Bangor University

DOCTOR OF PHILOSOPHY

Co-creating meaningful short breaks: Integrating research, policy, and practice

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Award date:
2024

Awarding institution:
Bangor University

[Link to publication](#)

Co-creating meaningful short breaks: Integrating research, policy, and practice

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Thesis submitted to the School of Health Sciences, Bangor University,

in fulfilment for the degree of Doctor of Philosophy

September 2023

Statement of Declaration

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

Summary

This thesis contributes evidence to support the implementation of UK national policy commitments for unpaid carers into practice, specifically, the commitment to support a life alongside caring through meaningful short breaks.

Aim:

This research aimed to generate evidence to enrich the development, commissioning, and delivery of meaningful short breaks for spousal carers (aged 65 years and over) for persons living with dementia.

Method:

Underpinned by a constructivist collaborative approach to knowledge generation, the research progressed through four phases of inquiry. The first three phases involved extensive stakeholder engagement with a diverse range of social care professionals and unpaid spousal carers. The Developing Evidence Enriched Practice approach guided the delivery of a knowledge exchange event that integrated stakeholder perspectives and consolidated learning. The data collected in the first three phases of study, along with insights from a recent seminal scoping review on short break outcomes (Seddon & Prendergast, 2019) identifying knowledge gaps, played a crucial role in shaping and justifying the focus and placement of the scoping review in Chapter Eight.

Findings:

Collectively, the four phases of study contributed a holistic understanding of short breaks provision, underpinned by a whole systems approach to supporting interdependent well-being through short breaks.

A dynamic descriptive model of the short break landscape in north Wales was produced, describing factors shaping local and regional decision-making. The model interprets key challenges and opportunities that shape the planning, commissioning, and delivery of short breaks.

A collective narrative of the caregiving career was constructed to explore how unpaid carers' short break needs evolved in response to the degenerative course of dementia.

Consensus was reached on the features that contribute towards a meaningful short break and social care policy and practice recommendations were co-created with stakeholders.

A review and synthesis of developmental temporal models of dementia caregiving informed thinking around the need for a new conceptual model for breaks across the caregiving career, reasserting the value of short breaks that are regular and help preserve unpaid carers' sense of identity and purpose as an essential resource to support a life alongside, and beyond caregiving.

Recommendations:

Practice and policy recommendations have relevance to assessment and support planning processes and to the conceptualisation, design, and delivery of short breaks.

Identifying and understanding of short break needs and outcomes necessitates genuine dialogue and practitioner support to identify solutions, negotiate options, and balance priorities. This is complex, interpersonal work that requires confidence to think about breaks in their broadest sense., e.g., as a service, an activity, or an item. Proactively supporting short breaks throughout the caregiving career must be underpinned by a temporal understanding of short break needs in dementia caregiving and requires ongoing practitioner engagement to aid and smooth transitions to breaks of mutual value for the unpaid carer and the person with dementia.

Commissioning for sustainable short breaks necessitates a multi-agency and multi-sector response. Partnerships, underpinned by long-term secure funding arrangements, that enable coordination and collaboration between organisations and sectors is vital to achieve this. Processes that help coordinate and collate information about unpaid carer short break needs and desired outcomes are needed to drive service improvements, at a local and regional level. This research spotlights the need for a drastic shift in the cultural orientation and structural underpinnings of the social care system, to reassert what best supports adult social care to deliver sustainable short breaks, namely, the nurturing of long-term continually evolving relationships.

A better understanding of the developmental changes in short break needs and preferences could help unpaid carers in their thinking around breaks as circumstances change, as well as serve as an indicative guide for practitioners to aid the proactive and responsive planning for breaks. This work has the potential to support commissioners to proportionately deploy resources to ensure an appropriate range and balance of short breaks throughout the caregiving career.

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Glossary

Carer(s) (unpaid): is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support (Carers Trust, 2023b). It does not include people who work as volunteers or are employed as paid carers who are referred to as 'care staff' or 'care professionals'.

Commissioning: the process by which health and social care services are planned, purchased, and monitored. The commissioning cycles comprises a range of activities, including assessing needs, planning services, procuring services, and monitoring quality (The Kings Fund, 2019).

Definition of well-being: reference to well-being in this thesis is in relation to the well-being of a person who needs care and support and unpaid carers who need support and may relate to any of the following aspects (Welsh Government, 2015b):

- physical and mental health, and emotional well-being
- protection from abuse and neglect
- education, training, and recreation
- domestic, family, and personal relationships
- being able to participate and contribute to society
- respecting and securing rights and entitlements
- achieving social and economic well-being
- having suitable living accommodation.

Direct payments: direct payments are a funding choice in personal budgets. They are monetary payments made by councils directly to individuals (who have been assessed as having needs that are eligible for certain services) to purchase their own care and support services, with the aim of maximising involvement and control over how needs are met (Age UK, 2023).

Information, advice, and assistance service: a system or service that provides people with timely and relevant **information** to enable an individual to make an informed choice about their well-being; **advice** through working jointly with the individual to learn what is important and what matters to them and what they want to achieve; and ensuring that proportionate action is taken to **assist** the individual to access appropriate care or support (Welsh Government, 2015b).

Personal budget: is the overall cost of the care and support the local authority provides or arranges. It specifies how much, if any, the unpaid carer or person with care and support needs must pay towards the overall cost, with the remaining amount paid by the local authority (Age UK, 2022)**.**

Personal outcome(s): an outcome is the impact, or result, of support, services or an intervention on a person's life and can be used to both determine and evaluate activity.

Respite: relates to the outcomes or benefit experienced by the unpaid carer, person living with dementia and other family members affected by the caring situation, because of having a break from the caregiving routine or responsibilities (Rochira, 2018).

Social care professionals: in this thesis social care professionals refer to a diversity of professionals working in senior managerial positions (e.g., CEO, well-being manager), as commissioners and team leads, and employed in a range of operational roles (e.g., carer officer, social worker, dementia support worker, care staff etc).

Short break:

> **Definition:** any form of service or assistance which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities.
>
> **Purpose:** To support the caring relationship and promote the health and well-being of the unpaid carer, the supported person, and other family members affected by the caring situation.
>
> **Breaks from caring may:**
>
> - be for short or extended periods
> - take place during the day or overnight
> - involve the person with support needs having a break away from home allowing the unpaid carer time for themselves
> - allow the unpaid carer a break away with replacement care in place
> - take the form of the unpaid carer and the person they care for having their break together, with assistance if necessary, providing a break from the demands of their daily caring routines
>
> (Shared Care Scotland, 2023) https://www.sharedcarescotland.org.uk/about-short-breaks/short-guides/

Spousal caring dyads: in the context of this research, spousal caring dyads refers to the unpaid carer and their partner living with dementia, who are married, in a civil partnership, or co-habiting.

Outputs

Publications

Caulfield, M., Seddon, D., Williams, S., & Hedd Jones, C. (2022). Planning, commissioning, and delivering bespoke short breaks for carers and their partner living with dementia: Challenges and opportunities. *Health & Social Care in the Community*. https://doi.org/10.1093/bjsw/bcac178

Caulfield, M., Seddon, D., Williams, S., & Hedd Jones, C. (2022). Understanding Break Needs, Break Experiences and Break Outcomes over the Care-giving Career: A Narrative Approach. *The British Journal of Social Work*. https://doi.org/10.1111/hsc.13533

Conference and webinar presentations

Caulfield, M. 'Planning, commissioning, and delivering meaningful short breaks for unpaid carers and their partner living with dementia: staff reflections on challenges and opportunities'. *The International BREAK (Building Respite Evidence and Knowledge) Exchange Webinar*. Hosted by the University of Wisconsin, 9th December 2020.

Caulfield, M. 'Co-creating meaningful breaks: integrating research, policy, and practice'. *Health Sciences Summer School.* Bangor University, School of Health Sciences, 5th July 2021

Caulfield, M. 'Challenges and opportunities involved in sustainably delivering short breaks for unpaid carers and people living with dementia'. *The Centre for Ageing and Dementia Research (CADR) Conference: A time of change; A time to change*? CADR, 23rd to 25th March 2021 https://www.cadr.cymru/en/event-info.htm?id=228

Caulfield, M. 'Understanding break needs, break experiences, and break outcomes over the caregiving career: A narrative approach'. *The International BREAK (Building Respite Evidence and Knowledge) Exchange Webinar.* Hosted by the University of Wisconsin, 13th July 2023 https://www.breakexchange.org/webinars

Caulfield, M., Seddon, D., Williams, S., and Hedd Jones, C. (2023). 'Planning, commissioning, and delivering meaningful short breaks'. *Alzheimer's Europe Conference: New opportunities in dementia care, policy, and research*. Helsinki, Finland, 16th to 18th October 2023.

Awards

The Drapers' Company Award (Bronze) for 'An Outstanding Postgraduate Contribution' Bangor University, March 2023.

Foreword

Prior to embarking on this PhD programme, I spent three years as a Research Project Support Officer, contributing to various research and delivery projects at the Dementia Services Development Centre, Ageing and Dementia@Bangor, Bangor University. During this time, I sought to develop my capacity for independent research, and gained a foundational understanding of the research process and knowledge of international policy ambitions for healthy ageing and living as well as possible with dementia. I had the opportunity to support research projects that involved working with people living with dementia and their families, and in doing so listened to the personal endeavours and hardships they encountered to live, or to care, with dignity, respect, and resolve. For many families, particularly for spousal couples, a diagnosis radically changed their hopes and aspirations for a future that they had planned together. Given the rising prevalence of dementia, in Wales and across the United Kingdom, the stark policy-practice gap was evident, characterised by the lack of local health and social care coordination, and the under-provision and resourcing of local and responsive community services.

In 2019, I was awarded a scholarship by the Wales School for Social Care Research, on behalf of Health and Care Research Wales, Welsh Government, to undertake an independent research project. This offered me the chance to consolidate and advance my research skills and understanding of an evolving and complex area of support provision in dementia caregiving provision: to support interdependent caregiving relationships through meaningful short breaks. The proposal was informed from discussions with key stakeholders, including local carer organisations, local authorities in north Wales, and the United Kingdom short break research and practice development group. The research strategy was developed in full and refined following the award of the scholarship. The skills, maturity, and knowledge I have developed through this PhD programme have been instrumental to my continuing personal and professional development.

Chapter One: The study in context

1.1   Introduction

The research presented in this thesis provides evidence to enrich the development, commissioning, and delivery of meaningful short breaks for unpaid spousal carers for persons living with dementia (aged 65 years and over). It is an original contribution to critical and complex knowledge gaps at the forefront of a global policy priority for unpaid carers, specifically, enabling unpaid carers to have a life alongside caring.

Short breaks are an essential preventative intervention for unpaid carers that can help reduce stress, maintain well-being, and enable a life alongside caring (Brimblecombe et al., 2018; Roberts & Struckmeyer, 2018; Vandepitte, van den Noortgate, Putman, Verhaeghe, Verdonck, et al., 2016; Zarit, Kim, et al., 2014). Short breaks from caregiving routines and responsibilities are one of the most requested and valued sources of preventive support, yet worldwide, they remain underutilised and poorly regarded by unpaid carers and those they support (Carer Respite Alliance, 2021; Carers UK, 2021; Spiers et al., 2021). Challenges relating to their acceptability and accessibility are recognised worldwide and undermine their potential as a preventative intervention. Ensuring better access to short breaks is a core and critical component of global strategy for unpaid carers (Euro Carers, 2018; International Alliance of Carer Organizations, 2018). The 2021 Global State of Caring report identified the ability for unpaid carers to pursue interests outside of their caring responsibilities through short breaks as one of six priority areas of universal importance and policy priority (International Alliance of Carer Organizations, 2021).

Within the context of United Kingdom (UK) social care reform and declining public budgets and resources, the challenges underpinning the provision of short breaks are vast. This thesis explores these challenges, and the opportunities, to contribute evidence about the ways that short breaks can better reflect the needs and preferences of unpaid carers for persons with dementia, and so support a more meaningful short break experience and outcomes. Through four iterative phases of inquiry and sustained stakeholder engagement, this research has produced two peer reviewed publications offering a unique regional perspective of the complexities associated with the provision of short breaks, and a narrative description of how unpaid spousal carers negotiate and access short breaks over time, as needs and circumstances change. Informed by the knowledge gathered through this inquiry, social care policy and practice recommendations were co-created with key stakeholders to enhance the real-world impact of this research for intended beneficiaries. For the intended

preventative purpose of short breaks to be realised, fundamental change is needed in how they are conceptualised, commissioned, and supported; this research is presented as a contribution to this endeavour.

