, a skilled baker... That would kill me... Unless that person had the right attitude and I knew that they respected me...they would need to see me and I would need to feel that they held me in some esteem...”*

Interestingly, Noelle, like John, also mentioned how she values genuineness in her interactions with others, and feels that since her diagnosis, even when people are trying to be kind and encouraging, she senses that they are sometimes “*plámásing*” [i.e. Irish term denoting disingenuous praise] her. She notes this is not something she would value in respite or support service staff either. “*“I don't want to feel like it's a condescending thing I just hate that feeling...”*

#### **7.5.4 Narrative Citizenship**

Another way in which the care approach was considered by interviewees was in terms of how their narrative agency and citizenship was sometimes challenged. Some interviewees reported feeling silenced by staff because they were not given the opportunity to communicate their stories, motivations, and/or their care needs and preferences.

Cora talks throughout the interview about how her favourite drink is milk, but the day service staff “*quibble*” and “*get cross*” at her when she asks for it. She says they often “*stop*” her and tell her not to ask again, but describes how she opportunistically takes power back, leading her to see herself as a renegade of sorts:

*“I love milk... I’m addicted to it... and at 86 and a half, so what? Sometimes when they are not looking I get the kitchen woman to give me some... I’m a rebel!”*

John depicts his experience of feeling stripped of his narrative agency and autonomy by staff in a much more distressing light. He describes two incidents; in the first, he wanted to move his chair in a circular group set-up, but he was “blocked” by staff. He felt they hadn’t even tried to understand why he wanted to move it, because they didn’t give him the opportunity to explain his motivation. This blocking of his narrative agency by the staff “frustrated” and “humiliated” him, and he was surprised to find himself lashing out physically. The second incident was centred on his food choices being ignored by staff. While Cora’s solution was to be a ‘rebel’ in secret and at opportune times, John wanted to affect real change and challenge the “*hierarchy*”. His plan was to “*mobilise*” a group of people to affect this change with him:

*“You can be certain, there will be something signed by me and signed by at least half a dozen others to say why we are not attending...”*

However, he came to realise that he would face obstacles in recruiting his peers, because of the difficulties of co-constructing a joint narrative with them, and so he devised an alternative plan to take his grievance directly to the manager, by posing a question designed to appeal to her human empathy:

*“The lady in charge the manager inside... I will channel her because she’s the one person who is in charge of the whole set-up... and they ignored our choices... and why? and ask if she were in my shoes what would she do about it?”*

In terms of what services must do to address this issue, he says staff need to be educated on the importance of asking clients’ preferences and giving them choice over their care. He noted that they must “*survey their clients*” so that they don’t continue to make “*a mistake of the market*”:

*“Nobody asked the right questions here... therefore [they] are all losing out on an opportunity of learning from us... but it isn’t easy to educate people to do that... what do they like... how do you know they like it... when did you last ask them?”*

In this way he is calling for at least the opportunity for co-construction and negotiation of a narrative around not only his own care preferences, but those of his peers also.

Two other interviewees highlighted how dementia is framed in stigmatising ways by society and within health and social care services, and how people can internalise that stigma as part the dementia experience.

*“I really do feel more sensitive to how people see me... now I just assume that people feel sorry for me sometimes...” [Noelle].*

This stigma and disempowerment can be constructed through certain meta-narratives that society and services use to tell the story of dementia. Two stigmatising meta-narratives are outlined below around the infantilisation of people with dementia (*“like a child”*), and discrimination based on perceived abnormal cognition and behaviour (*“they went mad”*).

Noelle had witnessed how her mother had been stigmatised and disempowered through infantilisation by respite and day service staff. It made her guilt as a carer worse and now has made her cautious about service use, fearing the same stigma would be dealt to her:

*“Those places have the feel of a crèche to them... it would crush me to be made to feel like I was just being cared for like a child... I used to feel awful dropping mum there and listening to the god awful tone they would use talking to everyone there... Like they were talking to children...”*

Anna outwardly stigmatises other people with dementia in her day service, even though she herself has a diagnosis and has some awareness of this. Mid interview, she points down the room to another client and declares *“she’s a pity, isn’t she”*, shaking her head. When later asked broadly about the other people attending the service she refers to them on a number of occasions as *“mad”*, but indicates that it doesn’t affect her much: *“I didn’t take any notice anyway, I was only laughing at them.”* This indicates how deeply entrenched the stigmatising meta-narratives are around dementia, and how the drive to dissociate from that can be amplified in a group/ service setting.

## **7.6 Discussion**

The aim of this study was to develop an understanding of the perspectives of people with dementia on respite and day services. The four major themes (‘Acceptability of Service Characteristics’, ‘Meaningful Activity’, ‘Personhood’ and ‘Narrative



Citizenship’) are discussed below. We also consider the findings in the context of Kitwood’s warning around the superficial implementation of person-centred care, as outlined at the beginning of this chapter.

The findings indicate that day services are more acceptable to people with dementia than residential respite admissions, but for some people with dementia, the preferred location of care is in their own home. This preference for home-based models of respite by some people with dementia has also been reported in the recent ‘Rethinking Report’ report by the Older People’s Commissioner for Wales (2018). However, given that the Irish government is spending more than twice as much on residential care than on community-based care for people with dementia, and that home care of any kind is not provided on a statutory basis in Ireland, service reform will likely be challenging (Shea et al., 2017; O’ Shea et al., 2018). It is worth noting that service acceptability was particularly poor for the interviewee with early onset dementia. Having been exposed to day and respite services as a carer for her own mother, the thought of needing support for herself from these services is not one that she can bear to contemplate.

For those who felt day services were a good fit, they cited the importance of factors such as good food, transport and perceived value for money. They also cited the importance of the social milieu of the facility, particularly the communicative abilities of other people attending the service. This corresponds with the findings by Rokstad et al. (2017b) and Strandenæs et al. (2018) who interviewed people with dementia about their experiences of day services; food, transport and social engagement were all noted as significant factors influencing service acceptability. It is important to indicate that the interviews presented here were a once-off snapshot, and that what is acceptable in terms of service provision to people with dementia may, or may not, change over time, especially as the dementia progresses. Therefore, it is important that respite service staff and family members check in with people with dementia regarding their preferences over time.

Meaningful activity and engagement represents different things to each person with dementia in relation to respite services. For some, this is something that is participatory or plays to their personal interests. For others, this is about doing something that they feel is of value to others, which gives them a sense of purpose and reciprocity, thus increasing their self-worth. Other studies have also reported that

what is considered ‘meaningful’ activity is different for each person (Strandenæs et al., 2018; Rokstad et al., 2017b; Brataas et al., 2010), and that identifying each individual’s needs and preferences is important for matching a person with activities that will ultimately be meaningful, satisfying and beneficial to them (Han et al. (2016). The ‘Rethinking Respite’ (2018) report noted that people with dementia value being ‘productive’ and ‘making a contribution’. Interestingly, the findings here about 1) giving to others professionally in terms of knowledge and skills, and 2) nurturing children, as examples of ‘purposeful’ activity, seem to echo Erikson’s (1950) concept of ‘generativity’, the seventh of his eight stages of human development. Generativity is defined as the concern to nurture, guide and ensure the wellbeing of future generations and, ultimately, to leave a lasting legacy, and when negotiated successfully, this strengthens the self (Villar, 2012; Erikson, 1950). These findings suggest that if services and supports are serious about providing person-centred care, they must focus a great deal more resources and attention on creating opportunities for reciprocity for people with dementia.

The final two themes, ‘Personhood’ and ‘Narrative Citizenship’ are closely linked, in that they speak to what people with dementia want the care approach in these settings to look like, and how they want to be seen and treated by service providers. This brings us to the question outlined in the introduction regarding the validity of Kitwood’s warning, over 20 years ago, about how person-centred care will only be superficially adopted by services, through discourse and window-dressing. The findings indicate that ‘malignant social psychology’, or behaviours that serve to undermine personhood (Kitwood, 1997) continue to persist in services and are felt deeply by some people with dementia, despite the widespread rhetoric that ‘person-centred care’ is now care-as-usual. Specifically, participants highlighted incidences where they have felt their personhood and self-esteem were diminished through the damaging effects of one or more of the following malignant social psychologies: disempowerment, infantilisation, stigmatisation, invalidation, imposition, and/or disparagement. While some people with dementia in this study did indeed experience personhood as being bestowed upon them in day services, others clearly outlined damaging intersubjective experiences with staff. A more nuanced finding in the present study is that some more positive interactions with staff were not perceived to be genuine, and people with dementia sensed shallowness in their interactions, which

can be experienced as a lack of respect. This, in particular, seems to speak to Kitwood's warning about superficiality in the implementation of the person-centred approach. These findings validate the assertion by Mitchell and Agnelli (2015) that Kitwood's work remains highly relevant to this day because of the difficulty we continue to have in terms of delivering dementia care that supports personhood.

The notion of 'narrative citizenship', which could be considered an operational element of a person-centred approach to care, was also a hugely important theme in this study. 'Narrative citizenship' is a novel concept in the context of respite care for people with dementia. According to (Baldwin, 2008: 226), supporting narrative citizenship is about 'maximising the opportunities for narrative expression for people with dementia'. He notes that narrative expression need not be linguistic, and that stories can also be articulated through movement and other artistic expression. In our study, interviewees reported feeling disempowered and stigmatised, in part because staff sometimes denied them of opportunities to co-construct their narrative, and in part because of the larger stigmatising meta-narratives around dementia and people who live with dementia. These findings evoke the theoretical work of Gilleard and Higgs (Gilleard and Higgs, 2010; Higgs and Gilleard, 2014) on the 'othering' of older adults, where "choice, autonomy, self-expression" are lost and citizenship is therefore diminished. This discursive 'othering' is likely maintained by the continued dominance of a biomedical framing of dementia in the media and in health and social care settings, which fosters the flawed idea that once a person is diagnosed with dementia, their abilities and rights regarding autonomy, including decision making capacity, are inevitably diminished (Shea et al., 2017). It is also worth noting the work of McColgan (2005) on how resistance strategies are often employed by people with dementia who are 'subject to rules and restrictions which are not of their choosing'. This seems especially relevant in light of some of the self-constructions of people with dementia here as "rebel" and challenger of the "hierarchy", in response to having their agency slighted by staff. McColgan (2005) described how such strategies are used in particular to reject certain constructions/ labels and the group control asserted over them by staff, and to create a sense of personal space, territory (with particular reference to seating arrangements, as in this study), home and routine. It is clear from these findings in the present study that some people with dementia are capable of and want to be active agents, but that staff

do not always create opportunities for them to co-construct their narrative(s) in a way which would empower them to achieve the outcomes they want.

The failure of some staff to support the personhood and narrative citizenship of people with dementia in an authentic way highlights that Kitwood was justified in being concerned about the implementation of a person-centred care approach. The findings are also consistent with those of a qualitative study by Kirkley et al. (2011), who have also validated Kitwood's prediction in a respite setting, but from the perspectives of service providers. The authors noted that although participants spoke about person-centred care as a positive thing, there was a wide range of understandings around the concept, many lacking depth. The authors concluded that some providers would describe their service as being person-centred, but they have not made the necessary cultural shift to implement this care approach in practice. In contrast, Rokstad et al. (2017b) and Strandenæs et al. (2018) have reported on the experiences of people with dementia attending day services, which detailed only positive interpersonal experiences with staff. Both of these studies report on experiences with day services in Norway which were designed specifically for people with dementia, and at that time were enrolled in a wider 24-month trial investigating effectiveness and costs. Perhaps these purposefully-designed centres, being investigated in this way, contributed to more person-centred practices.

We have to be careful not to colonise the views of the people with dementia represented here, or to suggest that service development should be based on these findings alone, given that the small group of people with dementia interviewed here was quite homogenous. However, the perspectives outlined here do demonstrate that for some people with dementia, person-centred care is not experienced and that personhood is sometimes assailed, perhaps unwittingly by staff. While it is not clear from the present study what the specific barriers to implementing person-centred care were, it is worth turning to theory to understand how we might begin to conceptualise and tackle this situation. Kitwood (1990) has previously observed that staff in health and social care services are constricted in their ability to provide authentically person-centred dementia care because they essentially operate on a sort of "double-think", i.e. their practice is influenced by two paradoxical schemas. The first comes from what he called the 'standard paradigm', referring to the biomedical model, which formal carers are trained into. This, he says, is typically nihilistic and

focuses on the neuropathology of the disease, not the person. The second schema is the staff members' natural human inclination which is often (but not always) towards empathy for other people. This allows windows of "more optimistic and less deterministic" thinking and practice regarding dementia (p 179). However, he notes that the influence of the biomedical model tends to prevail, despite the "great deal of goodwill, kindness and commitment" (p186), in large part because of the "the lack of inter-subjective insight" and critically, the absence of widespread "moral education" for staff (Kitwood, 1990; Kitwood, 1998). Kitwood (1990) noted that very high levels of empathy and imagination, as well as flexibility in thinking are critical in interactions with people with dementia, in terms of supporting and maintaining their personhood, and that these complex skills "do not feature strongly in the training of professionals" (p185). Health and social care staff can therefore lack insight that they are not seeing people with dementia as fellow human beings, deserving of genuine empathy and unconditional positive regard in interpersonal interactions. Consequently, through their behaviour and styles of interaction, staff can unintentionally propel the types of 'malignant social psychology' that diminish the self-worth and personhood of people with dementia (Kitwood, 1990; Kitwood and Bredin, 1992). This interpretation is supported by the findings in chapter 6, regarding how biomedical constructions of dementia seem to impede true understanding of what 'person-centred' means, in relation to dementia care provision.

We would suggest that in addition, based on the findings in chapters 4 and 6, there are a range of organisational pressures that reduce staff time and capacity to be person-centred, including large volumes of administrative work and physical care tasks, often in the context of being under-staffed, which significantly impact staff morale, and in turn their ability to be consistently person-centred in their interpersonal approach to care. Future research should investigate the organisational barriers and facilitators relating to the implementation of person-centred care, in the context of any future respite service reform.

Person-centred dementia care is a central aim of national policy documents and dementia strategies worldwide. While some services may indeed provide consistently person-centred care, this study shows that an implementation gap may still persist in some services. It is clear that we have to make a concerted effort to address any shortcuts that have been taken, to make it appear as if the

implementation work has been done. It is time that we heed Kitwood's warning; we must deeply consider how we can build the type of self and shared organisational awareness necessary among all health and social care staff and management, to facilitate the fundamental cultural shift required to embed person-centred care in the organisational cultures of all respite and day services.

Additionally, it is worth noting that there have been calls for a fundamental shift in how we conceptualise 'respite' and services which aim to provide respite (O' Shea et al., 2017c), because the term 'respite' speaks only to the experience of the carer and their need for a break, and the term is associated with the use of other terms which stigmatise people with dementia and position them as burdensome. The language we use is central to guiding service development, and the findings here support the notion that the term 'respite' cannot encompass the clear, nuanced vision for person-centred dementia care that people with dementia possess, and here state they are not always experiencing in practice. It seems likely that the continued use of this value-laden term is hindering the implementation of person-centred care, as the stigmatising tenets underpinning this word 'respite' trickle down into the experiences of people with dementia in care settings. In chapter 3, 'restorative care' was proposed as alternative nomenclature, and this may be fitting to speak to the experiences and perspectives of both members of the dyad. The people with dementia here are calling on us in some respects to support and restore their personhood, narrative citizenship and sense of purpose, through the provision of person-centred care.

### ***7.6.1 Strengths and Limitations***

Some limitations must be noted for this study. This was a small study with a sample of just six people with dementia. All participants were white Irish/British, and English was their primary language. The findings therefore do not speak to experiences of ethnic minorities who might have very different perspectives on, and experiences of, the range of respite services. Furthermore, it is possible that gatekeepers within services were biased towards providing access to people with dementia who they perceived would have more positive perspectives on services, or who were more articulate. We also must note that we did not collect data on the length of service use, and so it is not clear how this factor might differentially

influence perspectives across the range of services. However, there was a considerable degree of variation in the sample in terms of some other socio-demographic characteristics (sex, age, cause of dementia, living arrangements, marital status), and it was the first of its kind to explore the perspectives of people with dementia on the range of respite services available in Ireland.

## **7.7 Chapter Conclusion**

Again, we must reiterate that do not wish to colonise the views of a small number of people with dementia. However, the perspectives here indicate that at least for some people with dementia, respite services have low acceptability, and that the care approach is suboptimal. Day services and in-home services may be more acceptable to some people with dementia than residential respite services that take people out of their homes for prolonged periods. Regarding the care approach, it might be useful for service providers to focus on understanding what ‘meaningful activity’ means for people with dementia. This could include creating opportunities for people with dementia to take on valued roles, so that they can feel a sense of reciprocity and purpose, which many people here outlined would particularly enrich their lives. Regarding the care approach, some, but not all, people with dementia represented in this study are still experiencing ‘malignant social psychology’, or behaviours that serve to undermine personhood. For these people with dementia, person-centred care is not simply about care being individualised, it is about staff *genuinely* and consistently respecting, validating and meeting personhood needs, and providing opportunities for purposeful engagement, narrative agency and citizenship. This type of change will require more resources. However, it will also require that we educate respite staff on 1) dementia and their framing of the personhood status of people with dementia, and 2) how to be more self-aware and reflexive in dementia care practice.

The next and final chapter contains a review, synthesis and discussion of the main findings of this thesis. The methodological strengths and limitations are considered, as well as the implications of the findings for research policy and practice. Lastly, the conclusions of this thesis as a whole are outlined.

## **8 GENERAL DISCUSSION**



## 8.1 Review of Main Findings

The overall aim of this thesis was to gain a rich understanding of multiple stakeholders' perspectives on current respite service provision, as it relates to dementia, with a view to informing service development. The findings of this thesis will now be considered under four headings, which encompass the range of findings presented in this research, and together serve to address the aim and objectives of this thesis. The headings under which the findings will be discussed are as follows:

- The meaning of 'respite';
- Accessing respite services;
- Experiences of respite care;
- Service reform.

### *The meaning of 'respite'*

As reported in the concept analysis presented in Chapter 3, 'respite' has been defined almost entirely from the perspectives of carers in the existing literature. Carers characterise respite, as both a service and an outcome. The 'outcome' formulation was more personally meaningful to carers, and was defined, based on the present concept analysis, as: "*A psychological outcome of a mental break for carers, which can be facilitated by the use of formal health and social care services under certain conditions, when the carer perceives that service use is necessary and mutually beneficial for the dyad*" (p. 64). Notably, the principal antecedent to carers experiencing a positive 'respite' outcome was the perception of mutual benefit, i.e. the carer must trust that the person with dementia is safe, meaningfully engaged, and treated with dignity, respect and empathy by staff in respite services, to benefit from service use.

An auxiliary goal of the concept analysis was to appraise the term 'respite', in the context of the 'person-centred' care paradigm (Kitwood, 1997). It was clear from this review that the experiences and perspectives of people with dementia cannot be encompassed by the term 'respite'. Other concepts which co-occur with 'respite' in the existing literature are fundamentally connected to the carer's experience, and are loaded with negative and stigmatising connotations, e.g. 'burden', 'stress', and 'burnout'. Paradoxically, this failure of the 'respite' narrative to consider the experiences of people with dementia is inherently problematic for the

conceptualisation of respite as an outcome, as carers define it; in order for carers to attain a respite experience, they must trust that the wellbeing of the person with dementia is a main priority for the service. In this way, there is a certain antagonism between the two conceptualisations of respite (i.e. a service type and a carer outcome), for carers.

The inclusion of other stakeholders provided some unique insights on this topic in chapters 5 and 6, relating to the Irish context. The findings in chapter 5 indicated that often, carer reluctance to seek help is intricately tied up in, and complicated by, how carers' understandings of 'respite' clash with service providers' understandings. Instead of emphasising mutual benefit, many service providers tend to frame respite as a carer-centred endeavour, as a break from the "*burden*" of caring; in essence problematizing the person with dementia: "*I would say 'respite' it's really to do with giving a carer a break... it's not really to do with the actual individual*" (see p. 135). Some providers even explicitly indicate this to carers, albeit with the intention of validating the carer's need for a break. Therefore, the burden-based conceptualization of respite, which some providers here espouse, can jar with carers' needs to perceive mutual benefit, making it challenging for carers to legitimize seeking respite support.

In chapter 6, a minority of participants (including academics, policy-makers and healthcare professionals) specifically noted that the term 'respite' is constraining service reform. Some indicated that it may be necessary to replace this term with alternative nomenclature if we are going to successfully reform services, e.g. "*'Respite' suggests that...if you're getting respite from something, it must be hell... that the person must be hell? Words have to mean what they mean and the use of words like 'respite', they may be muddying the waters*" (p. 135). These findings support the deduction in chapter 3, that 'respite' is no longer a befitting term, because ultimately, it is not in line with the principles of person-centred dementia care, and can sabotage carers' abilities to achieve a meaningful psychological break. It is time that we replace the concept of 'respite' with alternative nomenclature. In this thesis I have suggested 'restorative care' as a potential alternative.

### *Access to respite services*

The findings of the qualitative systematic review and meta-ethnography in chapter 4 indicated that respite access was challenging for carers due to poor availability, an unnavigable health system, lack of transport, and to a lesser extent, cost-sharing. Many providers agreed that the system is difficult to navigate, indicating that carers sometimes attend emergency departments, just to gain access. Carers also highlighted how people with dementia are sometimes reluctant/refuse to attend out-of-home respite services. Additionally, carers can experience feelings of guilt, failure, and fear regarding respite service use, which make them reluctant to pursue access. Many of the findings in chapter 5, based on key stakeholder perspectives in the Irish context, corroborate the findings of the above review. We do not have Irish data pertaining to total respite service provision for dementia. However, a 2018 national mapping study of dementia-specific services by the Alzheimer Society of Ireland, in conjunction with the National Dementia Office, determined that service provision is fragmented and weak (Alzheimer Society, 2018). For example, day service capacity varies greatly across CHO areas, ranging from 106-350 places per region.