This introductory chapter sets out the context in which short breaks are considered. To begin, caregiving as a global issue, affecting the quality of life of millions of people around the world and of growing political consequence is stated. Next, the global public health challenge that dementia poses to societies and health and social care systems is introduced, to outline the critical role of unpaid carers. The study is situated within the context of an older spousal dementia caregiving relationship (65 years and over). Throughout the thesis, the term spousal carer is used, however, this term is used broadly and is also intended to refer to couples in a relationship who may co-habit but are not legally married or are in a civil partnership. Attention is drawn to the reciprocal influence of dementia and the dyadic caregiving relationship, laying the foundation for which short break planning and negotiation occurs. To sustain caregiving relationships, unpaid carers and people with dementia need a range of flexible, responsive, and personalised support (Atoyebi et al., 2022; Dawson et al., 2015; Morrisby et al., 2018). An overview of the spectrum of psychosocial interventions for unpaid carers is presented, in which the concept of a short break is discussed. The short break evidence base and knowledge gaps are highlighted and underpin the rationale for this research. To conclude this chapter, the research aim, and research objectives are presented, and the thesis structure is outlined.

1.2   Caregiving as a global phenomenon

Unpaid carers provide care to a friend or family member who due to illness, disability, a mental health problem, or an addiction cannot cope without their support (Carers Trust, 2023b). In this thesis henceforth, the term 'carer(s)' is used to refer to unpaid family, friends, or neighbours, who look after someone with care and support needs.

Worldwide, the unpaid care and support provided by family and friends has become of the most prominent social and economic policy issues (International Alliance of Carer Organizations, 2021). All countries, no matter the effectiveness of their health and social care systems or infrastructure depend on carers to support people living with disability, life limiting conditions, or through ageing and ill health to stay living as well as possible in their communities (United Nations Economic Commission for Europe, 2019). Due to a confluence of demographic trends, countries around the world are experiencing changes to their population structures, in the context of improved longevity and lower fertility rates, which has resulted in a larger proportion of populations living into older age. Concurrently, there is an increase in the number of people living with chronic disabling conditions for

longer, and who need extensive care and support (World Health Organization, 2022). Hence the dependence on carers to provide care and support is greater than ever and is expected to increase (Broese van Groenou & De Boer, 2016; Petrillo et al., 2022). In the UK from 2010 to 2021, on average, the net number of carers increased by 261,000 every year (Petrillo et al., 2022). The economic value of unpaid care to societies worldwide is substantial. The care and support provided by carers in Wales and England is estimated to save the economy £164 billion per year; in 2020/2021 this was equivalent to funding a second National Health Service (NHS) (Petrillo et al., 2022). In recognition of the magnitude of the contributions and critical role of carers to the sustainability of health and social care systems worldwide, political rhetoric and support for carers, in economically developed nations, has risen to prominence (Cahill et al., 2022; Hinton et al., 2019; Wieczorek et al., 2022).

Whilst caregiving, with appropriate supports and resources, can be a fulfilling and worthwhile experience, bringing sources of growth, satisfaction, and enriched relationships (Carbonneau et al., 2010; Yu et al., 2018), the public health ramifications of caregiving are nevertheless substantial. The deleterious outcomes carers experience transverse cultures, races, and ethnicities (Bom et al., 2019; Magaña et al., 2020), and have cascading effects on the health and prosperity of societies and economies (Kannan et al., 2011; Petrillo et al., 2022). The responsibilities and stressors associated with caregiving, particularly over sustained periods (Bom & Stöckel, 2021; Stöckel & Bom, 2022), can adversely affect mental and physical health, limit capacity for employment, compromise the ability to partake in education and lifelong learning, and constrain opportunities for social engagement (Fujihara et al., 2019; Stall et al., 2019; Tulek et al., 2020; Vicente et al., 2022). In consequence, the long-term economic, social, physical, and emotional well-being of unpaid carers is challenged (Future Care Capital, 2019). The burgeoning evidence demonstrating the negative outcomes associated with caregiving has propelled the case that caregiving should be viewed as a social determinant of health (Public Health England, 2021; Spiers et al., 2021). In recognition, policy developments in the UK, Europe and beyond, have demonstrated an explicit commitment to foster carer well-being and to support their resilience to care (Cahill et al., 2022; Courtin et al., 2014; Ministry of Social Development, 2021). A core manifestation of this commitment is to support quality of life and well-being alongside the caring role through access to regular short breaks (Carer Respite Alliance, 2021; Rose et al., 2015; Welsh Government, 2021f).

1.3   Dementia: a global public health priority

Globally, dementia is one of the leading causes of disability and care dependency (World Health Organization, 2021). The effects of dementia are life altering for individuals and for their families and have enormous economic and societal impacts (Wittenberg et al., 2019). The term 'dementia' does not describe a single condition or pathological process, rather it refers to a syndrome that can be caused by a variety of neurodegenerative diseases (Gauthier et al., 2021). These diseases are chronic and progressive and cause the gradual decline in higher cognitive functioning severe enough to compromise an individual's ability to carry out day-to-day tasks and self-care activities. Dementia can also develop because of infection or injury that causes irreversible damage to the brain, such as stroke, unsafe consumption of alcohol, repetitive physical injuries to the brain (e.g., chronic traumatic encephalopathy) or nutritional deficiencies (World Health Organization, 2012). There is currently no cure for dementia.

Alzheimer's disease is the most prevalent cause of progressive dementia in older adults aged 65 years and over; frontotemporal dementia, vascular dementia, and dementia with Lewy bodies being three other major forms (World Health Organization, 2012). Reflecting the pathological overlap between diseases, mixed forms of dementia are common (Zekry et al., 2002). With deepening cognitive impairment, difficulties with memory, organisation, orientation, problem solving, planning and concentration can occur (Alzheimer Association, 2019). Decline in cognitive function is commonly accompanied, and sometimes preceded, by diminishing emotional regulation. Rare dementias, such as posterior cortical atrophy (Tang-Wai et al., 2004) or primary progressive aphasia (Harciarek et al., 2014) are proportionately more likely to develop before the age of 65. Symptoms of rare dementias are often unrelated to memory loss but involve difficulties with language, vision, movement, and behaviour. Dementia is arbitrarily described as progressing in stages, from early, through to middle, to late/advanced stage disease, with individual impairment becoming more pronounced with each clinical stage (Giebel et al., 2014, 2015; Perneczky et al., 2006). However, for each person affected, and for each disease, the trajectory of symptoms and the experience of dementia varies; as such there is no singular experience of dementia, for both the person living with dementia, and for their families (Larson & Stroud, 2021).

Dementia is not a normal part of the biological ageing process and can be distinguished from natural changes in cognitive abilities related to memory (e.g., decline in prospective memory) or processing speed that typically occur with ageing (Harada et al., 2013). It is, however, a condition predominately of later life, and ageing remains the strongest risk factor. Population ageing, characterised by the rising

proportion of people aged 65 years and over (United Nations, 2020), is driving dementia prevalence (World Health Organization, 2018). Over 55 million people are thought to be living with dementia worldwide, and by 2030 it is estimated that there will be 78 million people living with dementia worldwide (World Health Organization, 2021). The challenges borne by dementia to society and to health and social care systems are significant and complex and they are underscored by a global cost estimated at 1.3 trillion US dollars; half of this cost is attributed to care and support provided by unpaid carers (Pickett & Brayne, 2019). In view of the expected worldwide increase in cases of dementia, combined with the rise in costs of providing care, global dementia costs are forecast to reach 2.8 trillion US dollars by 2030 (World Health Organization, 2021).

The World Health Organization recognised dementia as a public health priority in 2012 (World Health Organization, 2012) and has since sought to galvanise a response on an international scale to improve awareness and understanding of dementia, and address barriers to diagnosis and to the seamless provision of long-term support (Burns et al., 2013; Lynch, 2021; World Health Organization, 2018). Governments of high-income countries, including the four countries of the UK, have developed national dementia action plans or strategies (e.g., Dementia Action Plan for Wales (Wales); Prime Minister's challenge on dementia 2020 (England); National dementia strategy: 2017-2020 (Scotland); Improving Dementia Services in Northern Ireland, A Regional Strategy (Northern Ireland)), each offering a tailored strategic response, reflective of their culture and population demographics, to transform services and improve outcomes for people with dementia and their carers. For example, the Dementia Action Plan for Wales (2018-2022) follows a pathway approach to dementia care, identifying outcomes to reduce the risk and to prevent the onset of dementia, through to improving the coordination of care and support for people with dementia, carers, and their families (Welsh Government, 2018).

Advances in biomedical research have transformed our understanding of the pathophysiology of dementia and led to the development of treatments that can delay early symptom progression in Alzheimer's disease (Fish et al., 2019; Shcherbinin et al., 2022). However, the legacy of the biomedical approach to dementia care, with its focus on the clinical pathology of dementia and symptom management, has by large, neglected the influence of the social, environmental, and psychological factors, modulating the onset of dementia, its progression, and lived experience (Hersi et al., 2017; Livingston et al., 2020; Vernooij-Dassen et al., 2021). Adopting a more holistic view, the bio-psycho-social model embraces the influences of and interplay between biological, psychological, and social-environmental factors in the understanding of health and disease (Fazio et al., 2018). The bio-psycho-

social model has been applied to dementia to offer good-practice advice on care and support (National Institute for Health and Clinical Excellence, 2018; Nygaard et al., 2022; Steele et al., 2022). This approach integrates the understanding of the pathology of dementia with psychosocial experiences such as the social environment and relationships to help develop personalised interventions and support for people with dementia, their families, and unpaid carers. Person-centred care is closely aligned to the bio-psycho-social approach to care (Keady et al., 2013; Nicholson, 2021).

Person-centred care is a philosophy of care that is founded on the recognition of the human value and uniqueness of each individual and their needs, within the context of mutually respectful and recognising relationships (Kitwood & Bredin, 1992). Person-centred care has transformed the way services and professionals engage with people with dementia in ways that privilege their perspective, individuality, and self-determination to direct their own care. In health and social care practice, person-centred care recognises that the best possible care gives precedence to a person's needs, preferences, and values, within context of their life history and current circumstance, rather than solely on their diagnosis and symptom management (Miller, 2021; National Institute for Health and Clinical Excellence, 2018). Person-centred care is built on mutually beneficial partnership working between professionals, the person with care and support needs, their unpaid carer(s), and family. Clear, respectful, and open communication should underpin these working partnerships (Kuluski, 2020). People with care and support needs are encouraged to be active partners in decisions about their treatment and care, and personalised care planning supports people to identify 'what matters' to them, building on their strengths and capabilities in informing and prioritising outcomes; the importance of trusting and compassionate relational approaches to the personalisation of care and support is emphasised here (Miller, 2021). In the early 1990's, the commitment to developing person-centred care transformed the culture and approaches to practice in dementia care (Kitwood, 1998). Irrespective of age or declining cognitive abilities, recognising and preserving personhood and the fundamental attributes of a person became the guiding philosophy of theory and models in dementia care (Dewing, 2008; Manthorpe & Samsi, 2016). Supporting personhood means recognising the personal potential, autonomy, and self-determination of people with dementia but also their ability and need to experience interdependence and interconnectedness through social relationships (Morhardt & Spira, 2013). Thus, person-centred care embraces the interdependencies and reciprocities of everyone involved in the caregiving endeavour. Within the context of short breaks, O'Shea et al., (2020) found that nurturing personhood is a fundamental tenet in delivering high-quality short breaks. Their research found that people with dementia were able to discern the genuineness of interactions with staff, thereby influencing the nature of the engagement—either fostering

empowerment or instigating a perception of shallowness, amounting to a lack of respect or belittlement. A person-centred approach is embodied in a model for assessing, planning, and commissioning short breaks (Figure 5) which recognises the importance of 'understanding what matters'. This approach entails a holistic exploration of short break preferences and needs, to help identify and address differences and/or tensions in dyadic priorities and desired outcomes. Moreover, sufficient time should be given to thoroughly consider the most effective ways to support these outcomes.

In many western societies, the trend towards de-institutionalisation of care allied with an 'ageing in place' philosophy (Bigonnesse & Chaudhury, 2019; Ilinca et al., 2012; van Hoof et al., 2009) has meant older persons and persons with long-term health conditions, such as dementia, are encouraged to live and be supported at home, in environments of familiarly and attachment. To be supported at home reflects the preferences of many people with dementia, enabling them to preserve their independence and a sense of connection (Rapaport et al., 2020), and for spousal carers it is often the preferred choice as it can help maintain their status as a couple and a sense of couple hood (Dempsey et al., 2020; Førsund et al., 2015; Tu et al., 2022). This move towards care in the community is attractive for governments in helping reduce or delay the high cost of nursing or residential care home placements (Wiles et al., 2012; Yeandle et al., 2012). It has also driven the expansion of community-based support services, including short breaks options (Dawson et al., 2015). In Wales, the shift towards support embedded in the community has elevated the importance of social value organisations and the third sector to help sustain caregiving relationships through promoting inclusive and connected communities (National Assembly for Wales, 2019; Welsh Government, 2020). However, the reality of providing intensive care and support at home is challenging. Dementia caregiving can eclipse pre-existing identities, alter relationship dynamics (Egilstrod et al., 2019; Fontaine et al., 2016; Pozzebon et al., 2016), and it can compromise carer health and well-being (Lethin et al., 2017; Tatangelo et al., 2018). It is important, therefore, to acknowledge some of the distinct challenges that people with dementia and their carers face to continue to live as well as possible with dementia.

1.4   Caregiving within the context of dementia

Unpaid care varies in intensity, the type of care and support provided, and in duration. The dementia caregiving experience, compared to persons with other disabilities, older age, or health conditions (Ma et al., 2018; Sheehan et al., 2021), is profound in many ways. Dementia is a progressive, insidious, and irreversible disease. It has been described as starting 'like a rain in the night, imperceptibly at first, until it amounts to a flood' (Pfeiffer, 2011, p. 16) that threatens to consume and reconfigure all aspects

of family life (Clemmensen et al., 2019; Miller-Ott et al., 2022). Throughout the UK and around the world the prevalence of dementia is rising (World Health Organization, 2021). Consequently, there is a commensurate increase in the number of family and friends who provide long-term care, and support people with dementia to live as well as possible. These close personal or familial caregiving relationships are significant, particularly as the dementia advances, in enabling people with dementia to stay living at home, as part of families and communities, and to preserve their independence and self-esteem (Martyr et al., 2018; Quinn et al., 2020; Rippon et al., 2020).

In the UK, current estimates suggest that over 900,000 people are living with dementia (Wittenberg et al., 2019), an estimated two thirds of whom live in communities, supported by family and friends (Kane & Terry, 2015). In the UK, approximately 670,000 people act as primary carers for people with dementia (Wittenberg et al., 2019). It is the commitment, determination, and dedication of carers that enable people with dementia to be supported at home, in environments of comfort and familiarity, and they often continue to provide support following admission to a care home (Lethin et al., 2016; Tu et al., 2022). This saves the UK economy approximately £13.7 billion a year, a figure projected to increase to £35.7 billion by 2040 (Wittenberg et al., 2019).

As dementia is predominantly a condition of later life, caregiving is often undertaken by the spouse or partner and, whether out of obligation, loyalty, or affection, they assume the role of the primary carer (Pertl et al., 2019). The experience and impact of caring for a spouse living with dementia is distinct from that of other groups of carers, such as adult children, who are another common source of long-term support for people living with dementia (Johansson et al., 2021). Compared to adult children carers, spousal carers are more likely to co-reside with their partner with dementia and provide greater intensity of care, including personal care, making it challenging for them to experience a life alongside caring (Wawrziczny et al., 2020) and maintain social connections over time (Macdonald et al., 2020; Wang et al., 2023). This can exacerbate their sense of isolation (Wawrziczny et al., 2020). Rigby et al., (2019) found that compared to adult children carers, spousal carers experience greater grief with advancing disease. Furthermore, spousal carers tend to be of an older age, and therefore more suspectable to health conditions of their own which can compound the stressors of caregiving and reduce their resilience to care and intensify the need for a break (Caulfield et al., 2022b; Larkin et al., 2019). Spousal carers are recognised as an especially vulnerable group of carers (Johansson et al., 2021) and this is why they were chosen as the focus for this PhD research. Furthermore, given this was a PhD project with a specific timeframe and limited resources, focusing on one caregiving

population, was deemed appropriate to allow more detailed inquiry of an important caregiving dynamic and to provide a platform for the voices of these carers to be shared.

As could be expected, research and knowledge on spousal carers and that of older carers (i.e., aged 65 years and over) intersects (Larkin et al., 2022). Most spousal relationships predate the onset of dementia (Ablitt et al., 2009; Cooper et al., 2022) and thus the act of giving and receiving care is typically embedded in the context of a long-term relationship, motivated by degrees of reciprocity, satisfaction, and co-dependence (Larkin et al., 2022; Quinn et al., 2015; Zarzycki, Seddon, Bei, et al., 2022). The symbiotic nature of caregiving in long-term relationships has been shown as one reason why spousal carers tend to not identify with the term 'carer', rather caring for their spouse with dementia is instinctively perceived as a continuum of their natural tendency to help and support and their perceived moral responsibility (Carers UK, 2022a; Peterson et al., 2016). Carers who do not recognise themselves as such can fail to avail themselves of vital support services that can help aid their emotional, practical, and financial capacity to care and help them to achieve personal well-being outcomes (Carers UK, 2022a, 2023; Caulfield et al., 2022a; Montgomery & Kosloski, 2000).

With disease progression, spousal carers tend to assume greater responsibility for household tasks, as well as carry out increasingly extensive and quasi medical care tasks for their partner with dementia (Johansson et al., 2021; Kasper et al., 2015; Macdonald et al., 2020). This may start by assisting the person with dementia in keeping active and engaged in activities and hobbies of interest and help with decision-making (Gallagher-Thompson et al., 2020). With time, this can progress to supporting with activities of daily living, including communication with others, dressing, personal care, meals, and medication, as well as offering emotional support, and coordinating care and support with a multidisciplinary team of professionals (Mole et al., 2021; Ozcan & Akyar, 2021; Prizer & Zimmerman, 2018). Through supporting their independence and agency, carers are central in enabling people with dementia to live a life of meaning and purpose, and in the advanced stages of dementia, communicate on their behalf to try to ensure care and support is tailored to their specific needs and preferences (Kokorelias et al., 2020; Sellars et al., 2019).

Over the last two decades the experience of caring for a family member living with dementia has received increased policy attention, with particular attention paid to the support interventions and resources that help buffer the stressors associated with caregiving and foster sustainable caregiving relationships (Britton & Zimmermann, 2022; Gaugler, 2022). Given the intensity and duration of dementia caregiving, carers for people living with dementia identify access to short breaks as a priority

intervention to support their well-being and resilience to care (Keogh et al., 2021; Oliveira et al., 2019; Pierse et al., 2022; Teahan et al., 2021; Wammes et al., 2021). The variation and progression in the intensity of carer role related responsibilities demonstrates the importance that preventative interventions, such as short breaks, can accommodate for a diversity of caregiving circumstances and situations, and can help sustain important caregiving relationships as demands and responsibilities wax and wane.

1.4.1 The impact of dementia caregiving on carer health and well-being

Caring for someone living with dementia can be satisfying and bestow meaning and pride. Positive aspects of caregiving, such as personal, spiritual, and relational growth, a sense of purpose, reward, and satisfaction have been identified (Abdollahpour et al., 2018; Lloyd et al., 2016; Quinn et al., 2022) and associated with higher carer well-being and protective health effects (Lloyd et al., 2016; Yu et al., 2018). However, compared to other neurological diseases and older adult caregiving where physical decline is the presenting challenge, the challenges that dementia presents are complex for individuals, their families, and carers (Draper et al., 1992; Ory et al., 1999).

Despite the satisfaction and sense of fulfilment derived from the caring role, the profound impact of caring for someone living with dementia on carer well-being and resilience to care is widely acknowledged (Allen et al., 2017; Bremer et al., 2015; Goren et al., 2016). Research on dementia caregiving has illuminated the immense challenges and transformations, which are associated with adverse outcomes for carers, including a deterioration in physical health and psychological well-being, increased social isolation, family conflict, and financial hardship (Cross et al., 2018; Fonareva & Oken, 2014; Greenwood et al., 2018; Karg et al., 2018; Kovaleva et al., 2018). Compared to carers for adults with other degenerative conditions, carers for persons with dementia provide more years of caregiving at home and care-related responsibilities generally increase in scope and intensity with disease progression (Alzheimer Association, 2019; Centers for Disease Control, 2020; Kasper et al., 2015; Nolan et al., 1996). An increase in dementia severity is significantly associated with poorer health outcomes for carers (Kannan et al., 2011). Compared to the general population, carers for people with dementia experience higher levels of depression, anxiety, insomnia, fatigue, and distress (Horner et al., 2012; Ma et al., 2018) and have a greater mortality risk (Schulz & Beach, 1999). Bertrand et al., (2006) reported that carers for persons with dementia demonstrated higher levels of perceived stress, greater intensity of caregiving in time and tasks, and feelings of captivity in their caring role, compared to those caring for older persons without dementia. In comparison to carers for persons with stroke, carers for persons with dementia are more likely to experience depressive symptoms and report more family conflicts (Huang et al., 2009). As such, dementia carers' needs for practical and

emotional support are especially high (Glasby & Thomas, 2018). Dementia family carers report the odds of needing a break as 5.3 times higher and 7.7 times higher than for family carers for persons with a musculoskeletal condition and circulatory conditions, respectively (Vecchio et al., 2018). Lee et al., (2022) found that dementia family carers who have a lower household income, nonworking status, and poorer health are in greater need for short breaks than non-dementia carers.

Grief, a complex psychological and emotional reaction to loss, is a common phenomenon of receiving a dementia diagnosis. The person with dementia and their family must negotiate feelings of loss, frustration, anger, guilt, overwhelm, and ambiguity for the future (Shuter et al., 2014). For carers, chronic pre-death grief, the experience, and processing of serial cumulative losses before the physical death of the person with dementia, can be a more significant and consequential experience than post death grief (Lemos Dekker, 2022; Meuser & Marwit, 2001). Evidence (Chan et al., 2013; Coelho et al., 2020; Cooper et al., 2022; Førsund et al., 2015) confirms that before the physical death of their partner, spousal carers experience progressive and anticipatory losses for themselves (e.g., companionship, support, recognition, personal freedom), the person with dementia (e.g., dignity, independence, purpose) and for their relationship (e.g., compromised communication, the loss of a shared lifetime together and for their future envisioned together). The grief experienced before the physical death of the person with dementia is often unrecognised by society, can lead to maladaptive coping strategies and is associated with a higher risk of health complications and complicated grief reactions post-death (Blandin & Pepin, 2017).

Loneliness is a natural part of grieving and is endemic in caregiving (Perez et al., 2021). Carers for people with dementia are at heightened risk of experiencing loneliness and social isolation because of their caregiving responsibilities and this is compounded by relational losses (Hajek et al., 2021; Kotwal et al., 2022). With dementia progression, there is often a correlative insidious loss of social connections. Zwaanswijk et al., (2013) found that half (49.1%) of a sample of 1494 carers for persons with dementia who had had symptoms of dementia for at least four years reported having less contact with friends and acquaintances, in contrast with a quarter (25.6%) of carers for persons with dementia in the initial stage of disease. In one of the first large scale studies to examine the prevalence and predictors of loneliness in 1238 family carers for people with dementia (81% were spouses), two in three carers (approximately 62%) reported feeling moderate or severe loneliness, measured using the De Jong Gierveld Loneliness Scale (De Jong-Gierveld & Van Tilburg, 1999), which was associated with increased caregiving stress, poorer well-being, and social isolation (Victor et al., 2021). However, a better quality of relationship with the person with dementia, measured using the Positive Affect Index

(Bengtson & Schrader, 1982), was associated with a lower relative risk of loneliness. These findings highlight the importance of interventions designed to help maintain relationship quality as a potential means of addressing carer loneliness. Short breaks are increasingly promoted to sustain or even strengthen important caregiving relationships through opportunities to foster connection through activities and time together in environments of shared enjoyment where the carer has minimal or reduced caregiving responsibilities (Caulfield et al., 2022b; Glasby & Thomas, 2018; Seddon, Andrews, et al., 2021; Shared Care Scotland, 2022b).

Some of the most notable challenges associated with caregiving in dementia arise from the progressive loss of cognitive, social, and functional abilities of the person with dementia (Abreu et al., 2020). Over time, these losses impede their independence and ability to carry out essential daily and self-care tasks (Andersen et al., 2004). As a corollary, carers frequently assume increasingly physical and emotionally demanding care tasks to support the quality of life of persons with dementia. (Kokorelias et al., 2020; Zwaanswijk et al., 2013). Additional care tasks can result from comorbidities; an estimated 90% of people with dementia in the UK are living with comorbid conditions, including stroke, Parkinson's disease, depression, coronary heart disease, and diabetes (Browne et al., 2017). For older spousal carers, managing their own health or disability alongside their caring role is also an important factor in the experience of later-life caregiving (Larkin et al., 2022; Tu et al., 2022). The health consequences of sustained caregiving combined with the experience of common health conditions in older age (e.g., cancer, arthritis, diabetes, osteoporosis) may deplete carer resilience, ability, or willingness to continue to care for their partner with dementia at home. This emphasises the importance for short breaks to enable sufficient and regular time for older carers to rest and recuperate.

Further to the practical caregiving tasks, carers must learn how to respond to the behavioural and personality changes that commonly accompany the experience of dementia. Behavioural and psychological symptoms of dementia describe a group of non-cognitive symptoms such as agitation, aggression, disinhibition, hallucinations and delusions, depression, anxiety, and sleep deprivation (Zhao et al., 2016). These symptoms tend to increase with dementia severity (Brodaty et al., 2015), and are associated with the accelerated progression of cognitive decline (Zahodne et al., 2015) and an increased risk of admission to a care home (Toot et al., 2017). It is estimated that 90% of people with dementia experience at least one of these symptoms at some point (Aalten et al., 2005; Steinberg et al., 2008). These symptoms can be extremely distressing for people with dementia and exacerbate the stresses for their carers (Black & Almeida, 2004). Concerns around the unpredictability of these

symptoms and not knowing how to respond to the person with dementia when experiencing distress can lead to the avoidance of social engagements and exacerbate the feeling of social isolation for the carer and person with dementia (Glasby & Thomas, 2018). As a symptom group, they are a primary factor of decreased quality of life for the person with dementia and in the experience of caregiver burden (Cheng, 2017; Chiao et al., 2015; Feast et al., 2016; Isik et al., 2019).