A novel insight regarding respite access in chapter 5 related to the construction and adjudication of need. According to these stakeholders' perspectives, it seems timely access is hindered by how the health system is configured and resourced to deliver a biomedical model of care. Consequently, respite needs often only gain legitimacy when the person with dementia has significant physical/medical needs, which the carer cannot manage without formal support. This is reflected in how the Single Assessment Tool, (INTERRAI), an IT-based standardised needs assessment which includes a section on carers' needs, is the new national standard in Ireland. The INTERRAI assessment only triggers entitlement in the context of two schemes: 1) those applying for care home placement under the Nursing Home Support ('Fair Deal') Scheme and 2) those applying for Home Support Services (which at present is focused primarily on physical and personal care needs).

Additionally, respite services sometimes reject people with 'challenging behaviours'. According to one PHN: *"...Our big bug bear with respite is we have two potential respite facilities available to us in this area but one of them won't take a dementia patient if they are mobile... definitely not if they have challenging behaviour..."* (p.

115). This is a prime example of how respite need is sometimes inconsequential to access in the Irish system; especially given that the presence of ‘behavioural and psychological symptoms’ is one of the strongest predictors of high carer ‘burden’ (Alvira et al., 2015; Brodaty and Donkin, 2009; Campbell et al., 2008; Conde-Sala et al., 2014; Kim et al., 2012). According to the policy-makers and providers, continued under-provision of respite is a consequence of the state’s failure to clearly delineate the boundaries of its responsibility regarding psychosocial needs, including respite.

### ***Experiences of respite care***

In the qualitative meta-ethnography (chapter 4), the findings indicated that person-centred care was the favoured approach across carer and service provider groups. While some carers were satisfied with care, not all were, and residential respite care was considered less favourable than care in day services. Many carers felt unwelcome and disregarded during the initial transition period, which damaged the client-service relationship and sometimes led to early discharge. While some providers demonstrated a refined understanding of ‘person-centred’ care, others had only a superficial grasp of its relational basis (e.g. in Kirkley et al., 2011). Lack of fiscal and human resources were considered the primary barriers to supporting personhood and meaningful activity. These findings were corroborated in chapter 6 in the Irish context, where under-resourcing forces rationing in the form of prioritising physical care needs over ‘other’ needs, e.g. *“It would be great to have the time to sit down and meet all of these kinds of other needs but when we haven’t enough staff it’s difficult because we have needs that we really need to attend to like their eating drinking and toileting...”* (p. 132).

The qualitative studies in chapters 6/7 also contributed novel findings regarding the approach to dementia care in respite settings. People with dementia provided rich insights into their experiences in relation to personhood, and ‘meaningful’ engagement. While some were satisfied with the care approach in day services, others highlighted scenarios in which their personhood and narrative agency were diminished by staff. A more nuanced finding is that some staff were perceived to lack authenticity, which is received as especially disrespectful: *“They’re not even trying to meet the needs of the customer, they’re leading everyone up/down the pathway... It needs to be more sincere but it’s not at all - there’s no real respect...”* (p. 156). For some, any activities conducted in a social context were considered

enjoyable, but five of the six people with dementia were mourning the valued roles they once occupied, in a time when they felt more than just “*the cared for*”. The importance of being supported to contribute to other peoples’ lives has also been reported by other authors in non-respite contexts (Herron and Rosenberg, 2017; Hellström et al., 2015; von Kutzleben et al., 2012). Interestingly, none of the service providers in the primary qualitative study recognised or referred to this need for reciprocal engagement. The experiences of people with dementia reported here are in contrast to those reported by Strandenæs et al. (2018) and Rokstad et al. (2017b), in Norway, based on samples from the ECOD project (see Rokstad et al., 2014). People with dementia reported being highly satisfied with care in day services, though some felt that activities could be more individualised. However, the services in question were ‘specially-designed’ dementia-specific day services undergoing a two-year multicomponent evaluation. Therefore, it is likely that the findings of these studies do not reflect current day service provision in Norway.

Finally, in chapter 6, the discourse of some providers revealed insights into schematic barriers to the delivery of personhood-supporting care. This was exposed through biomedical constructions of dementia, which suggested latent beliefs that dementia progressively annuls personhood. This finding is consistent with the writings of Sabat (2003), McParland et al. (2017) and Behuniak (2011), which highlight the damaging effects that a biomedical construction of dementia can have on the social positioning, and experience, of people with dementia. A handful of policy-makers, academics and other providers substantiated that this type of framing of dementia is not uncommon, in their experience.

### ***Service Reform***

This section addresses the issue of respite service acceptability, across stakeholder perspectives. It is worth noting, that while ‘service development’ was presumed to be the primary concern at the outset of this thesis, it was clear that stakeholders in the Irish context did not feel that ‘development’ would be sufficient to improve the acceptability and effectiveness of services; instead, many participants across stakeholder group noted that wide scale reform of respite services is warranted.

In the qualitative systematic review (chapter 4), a number of areas for service development were identified in relation to improving access and care transitions,

increasing service flexibility and responsiveness, increasing community support provision, improving care quality, and building a client-service partnership. Providers perceived that a substantial barrier to service development, outside of a lack of resources, was a lack of capacity to mobilise culture change in respite settings. While these same problems were reported by stakeholders in the Irish context, many felt that culture change would not be sufficient to resolve the inherent philosophical, empirical and ethical problems associated with traditional models of respite provision.

Carers in this study (chapter 6), lamented the lack of choice and flexibility, noting that there is no evening, night or weekend respite available, unless it is financed out-of-pocket, using private domiciliary care providers. Consequently, carers often feel undervalued for the extensive role they play in care provision. Respite service inflexibility means carers sometimes cannot sustain valued relationships, community connections, gainful employment, and/or personal interests/hobbies, which would serve to maintain or improve their psychosocial wellbeing. Many stakeholders, including people with dementia, felt that a shift in resource allocation is required, to facilitate responsive respite options in the home. Policy-makers and providers suggested that developing a coordinated and integrated continuum of personalised home and community-based respite options, with an emphasis on meaningful engagement for the person with dementia, would address the most prominent acceptability issues. Processes of “co-design” and “co-production” were cited as potentially useful in determining how value could be added to improve outcomes.

A central barrier to respite reform, according to policy-makers and academics, will be convincing decision-makers to rebalance resource allocation in favour of community and home-based support, especially given the absence of randomised control trial data pointing to effectiveness and cost-effectiveness of alternative respite models. However, as Zarit et al. (2017) notes, randomisation to respite/control conditions cannot be performed. Since respite services are widely available, withholding this intervention from a control group, when it is necessary or even urgent, is infeasible and unethical. In this way we must rely on data from non-randomised designs. To reiterate, evidence from two systematic reviews of the effectiveness of respite and day services, indicate that while day services have some benefits for dyads, residential respite services are not effective, and can lead to

adverse outcomes for people with dementia (Maayan et al., 2014; Vandepitte et al., 2016).

## **8.2 Mobilising Service Reform**

These findings, as a whole, suggest that traditional respite service provision is not fit-for-purpose. This section will examine the mechanisms that influence respite provision in Ireland, to understand how the required paradigm shift might be actualised. First the issue of path dependence in respite provision, and the factors which have contributed to this, will be examined. Subsequently, the issue of how instating a social model of dementia could facilitate movement towards a ‘restorative care’ model for dementia dyads will be discussed.

### ***Breaking Path Dependence***

Path dependence is a concept which refers to the imprinting effects of the past on current organisational structure and behaviour (Schreyögg and Sydow, 2011; Sydow et al., 2009). It refers to how organisations, and the individuals that comprise them, adapt their behaviour to make institutions self-sustaining; once homeostasis is reached in institutions, structures and behaviours become very difficult to modify (North, 1990).

Institutionalisation has played a key role in the care of sick and older adults in Ireland, since the workhouses of the 1800s (O’ Shea et al., 1991; Timonen and Doyle, 2008). ‘Poor law’ at that time dictated that only the sickest or most ‘destitute’ could access care. This system was not dismantled until the early years of the Irish state, when care was relocated to hospitals and nursing home settings, many of which were governed by the Catholic Church. At that time, the Catholic Church held a ‘special position’ in the Irish constitution, giving them substantial power politically as well as culturally (Wren, 2003). The church dictated that non-medical care should be a private, family responsibility (McDaid et al., 2009; Wren and Connolly, 2017; Browne, 1989) and this was supported by Article 41 of the Irish constitution, which designates the family is an institution with which the state should not intervene.

The tide began to slowly change after the Health Act of 1953, which began state intervention through the provision of domiciliary nursing care. Subsequently, the *Care of the Aged* report (1968) recommended that older adults should be supported

by the state to remain at home, through the expansion of community supports. This policy was not implemented; instead the nursing home sector continued to be prioritised (O' Shea et al., 1991; Wren, 2003). *The Years Ahead* report (Robins, 1988) specifically outlined a need for flexible in-home respite, but to no avail. Respite, at this time, was intended as an opportunity for medical assessment and rehabilitation for the 'dependent elderly', highlighting how physical needs have long been the qualifier for respite access in Ireland. The first dementia-specific policy, '*An Action Plan for Dementia*' (O' Shea and O' Reilly, 1999), also advised an expansion of community supports, however the focus remained firmly on developing the residential care sector. In 2014, the national dementia strategy made many of the same pleas as the policies of the previous 40 years, highlighting the unshakeable path dependency that persists in the Irish health system. The factors that contribute to this in relation to respite service provision are outlined below.

#### *'Self-reinforcing mechanisms'*

Sydow et al. (2009) highlight that it is important to understand the 'self-reinforcing mechanisms' which create the conditions for path dependency, particularly if reform is intended. Self-reinforcing mechanisms contribute to positive feedback processes, and serve to maintain and further rigidify current practices. The authors outline a process model of self-reinforcing mechanisms, which include 'coordination and learning effects'; 'complementarity effects'; 'adaptive expectation effects' and 'contextual effects'. These will now be considered in the context of respite service provision in Ireland, as per the present findings.

#### *'Coordination and learning effects'*

'Coordination effects' refer to organisations having a shared understanding of their remit and rules, which enables efficient communication and operation. In residential respite services especially, management value a task-based approach that prioritises physical care, and front-line staff understand implicitly that this biomedical mode of operating is what is expected of them. As one interviewee noted this is "*a formula that has been around for a long time*" (p. 134). 'Learning effects' are closely-related to coordination effects in that they refer to how, over time, practices become routine, and are continuously refined to maximise efficiency. Learning effects are evident in both residential and day service settings, which are highly routinized in terms of



admission, assessment and care processes: *“We have to think on admission about medication reconciliation for respites, but we have the same routine, the same paper work for a respite admission as we do for our long term care patients”* (p. 134). One healthcare assistant noted that a significant obstacle she faces in completing her tasks to time-target, is the use of agency staff who are unfamiliar with ward routines: *“Often we’d have people from agencies who just come in and they basically just walk around the place...Whereas if you have the staff that are normally there, then you have your routine and you know what each of you are doing... Routine is important, especially with [low] staffing levels”* (p. 132).

#### *Complementarity effects*

‘Complementarity effects’ refer to how the cost of providing two services together is lower than the cost of providing them separately. This is particularly relevant to residential respite, given that a small number of respite beds are generally tacked-on to nursing home or community hospital units. Routines and practices of the dominant element of the service guide how the minor elements are provided. The care in nursing homes and community hospitals has a necessary and appropriate focus on physical/medical needs for long-term residents. However, respite admissions receive these same patterns of care, regardless of their individual needs. Residential respite providers here indicate that long-term residents are their main priority, and when respite admissions cause distress to residents, or are too mobile, they have to be discharged home: *“Often we find that the person is too good yet to be in the dementia unit and they can’t stay if they are a safety risk, especially if they are mobile...”* (p. 129). This illustrates how the respite service is secondary to the residential element, and is maintained, despite being a “nuisance”, because it is efficient at the systems-level to structure service provision this way: *“When respites come in there can be an awful lot of issues, which takes up an awful lot of time... I know that sounds very, very negative but we have to spend so much time and resources on people that we don’t really know, which takes away from our residents. So we have just four [respite] beds now and that’s manageable”* (p. 134).

#### *Adaptive expectation effects*

Adaptive expectation effects refer to practices at the individual level, i.e. the behaviours and practices of frontline staff, which serve to maintain the status quo of

the service/organisation. Staff understand that upper management have certain expectations of them, with particular reference to physical care tasks, and so they behave in ways that satisfy management's expectations, even if that means respite care is not person-centred: *"We always have to prioritise people who come in with physical needs, its important at the end of every day that all the necessary tasks and paperwork are done and everyone is safe"* (p. 132). This type of focus on task-based activities, according to the classic study by Menzies Lyth (1960) serves to assuage organisational anxiety, by 1) eliminating the need for flexible decision-making at the front-line and 2) depersonalising clients. Management reinforce this by discouraging initiative-taking in staff, which minimises risk and increases efficiency. As long as the status quo is maintained, and operations remain efficient, management protect front-line staff and absorb the majority of responsibility (Menzies Lyth, 1960).

### *Contextual effects*

Sydow et al. (2009) indicate that it is important to consider contextual factors which serve to reinforce the structure and organisation of services. The present findings suggest that, regarding respite provision, the following contextual factors are significant: 1) political inertia, 2) biomedical ideology and 3) the role of segregation.

#### 1. Political Inertia

According to Burke (2016), Irish health policy is best characterised by political decisions not made. This rings particularly true in relation to respite, and is evidenced by a long-standing and steadfast policy-practice gap. As one primary care professional noted: *"they [government] do not want to take on this responsibility..."* (p. 135). A number of stakeholders pointed out, in chapter 6, that the continued lack of commitment to funding community supports, in favour of long-term residential care has contributed to this. As one carer noted: *"There are no services in the community to keep him here... They went away and organised 'Fair Deal' to support families to get people into nursing homes but they never organised something like that for people to stay at home"* (p. 115).

In a review of European dementia strategies/plans across 24 countries, Alzheimer Europe noted that Ireland was the only country in which funding was allocated to carry out an interim review and an external evaluation of the impact of the implementation of their strategy. It is likely that the decision to take this approach

arose, at least in part, because of the awareness of the funders and other stakeholders, of the long-standing policy-practice gap in relation to developing dementia care and supports in the Irish context.

## 2. Biomedical Ideology

Additionally, embedded within the system is a biomedical ideology, which has contributed to path dependency regarding respite. Respite was fashioned in a time when psychosocial support was not considered relevant to people with dementia, largely because they were defined by their diagnosis, and their presenting symptoms. Our understanding of dementia has evolved substantially since the inception of residential respite care, and yet it seems that care in respite settings has not evolved accordingly. People with dementia still experience malignant social psychologies, and some respite staff continue to use language which indicates that dementia progressively annuls personhood. It appears, based on the findings here that there are competing schemas at play for respite providers regarding the construction of dementia. The biomedical model remains extremely difficult to shift, because unlike person-centred care, it constitutes a deeply-entrenched ideology, with a systems-level backing.

According to Mullins (1972), an ideology is comprised of four components. Each ideology 1) has power over cognition; 2) guides one's evaluations; 3) provides guidance towards action; and 4) is logically coherent. Mullins explains that logical coherence is vital; it is what binds the ideology together and allows people to accept it as the truth. Once instated, all cognitions, evaluations and actions must be logically coherent with existing schema comprising the ideology; if ideas or assumptions don't fit, they are typically not assimilated. Unravelling a logically coherent ideology within the operations of a path dependent health system is a highly challenging endeavour. As one policy-maker in chapter 6 noted: *"What we need to do now is frame a new model...we absolutely need to build up person-centred community and in-home supports, but you know, it is difficult to turn this liner"* (p. 133).

## 3. The Role of Segregation

Foucault (1977) detailed how those who demonstrate patterns of behaviour which diverge from cultural norms are removed from the general population and sent to 'carcerals'. These are hierarchical institutional systems characterised by segregation,

constant surveillance, the use of expert knowledge, and the ‘rendering docile’ of those who are not compliant with structures and routines. Staff in these settings act as ‘technicians of behaviour’, who direct ‘the orderly movement of groups’. This is in line with those people with dementia who have felt disempowered and stripped of their narrative agency in this research, e.g. ‘John’, who referred to the staff in his day service as the “*hierarchy*” and stated, “*they wanted to inch me and keep me away from the headquarters*” (p. 38).

In a similar vein, Kate Swaffer (2014) has pointed to ‘prescribed disengagement’ in relation to the process of progressive withdrawal from society by people with dementia. Instead of care in institutional settings, Swaffer notes that what people with dementia need is a ‘re-investment in life’ (p. 4). It is clear from the findings of this thesis that in the context of ‘respite’, what dyads’ want is formal support to enable them, as Swaffer states, to (re)invest in aspects of their life that are personally significant to them. But as one person with dementia notes, “*nobody asked the right questions here... therefore [they] are all losing out on an opportunity of learning from us... but it isn’t easy to educate people to do that... but what do they like... how do you know they like it... when did you last ask them?*” (p. 158). Other stakeholders here confirm this, and indicate that we don’t currently have the necessary capacity, assets or capital in the community to realise this sort of de-segregation and de-medicalisation of life.

### **A Social Model of Dementia**

As discussed in chapter five, the unwillingness of the state to clarify the boundaries of responsibility for the non-medical care and support of dementia dyads has been a substantial barrier to timely respite service access. Given the structure and organisation of the health system, as well as the biomedical ideology guiding front line practices, we must question whether the Department of Health should bare unmitigated responsibility for supporting dementia dyads with aspects of everyday living.

A number of authors have suggested that dementia would be better positioned within a social model, similar to disability, because this allows for a distinction to be made between the illness/impairment associated with the dementia, and the oppression and social exclusion that people with dementia experience (Oldman, 2002; Keyes et al.,

2019; Cahill, 2018; Thomas and Milligan, 2018; Shakespeare et al., 2019).

Considering dementia as a disability would serve to establish eligibility for anti-discriminatory disability rights, related human rights and legal protections for people with dementia, which in turn, would support carers in their role. Additionally, the social model of disability encourages us to ‘think beyond the usual health and social care boxes’, which dementia is usually restricted to, and which creates a ‘medical model of life’ for dementia dyads (Oldman, 2002; Shakespeare et al., 2019).

According to Oldman (2002), the social model would be useful for critiquing and reconfiguring ageist, exclusionary public policies and practices, in particular by addressing the social, transport, and housing policy needs of people with dementia, with a view to improving their wellbeing. This is in line with findings in relation to health production, which demonstrate that outcomes are mediated by socio-environmental factors within homes and local communities, which are unrelated to health and social care interventions (O’ Shea & Connolly, 2012; Thornton, 2002). Respite services have been constrained by how other government departments see dementia as almost entirely a health responsibility, and are therefore not willing to assume responsibility for the everyday social health and wellbeing of people with dementia and their carers. This is further addressed in relation to implications for policy below.

### ***Alternative Models of Dyad Support***

In order to use these findings to inform a move away from traditional models of respite, towards a social model, it is worth examining existing models which focus on the psychosocial support of dementia dyads. Examining models and programmes which have components that are consistent with the perspectives of stakeholders in this thesis, will allow us to envision innovation in the Irish context, without reinventing the proverbial wheel.

#### ***The Meeting Centres Support Programme***

The Meeting Centres Support Programme was first developed in the Netherlands in 1993 (Dröes et al., 2003). The theoretical basis for the programme lies in the Adaptation-Coping Model (Dröes *et al.* 2000), a dyadic model of coping which considers the psychological, social, interpersonal and environmental factors which impact the experiences of people with dementia and their carers (Dröes et al., 2003).

These meeting centres are typically run in local community centres, as opposed to dedicated day service centres and the staffing mix is less clinical (e.g. consisting of a programme co-ordinator, an activity co-ordinator and a nursing assistant, plus local volunteers). According to Dröes et al (2003), this configuration makes this programme less intimidating than day services, especially for younger people with dementia, and encourages timelier support-seeking. Brooker et al (2018) notes that the programme is offered three days per week, and supports up to 15 dyads in accessible community locations. Dyads can attend separately or together and can participate in a range of activities, socio-cultural events, outings, peer support and discussion groups. Additionally, they can avail of individual and/or dyadic counselling (1 hour/week).

Multi-centre research in the Netherlands indicated that when compared to standard day services, the meeting centre support programme had a positive effect on self-esteem, mood, behaviour and in terms of delaying institutionalisation for the person with dementia (Dröes et al., 2000; Dröes, et al., 2004a; Dröes et al., 2004b). For carers, the programme has led to significant improvements in self-perceived competence (Dröes et al., 2004a), as well as reductions in ‘burden’ and psychological and somatic symptoms (Dröes et al., 2006). A multi-country study by Brooker et al (2018) compared the meeting centres programme to ‘usual care’ for people with dementia across Italy, Poland and the UK. The authors reported a significant positive effect of the programme on self-esteem ( $F = 4.8$ ,  $P = 0.03$ ), positive affect ( $F = 14.93$ ,  $P < 0.00$ ) and feelings of belonging ( $F = 7.77$ ,  $P = 0.01$ ) in those attending the MCSP, with medium and large effect sizes. The authors concluded that the programme is transferrable across countries, but further research is needed to understand contextual factors influencing implementation.

This model aligns with the perspectives of key stakeholders in this thesis, in relation to having a community-embedded, dyad-focused, (somewhat) flexible and frequently available programme, which offers a range of holistic supports, with a view to increasing the wellbeing of dementia dyads. Having a local hub provides dyads with a central meeting point, where it is possible for dyads to connect with a network of local peers in structured and unstructured ways. One distinct benefit of the meeting centres support programme is that it is guided by the Adaptation-Coping model. This provides a defined framework for identifying and addressing unmet psychological,

social, interpersonal and environmental needs in dyads, in an individualised way. However, home care is notably absent from this model, and given that flexible in-home support (day/evening/weekend/overnight) was the most frequently cited preference by people with dementia and carers, and was the most widely acknowledged client preference by other stakeholder groups, this type of programme, alone, would still not be acceptable to some dyads.

#### *GENIO Flexible Respite Model*

GENIO, a non-profit organisation focused on ‘social service transformation’, have designed and evaluated a consortium model of integrated community supports in Ireland (Cullen & Keogh, 2018). One of the objectives of the GENIO-funded dementia care projects was to evaluate flexible and responsive respite options for dementia dyads in their homes and local communities (O’ Shea and Monaghan, 2015; Cullen and Keogh, 2018; Cahill et al., 2014). The needs identified for dyads included occupation, social engagement and physical exercise. The report notes that the provision of ‘mainstream’ recreational and social activities, and the support to engage with same, resulted in a range of positive outcomes for the people with dementia and carers. Some people with dementia preferred one-on-one support, and so a ‘befriending’ component was put in place, whereby people with dementia received a block number of hours of personalised psychosocial support in the home, enabling a restorative break for the carer. This personalised in-home respite programme was highly acceptable to dyads, and was preferable to traditional models (Cullen & Keogh, 2018). For carers, perceiving the benefits of exercise and social engagement for people with dementia was the most important factor contributing to them achieving a respite experience. This reinforces the finding in this thesis that mutual benefit must be perceived by carers in order for the carer to achieve positive outcomes.

GENIO’s flexible in-home respite programme focuses on both members of the dyad, and is underpinned by principles of personhood and citizenship. However, it is not clear that there is any specific focus on the reciprocity needs of people with dementia in practice. Indeed, the evaluation report indicates that “the opportunity the intervention afforded these people for social engagement...was by far the most important and unique aspect of the programme” (Cahill et al., 2014, p. 12). In traditional respite services, even where satisfactory social engagement and activities

are provided, people with dementia still yearn to use their strengths and skills purposefully, to add value to the lives of others.

### ***Reimagining Respite as Restorative Care***

Both of the above models have components that could be useful to consider for the development of a social model of respite for dementia dyads. However, neither of these models are sufficient to actualising the vision outlined by the stakeholders in this thesis. Based on the findings here, it seems that a new model of ‘restorative support’ would preferably be comprised of the characteristics outlined in table 8.1.

**Table 8.1 A model of restorative care for dementia dyads**

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|---|
| <ol style="list-style-type: none"> <li>1) A dyadic, outcome-focused social model of support</li> <li>2) Underpinned by principles of personhood and citizenship</li> <li>3) A single point of contact to coordinate support and liaise between dyads and services</li> <li>4) A central hub in the local community</li> <li>5) A guiding framework for a holistic assessment of psychosocial and occupational needs, repeated at regular intervals to account for changing needs/circumstances</li> <li>6) A network of staff and volunteers, with appropriate dementia education and training</li> <li>7) Structure/processes for regularly communicating with carers to make them feel included and provide them with feedback regarding the benefits to the person with dementia</li> <li>8) Structures/processes for regularly communicating with the dyad, to ensure that all parties understand the values and preferences of the person with dementia and the carer</li> <li>9) A programme of supports which the dyad can choose to engage in, separately or together, based on their needs and their preferences. These will offer: <ol style="list-style-type: none"> <li>➤ Choice of setting (in-home, community) and format (group, one-on-one)</li> <li>➤ Flexibility in timing and duration (day, evening/overnight and weekend)</li> <li>➤ Provision of transport to facilitate engagement</li> <li>➤ Psychoeducation for carers</li> <li>➤ Tailored activities for people with dementia</li> <li>➤ Valued roles for people with dementia, if desired</li> </ol> </li> <li>10) A programme for promoting dementia awareness and the inclusion of people with dementia in the community, coordinated by staff and volunteers from the central hub.</li> </ol> |
|---|



### 8.3 Practice Implications

Significant implications for practice also arise from the findings of this thesis, with particular reference to the need for training and education for all support staff and volunteers working within respite services. Firstly, training must emphasise that i) a dyadic approach should be taken, and ii) empathic communication is essential from the outset, to build partnerships based on reciprocated trust and respect. Importantly, providers must learn the importance of actively demonstrating the centrality of the person with dementia to the carer.

It will be necessary to continue to resource high-quality, evidence-based training and education programmes for respite staff, which emphasise the importance of the principle of mutual benefit. According to the findings of a systematic review of dementia education and training programmes by Surr et al. (2017), the most efficacious had a number of components in common. They were relevant to participants' role/experience, had active face-to-face participation, underpinned practice-based learning with theory, were delivered by an experienced facilitator, were of (at least) eight hours in duration, and supported application of learning in practice. In relation to the 'underpinning practice-based learning with theory' recommendation, it is clear in the context of traditional respite provision that relaying existing definitions and descriptions of theoretical concepts such as 'person-centred', 'personhood', 'narrative agency' and 'citizenship', which themselves incorporate other high level concepts, has not been especially effective to date, in terms of changing interpersonal care practices.

Given that mutual benefit is a key antecedent in the context of respite, a key focus must be on supporting personhood for people with dementia, and demonstrating/communicating the ensuing benefits of this approach for the person, to the carer. Training which educates staff on the practice of taking the 'intentional stance' (i.e. assuming meaning-making ability and intentionality in the person with dementia) could be a useful approach to demonstrate how personhood can be supported interpersonally. While the term 'intentional stance' need not be employed, given this is a high-level concept, it would be useful to distil what the 'intentional stance' means, and how it can be manifested in interpersonal interactions, to facilitate meaningful, personhood-supporting engagement. The key educational point is that it is vital to operate off the assumption that people with dementia are verbally and/or

non-verbally communicating *something* meaningful, even if the meaning is not easily discernible. Working with the person to decipher what the meaning of a given communication is, and how to honour it appropriately in terms of their approach to supporting the person, may be seen as a core responsibility of staff working with a social model of restorative care for dementia dyads.

Another important issue to address is the concern of respite service providers regarding the struggles that family carers face in providing dementia care in between respite service use. Many believe stress could be minimised if carers were provided with tailored psycho-education, as part of a respite programme. Perhaps providing carers with the appropriate psycho-education as part of respite programmes could help increase their confidence and capacity to navigate the caring role and relationship, in the periods between respite service use. However, for such psycho-education to be useful as part of a respite or ‘restorative care’ model, timely access for dyads has to be a priority.

## **8.4 Policy Implications**

We know from this research that respite needs often only achieve legitimacy and trigger referrals when the person with dementia has significant physical needs and/or the carer is approaching burnout. Hennelly and O’ Shea (2019) note in their analysis of the Irish National Dementia Strategy (2014), that informal carers are referred to as ‘natural supports’ (p. 12), indicating the implicit attitudes of policy-makers, that dementia care is primarily a private family issue, but temporary relief for carers may be provided, to sustain them in their carer role. The strategy specifically states that respite services which are “responsive and tailored to the needs of the person with dementia as well as the carer” are important. However, the resulting ‘priority action’ only pertains to carer support.

Furthermore, as highlighted by O’ Shea et al. (2018), the significant inequities in service provision for dementia, including respite, were not addressed in the national dementia strategy (2014). Future policy will need to underline the need for an appropriate volume and distribution of respite services, which aim to address the psychosocial and relational needs of both members of the dyad, in their homes and communities. While there is government legislation currently being developed in Ireland, which intends to designate rights for homecare in Ireland, details relating to

service characteristics, and whether there will be a respite component, are not currently available (Carter et al., 2019).

Carers want to feel valued by the state for their role in dementia care provision and indicate that this could be achieved by the state through the provision of respite services that maximise personalisation, choice and flexibility. If there is to be a second dementia strategy in Ireland, it should address these specific issues. It is also important that any future strategy formulation process considers that delivering a social model of respite, as envisioned by the stakeholders in this thesis, may not be the sole remit or responsibility of the Department of Health. Rather than a rebalancing of the health system alone, implementing a social model will require cross-departmental collaboration at government level. In the ‘Sláinte Care’ (2017) and the ‘Healthy Ireland’ (2013) policies, partnerships and cross-sectoral work are considered key themes that are central to improving population health and wellbeing generally, by “*moving beyond the health service, across national and local authorities, involving all sectors of society, and the people themselves*” (Healthy Ireland, 2013, p. 8). Such an approach may be necessary to unstick the biomedical model of traditional respite provision, in favour of a social model of restorative care for dementia dyads.

This will require policy recommending wide-scale reform, regarding respite service organisation, governance and coordination. However, what is perhaps more important is the need to shift the philosophical paradigm underpinning respite service provision. Specifically, a paradigm shift will be required in relation to 1) the nomenclature of ‘respite’, 2) the nature, aims and proper location of respite service provision, 3) the personhood status and needs of people with dementia, and 4) the need for carers to perceive mutual benefit, through ongoing service-dyad partnership. Policy must outline that such a model must be coordinated and regulated in a way that supports early access, and flexibility in terms of the setting, availability/duration, and focus (i.e., dyadic; tailored). Specifically, a strong orientation to home-based respite should be indicated, given that this is the clear preference of people with dementia and carers.

It should also be noted that while this research was conducted in Ireland, and was discussed and contextualised here largely in light of factors relating to the Irish health system, this does not mean that the findings regarding the need for respite

reform are unique to the Irish context. Indeed, many of the findings here are in line with the findings of international literature from carers' perspectives on respite access and provision, and are consistent with international perspectives regarding a de-medicalisation of the lives of dementia dyads. It is likely that the novel findings identified here regarding respite reform arose out of the decision to include and synthesize multiple stakeholders' perspectives for the first time, as opposed to any major distinction between Ireland and other international contexts. Therefore, these findings will likely have relevance to the future provision of respite care for dementia in other countries also.

## **8.5 Contributions to the Literature**

### *Strengths*

A key strength of this work is the focus on the meaningful inclusion of the perspectives of people with dementia. In particular, the empathetic approach to the interviews with people with dementia, teamed with the adoption of the intentional stance as outlined in chapter two, is novel, and allowed for the collection of rich data on the care experiences and preferences of people with dementia regarding respite services. The 'intentional stance' has not previously been invoked in methodological guidance papers regarding the meaningful inclusion of the perspectives of people with dementia in qualitative interview research. Novek and Wilkinson (2019), highlighted a study by Digby et al (2016) which indicated that 'tangential stories' can be a deflection tactic for people with dementia, to avoid sensitive subjects or those for which they have poor recall. While that might sometimes be the case, it is not useful to assume that seemingly tangential narratives do not contain any useful insights. This research highlights that when the researcher assumes there is meaning to be co-constructed, and has some background knowledge of the person and their life, communications which otherwise might have been ignored or dismissed as irrelevant, can be recognised and explored as avenues to experiences/ perspectives that are relevant to the research question.

Secondly, employing person-centred care theory as a standard against which to contextualise the meaning of 'respite' and the experiences and perspectives of multiple stakeholders, generated a number of novel insights. Regarding the concept analysis (chapter three), had the results not been considered in the context of person-

centred care theory, the conclusion of that study would likely have been in line with those of previous concept analyses in other populations, which have been more accepting of the dual meaning of respite (i.e. a service and a carer outcome) (Chappell et al., 2001; Evans, 2013a; Hanson et al., 1999; Whitmore, 2017). However, by further interrogating the meaning, against a backdrop of person-centred care theory, it became clear that ‘respite’, is fundamentally discordant with the principles of person-centred dementia care and may be impeding respite service acceptability, use and effectiveness.

This work was guided by an interdisciplinary supervisory team with expertise in psychology, nursing, geriatric medicine, health systems research, social policy, and economics. Each team member had a distinct disciplinary perspective, which challenged and broadened my perspective on dementia and dementia care. These divergent, but often complementary perspectives forced me to grapple with some of the key debates in relation to dementia care research that I would perhaps not otherwise have become cognisant of (e.g. regarding constructions of dementia). It also served to correct and/or balance my interpretations of some of the findings of this research and ensured that I paid attention to my own biases and assumptions.

Finally, throughout this thesis, a key priority was to maintain a focus on high-quality and transparent reporting of the research studies, using the relevant reporting guidelines for each study design. The reporting guidelines used were endorsed by the EQUATOR Network, which seeks to improve transparent, detailed and accurate reporting of scientific research. In chapter 4, the qualitative systematic review and meta-ethnography was reported in line with the ‘Enhancing Transparency in Reporting the Synthesis of Qualitative Research’ (ENTREQ) statement (see appendix D). The manuscripts relating to the primary qualitative interview data collected with multiple stakeholders, and reported in chapters 5-7, were reported in accordance with the Consolidated Criteria for Reporting Qualitative Research guidelines (COREQ) (see appendix G).

### *Research and Theory*

A key finding of this research is that people with dementia want support that acknowledges their personhood, including their human need for reciprocal engagement. Future research should further explore how community capacity can be

built, to support people with dementia to occupy personally-meaningful and valued roles, which enable them to contribute, as well as receive. An action research approach may be useful to facilitate the co-production of knowledge and social change, in context. However, this would necessitate flexibility in how resources and funding are used in relation to respite provision.

The findings regarding reciprocity also have implications for person-centred care theory. Kitwood (1997) outlined a framework of inter-connected needs (attachment, inclusion, occupation, identity and comfort) that contribute to an experience of love and wellbeing, when they are met. The need for reciprocity is not represented in Kitwood's work. While one could argue that reciprocal engagement could be an element of the need for occupation, this is not suggested by Kitwood. In relation to Kitwood's positive person work approach, the same could be argued for the concepts of 'facilitation' and 'collaboration'. These indicate that people with dementia should be supported to achieve their goals, but neither concept specifically acknowledges the human need for reciprocity. Kitwood also outlines a concept of 'giving' as part of the positive person work framework, which refers to being accepting of what people with dementia offer interpersonally, to reinforce their personhood. However, this is about staff responding to 'giving' behaviours with kindness and appreciation, as opposed to proactively supporting them to actualise their need for reciprocity, by creating opportunities for a valued role. Perhaps 'reciprocity' would be a useful addition to the 'needs' framework outlined as part of the person-centred care theory. This addition would serve to more clearly recognise the agency of those living with a dementia diagnosis, and supporting their human need to contribute to the lives of others.

Finally, future research must explore how governmental departments can work in partnership, as appropriate to their remit, to build capacity in local communities in a way that can facilitate a social model of restorative care.

## **8.6 Limitations and Challenges**

The plan for this research was to include as many people with dementia in the qualitative interviews as possible, to maximise the diversity of experiences that were represented. However, gatekeepers in respite services complicated access to this population to a degree I did not foresee. A recent review by Novek and Wilkinson

(2019) highlighted that negotiating with gatekeepers can be challenging in relation to recruiting people with dementia for research. In the present study, it appeared that gatekeepers blocked access to people with dementia for one of two reasons. Firstly, gatekeepers were often genuinely and appropriately protective of those under their care, and felt that participating in research, at that time, was not in the person's best interest, (e.g. if the person was exhibiting high anxiety, low mood, significant confusion, and/or was not feeling well physically, on the day). However, at other times, management were making decisions based on assumptions about the abilities of the person with dementia to contribute useful data, because they felt the person lacked the necessary communicative abilities. While I tried to assure management that meaning-making was part of my responsibility, some continued to feel this was a pointless endeavour.

Having gone through this process, I would now approach the recruiting of people with dementia, through gatekeepers, in a different way. In hindsight, it seems that the term 'interview' was a red flag of sorts for some staff and immediately made them concerned about the 'capacity' and cognitive ability of people with dementia to engage in what they considered a formal and complex interpersonal process. I now see that the framing of this research interaction as an 'interview' was a deterrent for some gatekeepers in terms of granting access to people with dementia. In retrospect, I think that staff assumed that my approach to interviewing would be akin to the traditional social science interview where the interviewee remains neutral in an effort to not influence the process in any way. The post-modern approach to interviewing adopted here allowed for a more conversation-like tone, where empathy and validation are welcome and encouraged to connect with the interviewee and to gain an in-depth understanding of their experiences and perspectives on the topics at hand.

It may have been more useful to frame the research approach as ethnographic in nature, which would include having recorded conversations with people with dementia. While this could be conceived of as misrepresenting the data collection method, I would argue that I actually inadvertently ended up adopting a more ethnographic approach in the endeavour to ethically and meaningfully include people with dementia in this research. For example, I spent time in services (informally) observing dynamics and I spoke informally with family members and/or respite staff

to better understand the person with dementia that I was going to interview, as well as the respite context. This helped me to tailor and refine my interviewing approach with people with dementia. In future, I would consider the framing of the research approach in greater depth. Again, this would not be to misrepresent the research, but to consider that research methods jargon is loaded with meaning that some gatekeepers working in respite services may feel is inconsistent with their perceptions of the semiotic abilities and/or cognitive loads of many of the people with dementia that they care for.

This research focused solely on the perspectives of past/present service users. In this way, those people with dementia and carers who choose not to use respite services, are not aware of the available services, or have not been able to negotiate service access, are not represented here. Future research should consider the perspectives of non-users in relation to respite services. Similarly, the carers and people with dementia represented here are English-speaking people of Irish or British nationality, so the data cannot account for the perspectives of non-English-speaking individuals, non-nationals, and/or other minority groups (e.g. the travelling community, LGBTQ+ community, ethnic minorities, those with an intellectual disability), on current respite service provision. The systematic exclusion of the perspectives of people who either have chosen not to use formal respite services, or who have perhaps failed to negotiate access, has implications for the interpretation of the findings in this thesis. It is possible that the range of perspectives on the barriers and facilitators to respite service access and initiation have not been addressed, and that the perspectives included here do not represent the worst-case scenario. It is important that future research is more inclusive of less visible and/or minority groups, to capture any specific needs and preferences that members of these groups might have in relation to respite support.

In relation to the data analysis procedures regarding the primary qualitative study, the data was coded by just one person, which is often considered a limitation. However, Braun and Clarke (2006) argue that in a reflexive thematic analysis of qualitative data, double-coding is a contradiction to the constructivist paradigm, because the notion of inter-rater reliability is rooted in post-positivist assumptions about the nature of reality (i.e. that there is an objective reality that can be discovered). Given the pragmatic, subtle realist philosophy adopted here, I believe



that all reality is filtered through the subjective mind of the researcher, and two or more minds will not cancel out the subjectivity of interpretation. Instead, it arguably makes the reflexive processes which drove the research less transparent, since the second coder's process and biases, which would have influenced the analysis, would not be declared.

It was also challenging to manage and analyse large amounts of qualitative data (approximately 70 hours of interview data), even with the use of the NVivo programme. The challenge regarding the quantity of data was compounded by the fact that the sample was comprised of multiple stakeholder groups, across three potential respite models (residential, day service, in-home). To surmount this challenge, I developed an initial coding framework, based off of seven of the 35 interviews (20%), which acted as a template for the remaining interviews; however, this original framework was by no means comprehensive or complete. With the coding of each of the remaining interviews, the framework was revised and refined, to incorporate new learning. NVivo was particularly useful in this respect, facilitating rapid and straightforward recategorising and renaming to incorporate new, or more nuanced understanding of phenomena. Once initial coding of all interviews was complete, I then had to become very familiar with both the descriptive and analytic codes, and iteratively compare and contrast codes and the data which comprised them, in terms of the context which they relate to. This process led to re-categorisation and renaming of both codes and category definitions.

Throughout this process, I came to learn that NVivo is not a data analysis tool, and that analysis can only be conducted through the researcher's engagement with the data. My goal was to engage with the data in a way that moves beyond the descriptive, to identify latent patterns of meaning and consider the significance of such meaning within the context that it was offered. In trying to achieve this, it was very clear from early in the process that NVivo is simply a tool to facilitate how researchers can engage with different organisations and configurations of segments of the data. The real *analysis* comes from how the researcher compares and unpacks participants' perspectives, in light of their positionality, in ways that relate to the research questions.

The analysis of the primary qualitative data collected from people with dementia was amongst the greatest of the challenges I faced in relation to this PhD. While I am

sure that the intentional stance has substantial potential as an approach to meaningfully engaging people with dementia, in my experience, this approach also carries significant risks. When you are, by definition, looking for meaning and relevance in every communication and behaviour, and your central agenda is to answer your research question, there is always a chance that a researcher will project meaning onto what a person with dementia has said, that doesn't reflect what the person really meant to indicate.

I have learned throughout this process, that interpreting the meaning of communications with people with dementia, can have at least two critical points where bias and imposed meaning can seep in. The first is during the interview process itself, where the researcher is trying, in real time, to navigate and interpret a range of communications. In this instance, the researcher can either miss an opportunity to connect with the person's perspective on an issue relating to the research question, or alternatively they can impose meaning that doesn't reflect the perspective of the participant, or simply had nothing to do with the research question, for the interviewee.

Throughout my interviews with people with dementia, there were times when participants were lucid, clear and obviously intentionally communicating a specific perspective or experience. However, there were other times where the meaning of a line of communication was not entirely clear to me, and this is where the risk lies. I learned that in order to mitigate these risks, I had a significant amount of preparatory work to do in advance of the interviews with people with dementia. I had to gain an in-depth understanding from family and staff about the interviewee's personality, life and occupational history, communication patterns or quirks, and any special interests, concerns or anxieties. While this certainly provided useful context for me many times during interviews, there were still numerous times when I struggled in the moment to interpret a communication, or to know if it was relevant and should be interpreted at all.

At the point of data analysis, a second layer of interpretation comes into play. This second critical juncture is even more complex in some respects. It allows more space and time to consider the meaning of each data segment, without the pressure of performing as the interviewer. However, this is only an advantage if the researcher takes the issue of reflexivity seriously, by questioning their own biases and

motivations, and bringing elusive or contentious data to supervision to work through potential blind spots. This, for me, was the most important element of ensuring that I was not unwittingly colonising the perspectives of people with dementia, and manipulating them somehow, to answer my research questions. In my supervision sessions, I was challenged to justify both of the two main critical junctures of interpretation, i.e. my inferences and responses in the interpersonal interactions during the interview, and my interpretations of data during the analytic process. In sum, I have learned that meaningfully including the perspectives of people with dementia is not a clean cut process, or one on which I can provide a linear, packaged formula; it is a dynamic process, in which the researcher must commit to staying as person-centred and reflexive as possible, prior to and during the interview, and again during the data analysis phase.