Caregiver burden refers to the adverse effects on carer well-being when the demands of caregiving exceed the available resources to manage these demands (Liu et al., 2020), and can include both subjective burden (i.e., the perceived emotional and psychological impact of caregiving) and objective burden (i.e., time and tasks associated with caregiving) (Montgomery et al., 1985). Caregiver burden is associated with depression (Epstein-Lubow et al., 2008; Ornstein & Gaugler, 2012) and poor health (Cheng, 2017), which can erode carers' capacity, willingness, and resilience to care. The destabilising consequences of caregiver burden on the sustainability of the caregiving relationship can lead to premature admission to a care home for persons with dementia (Eska et al., 2013; Tate et al., 2022; Terum et al., 2021). The experience and perception of caregiver burden are mediated by several sociodemographic and caregiving-related factors, such as gender, spousal status, co-habitation (Chappell et al., 2014; van den Kieboom et al., 2020), and the coping strategies and access to care and support services that can help carers to cope and sustain their well-being (Sutcliffe et al., 2017; Torti et al., 2004).

The evidence discussed thus far demonstrates that dementia can be a life changing diagnosis for families and affect all aspects of life, including the relationships with family and friends (Alzheimer's Research UK, 2015; Miller-Ott et al., 2022). The sustainability and quality of the spousal relationship is important for people with dementia, as it can help preserve their self-esteem and sense of identity (Groenendaal et al., 2022; Zhang et al., 2022), as well as extend their time spent living at home (Dawson et al., 2015). It is therefore pertinent to consider the impact of dementia on the spousal relationship.

1.4.2   The impact of dementia on the spousal relationship

It is understood that the experience of dementia not only affects both members of a couple separately but also the quality of the caregiving spousal relationship (Fontaine et al., 2016; Hayes et al., 2009; Wadham et al., 2016). The form the relationship takes following the onset of dementia, particularly the ways in which carers and people with dementia cope with the experience of dementia, is influenced to varying degrees by the presentation and progression of the dementia (Egilstrod et al., 2019; Evans & Lee, 2014), and the characteristics and the quality of the prior and current relationship

(Betts Adams et al., 2008; Fauth et al., 2012; Norton et al., 2009). Thus, the experience of dementia, both for the carer and for the person with dementia, is intimately connected to the relationship in which it occurs and is bounded (Fontaine et al., 2016).

An extensive body of research has explored the impact of dementia on a diversity of relational aspects and concepts, including the continuation of couple hood (i.e., partners' shared feeling of mutuality and reciprocity within the relationship) (Hellström et al., 2007; Kaplan, 2001; Swall et al., 2020), and relationship continuity/ discontinuity (Chesla et al., 1994; Lewis & Riley, 2021; Riley, 2019). This work has identified the changes in opportunities for shared activities and experiences, communication, intimacy, and for reciprocity of warmth and support (Egilstrod et al., 2019; Fletcher, 2020; Hammar et al., 2021). Wang et al., (2017) termed the concept 'unbalanced intimacy' to describe the progressive changes in the carers' perception of balance and reciprocity in the relationship as they compensated for their partners growing dependency.

While not overlooking the relational losses and difficulties owing to dementia, a relational perspective of the experience of dementia, albeit predominately informed by the viewpoint of the carer (Ablitt et al., 2009; Braun et al., 2009), has challenged the narrative of hopelessness and despair (Hydén & Nilsson, 2015; McGovern, 2011). Research has shown that the experience of dementia can preserve or even enhance a couple's bond and affection for one another and reinforce their commitment to maintain mutuality despite the challenges (Eloniemi-Sulkava et al., 2002; Shavit et al., 2019; Wadham et al., 2016). The uncertain progression of cognitive and functional decline is such that changes experienced to the spousal relationship are not necessarily linear nor culminative (Aneshensel et al., 1995; Evans & Lee, 2014). A trajectory of relational growth and decline can be simultaneously experienced. Spousal carers are on a path in which their partner's decline is inexorable, yet they strive to maintain, and sometimes transcend dementia through closeness and connection (Cooper et al., 2022). Within the context of short breaks, the relational quality and dynamics are likely to shape needs and preferences for short breaks. Short breaks, as well as providing opportunities to restore individual well-being and sense of self (Roberts & Struckmeyer, 2018), have considerable potential to support relationships as longstanding roles and responsibilities are renegotiated and adjusted. Increasingly, research has drawn attention to the purposeful intention for short breaks to sustain a sense of couple hood and support the positive reframing of the relationship. Research on short break provision conducted during the COVID-19 pandemic where services where limited, demonstrated how the creative use of equipment bought through a short break fund (e.g., garden bench, green house) opened possibilities to integrate regular short breaks into the caring environment at home, enabling

couples to stay together but offer new experiences, activities, and hobbies that could support a positive caregiving relationship (Shared Care Scotland, 2022b).

1.5   The caregiving career

Researchers have contended that caregiving, far from being a stagnant occurrence, exists along a continuum around which a discernible career is constructed (Gaugler & Teaster, 2006; Montgomery & Kosloski, 2000; Nolan et al., 1996; Pearlin & Aneshensel, 1994). The concept of a career is useful to encapsulate the prolonged caregiving experience for a person with a chronic condition, such as dementia, as it shares some comparable features. According to Aneshensel et al., (1995), a career implies a temporal dimension that spans many years, change, particularly personal growth or maturation, and a cumulative experience that manifests into a holistic entity.

The concept of the caregiving career was developed by Aneshensel and Pearlin in the early 1990's (Aneshensel et al., 1995; Pearlin, 1992; Pearlin & Aneshensel, 1994) based on the longitudinal observation of over 500 family carers taking care of a spouse or parent living with Alzheimer's disease. Their research illuminated the evolving character of caregiving and the carer's transition through multiple stages of caregiving. As carers are channelled through their career, driven chiefly by the pathogenesis of dementia, considerable change is experienced both between and within stages. These changes are characterised by shifts in role related responsibilities, self-identification and self-concept, rewards, coping strategies, stressors, and resources. Spousal carers must learn to navigate change and the stressors and imbalances that arise on a practical, interpersonal, and intrapersonal level (Esandi et al., 2018; Liu et al., 2021). The career, therefore, is an unexpected one; it is not planned for, prepared for, or easily adjusted to (Pearlin & Aneshensel, 1994). It is the cumulative experience of the transition through the different stages, named as role acquisition, role enactment, and role disengagement, that characterise a career. **Throughout this thesis, the term caregiving career is used heuristically to denote the fluid nature of caregiving and the change experienced because of the evolving constellation of stressors, resources, and outcomes.**

Aneshensel and Pearlin's description of caregiving as a 'continually shifting terrain' (Aneshensel et al., 1995, p.70), draws attention to the reconfiguration of stressors over time. Stressors are described as the 'conditions, experiences, and activities that are problematic for people' (Aneshensel et al., 1995, p.69) that strain the carer's ability to adapt. Primary stressors are those that emanate directly from providing care and evolve from difficulties related to the needs of the person with dementia and the presentation of dementia., e.g., level of functional dependency, presence of comorbidity, behavioural and psychological symptoms of dementia etc. Secondary stressors relate to the strains in domains of

life outside of caregiving, aggravated by primary stressors, such as paid employment, family relationships and dynamics, social engagement, and financial resources (Skaff et al., 1996). It is the proliferation of stressors that differentiates the dementia caregiving career from most other careers (Pearlin & Aneshensel, 1994). The interrelationship between the proliferation of care-related stressors, manifestations of these stressors (outcomes), and the psychosocial resources that can moderate the impact of care-related stressors is the basis for the existence of a complex stress process in dementia caregiving (Aneshensel et al., 1995). An appreciation for how stress proliferates, and the presence of, and distinction between, primary and secondary stressors, is important to understand why some carers, exposed to a similar intensity of caregiving or comparable circumstances, can perceive the demands of caregiving differently and realise different outcomes. How short breaks can help alleviate different stressors (i.e., primary, or secondary) to support a better equilibrium and balance within the caregiving relationship may be an important consideration in support planning and delivery.

There is no identical career route and, as carers venture into their career, their needs for support will fluctuate over time (Kinchin et al., 2022; Novais et al., 2017; Whitlatch & Orsulic-Jeras, 2018; Zwaanswijk et al., 2013). To sustain carer well-being, resilience, and the caregiving relationship, research has demonstrated the importance of proportionate and preventative support throughout the caregiving career (Bangerter et al., 2019; Gaugler & Teaster, 2006; Lethin et al., 2016). For carers, preventative support aims to provide timely and targeted intervention, information, or support to reduce or prevent the likelihood of a breakdown or crisis in the caregiving relationship (Social Care Wales, 2018). For carers who provide prolonged and intensive assistance, short breaks have a unique potential to support carers throughout their caregiving career (Bangerter et al., 2019; Gaugler, Jarrott, et al., 2003; Gaugler, Zarit, Townsend, et al., 2003; Liu et al., 2015). There is a growing political and practice consensus that short breaks should be an integrated resource available throughout the caregiving career with recognition that different types of short breaks will be more appropriate for different people at different points in time (Newbronner et al., 2013; Welsh Government, 2021f; Zarit, 2018).

While it is not possible to alter the physiological course of dementia and the objective difficulties experienced because of dementia, it is possible to buoy the caregiving experience through timely and responsive psychosocial support (Cheng & Zhang, 2020). The next section considers the psychosocial interventions that can support well-being and sustain the caregiving relationship. For many carers, a short break is an essential preventative intervention.

1.6 Psychosocial interventions and support for carers

With the recent recognition of carers' needs, rights, and substantial contributions, the exploration of carers' support needs is a relatively nascent yet rapidly evolving field of knowledge. There is a substantial body of research focused on understanding the self-perceived support needs of individuals caring for persons with dementia (Janssen et al., 2020; Mansfield et al., 2022; Soong et al., 2020). Carers' needs for help and support are influenced predominantly by the care and support needs for the person with dementia (Zwingmann et al., 2019), but also by the goals and priorities for carers (e.g., maintaining a relationship with the person with dementia amongst their changing abilities and behaviours) (Kokorelias et al., 2022), and the personality, characteristics, and self-efficacy of the carer (Black et al., 2019; Marziali et al., 2010; Ong et al., 2022). Systematic reviews have delineated interrelated but diverse areas for help and support (Atoyebi et al., 2022; Bressan et al., 2020; McCabe et al., 2016; Waligora et al., 2019). These can be broadly classified as:

a. Carers' personal self-care needs, such as the need for sufficient sleep, social engagement, emotional support, time to themselves or with others, and to manage their own health needs.

b. Practical support and advice from professional services, or from family and friends, to help them to provide care and respond to the changing needs and behaviours of the person with dementia, such as help with activities of daily living, and information, education, and knowledge about dementia, respectively. This may include financial and legal support.

These reviews highlight the multiplicity of support, from formal and informal sources, that carers are likely to require, and the delicate process undertaken by carers in balancing their caregiving responsibilities with maintaining their own well-being and a life alongside caring (Esandi et al., 2018; Gottschalk et al., 2021; Kokorelias et al., 2022; Quinn et al., 2015). The carers' continual adjustment to emergent needs reinforces the caregiving career as a dynamic process that calls for the right support and interventions provided at the right time. Research with carers for people with dementia living in the UK, North America, Australia, Norway, and South Africa, reinforced the international perception that the provision of support for carers tended to be 'short term' and 'issue specific'. Whereas what carers required was long-term continuous holistic engagement that adapts to the different stages of the caregiving career (Glasby & Thomas, 2018). Wyman et al.'s, (2022) systematic review of process evaluations for psychosocial interventions for people with dementia and their carers found that a key influencing contextual factor in the success of the intervention was alignment to **stage** of dementia.