## 8.7 Research Translation and Impact

A number of research outputs have arisen from this PhD work, in addition to the four published papers presented as part of this thesis (in *Dementia*, *The Gerontologist*, *BMC Geriatrics* and *Ageing & Society*). The following oral presentations (see table 8.2) have also been delivered, at national and international conferences, based on the research presented in this thesis. For oral presentation number 4, in table 8.3, I won the award for best oral presentation.

**Table 8.2. List of oral presentations**

1. **O' Shea, E.**, Timmons, S., O' Shea, E., & Irving, K. (2019). Accessing respite services for dementia: Multiple stakeholders' perspectives. Alzheimer Europe, The Hague, Netherlands.
2. **O' Shea, E.**, Timmons, S., O' Shea, E., & Irving, K. (2019). The perspectives of people with dementia on day and respite services: A qualitative interview study. Engaging Dementia Conference, 2<sup>nd</sup> April, Croke Park, Dublin.
3. **O' Shea, E.**, Timmons, S., O' Shea, E., & Irving, K. (2019). The perspectives of people with dementia on day and respite services: A qualitative interview study. SPHERE Conference, 26<sup>th</sup> February, Royal College of Surgeons, Dublin.
4. **O' Shea, E.**, Timmons, S., O' Shea, E., Fox, S., & Irving, K. (2018). Respite in dementia: An evolutionary concept analysis. Research Expo, December 2018, School of Nursing and Human Sciences, DCU.
5. **O' Shea, E.** (2018). Enabling 'ageing-in-place': Developing acceptable respite services and community supports for people with dementia and their carers. British Society of Gerontology. July 2018. Birmingham.

- 6. O' Shea, E.** (2017). Thesis-in-three competition. DNNI Conference November 2017. King's Inns, Dublin.
- 7. O' Shea, E.,** Timmons, S., O' Shea, E., Fox, S., & Irving, K. (2017). Key stakeholders' experiences of respite services for people with dementia and their perspectives on respite service development: A qualitative systematic review. Irish Gerontological Society 65th Annual & Scientific Meeting 2017, Clayton White's Hotel, Wexford.

In addition, the following poster presentations (see table 8.3) have been delivered, at national and international conferences, based on the research presented in this thesis.

**Table 8.3. List of poster presentations**

- 1. O' Shea, E.,** Timmons, S., O' Shea, E., & Irving, K. (2019). Respite Care for People with Dementia and their Carers: A Qualitative Study with Multiple Stakeholders. Alzheimer Europe, The Hague, Netherlands.
- 2. O' Shea, E.,** Timmons, S., O' Shea, E., & Irving, K. (2019). Multiple Stakeholders' Perspectives on Accessing Respite Services for Dementia. Engaging Dementia Conference, 1<sup>st</sup> April, Croke Park, Dublin.
- 3. O' Shea, E.,** Timmons, S., O' Shea, E., & Irving, K. (2018). Methodological challenges in including people with dementia in qualitative interview research. New Horizons Conference WGB, UCC, Cork, December 2018.
- 4. O' Shea, E.,** Timmons, S., O' Shea, E., Fox, S., & Irving, K. (2017). Key stakeholders' experiences of respite services for people with dementia and their perspectives on service development: A qualitative systematic review and meta-ethnography. Alzheimer's Europe, Berlin.
- 5. O' Shea, E.,** Timmons, S., O' Shea, E., Fox, S., & Irving, K. (2017). Key stakeholders' experiences of respite services for people with dementia and their perspectives on service development: A qualitative systematic review and meta-ethnography. AAIC, Chicago, USA.
- 6. O' Shea, E.,** Timmons, S., O' Shea, E., Fox, S., & Irving, K. (2017). Respite in dementia: An evolutionary concept analysis. SONAS Conference Dublin 2016 & New Horizons Conference WGB, UCC, Cork, December 2017.

Another way in which this research has been translated, is through the publication and dissemination of a policy brief (see appendix Q), which outlined the most significant findings and implications of this body of work. The policy brief has been disseminated online through the SPHeRE network, which is the largest network of health researchers in Ireland.

The policy brief was also sent directly, upon request, to a key decision-maker from ‘Services for Older People’ in the Department of Health. This decision-maker has stated that they are considering the implications of the findings for respite service development in Ireland. Engaging this person in a discussion about my PhD, arose as a result of many years of networking, collaborating and relationship-building with other dementia researchers in Ireland, some of whom have influence in the policy sphere, and good working relationships with decision-makers.

## **8.8 Thesis Conclusions**

This thesis presents a comprehensive body of research exploring key stakeholders’ perspectives on respite services for people with dementia and their carers, with a view to informing service development. The findings have indicated that service development alone would not be sufficient in the Irish context. Many stakeholders’ perspectives indicate that wide-scale reform of respite services, and the assumptions and philosophies guiding their provision, is required.

The term ‘respite’ is stigmatising to people with dementia and discordant with the principles of person-centred care. It inherently positions help-seeking as a carer-centred endeavour, as opposed to one grounded in mutual benefit, creating psychological barriers to role disengagement for carers. The access negotiation process is also affected; in a biomedical-orientated health system, ‘respite’ needs often do not gain legitimacy until physical needs are observed in the person with dementia, or carers are approaching burnout. This is potentially both a cause and consequence of longstanding under- and inequitable- respite provision.

The deficit-focused negative construction of dementia by some respite providers, points to how the biomedical model can lead to perhaps unintended malignant social psychologies, which are felt downstream by people with dementia whose personhood and narrative agency are diminished. The biomedical ideology is not easily overwritten in favour of a person-centred care approach, even when well-meaning respite providers are open to understanding and implementing person-centred care. Educating respite staff to operate off assumptions of personhood and semiotic ability, consistent with the ‘intentional stance’, may be a useful approach to improve dementia care practice in this context.

Key stakeholders, especially people with dementia and carers, describe an alternative, social model of respite, which goes beyond the realm and remit of the health system. A social model of respite would have a flexible and personalised homecare orientation, focused on the psychosocial and relational needs of both members of the dyad. It also should be capable of facilitating social inclusion and reciprocal engagement for people with dementia, either through day service attendance, or more community-embedded activities/events, depending on 1) individual needs and preferences and 2) the capacity of the local community.

Psycho-education for carers may also imbue carers with skills and knowledge that can serve to lessen the stress associated with caring between periods of respite service use. According to stakeholders, a central point of contact is necessary for successful coordination of such a model. Critically, the continued provision of short-term residential admission for the purposes of ‘respite’ is not considered a sensible use of resources by many stakeholders, including people with dementia. This should be reserved for emergency situations, and for assisting with the transition to long-term residential care.

Health funding continues to be biased towards residential care in Ireland, despite four decades of policy outlining the need for flexible and responsive in-home respite, and projections regarding the escalating prevalence of dementia. The Department of Health perhaps cannot achieve the paradigm shift required on its own. Implementing a social model of respite will likely require cross-departmental partnership and cost-sharing, akin to the disability rights movement. It is important that decision-makers heed the perspectives of stakeholders here and assume responsibility for supporting the psychosocial needs of carers and people with dementia.

## REFERENCES

- Abramson, C. M. (2009) 'Who are the clients? Goal displacement in an adult care center for elders with dementia', *The International Journal of Aging and Human Development*, 68(1), pp. 65-92.
- Alvira, M. C., Risco, E., Cabrera, E., Farré, M., Rahm Hallberg, I., Bleijlevens, M. H., Meyer, G., Koskeniemi, J., Soto, M.E., Zabalegui, A., and RightTimePlaceCare Consortium. (2015) 'The association between positive–negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study', *Journal of Advanced Nursing*, 71(6), pp. 1417-1434.
- Alzheimer's Association. (2018) 'Alzheimer's disease facts and figures', *Alzheimer's & Dementia*, 14(3), pp. 367-429. doi: <https://doi.org/10.1016/j.jalz.2018.02.001>.
- Alzheimer Society of Ireland (2018) *Dementia specific services in the community: mapping public and voluntary services*. Dublin: Alzheimer Society of Ireland and the National Dementia Office. Available at: <https://www.understandtogether.ie/news-and-events/news/Final-Report-Dementia-Specific-Services-Mapping-Project.pdf>. (Accessed: 1 October 2019).
- American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders (DSM-5®)*. USA: American Psychiatric Association Publishing.
- Aneshensel, C. S., Pearlin, L. I., Levy-Storms, L., and Schuler, R. H. (2000) 'The transition from home to nursing home mortality among people with dementia', *The Journals of Gerontology: Series B*, 55(3), pp. S152-S162.
- Arksey, H. and Bamford, C. (2007) 'Respite care for people with dementia: the range of models for getting a break', *Journal of Dementia Care*, 15(3), pp. 37-39.
- Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., and Volmink, J. (2008) 'Conducting a meta-ethnography of qualitative literature: lessons learnt', *BMC Medical Research Methodology*, 8(21), pp. 1-10. doi:10.1186/1471-2288-8-21.

- Baldwin, C. (2008) 'Narrative(,) citizenship and dementia: the personal and the political,' *Journal of Aging Studies*, 22(3), pp. 222-228.
- Baldwin, C. and Capstick, A. (2007) *Tom Kitwood on dementia: a reader and critical commentary*. London: McGraw-Hill Education.
- Barca, M. L., Engedal, K., Laks, J., and Selbæk, G. (2011) 'Quality of life among elderly patients with dementia in institutions', *Dementia and Geriatric Cognitive Disorders*, 31(6), pp. 435-442.
- Barnes, D. E. and Yaffe, K. (2011) 'The projected effect of risk factor reduction on Alzheimer's disease prevalence', *The Lancet Neurology*, 10(9), pp. 819-828.
- Bartlett, R. and O'Connor, D. (2007) 'From personhood to citizenship: broadening the lens for dementia practice and research', *Journal of Aging Studies*, 21(2), pp. 107-118.
- Baumgart, M., Snyder, H. M., Carrillo, M. C., Fazio, S., Kim, H., and Johns, H. (2015) 'Summary of the evidence on modifiable risk factors for cognitive decline and dementia: a population-based perspective', *Alzheimer's & Dementia*, 11(6), pp. 718-726.
- Beattie, A., Daker- White, G., Gilliard, J., and Means, R. (2004) 'How can they tell? A qualitative study of the views of younger people about their dementia and dementia care services', *Health & Social Care in the Community*, 12(4), pp. 359-368.
- Behuniak, S. M. (2011) 'The living dead? The construction of people with Alzheimer's disease as zombies', *Ageing & Society*, 31(1), pp. 70-92.
- Beisecker, A. E., Wright, L. J., Chrisman, S. K., and Ashworth, J. (1996) 'Family caregiver perceptions of benefits and barriers to the use of adult day care for individuals with Alzheimer's disease', *Research on Aging*, 18(4), pp. 430-450.
- Bieber, A., Nguyen, N., Meyer, G., and Stephan, A. (2019) 'Influences on the access to and use of formal community care by people with dementia and their informal caregivers: a scoping review', *BMC Health Services Research*, 19(1), p. 88. doi: 10.1186/s12913-018-3825-z.
- Black, B. S., Johnston, D., Leoutsakos, J., Reuland, M., Kelly, J., Amjad, H., Davis, K., Willink, A., Sloan, D., Lyketsos, C., and Samus, Q. M. (2019) 'Unmet needs in



community-living persons with dementia are common, often non-medical and related to patient and caregiver characteristics', *International Psychogeriatrics*, pp. 1-12.  
doi: 10.1017/S1041610218002296.

Bom, J. J., Bakx, P. P., Schut, E. F., and van Doorslaer, E. E. (2018) 'The impact of informal caregiving for older adults on the health of various types of caregivers', *The Gerontologist*. doi:10.1093/geront/gny137.

Brataas, H. V., Bjugan, H., Wille, T., and Hellzen, O. (2010) 'Experiences of day care and collaboration among people with mild dementia', *Journal of Clinical Nursing*, 19(19-20), pp. 2839-2848.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77-101.

Brodaty, H. and Donkin, M. (2009) 'Family caregivers of people with dementia', *Dialogues in Clinical Neuroscience*, 11(2), p. 217.

Brodaty, H., Thomson, C., Thompson, C., and Fine, M. (2005) 'Why caregivers of people with dementia and memory loss don't use services', *International Journal of Geriatric Psychiatry*, 20(6), pp. 537-546.

Brodaty, H., Woodward, M., Boundy, K., Ames, D., Balshaw, R., and PRIME Study Group. (2014) 'Prevalence and predictors of burden in caregivers of people with dementia', *The American Journal of Geriatric Psychiatry*, 22(8), 756-765.

Brooker, D. (2003) 'What is person-centred care in dementia?', *Reviews in Clinical Gerontology*, 13(3), pp. 215-222.

Brooker, D., Evans, S., Evans, S., Bray, J., Saibene, F. L., Scorolli, C., Szcześniak, D., d'Arma, A., Urbańska, K. M., Atkinson, T., and Farina, E. (2018) 'Evaluation of the implementation of the meeting centres support program in Italy, Poland, and the UK: exploration of the effects on people with dementia', *International Journal of Geriatric Psychiatry*, 33(7), pp. 883-892.

Browne, N. (1989) *Against the tide*. Dublin: Gill and Macmillan.

Burke, S. (2016) Reform of the Irish healthcare system: what reform? in Murphy, M. P. and Dukelow, F. (eds.) *The Irish welfare state in the twenty-first century*. Springer, pp. 167-191.

- Cahill, S. (2018) *Dementia and human rights*. Bristol: Policy Press.
- Cahill, S., Drury, M., Lawlor, B., O'Connor, D., and O'Connell, M. (2003) 'They have started to call it their club: a survey of staff views of dementia-specific day care centres in Ireland', *Dementia*, 2(1), pp. 85-103.
- Cahill, S., O'Shea, E., and Pierce, M. (2012) *Creating excellence in dementia care: a research review for Ireland's national dementia strategy*. Dublin: School of Social Work and Social Policy, Trinity College Dublin.
- Cahill, S., Pierce, M., and Bobersky, A. (2014) *An evaluation report on flexible respite options of the living well with dementia project in stillorgan and blackrock*. Dublin/Mullingar: Trinity College Dublin & GENIO.
- Campbell, P., Wright, J., Oyebode, J., Job, D., Crome, P., Bentham, P., Jones, L., and Lendon, C. (2008) 'Determinants of burden in those who care for someone with dementia', *International Journal of Geriatric Psychiatry*, 23(10), pp. 1078-1085.
- Cantley, C., Woodhouse, J., and Smith, M. (2005) *Listen to us: involving people with dementia in planning and developing services*. Dementia North: Northumbria University.
- Carney, P. and O' Shea, E. (2018) 'Philanthropy and dementia care in Ireland', *Dementia*. doi: 10.1177/1471301218791847.
- Carter, L., O'Neill, S., Keogh, F., Pierce, M., and O'Shea, E. (2019) 'Intensive home care supports, informal care and private provision for people with dementia in Ireland', *Dementia*. doi: 10.1177/1471301219863580.
- CASP (2006) *Ten questions to help you make sense of qualitative research*. Oxford: Public Health Resource Unit.
- Cepoiu- Martin, M., Tam- Tham, H., Patten, S., Maxwell, C. J., and Hogan, D. B. (2016) 'Predictors of long-term care placement in persons with dementia: a systematic review and meta-analysis', *International Journal of Geriatric Psychiatry*, 31(11), pp. 1151-1171.
- Chappell, N. L., Reid, R. C., and Dow, E. (2001) 'Respite reconsidered: a typology of meanings based on the caregiver's point of view', *Journal of Aging Studies*, 15(2), pp. 201-216.

- Cherryholmes, C. H. (1992) 'Notes on pragmatism and scientific realism', *Educational Researcher*, 21(6), pp. 13-17.
- Chertkow, H., Feldman, H. H., Jacova, C., and Massoud, F. (2013) 'Definitions of dementia and predementia states in Alzheimer's disease and vascular cognitive impairment: consensus from the Canadian conference on diagnosis of dementia', *Alzheimer's Research & Therapy*, 5(1), p. S2.
- Chow, S., Chow, R., Wan, A., Lam, H. R., Taylor, K., Bonin, K., Rowbottom, L., Lam, H., DeAngelis, C., and Herrmann, N. (2018) 'National dementia strategies: what should Canada learn?', *Canadian Geriatrics Journal*, 21(2), p. 173.
- Cohen, C.A., Colantonio, A., and Vernich, L. (2002) 'Positive aspects of caregiving: rounding out the caregiver experience', *International Journal of Geriatric Psychiatry*, 17(2), pp. 184-188.
- Conde-Sala, J. L., Turró-Garriga, O., Calvo-Perxas, L., Vilalta-Franch, J., Lopez-Pousa, S., and Garre-Olmo, J. (2014) 'Three-year trajectories of caregiver burden in Alzheimer's disease', *Journal of Alzheimer's Disease*, 42(2), pp. 623-633.
- Connolly, S., Gillespie, P., O'Shea, E., Cahill, S., and Pierce, M. (2014) 'Estimating the economic and social costs of dementia in Ireland', *Dementia*, 13(1), pp. 5-22.
- Cotrell, V. (1996) 'Respite use by dementia caregivers: preferences and reasons for initial use', *Journal of Gerontological Social Work*, 26(3-4), pp. 35-55.
- Creswell, J. W. (2009) *Research design: qualitative, quantitative, and mixed methods approaches*. London: Sage Publications.
- Cullen, K. and Keogh, F. (2018) *Personalised psychosocial supports and care for people with dementia in the community: investigation of the value case*. Dublin: Centre for Economic and Social Research on Dementia. Available at: <https://www.genio.ie/our-impact/research-evaluation/personalised-supports-community-dementia>. (Accessed: 1 October 2019).
- de Bruin, S., Oosting, S., Tobi, H., Enders-Slegers, M. J., van der Zijpp, A., and Schols, J. (2012) 'Comparing day care at green care farms and at regular day care facilities with regard to their effects on functional performance of community-dwelling older people with dementia', *Dementia*, 11(4), pp. 503-519.

- de Jong, J. D. and Boersma, F. (2009) 'Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers', *International Psychogeriatrics*, 22(1), pp. 268-277.
- de la Cuesta-Benjumea, C. (2010) 'The legitimacy of rest: conditions for the relief of burden in advanced dementia care-giving', *Journal of Advanced Nursing*, 66(5), pp. 988-998.
- de la Cuesta-Benjumea, C. (2011) 'Strategies for the relief of burden in advanced dementia care-giving', *Journal of Advanced Nursing*, 67(8), pp. 1790-1799.
- Deckers, K., van Boxtel, M. P., Schiepers, O. J., de Vugt, M., Munoz Sanchez, J. L., Anstey, K. J., Brayne, C., Dartigues, J. F., Engedal, K., Kivipelto, M., and Ritchie, K. (2015) 'Target risk factors for dementia prevention: a systematic review and Delphi consensus study on the evidence from observational studies', *International Journal of Geriatric Psychiatry*, 30(3), pp. 234-246.
- Dennett, D. C. (1987) *The intentional stance*. Cambridge: Bradford Books/ MIT Press.
- Denzin, N. K. and Lincoln, Y. S. (2011) *The sage handbook of qualitative research*. London: Sage Publications.
- Department of Health (2017) *Sláintecare report*. Dublin. Available at: <https://assets.gov.ie/22609/e68786c13e1b4d7daca89b495c506bb8.pdf> (Accessed: 1 October 2019).
- Department of Health (2014) *Irish national dementia strategy*. Dublin. Available at: <https://assets.gov.ie/10870/3276adf5273f4a9aa67e7f3a970d9cb1.pdf> (Accessed: 1 October 2019).
- Department of Health (2013) *A framework for improved health and wellbeing 2013 – 2025*. Dublin. Available at: <https://www.hse.ie/eng/about/who/healthwellbeing/healthyireland/hidocs/healthyirelandframework.pdf>. (Accessed: 1 October 2019).
- Dewing, J. (2002) 'From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia', *Dementia*, 1(2), pp. 157-171.

Dewing, J. (2007) 'Participatory research: a method for process consent with persons who have dementia', *Dementia*, 6(1), pp. 11-25.

Dewing, J. (2008) 'Process Consent and Research with Older Persons Living with Dementia', *Research Ethics*, 4(2), pp. 59-64.

Digby, R., Lee, S., and Williams, A. (2016) 'Interviewing people with dementia in hospital: recommendations for researchers', *Journal of Clinical Nursing*, 25(7-8), pp. 1156-1165.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., and Sutton, A. (2005) 'Synthesising qualitative and quantitative evidence: a review of possible methods', *Journal of Health Services Research & Policy*, 10(1), pp. 45-53.

Donath, C., Winkler, A., Graessel, E., and Luttenberger, K. (2011) 'Day care for dementia patients from a family caregiver's point of view: a questionnaire study on expected quality and predictors of utilisation - Part II', *BMC Health Services Research*, 11(1), pp. 76-76.

Donath, C., Winkler, A., and Gräbel, E. (2009) 'Short-term residential care for dementia patients: predictors for utilization and expected quality from a family caregiver's point of view', *International Psychogeriatrics*, 21(4), pp. 703-710.

Donnelly, N. A., Humphries, N., Hickey, A., and Doyle, F. (2017) "'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', *Health Policy*, 121(12), pp. 1280-1287.

Doyle, P. J. and Rubinstein, R. L. (2013) 'Person-centered dementia care and the cultural matrix of othering', *The Gerontologist*, 54(6), pp. 952-963.

Dröes, R. M., Breebaart, E., Van Tilburg, W., and Mellenbergh, G. J. (2000) 'The effect of integrated family support versus day care only on behavior and mood of patients with dementia', *International Psychogeriatrics*, 12(1), pp. 99-116.

Dröes, R. M., Meiland, F. J., de Lange, J., Vernooij-Dassen, M. J., and Van Tilburg, W. (2003) 'The meeting centres support programme: an effective way of supporting people with dementia who live at home and their carers', *Dementia*, 2(3), pp. 426-433.

- Dröes, R. M., Breebaart, E., Meiland, F. J. M., Van Tilburg, W., and Mellenbergh, G. J. (2004a) 'Effect of meeting centers support program on feeling of competence of family caregivers and delay of institutionalization of people with dementia', *Aging & Mental Health*, 8(3), pp. 201–211.
- Dröes, R. M., Meiland, F. J. M., Schmitz, M., and Van Tilburg, W. (2004b) 'Effect of combined support for people with dementia and carers versus regular day care on behavior and mood of persons with dementia: results from a multi-center implementation study', *International Journal of Geriatric Psychiatry*, 19(7), pp. 1–12.
- Dröes, R. M., Meiland, F. J. M., Schmitz, M., van Tilburg, W., and Mellenbergh, G. J. (2006) 'Effect of meeting centres support programme on informal carers of people with dementia: results from a multicentre implementation study', *Aging & Mental Health*, 10(2), pp. 112-24.
- Duncan, E. A. S. and Nicol, M. M. (2004) 'Subtle realism and occupational therapy: an alternative approach to knowledge generation and evaluation', *British Journal of Occupational Therapy*, 67(10), pp. 453-456.
- Dupuis, S., McAiney, C. A., Fortune, D., Ploeg, J., and Witt, L. D. (2016) 'Theoretical foundations guiding culture change: the work of the partnerships in dementia care alliance', *Dementia*, 15(1), pp. 85-105.
- Edvardsson, D., Winblad, B., and Sandman, P. O. (2008) 'Person-centred care of people with severe Alzheimer's disease: current status and ways forward', *The Lancet Neurology*, 7(4), pp. 362-367.
- Engel, G. L. (1977) 'The need for a new medical model: a challenge for biomedicine', *Science*, 196(4286), pp. 129-136.
- Erikson, E. H. (1950) *Childhood and society*. New York: Norton & Company.
- Etters, L., Goodall, D., and Harrison, B. E. (2008) 'Caregiver burden among dementia patient caregivers: a review of the literature', *Journal of the American Academy of Nurse Practitioners*, 20(8), pp. 423-428.
- Evans, D. (2013a) 'Exploring the concept of respite', *Journal of Advanced Nursing*, 69(8), pp. 1905-1915.

- Evans, D. (2013b) 'The provision of health and social care services for older people by respite providers', *Contemporary Nurse*, 45(2), pp. 255-263.
- Evans, S., Evans, S., Brooker, D., Henderson, C., Szcześniak, D., Atkinson, T., Bray, J., Amritpal, R., Saibene, F. L., d'Arma, A., and Scorolli, C. (2018) 'The impact of the implementation of the Dutch combined meeting centres support programme for family caregivers of people with dementia in Italy, Poland and UK', *Aging & Mental Health*, pp. 1-11. doi: 10.1080/13607863.2018.1544207.
- Farre, A. and Rapley, T. (2017) 'The new old (and old new) medical model: four decades navigating the biomedical and psychosocial understandings of health and illness', *Healthcare*, 5(4), p. 88.
- Farré, M., Haro, J. M., Kostov, B., Alvira, C., Risco, E., Miguel, S., Cabrera, E., and Zabalegui, A. (2016) 'Direct and indirect costs and resource use in dementia care: a cross-sectional study in patients living at home', *International Journal of Nursing Studies*, 55, pp. 39-49. doi: [10.1016/j.ijnurstu.2015.10.012](https://doi.org/10.1016/j.ijnurstu.2015.10.012).
- Finlay, L. and Gough, B. (2008) *Reflexivity: a practical guide for researchers in health and social sciences*. London: Blackwell Science.
- Fisher, B. and Tronto, J. C. (1990) 'Toward a feminist theory of caring', in Abel, E. K. and Nelson, M. (eds.) *Circles of care: work and identity in women's lives*. New York: SUNY Press, pp. 35-62.
- Fontana, A. and Prokos, A. H. (2007) *The interview: from formal to postmodern*. New York: Routledge.
- Fortinsky, R. H. and Downs, M. (2014) 'Optimizing person-centered transitions in the dementia journey: a comparison of national dementia strategies', *Health Affairs*, 33(4), pp. 566-573.
- Foucault, M. (1977) *Discipline and punish: the birth of the prison translated by A Sheridan*. London: Allen Lane.
- France, E. F., Ring, N., Thomas, R., Noyes, J., Maxwell, M., and Jepson, R. (2014) 'A methodological systematic review of what's wrong with meta-ethnography reporting', *BMC Medical Research Methodology*, 14(1), p. 119. doi: 10.1186/1471-2288-14-119.

- Galbraith, B., Larkin, H., Moorhouse, A., and Oomen, T. (2015) 'Intergenerational programs for persons with dementia: a scoping review', *Journal of Gerontological Social Work*, 58(4), pp. 357-378.
- Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., Walsh, C., Coakley, D., Walsh, J. B., Cunningham, C., and Lawlor, B.A. (2011) 'Determinants of the desire to institutionalize in alzheimer's caregivers', *American Journal of Alzheimer's Disease & Other Dementias*, 26(3), pp. 205-211.
- Gaugler, J. E., Yu, F., Krichbaum, K., and Wyman, J. F. (2009) 'Predictors of nursing home admission for persons with dementia', *Medical Care*, 47(2), pp. 191-198.
- Gibes, J. P. (2014) 'Technique in medicine and its implications for the biopsychosocial model', *The International Journal of Psychiatry in Medicine*, 47(4), pp. 309-316.
- Gilleard, C. and Higgs, P. (2010) 'Aging without agency: theorizing the fourth age', *Aging & Mental Health*, 14(2), pp. 121-128.
- Gillespie, P., O' Shea, E., Cullinan, J., Lacey, L., Gallagher, D., Ni Mhaolain, A., and Lawlor, B. (2013) 'The effects of dependence and function on costs of care for Alzheimer's disease and mild cognitive impairment in Ireland', *International Journal of Geriatric Psychiatry*, 28(3), pp. 256-264.
- Gilmour, J. A. (2002) 'Dis/integrated care: family caregivers and in-hospital respite care', *Journal of Advanced Nursing*, 39(6), pp. 546-553.
- Goren, A., Montgomery, W., Kahle-Wroblewski, K., Nakamura, T., and Ueda, K. (2016) 'Impact of caring for persons with Alzheimer's disease or dementia on caregivers' health outcomes: findings from a community based survey in Japan', *BMC Geriatrics*, 16(1), p. 122.
- Gottlieb, B. H. and Johnson, J. (2000) 'Respite programs for caregivers of persons with dementia: a review with practice implications', *Aging & Mental Health*, 4(2), pp. 119-129.
- Government of Ireland (1968) *Care of the aged: report of an inter-departmental committee on the care of the aged*. Dublin: Stationary Office. Available at: <https://www.lenus.ie/handle/10147/559466> (Accessed: 1 October 2019).



- Gresham, M., Heffernan, M., and Brodaty, H. (2018) 'The going to stay at home program: combining dementia caregiver training and residential respite care', *International Psychogeriatrics*, 30(11), pp. 1697-1706.
- Gústafsdóttir, M. (2014) 'The family's experience of sharing the care of a person with dementia with the services in specialized day-care units', *Dementia And Geriatric Cognitive Disorders Extra*, 4(3), pp. 344-354.
- Hammersley, M. (1992) *What's wrong with ethnography? Methodological explorations*. London: Routledge.
- Hammersley, M. (1995) 'Theory and evidence in qualitative research', *Quality and Quantity*, 29(1), pp. 55-66.
- Han, A., Radel, J., McDowd, J. M., and Sabata, D. (2016) 'Perspectives of people with dementia about meaningful activities: a synthesis', *American Journal of Alzheimer's Disease & Other Dementias*, 31(2), pp. 115-123.
- Hannes, K., Lockwood, C., and Pearson, A. (2010) 'A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research', *Qualitative Health Research*, 20(12), pp. 1736-1743.
- Hanson, E. J., Tetley, J., and Clarke, A. (1999) 'Respite care for frail older people and their family carers: concept analysis and user focus group findings of a pan-European nursing research project', *Journal of Advanced Nursing*, 30(6), pp. 1396-1407.
- Hellström, I., Eriksson, H., and Sandberg, J. (2015) 'Chores and sense of self: gendered understandings of voices of older married women with dementia', *International Journal of Older People Nursing*, 10(2), pp. 127-135.
- Hennelly, N. and O' Shea, E. (2019) 'Personhood, dementia policy and the Irish national dementia strategy', *Dementia*, 18(5), pp. 1810-1825.
- Herron, R. V. and Rosenberg, M. W. (2017) "'Not there yet": examining community support from the perspective of people with dementia and their partners in care', *Social Science & Medicine*, 173, pp. 81-87. doi: 10.1016/j.socscimed.2016.11.041.
- Higgs, P. and Gilleard, C. (2014) 'Frailty, abjection and the 'othering' of the fourth age', *Health Sociology Review*, 23(1), pp. 10-19.

Higgs, P. and Gilleard, C. (2016) 'Interrogating personhood and dementia', *Aging & Mental Health*, 20(8), pp. 773-780.

Hirschman, K. B. and Hodgson, N. A. (2018) 'Evidence-based interventions for transitions in care for individuals living with dementia', *The Gerontologist*, 58(S1), pp. S129-S140.

Hochgraeber, I., von Kutzleben, M., Bartholomeyczik, S., and Holle, B. (2015) 'Low-threshold support services for people with dementia within the scope of respite care in Germany: a qualitative study on different stakeholders' perspectives', *Dementia*, 16(5), pp. 576-590.

Holm, S. and Ziguras, S. (2003) 'The host homes program: an innovative model of respite for carers of people with dementia', *Australasian Journal on Ageing*, 22(3), pp. 141-145.

Howe, K. R. (1988) 'Against the quantitative-qualitative incompatibility thesis or dogmas die hard', *Educational Researcher*, 17(8), pp. 10-16.

Huang, S., Griva, K., Bryant, C. A., and Yap, P. (2016) 'Non-use of day care services for dementia in Singapore: a dilemma for caregivers', *International Psychogeriatrics*, 29(3), pp. 455-466.

Ibsen, T. L., Eriksen, S., and Patil, G. G. (2018) 'Farm-based day care in Norway: a complementary service for people with dementia', *Journal of Multidisciplinary Healthcare*, 11, pp. 349–358. doi: 10.2147/JMDH.S167135.

Innes, A. (2009) *Dementia studies: a social science perspective*. London: Sage.

Jansen, L., Forbes, D. A., Markle-Reid, M., Hawranik, P., Kingston, D., Peacock, S., Henderson, S., and Leipert, B. (2009) 'Formal care providers' perceptions of home- and community-based services: informing dementia care quality', *Home Health Care Services Quarterly*, 28(1), pp. 1-23.

Johnson, R. B. and Onwuegbuzie, A. J. (2004) 'Mixed methods research: a research paradigm whose time has come', *Educational Researcher*, 33(7), pp. 14-26.

Jönsson, L., Jönhagen, M. E., Kilander, L., Soininen, H., Hallikainen, M., Waldemar, G., Nygaard, H., Andreasen, N., Winblad, B., and Wimo, A. (2006) 'Determinants of costs of care for patients with Alzheimer's disease', *International Journal of Geriatric Psychiatry*, 21(5), pp. 449-459.

- Josselson, R. (2013) *Interviewing for qualitative inquiry: a relational approach*. New York: Guilford Press.
- Kasper, J. D., Wolff, J. L., and Skehan, M. (2018) 'Care arrangements of older adults: what they prefer, what they have, and implications for quality of life', *The Gerontologist*, 59(5), pp. 845-855.
- Keady, J. and Nolan, M. (1997) 'Raising the profile of younger people with dementia', *Mental Health Nursing*, 17(2), pp. 7-11.
- Kelly, F. (2010) 'Recognising and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care', *Ageing & Society*, 30(1), pp. 103-124.
- Kelly, F. and Innes, A. (2013) 'Human rights, citizenship and dementia care nursing', *International Journal of Older People Nursing*, 8(1), pp. 61-70.
- Keyes, S. E., Clarke, C. L., and Gibb, C. E. (2019) 'Living with dementia, interdependence and citizenship: narratives of everyday decision-making', *Disability & Society*, 34(2), pp. 296-319.
- Kim, H., Chang, M., Rose, K., and Kim, S. (2012) 'Predictors of caregiver burden in caregivers of individuals with dementia', *Journal of Advanced Nursing*, 68(4), pp. 846-855.
- Kim, S. K. and Park, M. (2017) 'Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis', *Clinical Interventions in Aging*, 12, pp. 381-397. doi: 10.2147/CIA.S117637.
- Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J., and Bond, J. (2011) 'The impact of organisational culture on the delivery of person-centred care in services providing respite care and short breaks for people with dementia', *Health & Social Care in the Community*, 19(4), pp. 438-448.
- Kitwood, T. (1990) 'The dialectics of dementia: with particular reference to Alzheimer's disease', *Ageing & Society*, 10(2), pp. 177-196.
- Kitwood, T. (1997) *Dementia reconsidered: the person comes first*. UK: Open University Press.

- Kitwood, T. (1998) 'Professional and moral development for care work: some observations on the process', *Journal of Moral Education*, 27(3), pp. 401-411.
- Kitwood, T. and Bredin, K. (1992) 'Towards a theory of dementia care: personhood and well-being', *Ageing & Society*, 12(3), pp. 269-287.
- Kuhn, T. (1962) *The structure of scientific revolutions*. Chicago: University of Chicago.
- Lawton, M. P., Brody, E. M., and Saperstein, A. R. (1989) 'A controlled study of respite service for caregivers of Alzheimer's patients', *The Gerontologist*, 29(1), pp. 8-16.
- Lee, D., Morgan, K., and Lindesay, J. (2007) 'Effect of institutional respite care on the sleep of people with dementia and their primary caregivers', *Journal of the American Geriatrics Society*, 55(2), pp. 252-258.
- Leocadie, M. C., Roy, M. H., and Rothan-Tondeur, M. (2018) 'Barriers and enablers in the use of respite interventions by caregivers of people with dementia: an integrative review', *Archives of Public Health*, 76(1), p. 72. doi: 10.1186/s13690-018-0316-y.
- Lethin, C., Leino-Kilpi, H., Roe, B., Soto, M. M., Saks, K., Stephan, A., Zwakhalen, S., Zabalegui, A., Karlsson, S., and RightTimePlaceCare Consortium. (2016) 'Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study', *BMC Geriatrics*, 16(1), pp. 32-32. doi: 10.1186/s12877-016-0210-9.
- Levin, E., Moriarty, J., and Gorbach, P. (1994) *Better for the break*. London: HM Stationery Office.
- Li, H. (2012) 'Unmet service needs: a comparison between dementia and non-dementia caregivers', *Home Health Care Services Quarterly*, 31(1), pp. 41-59.
- Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., and Cooper, C. (2017) 'Dementia prevention, intervention, and care', *The Lancet*, 390(10113), pp. 2673-2734.

- Lloyd, J., Patterson, T., and Muers, J. (2016) 'The positive aspects of caregiving in dementia: a critical review of the qualitative literature', *Dementia*, 15(6), pp. 1534-1561.
- Lloyd, V., Gatherer, A., and Kalsy, S. (2006) 'Conducting qualitative interview research with people with expressive language difficulties', *Qualitative Health Research*, 16(10), pp. 1386-1404.
- Logsdon, R. G., Pike, K. C., Korte, L., and Goehring, C. (2016) 'Memory care and wellness services: efficacy of specialized dementia care in adult day services', *The Gerontologist*, 56(2), pp. 318-325.
- Long, A. F. and Godfrey, M. (2004) 'An evaluation tool to assess the quality of qualitative research studies', *International Journal of Social Research Methodology*, 7(2), pp. 181-196.
- Maayan, N., Soares- Weiser, K., and Lee, H. (2014) 'Respite care for people with dementia and their carers', *Cochrane Database of Systematic Reviews*, 1, CD004396. doi: 10.1002/14651858.CD004396.pub3.
- Macleod, A., Tatangelo, G., McCabe, M., and You, E. (2017) "There isn't an easy way of finding the help that's available." Barriers and facilitators of service use among dementia family caregivers: a qualitative study', *International Psychogeriatrics*, 29(5), pp. 765-776.
- Mangiaracina, F., Chattat, R., Farina, E., Saibene, F. L., Gamberini, G., Brooker, D., Evans, S. C., Evans, S. B., Szcześniak, D., Urbanska, K., and Rymaszewska, J. (2017) 'Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries', *Aging & Mental Health*, 21(1), pp. 40-48.
- Mansfield, E., Noble, N., Sanson-Fisher, R., Mazza, D., and Bryant, J. (2018) 'Primary care physicians' perceived barriers to optimal dementia care: a systematic review', *The Gerontologist*, gny067. doi: 10.1093/geront/gny067.
- Manthorpe, J. and Samsi, K. (2016) 'Person-centered dementia care: current perspectives', *Clinical Interventions in Aging*, 11, 1733-1740. doi: 10.2147/CIA.S104618.

- Matthews, F. E., Stephan, B. C., Robinson, L., Jagger, C., Barnes, L. E., Arthur, A., Brayne, C., Collaboration, A. S. C., Comas-Herrera, A., Wittenberg, R., and Denning, T. (2016) 'A two decade dementia incidence comparison from the cognitive function and ageing studies I and II', *Nature Communications*, 7, p. 11398. doi: 10.1038/ncomms11398.
- McClendon, M. J., Smyth, K. A., and Neundorfer, M. M. (2006) 'Long-term-care placement and survival of persons with Alzheimer's disease', *The Journals of Gerontology: Series B*, 61(4), pp. 220-227.
- McColgan, G. (2005) 'A place to sit: resistance strategies used to create privacy and home by people with dementia', *Journal of Contemporary Ethnography*, 34(4), pp. 410-433.
- McCormack, B. (2004) 'Person-centredness in gerontological nursing: an overview of the literature', *Journal of Clinical Nursing*, 13(1), pp. 31-38.
- McDaid, D., Wiley, M., Maresso, A., and Mossialos, E. (2009) 'Ireland: health system review', *Health Systems in Transition (European Observatory on Health Systems and Policies)*, 11(4). Available at: <http://www.euro.who.int/.../E92928.pdf> (Accessed: 1 October 2019).
- McGrath, W. L., Mueller, M. M., Brown, C., Teitelman, J., and Watts, J. (2000) 'Caregivers of persons with Alzheimer's disease: an exploratory study of occupational performance and respite', *Physical & Occupational Therapy in Geriatrics*, 18(2), pp. 51-69.
- McGregor, S. (2001) 'Neoliberalism and health care', *International Journal of Consumer Studies*, 25(2), pp. 82-89.
- McKeown, J., Clarke, A., Ingleton, C., and Repper, J. (2010) 'Actively involving people with dementia in qualitative research', *Journal of Clinical Nursing*, 19(13-14), pp. 1935-1943.
- McParland, P., Kelly, F., and Innes, A. (2017) 'Dichotomising dementia: is there another way?' *Sociology of Health & Illness*, 39(2), pp. 258-269.
- Menzies Lyth, I. (1960) 'Social systems as a defense against anxiety: an empirical study of the nursing service of a general hospital', *Human Relations*, 13(2), pp. 95-121.

- Mitchell, G. and Agnelli, J. (2015) 'Person-centred care for people with dementia: Kitwood reconsidered', *Nursing Standard*, 30(7), pp. 46-50.
- Montoro-Rodriguez, J., Kosloski, K., and Montgomery, R.J. (2003) 'Evaluating a practice-oriented service model to increase the use of respite services among minorities and rural caregivers', *The Gerontologist*, 43(6), pp. 916-924.
- Morgan, D. L. (2014) 'Pragmatism as a paradigm for social research', *Qualitative Inquiry*, 20(8), pp. 1045-1053.
- Morrisby, C., Joosten, A., and Ciccarelli, M. (2018) 'Do services meet the needs of people with dementia and carers living in the community? A scoping review of the international literature', *International Psychogeriatrics*, 30(1), pp. 5-14.
- Mullins, W. A. (1972) 'On the concept of ideology in political science', *American Political Science Review*, 66(2), pp. 498-510.
- Murphy, K., Jordan, F., Hunter, A., Cooney, A., and Casey, D. (2015) 'Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies', *Dementia*, 14(6), pp. 800-824.
- Myren, G. E. S., Enmarker, I., Saur, E., and Hellzen, O. (2013) 'Relatives' experiences of everyday life when receiving day care services for persons with dementia living at home', *Health*, 5(8), pp. 1227-1235.
- Nelson, P. T., Dickson, D. W., Trojanowski, J. Q., Jack, C. R., Boyle, P. A., Arfanakis, K., Rademakers, R., Alafuzoff, I., Attems, J., Brayne, C., and Coyle-Gilchrist, I.T. (2019) 'Limbic-predominant age-related TDP-43 encephalopathy (LATE): consensus working group report', *Brain*, 142(6), pp. 1503-1527.
- Neville, C., Beattie, E., Fielding, E., and MacAndrew, M. (2015) 'Literature review: use of respite by carers of people with dementia', *Health & Social Care in the Community*, 23(1), pp. 51-53.
- Neville, C. C. and Byrne, G. J. A. (2008) 'Effect of a residential respite admission for older people on regional Queensland family carers', *Collegian*, 15(4), pp. 159-164.
- Noblit, G. W. and Hare, R. D. (1988) *Meta-ethnography: synthesizing qualitative studies*. Newbury Park, CA: Sage.