Helping carers to look after themselves and to sustainably provide care is one of most effective ways to support the well-being of people with dementia (Lamont et al., 2019; Quinn et al., 2020; Stall et al., 2019). It is widely accepted that there is no 'one-size-fits-all' approach to supporting carers and people living with dementia (Zarit, 2018; Zarit & Femia, 2008). Interventions for carers have been largely underpinned by a stress-coping model (Kneebone & Martin, 2003; Zarit et al., 1987), with efforts to reduce caregiver stress, or increase support resources to better manage stress, being the main motivation and priority for intervention outcomes (Gilhooly et al., 2016; Liu et al., 2018). However, heralded by a multidimensional understanding of caregiving, motivation, and willingness to care (Nolan et al., 1996; Zarzycki, Seddon, Bei, et al., 2022), greater attention has been brought to improving satisfaction and expertise in caregiving to support well-being and independence through positive functioning (Beach et al., 2022). This has given rise to an ever-expanding variety of interventions (Bielsten & Hellström, 2019a; Dam et al., 2016) that reflect the dynamic and reciprocal nature of dyadic caring relationships and family caregiving relationships (Moon & Adams, 2013; Ramachandran et al., 2023; Zhang et al., 2022), and thus support a more diverse set of outcomes, such as building good partnerships with services, maximising a sense of autonomy, having their expertise valued and recognised, and choices and satisfaction in caring (Bamford & Bruce, 2000; Bielsten & Hellström, 2019b; Cook & Miller, 2012).

While emergency interventions have an important place, for example if the carer falls ill, many interventions take a preventative approach with the aim to sustain carer well-being and resilience and promote competence to care. The effectiveness of different interventions on a range of carer related outcomes, such as quality of life, caregiver depression and anxiety, sense of competence and self-efficacy to care, are the focus of continual and substantive international review (Brimblecombe et al., 2018; Cheng et al., 2020; Cheng & Zhang, 2020; Dalton et al., 2018; Whitlatch & Orsulic-Jeras, 2018; Williams et al., 2019). Examples of widely implemented interventions that have been shown to have efficacious effects for carers for people with dementia include psychological therapy or counselling (Cheng et al., 2019; Kishita et al., 2018), physical or leisure activities (Lee et al., 2020; Orgeta & Miranda-Castillo, 2014), communication training (Eggenberger et al., 2013; Morris et al., 2018), psychoeducational and skills-based training (Jensen et al., 2015; Vandepitte, van den Noortgate, Putman, Verhaeghe, Faes, et al., 2016), peer and social support (Dam et al., 2016) and community support services for the person with dementia that offer carers a break (Maffioletti et al., 2019; Vandepitte, van den Noortgate, Putman, Verhaeghe, Verdonck, et al., 2016). Across this range of support, formal support services for carers are often denoted by those arranged and provided directly

by health and social care services, through Direct Payments, or a specific commissioned service (e.g., short break service) provided by a third sector or private organisation on behalf of the local authority. Eligibility for support is often determined via an assessment of need(s) for the carer and/or person with dementia. Conversely, informal support is more regularly offered through peer and social networks, community groups, charities, and social enterprises, and may not require a needs assessment.

In many interdependent caregiving relationships, maintaining the quality of the caregiving relationship is important in shaping how the carer and person with dementia adapt to the caring role and experience dementia, respectively, throughout the course of the disease (Rausch et al., 2017). Higher prior and current relationship quality in dementia spousal caregiving relationships has shown to be strongly associated with intrinsic motivation to care and a greater ability to find meaning in the caregiving role (Quinn et al., 2012). Higher relationship quality can serve as a protective factor against loneliness (Victor et al., 2021) and fortify the relationship through role transformation, enabling the effective adaptation to the impact of dementia and realisation of losses in the relationship (la Fontaine & Oyebode, 2014; Norton et al., 2009). Alongside interventions that target either the personal support needs of the carer or the person with dementia, there is increased recognition of the need for relationship-centred support, where both the carer and person with dementia are considered as co-beneficiaries and, as such, interventions are tailored to their dyadic needs and interpersonal issues (Bielsten & Hellström, 2019a; Zhang et al., 2022). Some examples in the literature include couple counselling following a dementia diagnosis (Auclair et al., 2009), shared art, dance, and music-based activities (Camic et al., 2013; Clark et al., 2020; Dupuis et al., 2012; Skingley et al., 2021), joint physical exercise programmes (Prick et al., 2015), and short breaks (Ryan et al., 2008). Some examples of couple based short breaks include the of use of cottage breaks (Harkin et al., 2020), caravans (Carers Outreach Service, 2023) or clubs or groups (Dröes et al., 2006) that welcome couples and/or families and offer appropriate support for couples to derive mutuality of benefit, to preserve the integrity and health of the relationship, and the sense of well-being of each partner.

Within the spectrum of support for carers and people with dementia, short breaks have long been recognised by professionals and carers as an essential, and amongst the most frequently requested, resources in caregiving (Arksey et al., 2004; Carers UK, 2021; Clarke & Finucane, 1995; Oliveira et al., 2019; Parkinson et al., 2017; Phillipson et al., 2019; Pierse et al., 2022; Teahan et al., 2021). A life alongside caring through short break provision contributes towards healthy, sustainable societies, and has been a Welsh Government national priority since 2019 (Welsh Government, 2021e). Short breaks

are distinguished from other forms of social support by their purpose: they provide a physical and/or psychological temporary 'break' from the caregiving routine and responsibilities for the carer (O'Shea, Timmons, O'Shea, Fox, et al., 2019).

This break can gift carers time to do the things that matter to them to experience a life alongside caring (Weir & Fouche, 2017). This may include time for carers to attend to their own well-being needs, however, services that enable the carer to engage in paid employment or that are arranged should the carer need hospital treatment should not be considered as a short break (Carers UK, 2019a; Shared Care Scotland, 2023).

The next section reviews the potential for short breaks to support carer well-being and sets out the current research priorities for knowledge enrichment in short break provision that inform the research aim and objectives for this thesis.

1.7 A short break from the caregiving routine and responsibilities

To reiterate, in this thesis, a short break is defined as any form of service or assistance which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities. The purpose is to support the caring relationship and promote the health and well-being of the carer, the supported person, and other family members affected by the caring situation (Shared Care Scotland, 2023). This definition of a short break infers a dual purpose, accentuating the role of a short break in supporting individual well-being and in sustaining interdependent caregiving relationships. The definition is deliberately broad as to encourage choice and creativity in the ways services or assistance can accommodate for variation in caregiving circumstances, and it encourages the meaningful consideration of break needs, preferences, and desired outcomes for all those affected by the caregiving situation.

Short breaks enable carers to have time away from their caregiving responsibilities (Zarit et al., 2017). The basic premise of a short break follows that temporary rest or recuperation from the caring role can help ameliorate the stressors and demands associated with caregiving. This in turn can help restore or sustain carer resilience and motivation to care and postpone or prevent the permanent admission of the person with dementia to a care home. People with care and support needs can also benefit from short breaks that help to maintain their well-being in ways that are meaningful to them, through appropriate activities, quality care, and opportunities for social engagement and stimulation (de Bruin et al., 2021; Harkin et al., 2020; Lole et al., 2023; Rokstad et al., 2019).

Traditionally referred to as respite care or respite, the term 'respite' and' short break' are still used interchangeably. There is no one universally accepted definition of respite and it is inconsistently defined in the literature (Kirk et al., 2015), simultaneously considered both as an 'outcome' and as a 'service' (Chappell et al., 2001; Evans, 2013; O'Shea, Timmons, O'Shea, & Irving, 2019; Silverman, 2018).

Respite care has long been synonymous with the 'burden of caregiving' and can be perceived as pejorative (Carer Respite Alliance, 2021; Glasby & Thomas, 2018). This implicit assumption serves to accentuate the person with dementia as the 'problem' and the carer's wish to escape from their caregiving role (de la Cuesta-Benjumea, 2011; Strang et al., 1999), overlooking the positive and rewarding aspects to caregiving (Quinn et al., 2022). Respite is habitually equated with the more traditional break models, that involve separation and the person with care and support needs being cared for outside of the home in settings such as day care centres, residential or nursing care homes, or in hospitals. In accord with a more relational-centred approach to the care of people with dementia, the term 'short break' or a 'break from caregiving' invites a holistic perspective founded on sustaining well-being to support or strengthen important relationships, and potentially including a break from routine *together.*

The need for a break is highly individualised and, as with other forms of support, is likely to evolve as circumstances change. Over the last two decades, with the advance of person-centred and outcome-focused support, the international policy and practice narrative encompassing the potential vision for short breaks has undergone considerable change; there is greater public and policy expectation and aspiration for short breaks that are responsive to the changes and fluctuations in the needs and circumstances of carers and those they support, and that contribute towards meaningful outcomes (O' Shea et al., 2020; Phillipson et al., 2021; Rochira, 2018; Seddon, Miller, et al., 2021; Shared Care Scotland, 2022b). Following the independent review of adult social care in Scotland (Feeley, 2021), the Scottish Government has committed to introducing a legal right to short breaks from caring for all unpaid carers, and draft legislation is currently being reviewed in the Scottish Parliament. In Wales, the Welsh Government commitment to short breaks is reflected in a £9million investment to support a National Short Breaks fund for carers to increase opportunities to take breaks (Welsh Government, 2022d). While these commitments are to be commended, considerable challenges pertain to enabling access to short breaks that meaningfully support and sustain the diversity of caregiving relationships (Seddon, Andrews, et al., 2021).

1.7.1 The evidence base

Short break models encompass a wide range of formal and informal services and options, in which break length, break location, break activity, and break provider can vary. Breaks can be planned and provided on a pre-arranged basis, or offered in an emergency, if for example, the carer falls ill or has an accident. Emergency break preferences and options can be detailed in an emergency care plan; however, emergency breaks provision and the development of care plans were not the focus of this research.

Some examples of how planned breaks are supported include day care centres, temporary residential care, Direct Payments, inclusive community groups, dementia and/or carer peer support activities, self-funded options, supported holidays, communities of interests, in-home breaks provision involving paid care staff supporting the person with dementia at home, and informal arrangements from friends and wider family members (Public Health England, 2021). It is important to note that how carers and people with dementia refer to these arrangements may differ, and the term short break, respite or replacement care may not be explicitly articulated during assessment and support planning (Vullings et al., 2020). The variety of break options underscores the diversity of caregiving circumstances and situations, and variation in the needs and preferences for short breaks (van Exel et al., 2006). There is heterogeneity across and within model provision. Maffioletti et al.'s, (2019) systematic review demonstrated the heterogeneity of day care services, in terms of structure, organisation, intended audience (e.g., carers and/or people with dementia), and degrees of programme tailoring, intervention content, and outcomes measured. Across the UK countries and their regions, the local variation and inconsistency in choice, quality, and access to short breaks has propelled the perception that quality short breaks are a 'postcode lottery' (Allen et al., 2020; Giebel, Hanna, et al., 2021).

Systematic reviews (Maayan et al., 2014; Maffioletti et al., 2019; Pinquart & Sörensen, 2006; Vandepitte, van den Noortgate, Putman, Verhaeghe, Verdonck, et al., 2016) and qualitative syntheses of research (Neville & Byrne, 2007; Seddon & Prendergast, 2019; Tretteteig et al., 2016) have reported on the experience and outcomes supported by break options for both carers and people with dementia. Research on short breaks has predominantly focused on the three traditional models: day care, in-home breaks provision, and temporary residential care (Arksey et al., 2004). Studies have evidenced their potential to relieve caregiver burden and perceived sense of overload (Bangerter et al., 2019; Tretteteig et al., 2016), improve feelings of competence, self-confidence, and motivation to care (Maffioletti et al., 2019; Tretteteig et al., 2017b), enhance resilience to care (Roberts & Struckmeyer, 2018; Zarzycki, Seddon, & Morrison, 2022), increase carer sleep quality (Lee et al., 2007;

Leggett et al., 2016; Sakurai & Kohno, 2020), prompt positive self-care behaviours (Parker et al., 2019; Weir & Fouche, 2017), decrease the frequency of distressing behaviours in persons with dementia (Femia et al., 2007; Gaugler, Jarrott, Zarit, et al., 2003; Neville & Byrne, 2007), and reduce the risk of permanent admission to residential care for persons with dementia (Harkin et al., 2020; Harrison et al., 2020; Vandepitte et al., 2019). The use of day care and in-home breaks services have demonstrated their potential to improve carer's physiological stress responses and reduce emotional distress (Grant et al., 2003; Klein et al., 2016; Zarit, Whetzel, et al., 2014).

1.7.2 The evidence gaps

Despite the potential of short breaks as a preventative resource for carers and people with dementia, its efficacy continues to be questioned by the discrepancy between carers' long-standing expressed need for short breaks and the limited utilisation of short breaks (Allen et al., 2020; Lamura et al., 2006; Moholt et al., 2021; Phillipson et al., 2013; Phillipson & Jones, 2011; van Exel et al., 2008), and poor satisfaction with the break experience and the outcomes realised (Brodaty et al., 2005; Leocadie et al., 2018; Neville et al., 2015; O'connell et al., 2012; Robinson et al., 2012). In Wales, carers who participated in the 2022 State of Caring survey reported their greatest need was more support to enable them to look after their health and well-being (Carers Wales, 2022). However, 42% of carers reported that they had not had a break in the last 12 months. Of those, 10% said they had tried to take a break but had not been able to, and 26% hadn't tried to take a break because they felt it was too difficult. This disparity highlights fundamental knowledge gaps in understanding what is important to carers to improve the access to, experience of, and outcomes supported through short breaks (Kelly & McSweeney, 2009; Lole et al., 2023; Rochira, 2018; van Exel et al., 2006).

Existing studies have yielded some insight into this conundrum by highlighting the complexity of barriers and enablers to the use and acceptance of short break services (Carer Respite Alliance, 2021). Research has identified information, behavioural, attitudinal, and systemic factors which differentially interact to influence short break access, satisfaction with short break experience, and short break outcomes (Brandão et al., 2016; Gottlieb & Johnson, 2000; Leocadie et al., 2018; Neville et al., 2015; O'connell et al., 2012; Phillipson et al., 2013, 2014). This body of work demonstrates the complexity in tailoring the many aspects of short break provision to reflect the unique nature of caregiving relationships and to support personal well-being outcomes. Collectively, this research has foregrounded prevalent issues in short breaks provision pertaining to inflexible and limited availability and accessibility of short break options, even in emergency situations (Carer Respite Alliance, 2021; O'Shea et al., 2017; Pierse et al., 2020; Shanley, 2006; Wakefield, 2020), and a fragmented and uncoordinated care system to navigate in order to access a break (Bieber et al., 2019; Giebel, Verbeek,

et al., 2021; Jansen et al., 2009; O'Shea, Timmons, O'Shea, & Irving, 2019; Vullings et al., 2020). It has underscored the lack of choice of short break options to meet the diversity of needs, interests, and preferences of carers and people with dementia at different stages of the disease to support their well-being (Harkin et al., 2020; Moholt et al., 2021; National Assembly for Wales, 2019; Rochira, 2018; Shared Care Scotland, 2012). There are concerns around poor communication, lack of awareness and access to accurate and timely information about short break options, and eligibility for different support options (Leocadie et al., 2018; MacLeod et al., 2017; Robinson et al., 2012), including the strength of direction from practitioners who can be anxious about raising expectations (Hanson et al., 2008; Seddon & Robinson, 2015). The lack of resources, both fiscal and human, has been voiced by care professionals and carers (Jansen et al., 2009; Laird et al., 2017; O'Shea, Timmons, O'Shea, & Irving, 2019), as thwarting the overall quality of care provided for the person with dementia, and this perspective, experienced or perceived, impacts on the willingness of carers to engage with certain short break models, notably residential care (Phillipson & Jones, 2011; Tang et al., 2011). In Wales, Carers Wales reported worrying trends around carers' reluctance to use short break services with 70% choosing not to re-access residential care, 42% choosing not to re-access sitting services, and 30% choosing not to re-access day care services (Carers Wales, 2022).

To support the efficacy of short breaks, fundamental change is needed. For short breaks to support the preferences, needs, and outcomes that matter most (i.e., a meaningful short break) to carers and people with dementia, there is a need to reconsider what a short break can mean and use that knowledge to underpin how short breaks needs and outcomes are identified, and supported (O' Shea et al., 2020; Rochira, 2018; Seddon, Miller, et al., 2021; Silverman, 2018). What constitutes a meaningful short break for carers and how to embed this understanding in short breaks provision is an area of rapidly evolving knowledge and work. In recent years, work by Seddon and colleagues shaped a future research agenda (Seddon, Miller, et al., 2021; Seddon & Prendergast, 2019). The research set out in Seddon, Miller, and colleagues' (2021) agenda intends to ensure carers rights under current UK legislation are effectively translated into practice in respect to their short break needs and the attainment of well-being outcomes. Their research agenda was informed by a scoping review of the national and international published literature which mapped the evidence base relevant to short breaks for carers for older people, including those living with dementia (Seddon & Prendergast, 2019). Several evidence gaps were identified including understanding how carer short breaks needs, preferences and desired outcomes change over time. For example, this could relate to changes in the optimal break length and/or type to realise positive health outcomes, changes in preferred settings and activities, and changes in needs for breaks taken together and taken apart (Seddon, Miller, et al.,

2021). This area of knowledge can be considered within a broader research priority within family caregiving intervention research, notably, the need to develop a conceptual framework or typology of the caregiving career to guide new interventions and promote understanding of the interventions that best support carers over time (Harvath et al., 2020). Such a comprehensive framework should reflect developmental stages, the dynamic and interdependent nature of the caregiving relationships, and the complexities at various timeframes along the career. Seddon and Prendergast's (2019) scoping review highlighted three broad priority areas of inquiry for future research-practice development, these included:

1. Understanding what matters: identifying and evidencing short break needs and intended outcomes.
2. Capturing what matters: outcomes from short breaks.
3. Commissioning, delivering, and scaling up short breaks provision to reflect what matters to carers.

These lines of inquiry were used to guide the research objectives for this thesis, discussed below.

1.8 Rationale for the study

This study has been designed to elicit an enriched understanding of meaningful short breaks provision for spousal carers who support their partner living with dementia (65 years or older). The evidence discussed thus far has shown that dementia caregiving is a dynamic and complex process, marked by acute and gradual changes to everyday life that can strain and strengthen caregiving relationships.

The rationale for this research is founded upon existing literature which demonstrates poor satisfaction with short breaks and the modest and inconsistent outcomes supported. Informed by work by Seddon and colleagues, significant knowledge gaps are apparent in the understanding of 'what matters' in short break provision and ensuring that understanding is embedded into the planning, commissioning, and delivery for short breaks (Seddon, Andrews, et al., 2021; Seddon, Miller, et al., 2021; Seddon & Prendergast, 2019). Knowledge gaps limit the successful realisation of UK and international policy intention for carers and those they support to access meaningful short breaks (International Alliance of Carer Organizations, 2021; Welsh Government, 2021f). Understanding the changing nature of carer short break needs over the caregiving career is essential if we are to effectively guide the work of practitioners engaged in assessment and support planning and the work of commissioners in utilising available resources to realise the preventative purpose for short breaks. This thesis seeks to develop a more sophisticated understanding of 'what matters' in the context of

short breaks for spousal carers for people living with dementia by addressing the following research aim and objectives:

1.8.1   Study aim and objectives

The **aim** of this research is to provide evidence that enhances the development, commissioning, and delivery of meaningful short breaks provision for spousal carers for persons living with dementia (aged 65 years and over).

There are four **objectives** addressed:

1. To understand 'what matters' in short break provision. This includes:

   - The hallmarks of impactful provision that support the realisation of carer generated outcomes (Cook & Miller, 2012), including health, well-being and sense of resilience, a life of their own, and a positive relationship with the person with dementia.

2. To identify ways to effectively develop, commission, and scale up short breaks that reflect 'what matters'. This objective includes developing insight into:

   - The challenges (barriers) and opportunities (facilitators) to take forward new policy ambition for meaningful short break provision.
   - Future sustainability and local capacity issues and how these might be addressed against a backdrop of rising short break demand and declining public budgets.
   - The emerging landscape of new providers and models that may offer greater flexibility and choice.

3. To explore the short break needs and preferences of spousal carers for people with dementia using short breaks, specifically:

   - How short break needs and preferences are evidenced in assessments following the implementation of the Social Services and Well-being Act (2014) and the degree to which these needs were met.
   - How carer short break needs, preferences, and desired outcomes evolve over time in response to the progression of dementia.

4. To develop policy and practice recommendations to support the delivery of improvements against Welsh Government national priorities for carers and those they support, specifically, a life alongside caring.

The new knowledge generated through this research has the potential to guide policy and practice development to contribute to improved well-being for carers and people with dementia as well as

ensuing benefits for sustainable, more inclusive, and healthy societies. While spousal carers supporting people with dementia is the demographic of interest, is it anticipated findings from this research will have transferability to other caregiving demographics. Although this research is situated in the Welsh policy context, given the international policy and practice interest in delivering short breaks that help carers realise the outcomes meaningful to them, findings and recommendations have international resonance.

The methods used to address the research aim are underpinned by a constructivist methodology, concerned with exploring the realities constructed and defined by individuals. The experiences, perspectives, and knowledge of professionals and carers for people with dementia were explored. Adopting an inductive approach to knowledge generation, qualitative data collection methods were employed to generate depth of knowledge, elicit contextual understanding, and allow for flexibility in how the researcher and participants co-constructed meaning. Following a generative process, the analytical techniques helped synthesise, interpret, and incorporate new meaning to supplement and augment understanding. Stakeholder involvement is a key determinant of policy impact and critical to the development and conduct of social care research. It was imperative therefore to undertake this research in collaboration with a Project Advisory Group; the first action and priority for this research was to convene a Project Advisory Group. The National Standards for Public Involvement in research (National Institute for Health and Care Research, 2019) were used to guide engagement with the Project Advisory Group and these standards are described in the methodological chapter (Chapter Three).

1.9   Thesis structure

Chapter one. In this introductory chapter, the research evidence backdrop to the study has been presented. The economic and societal challenges that dementia presents to health and social care systems worldwide is set to increase with global population ageing. The long-term support carers provide enable people with dementia to remain living at home. Recognition of the importance of carers to the sustainability of community care has elevated interest in and understanding of their needs to support their caring role and to live a life alongside caring. Short breaks are the main resource to support this need. However, as a broad category of support, short break services remain underused and poorly regarded. The literature delineated in this chapter demonstrates the need for new knowledge to generate an enriched understanding of meaningful short break provision and to use this understanding to guide policy and practice development.

Chapter two. In chapter two, an overview of the evolution of seminal UK and Welsh Government policy and strategy is presented to locate the current policy landscape in which short breaks are planned, commissioned, and delivered. It outlines the current policy impetus to promote carer well-being throughout the caregiving career through the provision of meaningful short breaks.

Chapter three. In this chapter the philosophical underpinnings for the study are discussed and the methodological approach presented. The ontological and epistemological assumptions are discussed to affirm the philosophical stance for this research. Aligned with a constructivist philosophy, justification is provided for adopting an explanatory and interpretive methodology.

Chapter four. Reflecting the complex and inter-sectoral nature of short breaks provision, chapter four explores the factors influencing local and regional decision-making around short break provision. It presents a descriptive model of the short break landscape from the perspective of social care professionals. The model depicts the multilevel contexts, processes, and contingencies involved in shaping short breaks provision across north Wales. Using this model, key challenges and opportunities associated with the planning, commissioning, and delivery of short breaks are described and contextualised.

Chapter five. This chapter constructs an experiential narrative of the caregiving career from the perspective of spousal carers. This narrative is used as a scaffold to explore how spousal carers' break needs evolve and provide insight into their experience of accessing breaks, including the provision of information, advice, and assistance, and the availability and choice of break options as their needs and circumstances change.

Chapter six. This chapter reports on the process and outcomes of a knowledge exchange event. Underscored by a collaborative and constructivist approach to knowledge mobilisation, the event aimed to share, integrate, and synthesis knowledge to generate understanding. Consensus was reached on the features that contribute towards meaningful short break provision. This process helped inform thinking around recommendations for social care policy and practice development to support the equitable access to short breaks throughout the caregiving career.

Chapter seven. Chapter seven presents preliminary work in the development of a new conceptual framework of short breaks across the dementia caregiving career based on identified career stages as experienced by carers. This work is an original response to the Welsh Government's national drive to

plan and implement support for carers and people with dementia along a pathway, in which support for carers must be offered throughout their career and must be stage appropriate (Improvement Cymru, 2021). Informed by a scoping review of the published literature, this chapter summaries career stages in eleven models of dementia caregiving to explore how short break needs are likely to progress and the short breaks most appropriate to stage. This work spotlights that a typical career involves transitions between several short breaks, and the fluxes in priorities for short breaks between the carer's need to rest and rejuvenate and sustain important relationships, both with the person with dementia and wider family and friends.

Chapter eight. This is the discussion and conclusion chapter which considers how the research presented in this thesis supplements current knowledge and contributes new evidence to the understanding of short breaks provision. Policy and practice implications are identified which reflect upon how short breaks are conceptualised, how short breaks are discussed and negotiated as part of the assessment process, and the inherent tensions at the heart of the health and social system that compromise the ability for short breaks to evolve throughout the caregiving career. Areas for future research are identified. Limitations of the methodological approach are acknowledged as well as how the researcher engaged with and benefited from the contribution of the Project Advisory Group.

1.10 Conclusion

To summarise, this thesis addressing four research objectives, seeks to augment understanding of meaningful short break provision for spousal carers for persons living with dementia. In this introductory chapter, the intent was to lay out the knowledge landscape. Attention was brought to the complex nature of dementia caregiving and the uncertain context this creates whereby spousal carers navigate change, challenge, and growth, on a personal, relational, and practical level. For carers to sustain their caring role, should they wish to, their well-being must be supported through the ability to take regular breaks from their caregiving responsibilities, that are responsive to their needs and circumstances. Reported difficulties in accessing short breaks and the dissatisfaction with short break choice and experiences has propelled the case for fundamental change in how short break are conceptualised and supported. To support positive caregiving relationships, the clear and pressing need to rethink how short breaks can contribute towards the outcomes that matter most has been underscored. The study's rationale, its aim and objectives have been presented. The next chapter reflects on the evolution of formative UK and Welsh Government policy and strategy that have informed the priority for improved access to meaningful short breaks for carers.