- North, D. C. (1990) *Institutions, institutional change and economic performance*. Cambridge: Cambridge University Press.
- Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K., and Brayne, C. (2014) 'Potential for primary prevention of Alzheimer's disease: an analysis of population-based data', *The Lancet Neurology*, 13(8), pp. 788-794.
- Novek, S. and Wilkinson, H. (2019) 'Safe and inclusive research practices for qualitative research involving people with dementia: a review of key issues and strategies', *Dementia*, 18(3), pp. 1042-1059. doi:10.1177/1471301217701274.
- O' Connell, B., Hawkins, M., Ostaszkievicz, J. and Millar, L. (2012) 'Carers' perspectives of respite care in Australia: an evaluative study', *Contemporary Nurse*, 41(1), pp. 111-119.
- O' Shea, E., Donnison, D., Larragy, J., Blackwell, J., and Marshall, M. (1991) *The role and future development of nursing homes in Ireland*. Dublin: National Council for the Elderly.
- O' Shea, E. and O' Reilly, S. (1999) *An action plan for dementia*. Dublin: National Council on Ageing and Older People.
- O' Shea, E. and Connolly, S. (2012) 'Reforming health production in Ireland', *The World Economy*, 35(10), pp. 1359-1371.
- O' Shea, E. and Monaghan, C. (2015) *Genio dementia programme: evaluation of year two*. Galway: National University of Ireland Galway.
- O' Shea, E., Cahill, S., Pierce, M., Rees, G., Irving, K., Keogh, F., Carney, P., Pierse, T., and Hennelly, N. (2017a) *Developing and implementing dementia policy in Ireland*. Centre for Economic and Social Research on Dementia: NUI Galway.
- O' Shea, E., Timmons, S., O' Shea, E., Fox, S., and Irving, K. (2017b) 'Key stakeholders' experiences of respite services for people with dementia and their perspectives on respite service development: a qualitative systematic review', *BMC Geriatrics*, 17(1), p. 282. doi: 10.1186/s12877-017-0676-0.
- O' Shea, E., Timmons, S., O' Shea, E., Fox, S., and Irving, K. (2017c) 'Respite in dementia: an evolutionary concept analysis', *Dementia*, 18(4), pp. 1446–1465. doi: 10.1177/1471301217715325.



- O' Shea, E., Keogh, F., and Heneghan, C. (2018) *Post-diagnostic support for people with dementia and their carers*. Centre for Economic and Social Research on Dementia & The National Dementia Office. Available at: <http://hdl.handle.net/10147/623091> (Accessed: 1 October 2019).
- O' Shea, E., Timmons, S., O' Shea, E., and Irving, K. (2019) 'Multiple stakeholders' perspectives on respite service access for people with dementia and their carers', *The Gerontologist*, 59(5), pp. e490–e500. doi:10.1093/geront/gnz095.
- Oldman, C. (2002) 'Later life and the social model of disability: a comfortable partnership?', *Ageing & Society*, 22(6), pp. 791-806.
- Oliveira, D., Zarit, S. H., and Orrell, M. (2019) 'Health-promoting self-care in family caregivers of people with dementia: the views of multiple stakeholders', *The Gerontologist*, 59(5), pp. 501-511. doi: [10.1093/geront/gnz029](https://doi.org/10.1093/geront/gnz029).
- Olsen, C., Pedersen, I., Bergland, A., Enders-Slegers, M. J., Jøranson, N., Calogiuri, G., and Ihlebæk, C. (2016) 'Differences in quality of life in home-dwelling persons and nursing home residents with dementia: a cross-sectional study', *BMC Geriatrics*, 16(1), p. 137. doi: 10.1186/s12877-016-0312-4.
- Osman, S. E., Tischler, V., and Schneider, J. (2016) 'Singing for the brain: a qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers', *Dementia*, 15(6), pp. 1326-1339.
- Parahoo, K., Campbell, A., and Scoltock, C. (2002) 'An evaluation of a domiciliary respite service for younger people with dementia', *Journal of Evaluation in Clinical Practice*, 8(4), pp. 377-385.
- Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., Leipert, B. D., and Henderson, S. R. (2010) 'The positive aspects of the caregiving journey with dementia: using a strengths-based perspective to reveal opportunities', *Journal of Applied Gerontology*, 29(5), pp. 640-659.
- Perry, J. and Bontinen, K. (2001) 'Evaluation of a weekend respite program for persons with Alzheimer disease', *Canadian Journal of Nursing Research*, 33(1), pp. 81-95.

- Phillipson, L. and Jones, S. C. (2011a) “‘Between the devil and the deep blue sea’”: the beliefs of caregivers of people with dementia regarding the use of in-home respite services’, *Home Health Care Services Quarterly*, 30(2), pp. 43-62.
- Phillipson, L. and Jones, S. C. (2011b) ‘Residential respite care: the caregiver's last resort’, *Journal of Gerontological Social Work*, 54(7), pp. 691-711.
- Phillipson, L. and Jones, S. C. (2012) ‘Use of day centers for respite by help-seeking caregivers of individuals with dementia’, *Journal of Gerontological Nursing*, 38(4), pp. 24-34.
- Phillipson, L., Magee, C., and Jones, S. C. (2013) ‘Why carers of people with dementia do not utilise out-of-home respite services’, *Health & Social Care in the Community*, 21(4), pp. 411-422.
- Phillipson, L., Jones, S. C., and Magee, C. (2014) ‘A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice’, *Health & Social Care in the Community*, 22(1), pp. 1-12.
- Pillemer, S., Davis, J., and Tremont, G. (2018) ‘Gender effects on components of burden and depression among dementia caregivers’, *Aging & Mental Health*, 22(9), pp. 1162-1167.
- Pinquart, M. and Sörensen, S. (2005) ‘Caregiving distress and psychological health of caregivers’, in: Oxington, K. V. (ed.) *Psychology of stress*. New York: Nova Biomedical Books, pp. 165-206.
- Pipon-Young, F. E., Lee, K. M., Jones, F., and Guss, R. (2012) ‘I’m not all gone, I can still speak: the experiences of younger people with dementia. An action research study’, *Dementia*, 11(5), pp. 597-616.
- Ploeg, J., Northwood, M., Duggleby, W., McAiney, C. A., Chambers, T., Peacock, S., Fisher, K., Ghosh, S., Markle-Reid, M., Swindle, J., and Williams, A. (2019) ‘Caregivers of older adults with dementia and multiple chronic conditions: exploring their experiences with significant changes’, *Dementia*, doi: 10.1177/1471301219834423.
- Popper, K. (1969) *Conjectures and refutations*. London: Routledge.
- Prince, M., Ali, G. C., Guerchet, M., Prina, A. M., Albanese, E., and Wu, Y. T. (2016) ‘Recent global trends in the prevalence and incidence of dementia, and

- survival with dementia', *Alzheimer's Research & Therapy*, 8(1), p. 23. doi: 10.1186/s13195-016-0188-8.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., and Ferri, C. P. (2013) 'The global prevalence of dementia: a systematic review and meta-analysis', *Alzheimer's & Dementia*, 9(1), pp. 63-75.
- Prince, M., Wimo, A., Guerchet, M., Ali, G. C., Wu, Y. T., and Prina, M. (2015) *The global impact of dementia, an analysis of prevalence, incidence, cost and trends*. Alzheimer's Disease International: World Alzheimer Report.
- Quinn, C. and Toms, G. (2018) 'Influence of positive aspects of dementia caregiving on caregivers' well-being: a systematic review', *The Gerontologist*, 59(5), pp. 584–e596.
- Reed, C., Belger, M., Dell'Agnello, G., Wimo, A., Argimon, J. M., Bruno, G., Dodel, R., Haro, J. M., Jones, R. W., and Vellas, B. (2014) 'Caregiver burden in alzheimer's disease: differential associations in adult-child and spousal caregivers in the GERAS observational study', *Dementia and Geriatric Cognitive Disorders Extra*, 4(1), pp. 51-64.
- Reed, C., Happich, M., Argimon, J. M., Haro, J. M., Wimo, A., Bruno, G., Dodel, R., Jones, R. W., Vellas, B., and Belger, M. (2017) 'What drives country differences in cost of Alzheimer's disease? An explanation from resource use in the GERAS study', *Journal of Alzheimer's Disease*, 57(3), pp. 797-812.
- Reed, J., Cantley, C., Clarke, C.L., and Stanley, D. (2002) 'Services for younger people with dementia: problems with differentiating needs on the basis of age', *Dementia*, 1(1), pp. 95-112.
- Robins, J. (1988) *The years ahead: a policy for the elderly. Report of the working party on services for the elderly*. Dublin: Stationary Office.
- Robinson, A., Lea, E., Hemmings, L., Vosper, G., McCann, D., Weeding, F., and Rumble, R. (2012) 'Seeking respite: issues around the use of day respite care for the carers of people with dementia', *Ageing & Society*, 32(2), pp. 196-218.
- Robinson, K. M., Buckwalter, K. C., and Reed, D. (2005) 'Predictors of use of services among dementia caregivers', *Western Journal of Nursing Research*, 27(2), pp. 126-140.

- Rodgers, B. L. (1989) 'Concepts, analysis and the development of nursing knowledge: the evolutionary cycle', *Journal of Advanced Nursing*, 14(4), pp. 330-335.
- Rodgers, B. L. (2000) 'Concept analysis: an evolutionary view', in: Rodgers, B. L. and Knafl, K. (eds.) *Concept development in nursing : foundation, techniques, and applications*. 2nd ed. Philadelphia: Saunders, pp. 7-37.
- Roehr, S., Pabst, A., Luck, T., and Riedel-Heller, S. G. (2018) 'Is dementia incidence declining in high-income countries? A systematic review and meta-analysis', *Clinical Epidemiology*, 10, pp. 1233–1247. doi: 10.2147/CLEP.S163649.
- Rokstad, A. M. M., Halse, I., Tretteteig, S., Barca, M. L., Kirkevold, Ø., McCabe, L., and Engedal, K. (2014) 'Effects and costs of a day care centre program designed for people with dementia: a 24 month controlled study', *Journal of Clinical Trials*, 4(182), pp. 2167-0870.
- Rokstad, A. M. M., Engedal, K., Kirkevold, Ø., Benth, J. Š., and Selbæk, G. (2018) 'The impact of attending day care designed for home-dwelling people with dementia on nursing home admission: a 24-month controlled study', *BMC Health Services Research*, 18(1), p. 864. doi: 10.1186/s12913-018-3686-5.
- Rokstad, A. M. M., Engedal, K., Kirkevold, Ø., Benth, J.Š., Barca, M.L., and Selbæk, G. (2017a) 'The association between attending specialized day care centers and the quality of life of people with dementia', *International Psychogeriatrics*, 29(4), pp. 627-636.
- Rokstad, A. M. M., McCabe, L., Robertson, J. M., Strandenæs, M. G., Tretteteig, S., and Vatne, S. (2017b) 'Day care for people with dementia: a qualitative study comparing experiences from Norway and Scotland', *Dementia*, 18(4), pp.1393-1409.
- Rorty, R. (1982) *Consequences of pragmatism*. Minneapolis: University of Minnesota Press.
- Rotarou, E. S. and Sakellariou, D. (2017) 'Neoliberal reforms in health systems and the construction of long-lasting inequalities in health care: A case study from Chile', *Health Policy*, 121(5), pp. 495-503.
- Sabat, S. R. (2003) 'Malignant positioning and the predicament of people with Alzheimer's disease', in: Harré, R. and Moghaddam, F. (eds.) *The self and others:*

*positioning individuals and groups in personal, political, and cultural contexts.*

Connecticut: Greenwood, pp. 85-99.

Sabat, S. R. (2006) 'Mind, meaning, and personhood in dementia: the effects of positioning', in: Hughes, J. Louw, S. and Sabat, S. (eds.) *Dementia, mind, meaning, and the person*. New York: Oxford University Press, pp. 287-302.

Sabat, S. R. (2001) *The experience of alzheimer's disease: life through a tangled veil*. Oxford: Blackwell.

Sabat, S. R. and Harré, R. (1992) 'The construction and deconstruction of self in alzheimer's disease', *Ageing & Society*, 12(4), pp. 443-461.

Sabat, S. R. and Harré, R. (1994) 'The Alzheimer's disease sufferer as a semiotic subject', *Philosophy, Psychiatry, and Psychology*, 1(3), pp. 145-160.

Sachdev, P. S., Blacker, D., Blazer, D. G., Ganguli, M., Jeste, D. V., Paulsen, J. S., and Petersen, R. C. (2014) 'Classifying neurocognitive disorders: the DSM-5 approach', *Nature Reviews Neurology*, 10(11), p. 634. doi: 10.1038/nrneurol.2014.181.

Sakellariou, D. and Rotarou, E. S. (2017) 'The effects of neoliberal policies on access to healthcare for people with disabilities', *International Journal for Equity in Health*, 16(1), p. 199. doi: 10.1186/s12939-017-0699-3.

Satizabal, C. L., Beiser, A. S., Chouraki, V., Chêne, G., Dufouil, C., and Seshadri, S. (2016) 'Incidence of dementia over three decades in the Framingham Heart Study', *New England Journal of Medicine*, 374(6), pp. 523-532.

Schreyögg, G. and Sydow, J. (2011) 'Organizational path dependence: a process view', *Organization Studies*, 32(3), pp. 321-335.

Sevenhuijsen, S. (2003) 'The place of care: the relevance of the feminist ethic of care for social policy', *Feminist Theory*, 4(2), pp. 179-197.

Shakespeare, T., Zeilig, H., and Mittler, P. (2019) 'Rights in mind: thinking differently about dementia and disability', *Dementia*, 18(3), pp. 1075-1088.

Shanley, C. (2006) 'Developing more flexible approaches to respite for people living with dementia and their carers', *American Journal of Alzheimer's Disease and other Dementias*, 21(4), pp. 234-241.

- Shaw, C., McNamara, R., Abrams, K., Cannings-John, R. L., Hood, K., Longo, M., Myles, S., O'Mahony, M. S., Roe, B., and Williams, K. (2009) 'Systematic review of respite care in the frail elderly', *Health Technology Assessment*, 13(20), pp.1-246.
- Stephan, A., Bieber, A., Hopper, L., Joyce, R., Irving, K., Zanetti, O., Portolani, E., Kerpershoek, L., Verhey, F., De Vugt, M., and Wolfs, C. (2018) 'Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries', *BMC Geriatrics*, 18(1), p. 131. doi: 10.1186/s12877-018-0816-1.
- Stirling, C., Andrews, S., Croft, T., Vickers, J., Turner, P., and Robinson, A. (2010) 'Measuring dementia carers' unmet need for services: an exploratory mixed method study', *BMC Health Services Research*, 10(1), pp. 122-122. doi: 10.1186/1472-6963-10-122.
- Stockwell- Smith, G., Kellett, U., and Moyle, W. (2010) 'Why carers of frail older people are not using available respite services: an Australian study', *Journal of Clinical Nursing*, 19(13-14), pp. 2057-2064.
- Strandenæs, M. G., Lund, A., and Rokstad, A. M. M. (2018) 'Experiences of attending day care services designed for people with dementia: a qualitative study with individual interviews', *Aging & Mental Health*, 22(6), pp. 764-772.
- Strang, V. R. (2000a) 'The respite experience: family caregivers and dementia patients', *Canadian Alzheimer Disease Review*, (September), pp. 14-20.
- Strang, V. R. (2000b) 'Caregiver respite: coming back after being away', *Perspectives: Gerontological Nursing Association Canada*, 24(4), pp. 10-20.
- Strang, V. R. (2001) 'Family caregiver respite and leisure: a feminist perspective', *Scandinavian Journal of Caring Sciences*, 15(1), pp. 74-81.
- Strang, V. R. and Haughey, M. (1998) 'Factors influencing the caregiver's ability to experience respite', *Journal of Family Nursing*, 4(3), pp. 231-254.
- Strang, V. R. and Haughey, M. (1999) 'Respite: a coping strategy for family caregivers', *Western Journal of Nursing Research*, 21(4), pp. 450-466.

- Surr, C. A., Gates, C., Irving, D., Oyeboode, J., Smith, S. J., Parveen, S., Drury, M., and Dennison, A. (2017) 'Effective dementia education and training for the health and social care workforce: a systematic review of the literature', *Review of Educational Research*, 87(5), pp. 966-1002.
- Swaffer, K. (2014) 'Dementia: stigma, language, and dementia-friendly', *Dementia*, 13(6), pp. 709–716. doi:[10.1177/1471301214548143](https://doi.org/10.1177/1471301214548143).
- Sydow, J., Schreyögg, G., and Koch, J. (2009) 'Organizational path dependence: opening the black box', *Academy of Management Review*, 34(4), pp. 689-709.
- Tang, J., Ryburn, B., Doyle, C., and Wells, Y. (2011) 'The psychology of respite care for people with dementia in Australia', *Australian Psychologist*, 46(3), pp. 183-189.
- Tashakkori, A. and Teddlie, C. (2010) *Sage handbook of mixed methods in social & behavioral research*. Thousand Oaks, CA: Sage Publications.
- Tatangelo, G., McCabe, M., Macleod, A., and You, E. (2018) "'I just don't focus on my needs.'" The unmet health needs of partner and offspring caregivers of people with dementia: a qualitative study', *International Journal of Nursing Studies*, 77, pp. 8-14. doi: [10.1016/j.ijnurstu.2017.09.011](https://doi.org/10.1016/j.ijnurstu.2017.09.011).
- Teitelman, J. and Watts, J. (2005) 'How family caregivers of persons with Alzheimer disease achieve mental breaks: preliminary analysis from a qualitative study', *Physical & Occupational Therapy in Geriatrics*, 23(1), pp. 9-24.
- Teitelman, J. and Watts, J. (2004) 'Family members' recommendations for achieving a mental break from caring for a loved one with Alzheimer's disease', *Alzheimer's Care Quarterly*, 5(3), pp. 252-260.
- Thoma-Lürken, T., Bleijlevens, M. H., Lexis, M. A., de Witte, L. P., and Hamers, J. P. (2018) 'Facilitating aging in place: a qualitative study of practical problems preventing people with dementia from living at home', *Geriatric Nursing*, 39(1), pp. 29-38. doi: [10.1016/j.gerinurse.2017.05.003](https://doi.org/10.1016/j.gerinurse.2017.05.003).
- Thomas, C. and Milligan, C. (2018) 'Dementia, disability rights and disablism: understanding the social position of people living with dementia', *Disability & Society*, 33(1), pp.115-131.

- Thornton, J. (2002) 'Estimating a health production function for the US: some new evidence', *Applied Economics*, 34(1), pp. 59-62.
- Timonen, V. and Doyle, M. (2008) 'From the workhouse to the home: evolution of care policy for older people in Ireland', *International Journal of Sociology and Social Policy*, 28(3-4), pp. 76-89.
- Toftthagen, R. and Fagerstrøm, L. M. (2010) 'Rodgers' evolutionary concept analysis: a valid method for developing knowledge in nursing science', *Scandinavian Journal of Caring Sciences*, 24(S1), pp. 21-31.
- Tong, A., Sainsbury, P., and Craig, J. (2007) 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups', *International Journal for Quality in Health Care*, 19(6), pp. 349-357.
- Toot, S., Swinson, T., Devine, M., Challis, D., and Orrell, M. (2017) 'Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis', *International Psychogeriatrics*, 29(2), pp. 195-208.
- Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., and Barker, K. (2014) 'Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies', *BMC Medical Research Methodology*, 14(1), p. 80. doi: 10.1186/1471-2288-14-80.
- Tretteteig, S., Vatne, S., and Rokstad, A. M. M. (2017) 'The influence of day care centres designed for people with dementia on family caregivers: a qualitative study', *BMC Geriatrics*, 17(1), pp. 1-11. doi: 10.1186/s12877-016-0403-2.
- Tretteteig, S., Vatne, S., and Rokstad, A. M. M. (2016) 'The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature', *Aging & Mental Health*, 20(5), pp. 450-462.
- Tronto, J. C. (1993) *Moral boundaries: a political argument for an ethic of care*. New York: Routledge.
- Tronto, J. C. (2017) 'There is an alternative: homines curans and the limits of neoliberalism', *International Journal of Care and Caring*, 1(1), pp. 27-43.
- Upton, N. and Reed, V. (2005) 'Caregiver coping in dementing illness: implications for short-term respite care', *The International Journal of Psychiatric Nursing Research*, 10(3), pp. 1180-1196.



- Urquhart, C. (2012) *Grounded theory for qualitative research: a practical guide*: Sage.
- van der Flier, W. M. and Scheltens, P. (2005) 'Epidemiology and risk factors of dementia', *Journal of Neurology, Neurosurgery & Psychiatry*, 76(S5), pp. v2-v7.
- Vandepitte, S., Putman, K., Van Den Noortgate, N., Verhaeghe, S., and Annemans, L. (2019) 'Effectiveness of an in-home respite care program to support informal dementia caregivers: a comparative study', *International Journal of Geriatric Psychiatry*, 34(10), pp.1534-1544.
- Vandepitte, S., Putman, K., Van Den Noortgate, N., Verhaeghe, S., Mormont, E., Van Wilder, L., De Smedt, D., and Annemans, L. (2018) 'Factors associated with the caregivers' desire to institutionalize persons with dementia: a cross-sectional study', *Dementia and Geriatric Cognitive Disorders*, 46(5-6), pp. 298-309.
- Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., and Annemans, L. (2016) 'Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review', *International Journal of Geriatric Psychiatry*, 31(12), pp. 1277-1288.
- Vecchio, N., Radford, K., Fitzgerald, J. A., Comans, T., Harris, P., and Harris, N. (2018) 'Intergenerational care: an exploration of consumer preferences and willingness to pay for care', *Aging & Mental Health*, 22(8), pp. 996-1004.
- Villar, F. (2012) 'Successful ageing and development: the contribution of generativity in older age', *Ageing & Society*, 32(7), pp. 1087-1105.
- von Kutzleben, M., Schmid, W., Halek, M., Holle, B., and Bartholomeyczik, S. (2012) 'Community-dwelling persons with dementia: what do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia', *Aging & Mental Health*, 16(3), pp. 378-390.
- Wade, D. T. and Halligan, P. W. (2017) 'The biopsychosocial model of illness: a model whose time has come', *Clinical Rehabilitation*, 31(8), pp. 995-1004.
- Older People's Commissioner for Wales (2018) *Rethinking respite for people affected by dementia*. Cardiff. Available at: <http://www.olderpeoplewales.com/en/reviews/respite.aspx> (Accessed: 1 October 2019).