Chapter Two: The policy context

2.1   Introduction

The provision of care by unpaid carers constitutes an intrinsic and essential component of global health and social care systems. This reliance on informal care is substantiated by findings from the 2018 Ageing Report, which underscores the financial repercussions associated with transitioning from informal to formal care by the year 2070 for European Union (EU) members states. According to the report, such a shift would necessitate an average 130% increase in the share of Gross Domestic Product (GDP) allocated to health and social care across the EU (Directorate-General for Economic and Financial Affairs, 2018).

Within EU member states, the ethical and economic imperative to support carers has culminated in the implementation of comprehensive and cohesive support measures, emphasising parity of esteem with those in need of care. The European Care Strategy, published by the European Commission in 2022, outlines a comprehensive agenda aimed at improving conditions for both professional paid carers and unpaid family carers, as well as those in need of care (European Commission, 2022). This strategy envisions a framework for care provision in an aging Europe with escalating demand for care and support services, offering guidance on reform directions to address shared challenges related to affordability, availability, quality, and the caregiving workforce. A fundamental tenet of the Commission's proposal for affordable, high-quality care and support is the establishment, by all member states, of clear procedures to identify unpaid carers and support them in their caregiving roles. This involves enhancing access to training, counselling, short breaks, and providing psychological and financial support.

In developing countries such as India, Malaysia, and Brazil, family members are expected to assume the primary caregiving role for older adults, and there is some progress toward recognising the support needs of carers (Canônico, 2020; Jawahir, 2021). The ageing populations and declining fertility rates in Malaysia and Brazil have compelled their respective governments to acknowledge, in principle, the policy imperative of establishing foundations for a robust care economy and infrastructure that effectively benefits and supports unpaid carers in their roles.

Supporting carer well-being has been an explicit policy focus of consecutive UK governments for over three decades (e.g., The Carers (Recognition & Services) Act 1995; Department of Health, 1999).

However, the recognition of carers' legal right to support and an independent assessment of needs has not all always been equal to people they support. Direct support for carers has grown from humble and modest origins (Britton & Zimmermann, 2022). Many of the principles that govern support for carers such as personalisation, flexibility, choice, are not new concepts in policy discourse but over the last decade how these principles can be better embedded into short break provision has garnered increased attention (Anderson et al., 2015; Carers UK, 2019b; Downes, 2013; Rose et al., 2015; Seddon, Andrews, et al., 2021).

In Wales, the provision for short breaks is interwoven with the rights and broader policy support directives for carers (Welsh Government, 2015b). This chapter provides a narrative overview of the evolution of key Welsh Government policy and strategy concerning carer well-being and social care support. While there are many similarities in the strategic direction of the different UK countries' social care policy, this study was conducted in Wales, therefore attention is given to Welsh Government legalisation that governs the direction of support for carers and people with dementia. An evolution of seminal Welsh Government policy and strategy for carers is presented in Figure 2.1.

Figure 2.1: **A timeline of seminal Welsh Government policy and strategy for unpaid carers 1995 – 2022**

The Carers (Recognition & Services) Act 1995: Introduced the right for carers providing *regular* and *substantial* amounts of care to request (at the same time the person for whom they cared for was being assessed for community care services) an assessment of their ability to care.

Caring for Carers: a national strategy 1999: Offered a policy package founded on improved information, support and care for carers.

The Carers and Disabled Children Act 2000: Established carer's right to request an assessment of their needs, independent of the person they care for. Local authorities were given new powers to provide direct services to carers that helped them to care.

Carers Strategy and Implementation Plan Wales, 2000: Provided local authorities with significant new monies to support the health and well-being of carers and increase support and service provision across five priority areas.

The Carers (Equal Opportunities) Act 2004: Placed a duty on local authorities to inform carers of their legal right to an assessment of support and to consider carers' wishes in relation to education, employment, and leisure.

The Carers Strategies (Wales) Measure 2010: Placed a duty on the NHS and local authorities in Wales to work collaboratively to prepare and implement a joint information and consultation strategy for carers.

Social Services and Well-being (Wales) Act 2014: Provides the legal framework for improving the well-being of people who need care and support and carers who need support. Granted carers unequivocal and equal rights and responsibilities as the person they care for.

The Well-being of Future Generations (Wales) Act 2015: Required public bodies in Wales to think about the long-term impact of their decisions, to work better with people and communities to improve the social, economic, environmental, and cultural well-being of Wales.

Dementia Action Plan for Wales 2018 – 2022: Outlines the Welsh Government actions to improve diagnosis, care and support for people affected by dementia.

A Healthier Wales 2018: Sets out a long-term vision of a whole system approach to health and social care that provides seamless services tailored to individual needs.

Strategy for Unpaid Carers 2021: Introduced four national priorities that renew Welsh Government commitment to improving the recognition of and support for unpaid carers in Wales

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2.2 Evolution of rights and support for carers

The Carers (Recognition & Services) Act 1995 (Department of Health, 1995) was the first piece of legislation to pay due recognition to the caring role and grant carers modest rights to support them to care. Local authorities had a duty to consider the impact of the caring role when deciding on the eligibility of community care services for the person with care and support needs. Carers had to be providing, or intending to provide, a substantial amount of care on a regular basis to be eligible for an assessment of support needs. Importantly, the carer's right to an assessment of their support needs was available on request *only* when and *if* a local authority was carrying out an assessment of the person for whom they cared. What constituted regular and substantial care was at the discretion of local authorities; eligibility criteria were therefore susceptible to considerable variation and inconsistencies within and across local authorities (Seddon & Robinson, 2015). Local authorities were under no statutory duty to provide direct services to support carers' needs, rather the support carers received was of indirect consequence of the type and level of care provided for the person for whom they cared. Despite these caveats, exploration of the 'caring system' was advocated to inform understanding of the caring relationship, circumstances, and context (e.g., cultural, religious). While this knowledge did not translate into planning a tailored package of support for carers, it helped identify informal 'networks of support' (i.e., support via family or friends) and where statutory services may 'fit'. While the Carers Act (1995) lacked sufficient detail on the type of support and outcomes that mattered to carers, it succeeded in giving carers a legal status and set the political tone and direction for good practice to evolve.

In the years following The Carers (Recognition & Services) Act 1995, came a succession of carer strategies (e.g., Caring for Carers: A National Strategy, 1999; Carers' Strategy and Implementation Plan for Wales, 2000). To instil pride in caregiving, there needed to be a change in the way society perceived and understood the role and impact of caregiving. These strategies aimed to place new emphasis and greater value on the vital work of carers through offering a more comprehensive package of support, broadly encompassing better sources of information about the help and services available to carers, support with caregiving responsibilities, and greater recognition of carers as individuals with a right to have their own health and well-being needs met.

Caring for Carers: A National Strategy (Department of Health, 1999) was the first cross Government strategy for carers in Britain. It identified approaches to supporting sustainable caring relationships with a priority focus on short breaks to maintain carer independence and allow them to enjoy a good quality of life alongside their caring role. To achieve this, the Government introduced new grants to

local authorities to review their current break provision and, together with voluntary and health services, enhance options that enable carers to take a break, with improved choices.

Against the backdrop of the national strategy, the Welsh Assembly Government launched its first Carers' Strategy and Implementation Plan for Wales in 2000 (The Welsh Assembly Government, 2000). Like the national strategy, the Welsh Strategy introduced Special Carers Grants to be used in targeted ways by the 22 local authorities in Wales to increase support and services for carers, based on local needs, including short break provision. The 2000 strategy was refreshed in 2007 and again in 2013. These updates honed focus and realigned priorities to further progress and deliver better and measurable improvements for carers.

In 2000, the Carers and Disabled Children Act (HM Government, 2000) enshrined in law some of the good practice highlighted in the National Carers Strategy, Caring for Carers (Department of Health, 1999). Four prominent changes were brought forward in the 2000 Act. Notably, carers' right to request an assessment of their needs and ability to care was no longer dependent on the person for whom they cared being assessed for community care services. Local authorities were therefore afforded the opportunity to provide services to support carers' assessed needs, within the context of helping them to continue to care. However, the extant nature of service provisions for carers were not exemplified, meaning that local authorities provided what they deemed appropriate and proportionate and which, in their judgment, best supported carers to care. Secondly, the 2000 Act empowered local authorities to make direct payments to carers to enable them to obtain the services they felt would best support them in their caring role; for the first time, the principle of self-directed support was introduced into the ethos of service provision. Thirdly, short breaks from caring were endorsed through the introduction of the short break voucher scheme. Voucher schemes were designed to offer some level of choice in the type and flexibility of community care services for the person with care needs, that then allowed the carer to take a short break. Lastly, the 2000 Act also introduced a new power for local authorities to charge carers for the services they receive.

Under the Carers (Equal Opportunities) Act 2004 (HM Government, 2004) supporting carers became more than a mechanism to sustain the act of caregiving but embodied a moral endeavour to ensure that carers were not placed at a disadvantage because of the care they provided. This meant taking account of carers' lives and wishes outside of their caring role. The 2004 Act, which applied to England and Wales only, championed three main changes to the law. Firstly, local authorities had a duty to proactively inform carers of their entitlement to request an assessment of their needs. In consideration

of how to meet this duty, the development of an information strategy was advised to inform carers of their rights to an assessment so appropriate support could be planned and delivered in a timely manner. A good strategy would be clear about what an assessment may involve and its purpose in identifying the help and support that could improve carer's quality of life, rather than a test of the carer's ability to care. The strategy should target in particular 'hidden carers', a term used to describe carers who do not self-identify as such but provide care out of loyalty or duty as a partner, parent, or child. It further extended to those subsets of 'hard to reach' carers, including black and minority ethnic groups, young and older carers (65 years and over), and rural, isolated carers.

Secondly, during an assessment of carers' needs, local authorities had to consider how service provision (or lack thereof) may impact on the carer's life in relation to opportunities to employment, and desire to partake in education or in training or leisure activities. Consideration should be given to carer's *willingness* and *ability* to care, and a distinction should be made between these. A carer-centred approach should underpin the assessment process. This required 'listening to carers and looking to achieve outcomes which, while helping the carer to care, take account of the carer's life beyond their caring' (Department of Health, 2005, p. 20). Direct payments were leveraged as a valuable tool to offer carers greater independence, choice, and flexibility in how they supported themselves to care than may be achieved through direct local authority provision of community care services.

To support the coherent and coordinated delivery of services for carers and those they care for, the third change to the law paved the way for a formal basis of cooperation between public authorities. The social service departments of local authorities could request public health bodies and other local authority directorates (i.e., education, housing) to help in planning and in the provision of carer services. It was theorised that greater cooperation between public bodies would foster a culture in which responsibility for the well-being of carers was shared by all organisations who could contribute. However, although local authorities were given the perception of having greater leverage to influence the priorities of other authorities, the 2004 Act did not obligate public authorities to meet or even comply with a request; requests, at minimum, were to be given due consideration. Whether a request went beyond the authority's powers remained a matter of local judgment. Therefore, joint working to support seamless service provision for carers remained firmly in the territory of 'good practice' (Wanless et al., 2006).

The Carers Strategy (Wales) Measure 2010 (The Carers Strategy (Wales) Measure 2010, 2010) placed the local health boards in Wales as the lead agency responsible for developing and implementing

strategies for the provision of information to, and consultation of, carers. For the first time, this measure placed a legislative duty on the NHS in relation to services for carers in Wales, reflecting the fact that the first point of contact for carers is often primary health care professionals. The measure needed to demonstrate how three core objectives were to be delivered and monitored: the systematic identification of carers by all NHS staff and throughout all levels of the NHS; carers informed of their legal right to an independent assessment of their support needs; and the continuous and seamless provision of relevant information at key stages of caregiving, including the availability and entitlement to short breaks. The information and consultation strategies were developed and functioned in close partnership with local authorities. The Carers Strategy was operationalised through pre-existing partnerships and working practices, and its success contingent on the proficiency and quality of these partnerships.

2.3 The Social Services and Well-being (Wales) Act 2014

The Social Services and Well-being (Wales) Act 2014, here on in referred to as the 2014 Act, is the current legislation that underpins the provision of care and support for carers in Wales. The 2014 Act came into force in April 2016 and repealed all existing community care legislation with the aim to simplify and consolidate the law and provide greater consistency to people who engage with social services and all persons exercising functions under the 2014 Act (Verity et al., 2019).

There are several prominent changes to legalisation that grants carers unequivocal and equal rights to the person they care for. The Act revised the definition of a carer, amending the requirement that a carer must be providing a 'substantial amount of care on a regular basis', to 'a person who provides or intends to provide care for an adult or disabled child'. Duties enshrined in the 2014 Act entitle carers to an assessment of support, regardless of the perceived level of support the carer may need or their financial wealth, and for eligible support needs to be met through the provision of a support plan where progression towards personal well-being outcomes are regularly monitored and reviewed. Carers should be at the centre of decisions about how they are supported. The Act also gives carers the absolute right to choose whether, and to what extent, they are, or remain carers, and to be supported in their decisions.