- Ward, A. R. and Parkes, J. (2017) 'An evaluation of a 'singing for the brain' pilot with people with a learning disability and memory problems or a dementia', *Dementia*, 16(3), pp. 360-374.
- Watts, J. and Teitelman, J. (2005) 'Achieving a restorative mental break for family caregivers of persons with Alzheimer's disease', *Australian Occupational Therapy Journal*, 52(4), pp. 282-292.
- Weaver, K. and Mitcham, C. (2008) 'Nursing concept analysis in North America: state of the art', *Nursing Philosophy*, 9(3), pp. 180-194.
- Whitmore, K. E. (2017) 'The concept of respite care', *Nursing Forum*, 52(3), pp. 180-187.
- World Health Organisation (2017) *Global action plan on the public health response to dementia 2017–2025*. Geneva: World Health Organisation.
- Williams, C., Tappen, R., Wiese, L., Newman, D., Corbett, M., Pinos, S., Curtis, B., and Murray, B. (2016) 'Stress in persons with dementia: benefits of a memory center day program', *Archives of Psychiatric Nursing*, 30(5), pp. 531-538.
- Wimo, A., Guerchet, M., Ali, G. C., Wu, Y. T., Prina, A. M., Winblad, B., Jönsson, L., Liu, Z., and Prince, M. (2017) 'The worldwide costs of dementia 2015 and comparisons with 2010', *Alzheimer's & Dementia*, 13(1), pp. 1-7.
- Wolinsky, F. D., Callahan, C. M., Fitzgerald, J. F., and Johnson, R. J. (1992) 'The risk of nursing home placement and subsequent death among older adults', *Journal of Gerontology*, 47(4), pp. S173-S182.
- Woods, R. (2001) 'Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects', *Aging & Mental Health*, 5(S1), pp. 7-16.
- Woolrych, R. and Sixsmith, J. (2013) 'Toward integrated services for dementia: a formal carer perspective', *Journal of Integrated Care*, 21(4), pp. 208-220.
- Wren, M. A. (2003) *Unhealthy state: anatomy of a sick society*. Dublin: New Island.
- Wren, M. A. and Connolly, S. (2017) 'A European late starter: lessons from the history of reform in Irish health care', *Health Economics, Policy and Law*, 14(3), pp. 355-373.

Wu, Y. T., Beiser, A. S., Breteler, M. M., Fratiglioni, L., Helmer, C., Hendrie, H. C., Honda, H., Ikram, M. A., Langa, K. M., Lobo, A., and Matthews, F. E. (2017) 'The changing prevalence and incidence of dementia over time: current evidence', *Nature Reviews Neurology*, 13(6), p. 327-339.

Zarit, S. H., Bangerter, L. R., Liu, Y., and Rovine, M. J. (2017) 'Exploring the benefits of respite services to family caregivers: methodological issues and current findings', *Aging & Mental Health*, 21(3), pp. 224-231.

# **APPENDICES**

## **Appendix A: Kitwood's five categories of human psychosocial needs**

Comfort	Developing warm bonds with others, in a way that minimises anxiety and distress.
Attachment	Linked to comfort, this is about experiencing familiarity and security in terms of social and environmental ties. More specifically, it is about having close proximity to an attachment figure, such that there is consistent and sustained interaction.
Inclusion	Being supported to be meaningfully involved in the lives of others and decision-making processes about your own life in a way that minimises feelings of isolation.
Occupation	Being involved in "personally significant" activity in a way that engages the individuals' interests/strengths.
Identity	Recognising what makes them unique as a person, in a way that creates a sense of continuity between the past and present, in a way that fits for them.

## Appendix B: ‘Malignant social psychology’ as outlined by Kitwood (1997)

<b>Malignant Behaviour</b>	<b>Description</b>
Treachery	The use of deception to distract, manipulate or force someone into compliance.
Disempowerment	Not allowing/enabling a person to use their abilities, or to finish tasks/actions they have initiated.
Infantilisation	Treating the person patronisingly, like a child.
Intimidation	Causing the person to experience fear, using verbal threats or physical power.
Labelling	Defining the person by their condition or their behaviour, e.g., terminology such as ‘demented’.
Stigmatisation	Treating the person as if they were an ‘alien’ or an ‘outcast’.
Outpacing	Providing information or choices too quickly for a person to process and understand.
Invalidation	Failing to acknowledge the subjective reality and/or the feelings of the person.
Banishment	Excluding the person either physically or psychologically.
Objectification	Treating the person as an object; not acknowledging and respecting that they are sentient beings.
Ignoring	Conversing with others in front of the person, as if they were not present.
Imposition	Forcing the person to do something or behave in a certain way.
Withholding	Failure to pay attention to the person and their needs.
Accusation	Blaming a person for their cognitive, social, emotional and/or functional deficits.
Disruption	Suddenly and crudely disturbing a person and interrupting their activity or thoughts.
Mockery	Making fun, mocking or joking at the expense of the person.
Disparagement	Telling the person that they are incompetent/worthless, or any name-calling that is damaging to self-esteem.

### Appendix C: ‘Positive person work’ as outlined by Kitwood (1997)

Positive Person Work	Description
<b>Recognition</b>	Recognising someone as a unique person and greeting/calling them by their name.
<b>Negotiation</b>	Having a dialogue with the person about their preferences, desires and needs to support their decision-making.
<b>Collaboration</b>	Working with the person with dementia and engaging their strengths, as opposed to ‘doing to’ them and forcing them into a passive role.
<b>Play</b>	Supporting creativity and self-expression in people with dementia, in a way that fosters for growth.
<b>Timalation</b>	Interactions which directly engage the senses of the person, but don’t require anything of them intellectually, e.g. aromatherapy, massage.
<b>Celebration</b>	Encouraging people with dementia to fully experience moments of joy and achievement, and being in those moments with them.
<b>Relaxation</b>	Giving people with dementia the space to relax, while surrounded by people that make them feel secure.
<b>Validation</b>	To accept the reality of the persons’ experiences, as it is conveyed by them, by responding empathically and without judgement.
<b>Holding</b>	Providing a safe space for people with dementia to experience distress, without rejection or abandonment.
<b>Facilitation</b>	Interacting in a way that offsets what people with dementia cannot do; this is a form of collaboration, however support is only given as needed, and in a way that supports the persons’ agency and self-efficacy.
<b>Creation</b>	People with dementia should be supported to be spontaneously creative through a medium of their choosing.
<b>Giving</b>	A form of interaction where, when a person with dementia offers something, the other person accepts it with kindness.

## Appendix D: The ENTREQ reporting guidelines (Chapter 4)

No.	Item	Guide and description	Reported
1	Aim	State the research question the synthesis addresses.	√
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	√
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	√
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	√
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	√
6	Electronic Search Strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	√
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	√



8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	√
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g., for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	√
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), and assessment of content and utility of the findings).	√
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	√
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	√
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	√
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies, e.g. all text under the headings “results/conclusions” were extracted electronically and entered into a computer software.	√

15	Software	State the computer software used, if any.	√
16	Reviewers	Identify who was involved in coding and analysis.	√
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	√
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	√
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	√
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	√
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, and development of a new theory or construct).	√

## Appendix E: Characteristics of included studies (Chapter 4)

First author, Year	Country	Study aim(s)	Method	Participants (N)	Respite Model	Data Collection	Data Analysis
Brataas, 2010	Norway	To understand how older adults with cognitive impairment perceive and experience day-care.	Qual	People with dementia; 2 males and 7 females (N=9).	Day-care	Semi-structured interviews	Narrative content analysis
Cahill, 2003	Ireland	To understand service providers' views on dementia-specific day-care.	Mixed Method	18 nurses, 17 branch chairpersons; (N= 35).	Day-care	Semi-structured interviews	Specific approach not stated
de Jong, 2009	Netherlands	To explore the needs and wishes of informal caregivers for the provision of skilled psychogeriatric day-care.	Qual	Family carers of PwD (4 spouses, 5 other); (N=9).	Specialist day-care	Semi-structured interviews	Thematic analysis
Donath, 2009	Germany	To explore the views of caregivers of PwD about the quality of short-term residential care.	Mixed Method	Carers of people with dementia; (N=254).	Residential respite	Open-ended survey questions	Content analysis

Donath, 2011	Germany	To explore the views of family caregivers of PwD who use/don't use on the quality of day care.	Mixed Method	Carers of people with dementia; (N=269).	Day-care	Open-ended survey questions	Content analysis
Gilmour, 2002	New Zealand	To explore family caregivers' experiences of in-hospital respite care for PwD and the factors that influenced their perceptions of the service.	Qual	Carers of people with dementia (4 women caring for their mothers, 2 women caring for husbands, 1 man caring for his mother, 1 man caring for his wife & another caring for his father; (N=9).	Residential respite	Repeated semi-structured interviews	Discourse analysis
Gústafsdóttir, 2014	Iceland	To explore the longitudinal experiences of families of PwD using specialised day care for the PwD.	Qual	Family carers of PwD (4 wives, 2 husbands, 1 daughter and 1 daughter-in-law); (N=8).	Day-care	Repeated semi-structured interviews	Interpretive phenomenological analysis (IPA)

Hochgraeber, 2015	Germany	To understand stakeholders' perspectives on low-threshold support services (respite) regarding service organisation and conceptualisation.	Qual	3 PwD, 6 family carers, 12 volunteers, 7 coordinators, 3 providers (3 males, 28 females); (N=31).	Day-care, in-home	Semi-structured interviews; Focus groups	Content analysis
Holm, 2003	Australia	To investigate what specific needs the program was intended to meet and how.	Qual	Family carers of PwD (N=7). There are indications that staff were also interviewed, but sample size is not stated.	Host-home	Semi-structured interviews	Not clear
Huang, 2016	Singapore	To understand the reasons for non-utilization of day care services for PwD in Singapore using IPA.	Qual	Carers of PwD who had never attended day care; (N=16).	Day-care	Semi-structured interviews	IPA

Jansen, 2009	Canada	To explore formal care providers' perceptions of home and community based services for PwD to inform care quality.	Qual	Rural and urban care providers (both professional [e.g. nurses] and non-professional [e.g. care aides]); (N=44).	Day-care, in-home	Semi-structured interviews; Focus groups	Thematic analysis
Kirkley, 2011	UK	To explore the role of organisational culture in barriers & facilitators to person-centred dementia care from perspectives of frontline staff and managers in respite.	Qual	Strategic managers (34), operational managers (11), frontline staff (17), academics/policy-makers (6), independent consultant (2); (N=70)	Day-care, in-home, residential, alternative models, e.g. short-break holiday services	Semi-structured interviews; Focus groups	Thematic analysis
McGrath, 2000	Canada	To explore the impact of caring for a family member with Alzheimer's on the caregiver's occupational performance and the perceived influence of respite on performance.	Qual	Family carers of PwD (2 adult children, 3 spouses); (N=5).	Any 'respite' service	Semi-structured interviews	Qualitative content analysis

O'Connell, 2012	Australia	To examine carers' experiences and views on using all types of respite.	Mixed Method	Carers of PwD; (N=62)	Day-care, in-home, residential alternative models e.g. 'regular outings' or 'cottage care'	Open-ended survey questions	Not clear
Parahoo, 2002	UK	To evaluate a domiciliary respite service for carers of younger PwD.	Qual	Family carers of PwD (N=8)	In-home	Semi-structured interviews	Not clear
Perry, 2001	Canada	To explore carers experience of a pilot respite program of weekend care for PwD.	Qual	Family carers of PwD (N=18)	Weekend respite (overnight service)	Semi-structured interviews	Latent content analysis
Phillipson, 2011 (IH*)	Australia	To understand the beliefs that caregivers of PwD have in regard to the use of in-home respite services.	Qual	Carers of PwD (10 male, 26 female) (25 spousal , 11 non-spousal); (N=36)	In-home	Semi-structured interviews; Focus groups	Content analysis

Phillipson, 2011 (RR*)	Australia	To understand the beliefs that caregivers of PwD have in regard to the use of residential respite.	Qual	Carers of PwD (10 male, 26 female) (25 spousal , 11 non-spousal); (N=36)	Residential respite	Semi-structured interviews; Focus groups	Content analysis
Phillipson, 2012	Australia	To understand the beliefs that caregivers of PwD have in regard to the use of day-care.	Qual	Carers of PwD (10 male, 26 female) (25 spousal , 11 non-spousal); (N=36)	Day-care	Semi-structured interviews; Focus groups	Content analysis
Robinson,2012	Tasmania	Explores carers' perspectives on day care for PwD, including barriers to attendance and strategies to facilitate attendance.	Qual	Carers of PwD who had used day care (10) and carers of PwD who have refused day care (17); (N=27)	Day-care	Semi-structured interviews	Analysis conducted "using strategies drawn from grounded theory research"
Strang, 2000	Canada	To understand caregivers' respite experiences within the context of caring for PwD.	Qual	Family carers of PwD (22 spouses, eight adult children and one niece); (N=31)	Any service providing an interval of rest or relief	Repeated semi-structured interviews	Not clear



Upton, 2005	UK	To understand 1) what's it like to be a carer and 2) carers' perceptions and experiences of day and short-term residential/ in-patient respite care.	Qual	Spousal caregivers of PwD; (N=46)	Day-care, residential respite	Semi-structured interviews	Not clear
Woolrych, 2013	UK	To understand the experiences of formal carers working within an integrated dementia service (in-home, day care & residential respite).	Qual	Formal carers; (N=24)	Integrated day-care, in-home and residential services; semi-private organisation	Semi-structured interviews and focus groups	Thematic analysis

\* Phillipson et al (2011); IH = 2011 paper focused on in-home respite, RR = 2011 paper focused on residential respite

## Appendix F: Third-order interpretations (Chapter 4)

<b><u>Transitioning to Service Use</u></b>
<ol style="list-style-type: none"><li>1. Timely access to services is impeded by cost (carers, providers), a mismatch in service and client perspectives on what constitutes an 'emergency' (carers), and a lack of designated personnel/staff to assist clients in navigating the system (carers, providers).</li><li>2. Timely access to services is impeded by under-resourcing and a lack of infrastructure at the systems-level (providers).</li><li>3. Service acceptability and fit is initially evaluated by the carer in terms of the services' capacity to 1) recognise and meet the individual needs and preferences of the person with dementia <u>and</u> the carer and 2) to keep the person with dementia safe (carers).</li><li>4. While safe and reliable transport is a key acceptability consideration for clients, and the absence of such a huge access barrier (carers), providers state that it is not always economically feasible to provide this (providers).</li><li>5. When service use is unacceptable to the person with dementia, service refusal can cause considerable relational strain in the dyad, which can lead to attrition for those carers who acquiesce, or for whom the conflict makes service use more trouble than its worth (carers).</li><li>6. Social and professional 'referents' can have a considerable role in normalising and legitimising service use for carer's who hold negative beliefs about services and the associated outcomes of using services.</li></ol>
<b><u>Expanding Organisational Capacity</u></b>
<ol style="list-style-type: none"><li>1. Increased human and fiscal resources, as well as improvements in infrastructure and governance/guidance are prerequisites for implementing service developments (providers).</li><li>2. Service fragmentation and poor infrastructure is considered responsible for poor continuity of care between and across services for people with dementia (providers), however carers feel that discontinuity results when staff don't communicate and co-operate.</li></ol>

3. Both carers and providers acknowledge the importance of the built environment. The preferred environment for carers is 'safe' and 'non-clinical' (carers), while providers need more space and better facilities which serve to offset dementia-related deficits in cognition and functional ability. However, providers maintain they are under-resourced to improve the environment.
4. Providers highlight the need for improved clinical governance, as well as national and international guidance to direct best practice in dementia care (providers).
5. Management often feel ill-equipped to lead on organisational cultural change, particularly with long-term staff that are considered to be set in their attitudes and practices.
6. Staff feel that they cannot implement the improvements desired by clients (i.e. to make services more flexible and responsive to individual needs), because organisational bureaucracy, in conjunction with a "risk-averse" managerial culture, makes management reluctant to give frontline staff the required autonomy over decision-making.

#### **Dementia Care Quality**

1. Carers homogenously describe an approach to care that is consistent with the 'person-centred' label. Some providers indicate they provide person-centred care, and understand what this means, while others employ the label superficially, without little understanding of how it actually translates, relationally, into practice.
2. The most valued care component, outside of personal care and medication-monitoring in in-home settings, was meaningful activity for the person with dementia, however carers have divergent views about what constitutes a 'meaningful' activity.
3. Care providers perceive that they are under-resourced to provide dementia care components that are not related to meeting physical care needs, particularly in in-home models of respite, and particularly as the dementia condition progresses.

#### **Building a Collaborative Care Partnership**

1. In carer's experiences, adverse outcomes result when services do not listen to their input regarding the person with dementia and their care routines, needs and preferences (carers).
2. Amongst satisfied carers, effective and empathic dyad-service communication, preferably with a designated point of contact, facilitated relationship-building and increased carer's trust in the quality of care (carers).

3. Some providers acknowledge collaborative, and not directive, communication as important, however they also feel that they must be better supported by management to accomplish this (providers).
4. Carers have informational support needs that they feel, if met, would improve the value of the service to them by increasing their care skills and capacity; however they don't always request this information, indicating the importance of the service initiating this conversation with carers (carers).
5. Providers suggest that it is difficult to meet carers informational/educational support needs, as they often arrive at services too late for this type of information to be useful (suggesting timely an access problem, again systems-level) (providers).

#### **Dyad Restoration**

1. For carer's the ultimate aim of using services is to achieve a physical and mental break from caregiving, however their ability to relinquish the carer role is dependent on the carer perceiving that the person with dementia also is benefitting from service use also (carer).
2. The way that carers utilise the time that they gain while the person with dementia is under the care of services influences, as well as the duration of the service use (influenced by service model) substantially impacts their ability to experience restoration (carers).
3. Post-respite, carers continually monitor and evaluate the post-respite experience to determine whether service use is indeed mutually beneficial (outcomes of people with dementia post-respite, stated satisfaction of people with dementia) (carers) - this ongoing evaluation teamed with ongoing open and empathic collaboration with the service, is central to facilitating ongoing dyad restoration through service use.

## Appendix G: The COREQ reporting guidelines

Item No.	Guide questions/description	Reported
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	√
2. Credentials	What were the researcher's credentials? (e.g. PhD, MD)	√
3. Occupation	What was their occupation at the time of the study?	√
4. Gender	Was the researcher male or female?	√
5. Experience and training	What experience or training did the researcher have?	√
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	√
7. Participant knowledge of the interviewer	What did the participants know about the researcher? (e.g. personal goals, reasons for doing the research)	√
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? (e.g. Bias, assumptions, reasons and interests	√

	in the research topic)	
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? (e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis)	√
<i>Participant selection</i>		
10. Sampling	How were participants selected? (e.g. purposive, convenience, consecutive, snowball)	√
11. Method of approach	How were participants approached? (e.g. face-to-face, telephone, mail, email)	√
12. Sample size	How many participants were in the study?	√
13. Non-participation	How many people refused to participate or dropped out? Reasons?	√
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? (e.g. home, clinic, workplace)	√
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	√
16. Description of sample	What are the important characteristics of the sample? (e.g.	√

	demographic data, date)	
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	√
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	√
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	√
20. Field notes	Were field notes made during and/or after the interview or focus group?	√
21. Duration	What was the duration of the interviews or focus group?	√
22. Data saturation	Was data saturation discussed?	√
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	√
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	√
25. Description of the coding tree	Did authors provide a description of the coding tree?	√
26. Derivation of themes	Were themes identified in advance or derived from the data?	√
27. Software	What software, if applicable, was used to manage the data?	√
28. Participant checking	Did participants provide feedback on the findings?	√

<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? (e.g. participant number)	√
30. Data and findings consistent	Was there consistency between the data presented and the findings?	√
31. Clarity of major themes	Were major themes clearly presented in the findings?	√
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	√



## Appendix H: Institutional ethical approval

Ollscoil Chathair Bhaile Átha Cliath  
Dublin City University



Ms Emma O'Shea  
School of Nursing and Human Sciences

1 March 2017

REC Reference: DCUREC/2017/018

Proposal Title: Key stakeholders' perspectives on services that provide  
respite for people with dementia and other carers

Applicant(s): Ms Emma O'Shea, Prof Kate Irving

Dear Emma,

Further to a full committee review, the DCU Research Ethics Committee approves  
this research proposal.

Materials used to recruit participants should note that ethical approval for this project  
has been obtained from the Dublin City University Research Ethics Committee.

Should substantial modifications to the research protocol be required at a later stage,  
a further amendment submission should be made to the REC.

Yours sincerely,

A handwritten signature in blue ink that reads 'Dónal O'Gorman'.

Dr Dónal O'Gorman  
Chairperson  
DCU Research Ethics Committee



Taighde & Nuálaíocht Tacalocht  
Ollscoil Chathair Bhaile Átha Cliath,  
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## Appendix I: Study information leaflet

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### Study Information Leaflet



Dementia and memory problems are increasingly prevalent as our population ages. This presents a number of key challenges to health and social care services, and to those personally affected by the condition.

A lack of appropriate support services and high carer strain contribute to earlier institutionalisation in this population.

Respite services, often defined as 'any service or group of services that provide a break for the caregiver' (e.g. residential respite, adult day care, and in-home supports), are considered key to maintaining the caregiving relationship and reducing/delaying institutionalisation.

However, the mixed evidence on the effectiveness of respite, along with research that suggests that there are high levels of non-use and dropout, calls into question the appropriateness and acceptability of the care that existing respite services provide.

There are numerous models of respite available (e.g. in-home, residential, community), but we have very little knowledge about how key stakeholders (i.e. people with dementia, carers, healthcare professionals, policy makers) in dementia care experience respite care, in terms of access/use/planning/provision.

There is also a lack of data on how we can develop our respite services for people with dementia or memory problems within the context of the Irish healthcare system, to improve the quality of care and make it more acceptable.

Ultimately, this research aims to collect the necessary information from key experts (i.e. people with memory problems or dementia, carers, healthcare professionals, and policy makers) to understand how we can feasibly develop respite services so that they better meet the needs and preferences of people with memory problems or dementia and their carers in Ireland.

If you are interested in participating in interviews or focus groups and would like more information – please contact the researcher Emma O' Shea on 0857889499 or [emma.oshea25@mail.dcu.ie](mailto:emma.oshea25@mail.dcu.ie).



## **Appendix J: Visual informed consent for people with dementia**

### **DUBLIN CITY UNIVERSITY**

Visual Informed Consent

**Title: Respite Care Services: Experiences and Perspectives on Improvement**

**Principle Investigator:**

Dr Kate Irving (Tel: +35317007985)

EMAIL: [kate.irving@dcu.ie](mailto:kate.irving@dcu.ie)

**Co- investigator:**

Emma O Shea (Tel: +353857889499)

EMAIL: [emma.oshea25@mail.dcu.ie](mailto:emma.oshea25@mail.dcu.ie)

**You will be asked to:**



**Write your name**

☐

**Answer questions about yourself**

☐

**Answer questions about your care**

☐

**The researcher will:**

**Record my answers**



**Put my answers on a computer**





## **Important**

**The researcher will:**

**Keep my answers private & nobody will know I took part**



**I understand that:**

**I don't have to take part**



**I'm a Volunteer**



**I can stop talking to the researcher at any time**



**I can choose to bring someone with me on the day**





## Consent

**I have asked any questions I have about the research and understand the answers**

☐

**I am happy to take part in the study**

☐

## **Appendix K: Written informed consent for people with dementia**

### **DUBLIN CITY UNIVERSITY**

Written Informed Consent Form: Interviews

#### **Title of Research Study: Respite Care Services: Experiences and Perspectives on Improvement**

**Principle Investigator:** Dr Kate Irving (Tel: +35317007985) EMAIL: [kate.irving@dcu.ie](mailto:kate.irving@dcu.ie)

**Co- investigator:** Emma O Shea (Tel: +353857889499) EMAIL: [emma.oshea25@mail.dcu.ie](mailto:emma.oshea25@mail.dcu.ie)

#### **Purpose of the research:**

The main aim of this study is to explore the experiences of people with memory problems, people with dementia, informal carers, and other key stakeholders, in relation to respite care, as well as their perspectives on the meaning of respite, its purpose and how we can improve current services.

#### **Confirmation of particular requirements as highlighted in the Plain Language Statement:**

I will be taking part in an interview with a researcher from DCU. During this interview we will talk about my personal experiences of respite. We will also talk about how I think services could be made better.

I can ask that my carer/family member is there during the interview. I can also ask that we be interviewed together.

The interview will last up to 90 minutes. The researcher will record what I say in the interview. I can take a break at any time I like.

If I want to, I can stop talking to the researcher and leave without consequence.

I understand that the findings of this project may be published in science journals or presented at conferences or to students.

**Please respond to the following statements by circling ‘yes’ or ‘no’:**

Have you read/heard the plain language statement? *Yes/No*

Do you understand the information provided in this? *Yes/No*

Have you had an opportunity to ask questions about the study? *Yes/No*

Are you aware that your interview will be audio-recorded? *Yes/No*

Are you aware that the findings may be published, presented at conferences and/or used for educational purposes? *Yes/No*

Have you received satisfactory answers to all your questions? *Yes/No*

**Confirmation that involvement in the research is voluntary**

I have received a plain language statement from the researcher. I understand the information contained in this consent form. I have had the opportunity to ask questions about the consent form and satisfactory answers have been provided to me.

I voluntarily agree to participate in this research study. I am satisfied that it respects my legal and ethical rights. I am aware that I may withdraw at any time.

I understand that withdrawing my participation at any time will not affect me or my caregiver in any way going forward.

**Information about confidentiality and privacy**

I understand that I will not be identifiable in this study. My name and address will be removed. Any other information that may identify me will also be removed.

Confidentiality is guaranteed, within the limitations of the law.

**Signature**

I have understood the information in this form. My questions and concerns have been answered.

I freely consent to participate in this research study.

**Participant's signature:** \_\_\_\_\_

**Name in Block Capitals:**\_\_\_\_\_

**Witness:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## Appendix L: Informed consent for family/informal carers

### DUBLIN CITY UNIVERSITY

#### Informed Consent Form for Carers

**Title of Research Study: Respite Care for People with Dementia and Carers**

**Principle Investigator:** Dr Kate Irving (Tel: +35317007985) EMAIL: [kate.irving@dcu.ie](mailto:kate.irving@dcu.ie)

**Co- investigator:** Emma O Shea (Tel: +353857889499) EMAIL: [emma.oshea25@mail.dcu.ie](mailto:emma.oshea25@mail.dcu.ie)

#### **Purpose of the research:**

The main aim of this study is to explore the experiences of people with dementia, informal carers, and other key stakeholders, in relation to respite care, as well as their perspectives on the meaning of respite, its purpose and how we can improve current services for people with dementia.

#### **Confirmation of particular requirements as highlighted in the Plain Language Statement:**

I will be taking part in an interview with a researcher from DCU. During this interview we will talk about my personal experiences of respite, and my perspectives on how services could be improved to better meet my needs and the needs of the person with dementia that I care for. I can ask that the person I care for is present at the interview. Furthermore, I can ask that we be interviewed together (as a dyad). The interview will last approximately 90 minutes. I can take a break at any time throughout the interview. Furthermore, I can withdraw my participation at any time without consequence. I have been made aware that there will be an audio recording of the interview. I have also been made aware that the findings of this project may be published in journals, presented at conferences, and/or used for educational purposes.

#### **Please respond to the following statements by circling ‘yes’ or ‘no’:**

Have you read/heard the plain language statement?	Yes/No
Do you understand the information provided in this?	Yes/No
Have you had an opportunity to ask questions about the study?	Yes/No
Are you aware that your interview will be audio-recorded?	Yes/No
Are you aware that the findings may be published/presented? at conferences and/or used for educational purposes?	Yes/No
Have you received satisfactory answers to all your questions?	Yes/No

**Confirmation that involvement in the research is voluntary**

I have received a plain language statement from the researcher. I have also read/heard the information contained in this consent form. I have had the opportunity to ask questions about the consent form and satisfactory answers have been provided to me. I voluntarily agree to participate in this research study. I am satisfied that it respects my legal and ethical rights. I am aware that I may withdraw at any time, without explanation. I understand that withdrawing my participation at any time will not affect me or my caregiver in any way going forward.

**Information about confidentiality and privacy**

In understand that my identity and other personal information that could make me identifiable will not be revealed, published or used in further studies. All information will have my name and address removed to protect confidentiality. Any other information that may identify me will also be removed. Confidentiality is assured, however I am aware that confidentiality can only be protected within the limitations of the law. It is rare, but possible, for data to be subject to subpoena, freedom of information claim, or mandated reporting by some professions.

**Signature**

I have read/heard and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I freely consent to participate in this research study.

**Participant's signature:** \_\_\_\_\_

**Name in Block Capitals:** \_\_\_\_\_

**Witness:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## **Appendix M: Informed consent for providers, policy-makers/academics**

### **DUBLIN CITY UNIVERSITY**

#### **Informed Consent Form for Health Professionals and Policy-Makers**

**Title of Research Study: Respite Care for People with Dementia and Carers**

**Principle Investigator:** Dr Kate Irving (Tel: +35317007985), EMAIL: [kate.irving@dcu.ie](mailto:kate.irving@dcu.ie)

**Co- investigator:** Emma O' Shea (Tel: +353857889499), EMAIL: [emma.oshea25@mail.dcu.ie](mailto:emma.oshea25@mail.dcu.ie)

#### **Purpose of the research:**

The main aim of this study is to explore the experiences of people with dementia, informal carers, and other key stakeholders, including healthcare professionals and policy-makers, in relation to respite care, as well as their perspectives on the meaning of respite, its purpose and how we can improve current services for people with dementia.

#### **Confirmation of particular requirements as highlighted in the Plain Language Statement:**

I will be taking part in an interview with a researcher from DCU. During this interview, we will talk about our personal experiences of providing/planning respite, and our perspectives on how services could be improved to better meet the needs of people with dementia and carers. The interview will last approximately 1-2 hours. I can take a break at any time throughout the interview. Furthermore, I can withdraw my participation at any time without consequence. I have been made aware that there will be an audio recording of the interview. I have also been made aware that the findings of this project may be published in journals, presented at conferences, and/or used for educational purposes.

#### **Please respond to the following statements by circling 'yes' or 'no':**

Have you read the plain language statement?	Yes/No
Do you understand the information provided in this?	Yes/No
Have you had an opportunity to ask questions about the study?	Yes/No
Are you aware that the interview will be audio-recorded?	Yes/No
Are you aware that the findings may be published/presented at conferences and/or used for educational purposes?	Yes/No
Have you received satisfactory answers to all your questions?	Yes/No

**Confirmation that involvement in the research is voluntary**

I have received a plain language statement from the researcher. I have also read the information contained in this consent form. I have had the opportunity to ask questions about the consent form and satisfactory answers have been provided to me. I voluntarily agree to participate in this research study. I am satisfied that it respects my legal and ethical rights. I am aware that I may withdraw at any time, without explanation. I understand that withdrawing my participation at any time will not affect me going forward.

**Information about confidentiality and privacy**

I understand that my identity and other personal information that could make me identifiable will not be revealed, published or used in further studies. All information will have my name, address and affiliation removed to protect confidentiality. Any other information that may identify me will also be removed. Confidentiality is assured, however I am aware that confidentiality can only be protected within the limitations of the law. It is rare, but possible, for data to be subject to subpoena, freedom of information claim, or mandated reporting by some professions.

**Signature**

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I freely consent to participate in this research study.

**Participant's signature:** \_\_\_\_\_

**Name in Block Capitals:** \_\_\_\_\_

**Witness:** \_\_\_\_\_

**Date:** \_\_\_\_\_



## **Appendix N: Interview schedule for people with dementia**

### **Interview Schedule for People with Dementia (used flexibly; adapted to the communication needs of each participant)**

- The word ‘respite’ is commonly used to describe a break in caregiving, however we know that the meaning of the word ‘respite’ is not always clear. What do you think ‘respite’ means?
  - Can you tell me what you think the purpose/point of respite is?
    - Why do you go? /Why would you go?
      - Does it serve other purposes?
  - Who do you think respite services are provided for?
    - For you? For your caregiver?
  - What do you think the benefits of using respite should be?
    - For the person with dementia?
    - For the carer?
- Can you tell me about your own experience of using respite?
  - What about when you first started?
- Do you like going to [name of respite service]?
  - Would you mind telling me why/why not?
  - Are there things you like/dislike about it?
  - What is the best thing about the service for you?
  - What is the worst thing about the service for you?
- How does [carer’s name] feel about the service?
- Do you think that it meets your needs/ helps you?
  - Could you tell me how/how not?
- Do you think there are ways that respite services could be made better?
- Is there anything they do there, that you feel could be done differently/better?
- Have you anything else that you would like to say about respite?
- Have you any questions for me?

## Appendix O: Interview schedule for family/informal carers

- The word ‘respite’ is commonly used to describe a break in caregiving, however we know that the meaning of the word ‘respite’ is not always clear. What do *you* think ‘respite’ means?
  - Can you tell me what you think the purpose/point of respite is?
    - Why do you use respite?
      - Does it serve other purposes?
  - Who do you think respite services are provided for?
    - For the carers?
    - For [PwD’s name]?
  - What do you think the benefits of using respite should be?
    - For the person with dementia?
    - For the carer?
- Can you tell me about your own experience of using respite?
- When you were seeking respite, how was the experience of trying to access it?
- Does [PwD’s name] like going to [name of respite service]?
  - Would you mind telling me why/why not?
  - Are there things he/she likes (or dislikes) about it?
- How do you feel about using respite services?
  - Did you always feel this way, even in the beginning?
- Do you think that it meets your needs? (how/how not?)
- Do you think there are ways that respite services could be made better?
  - To better suit the needs of [PwD’s name]?
  - To better suits your own needs?
- Is there anything they do there, that you feel could be done differently/better?
- In the literature, there is a movement towards more flexible models of respite e.g. in-home models, host-family respite, holiday respite, overnight-only etc. What do you think about this for your own situation?
- Have you anything else that you would like to say about respite?
- Have you any questions for me?

## **Appendix P: Interview schedule for providers, policy-makers/academics**

- The word ‘respite’ is commonly used to describe a break in caregiving, however the literature indicates that the meaning of ‘respite’ is not very clear and there is quite a lot of disagreement around this. What do you think the term ‘respite’ means in the Irish context, in relation to dementia?
- What do you think the purpose of respite is in relation to dementia?
- Does it serve other purposes? (can you give examples?)
- Who do you think respite services are provided for when it comes to dementia?
- Can you elaborate on/explain this?
- What do you think the outcomes/benefits of using respite services should be in relation to dementia?
- For the person with dementia? For the carer?
- What is your opinion of the current status of respite care for people with dementia in Ireland?
- In comparison to other countries, what do you think Ireland does (or doesn’t do) well in this area?
- What is your experience of providing/planning respite care for people with dementia?
- How do you think your experience of respite for dementia might compare to healthcare professionals/policy-makers in other countries?
- How do you think that PwD experience respite?
- How do you think that carers experience respite?
- We know from other countries that there are high rates of respite non-use and attrition in relation to dementia. Why do you think that is?
- What factors influence service use/non-use?
- Do you think that our current respite services are acceptable to people with dementia and carers?
- How do you think current respite services could be improved for this group?

- We know that creating change in the healthcare context is difficult. What kind of factors do we need to think about if we are going to improve respite for people with dementia?
  - Barriers/facilitators
  - Potential prompt topics:
  - Staff training
  - Resources (e.g. staffing? / funding streams?)
  - The culture of respite care?
  - Would there be an impact on power/responsibility structures?
  - Would such change be compatible with HSE goals?
  - Who would be responsible for leading change?
    - Governance issues?
- How do you think the idea of change would be perceived by other professional stakeholders, e.g. healthcare staff, managers and policy makers?
- Have you any other suggestions for how we could ensure that improvements/developments would be successfully implemented in the health system?
- (may have come up already) In the literature, there is a movement towards more flexible models of respite for people with dementia, given their complex needs. How do you think this would work in the Irish healthcare context?
- e.g. in-home models, host-family respite, holiday respite, overnight-only etc.
- Where do you think respite care for dementia lies in the public health agenda in Ireland?
- How do you think this compares to other countries?
- What can we do to change to ensure that it becomes more of a priority?
- Do you have any other thoughts on respite for dementia that we haven't discussed?

## Appendix Q: Policy brief



# POLICY BRIEF

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## BEYOND 'RESPITE' SERVICES: DEVELOPING A SOCIAL MODEL OF RESTORATIVE CARE FOR DEMENTIA DYADS

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### Why was it prepared?

To inform deliberations about health policies relating to the development of respite services and supports for people with dementia and their carers.

### Who is this policy brief for?

Policy- and decision-makers, their support staff, healthcare planners and providers, and other stakeholders with an interest in the development of respite services and supports for people living with dementia and their carers.

### What is the key policy lesson?

We need to move beyond the traditional residential respite model, towards the development of a consortium-led, integrated continuum of responsive and restorative community- and home-based supports for people living with dementia and their carers, which can facilitate mutual benefit for the dyad. This will require a measured recalibration of services. A number of policy options are outlined in the following brief.

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# POLICY BRIEF

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## BEYOND ‘RESPITE’ SERVICES: DEVELOPING A SOCIAL MODEL OF RESTORATIVE CARE FOR DEMENTIA DYADS

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### THE CONTEXT

The National Dementia Strategy places an emphasis on ageing-in-place and developing community supports and services which are underpinned by the principles of personhood and citizenship. This is with a view to improving the quality of life of people with dementia, and facilitating them to live well and participate in their community for as long as possible. ‘Respite’ is commonly defined as a temporary break in caregiving for the carer, purportedly aiding them to remain in the carer role for longer. ‘Respite’ services are services that can facilitate this break e.g. residential respite services, day services and in-home services.

### THE PROBLEM

A recent Cochrane review found no evidence of any benefit of respite care for people with dementia or for their caregivers for any outcome, including rates of institutionalisation and caregiver burden. Furthermore, the qualitative evidence internationally suggests service acceptability is low, particularly for residential respite. To actualize the objectives of the National Dementia Strategy, we need data on how we can feasibly develop acceptable and effective services for community-dwelling people with dementia and their carers, including respite, in the Irish context. This project provides such data.

### THIS PROJECT

The methods and the key lessons for policy are outlined below. The brief concludes with a number of policy options.

#### Research was undertaken to:

- Explore the concept of ‘respite’ in relation to service provision for dementia.
- Synthesize the international qualitative evidence on the range of key stakeholders’ experiences of ‘respite’ services.
- Understand the perspectives of key stakeholders on ‘respite’ services access, provision and development, in the Irish context.
  - To achieve this, in-depth interviews were conducted with 35 key stakeholders, including people with dementia, carers, primary care professionals, respite and day service managers and front-line staff, policy-makers and academics.

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## POLICY LESSON 1: THE LANGUAGE OF ‘RESPITE’

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- Our synthesis of the international research and our own primary data collected in Ireland, indicate that ‘respite’ is not a useful term to guide care, or service development.
- This concept, ‘respite’, speaks only to the experiences of the carer and their need for a break from caregiving, and is associated with discourse that implicitly designates people with dementia as a burden, from which carers need a break.
- The term is therefore loaded with stigmatising connotations, and is discordant with the fundamental principles of person-centered care. In this way, it acts as a semantic barrier to service development.
- We propose alternative terminology i.e. ‘*restorative care*’. We argue that this connotes a service aim of facilitating mutual benefit for the dyad, which is what is required to improve outcomes.

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## POLICY LESSON 2: STAKEHOLDERS’ PERSPECTIVES ON DEVELOPING COMMUNITY-BASED SERVICES AND SUPPORTS

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- Currently, there are many access barriers in relation to respite and day services for dementia; one such barrier is that respite is not seen as a legitimate need in primary care, that is until the person with dementia demonstrates substantial decline physically, and/or the carer has obvious signs of burnout; this approach is ‘too little, too late’ and will not lead to improved outcomes.
- Residential respite services in particular, are often not tailored to the needs of dyads; not only do they not benefit dyads, they can have adverse outcomes. Furthermore, middle-management in some residential respite services believe that client-service fit is about clients’ ‘readiness’, and that when the situation is ‘bad enough’ at home, people will accept residential respite; this highlights the one-size-fits, non-responsive approach in residential models of respite.
- ‘Respite’ supports should be provided in the preferred settings, i.e. the community and/or the home, and should be flexible/ responsive to the psychosocial needs of the dyad.
- People with dementia want strengths-based engagement, and care underpinned by the principles of personhood and citizenship. Staff must support people with dementia to be active participants in activities that are meaningful to them, and that give them a valued role and purpose.
- Perceived barriers to implementing the above include challenges relating to:
  - changing how staff think about dementia and people with dementia
  - confronting the issue of responsibility in the provision of dementia care (state vs. family)
  - co-ordination, integration and regulation of community-based supports
  - staffing levels and staff competency
  - securing sufficient financial investment
  - the lack of legislation granting entitlement to social care.

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## POLICY OPTIONS

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### FOUR COMPLEMENTARY OPTIONS TO DEVELOP SUPPORTS AND SERVICES IN LINE WITH THE LESSON ABOVE ARE:

1. Review the annual allocation for residential respite admissions; taking the person with dementia out of the home for prolonged periods when that is not their preference should be a last resort; there is no evidence that it improves outcomes, indeed the evidence suggests that it can lead to adverse outcomes for both the person with dementia and the carer.
2. Replace the current medical model of residential respite care with a consortium-led social model of integrated, individualised community and in-home supports, premised on restoration of wellbeing for both members of the dyad. For people with dementia who would prefer community-based purposeful engagement, outside of the home setting, this model could facilitate the creation of a central community-led 'hub', which would coordinate a range of interest groups (e.g. music, arts, social groups, golf, tennis, walking, intergenerational activities). This could be achieved by hub staff linking in with, educating, and supporting staff in local businesses and services to engage people with dementia as citizens, while also capitalising on existing infrastructure and supporting social inclusion, in line with the aims of the Understand Together campaign. Any such model, should have the following core aims:
  - a) Empathic client-service communication from the outset, to facilitate care transitions and to build the trust necessary for a triadic care partnership.
  - b) Creating opportunities for purposeful engagement for the person with dementia, in a way that is personally meaningful, and supports their personhood – knowing the person with dementia is benefitting, is necessary for carers to achieve a respite experience.
  - c) Psycho-educational support for the carer, tailored to their psychosocial needs.
3. Invest in adequate dementia education and support for all staff involved in the provision of 'restorative care', so that they can develop the self-awareness and shared organisational awareness needed to provide person-centred care for the person with dementia. This is about fostering a real understanding of how to support personhood for people with dementia in interpersonal interactions, and the importance of that. A number of the training and education programmes offered by the National Dementia Office currently, could be useful in this regard; including the 'Dementia Awareness' programmes, the 'Therapeutic Activities Training' programmes and the 'Community and Primary Care' programmes, provided they have a strong focus on supplanting latent negative assumptions about dementia, the personhood of people with dementia and the value of purposeful engagement.
4. Introduce a personalized care resource allocation model as part of the reform of respite services, so that people with dementia and their carers are allocated their preferred bundle of services/supports, as they need them. This will ensure that service provision becomes demand-led, as opposed to prescriptive, supply-driven and reactive.
5. Initiate on-going evaluation, including cost-effectiveness analysis, of any respite service reform initiatives.

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