The Act introduced new powers, processes, principles, and duties that aim to transform the way care and support is provided. The Act's vision for transformational change is driven by five interrelated principles: well-being, voice and control, prevention and early intervention, co-production, and co-operation and partnership (Welsh Government, 2015e). These principles infuse the Act and are

intended to propel change in the attainment of, and responsibility for, the working towards and maintenance of well-being (Figure 2.2).

Figure 2.2: *Interrelated principles that underpin the Social Services and Well-being (Wales) Act 2014*

Voice and control

Well-being

Principles that underpin the 2014 Act

Co-production

Prevention and early intervention

Co-operation and partnership
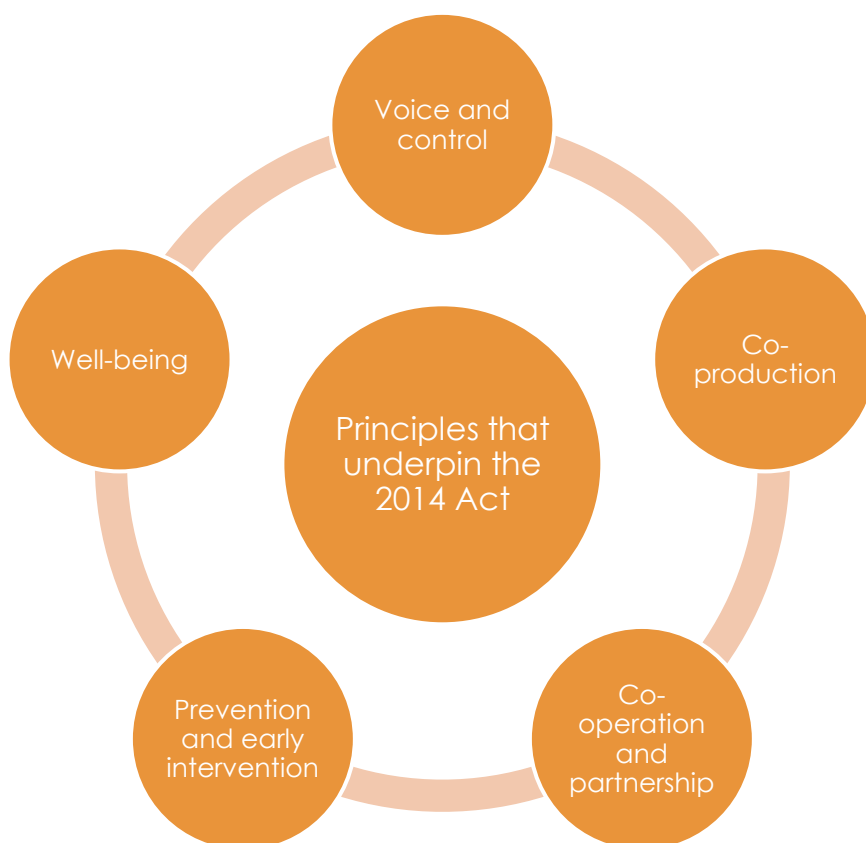
2.3.1   The strategic and operational duty to promote equity of access to high-quality short breaks across Wales

There are several duties embedded in the 2014 Act which exert influence on how short breaks are commissioned and delivered. To inform the strategic planning for care and support services and partnership working, there is a duty on local authorities and their local health board to conduct a Population Needs Assessment, to assess their population's care and support needs, including the support needs of carers, and identify the range and level of services required to meet and prevent needs from escalating (Welsh Government, 2015b). This should inform the sustainable social care commissioning process for short breaks undertaken by local authorities. At an operational level, local authorities are also under the duty to secure an information, advice, and assistance service (i.e., IAA service) (Welsh Government, 2015b). This service should mean that every carer has an accessible point

of contact to obtain up-to-date information and advice about their short break options, and assistance, where necessary, to access short breaks.

One of the boldest provisions of the 2014 Act is the duty on local authorities to take a proactive approach to the development, in their area, of the third sector (also referred to as the social value sector or not-for-profit sector) to provide support for carers, including community based short breaks (Welsh Government, 2015b). A diverse range of organisations make up the fabric of the third sector which can range in size and scale from small local groups to large multinational charities and may include community support groups, voluntary organisations, registered charities, faith-based organisations, social enterprises, co-operatives, and community interest companies. These organisations are considered to play a crucial role in organically developing solutions to meet local short break needs through recognised networks and connections within communities. As democratically led organisations, their ways of working align with the principles and practices of co-production in terms of involving people and communities in the design and delivery of support and building upon local strengths and opportunities.

2.3.2   Supporting well-being through an outcome approach

Well-being is a multidimensional concept and will mean different things depending on a person's circumstances, values, and priorities. Well-being is not a static dimension of a life, in which there is a definite end point or linear route upon which it can be achieved. Thus, realising well-being is best conceptualised as realising an aspect of a dimension of well-being or supporting or improving well-being (Barrie & Miller, 2015). The 2014 Acts' outcomes approach centres on maximising well-being by working collaboratively with people to identify 'what matters' to them and using that understanding to identify and define personal well-being outcomes (Social Care Wales, 2019a, 2022b). Thus, personal outcomes are fundamentally understood as 'what matters' to the person.

Personal well-being outcomes describe what a person wants to achieve. Personal well-being outcomes and personal outcomes are used synonymously (Welsh Government, 2015c). They are the impact, or result, of support, services, or an intervention on a person's life and can be used to both determine and evaluate activity (Cook & Miller, 2012; Social Care Wales, 2022a). Under the 2014 Act, supporting well-being outcomes should involve 'building on people's resources, including people's strengths, abilities, families, and communities' (Welsh Government, 2015a, p. 13). This does not mean ignoring obstacles, risks, or vulnerabilities but maximising strengths as one way to overcome them. Personal well-being outcomes must be set against realistic and observable milestones and both the

practitioner, and the person who needs care and support or carers who need support, understand their responsibilities to achieve these outcomes. Correspondingly, in accordance with the 2014 Act, the provision of care and support is based on and proportionate to the personal well-being outcomes that people want to achieve and, on the rights, and personal responsibility in supporting well-being.

Personal well-being outcomes are identified and discussed through meaningful and purposeful conversation; the setting for this conversation is normally the needs assessment process (Social Care Wales, 2022b). Conversations, and engagement about outcomes, are the vital first step in building relationships between practitioners, people with care and support needs, their carers, and families (Cook & Miller, 2012). The practitioner's role in enabling potential and supporting increased independence is important to a personal outcomes approach. During conversation, while it is acknowledged that people are best placed to explain what is important to them, they may need help and guidance to do this, especially as they may not be aware of the types of services and support available which can contribute towards supporting their outcomes. In the UK, short breaks are one type of support that can be accessed through the process of a Carer's Assessment. It is during the Carer's Assessment that short break needs, preferences, and desired outcomes, should be explored, and mutually understood, and this conversation should be guided by a What Matters approach. A conversation about 'What Matters' is a skilled way of engaging in conversation that reflects on the carer's lived experience and harnesses the expertise of practitioners to explore carer's desired outcomes and any support required to achieve these (Social Care Wales, 2019a, 2019b). It is a co-production exercise, the outcome of which should be the mutual understanding of the steps or actions that both the carer and the practitioner, or other professionals, have agreed to take to support the realisation of outcomes that reflects what matters to the carer (Welsh Government, 2015c).

2.3.3   Preventative approaches to well-being

Catalysed by acute financial pressures, the long-term sustainability of the health and social care system depends on balancing the meeting of immediate needs with shifting investment toward prevention (HM Government, 2021; Welsh Government, 2021a). The prevention approach is inextricably linked to the fundamental principle of promoting well-being and is central to future reform of sustainable health and social care (Department of Health and Social Care, 2018; Watt & Roberts, 2016). The logical corollary of timely and proactive preventative support for carers is that it can increase carer well-being, independence, and resilience, and reduce, or delay, the need for care and support services, for them and the person they support (Social Care Institute for Excellence, 2021a; Social Care Wales, 2018).

In Wales, the 2014 Act acknowledges preventative support can take many forms, for example, receiving the right information, advice, and assistance on short break options, at the right time, can enable people to make informed choices about the breaks best suited for them. The 2014 Act instructs local authorities to work collaboratively with health and the third sector to promote resourceful solutions to prevent, and proactively meet, local needs for care and support (Welsh Government, 2015b). Local authorities have a duty to provide a range of preventative services for carers and promote third sector organisations in the development of community-centred models of preventative support (Welsh Government, 2015a).

The Well-being of Future Generations (Wales) Act 2015 places further duties on local authorities and health boards to embed a preventative approach by considering the long-term impact of their actions (Welsh Government, 2015f). Whereas well-being in the 2014 Act is defined in relation to a person, well-being in the Future Generations (Wales) Act is in relation to the economy, society, environment, and culture across Wales. There are seven integrated well-being goals that promote collective accountability for the health and prosperity of Wales (Figure 2.3). Public bodies listed in the Future Generations (Wales) Act must maximise their contribution towards these goals through sustainable development, a process that recognises the interdependence between the health of the economy, society, environment, and culture to individual well-being and quality of life.

Figure 2.3: *The seven integrated well-being goals of the Well-being of Future Generations (Wales) Act 2015*
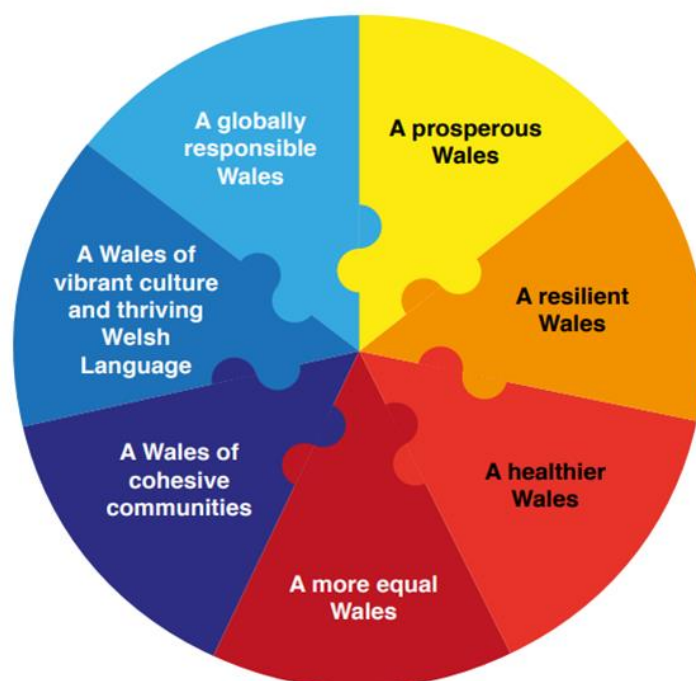
Under the sustainable development principle, when making decisions around the sustainable commissioning and delivery of short break models, local authorities must ensure they have a comprehensive understanding of their local communities' short breaks needs and desired outcomes, consider the long-term impact of how these needs and outcomes can be supported, and take an integrated and collaborative approach to support the resourceful provision of short breaks.

2.3.4 An integrated approach to improve well-being through the provision of preventative support

Following the implementation of the 2014 Act, The Carers Strategies (Wales) Measure (2010) was repealed, and consequently local health boards no longer hold the lead role in the identification and provision of information to carers. Instead, the 2014 Act provided for local authorities and local health boards to establish Regional Partnership Boards (RPBs) which bring together public bodies, third, and sector organisations to progress the delivery of integrated services across Wales (Welsh Government, 2015b). The aim of the RPBs is to enhance local authorities' resilience in terms of resources and ensure that an appropriate and consistent range of services are in place to meet the needs of their respective populations. RPBs have responsibility to manage and develop an integrated approach to the development of early intervention and preventative services that meet the care and support needs of their respective populations.

During the time span that this research was conducted, the primary funding mechanisms to deliver the requirements of the RPBs and support the delivery of various requirements of the 2014 Act changed. The Integrated Care Fund (ICF), delivered from 2014 to March 2022, was to be used by RPBs to drive forward the integration and collaborative working between social services, health, housing, and the third and independent sector. The ICF was intended as a key lever to assist RPBs to develop, pilot, and deliver new 'innovative' models and preventative approaches to health and social care. There were five priority population groups identified for increased service integration, of which carers and people with complex care needs, including dementia, were two. RPBs were to utilise the Integrated Care Fund in proportion to these priority groups, and guided by their regional Population Assessments, consider how collaborative and integrated approaches could support the specific needs of these groups. For carers, the ICF was to be used to support the strategic priorities for carers, as set out in the Welsh Government Strategy for Unpaid Carers (Welsh Government, 2021e). One of these four national priorities is to support life alongside caring: **all unpaid carers must have the opportunity to take**

breaks from their caring role to enable them to maintain their own health and well-being and have a life alongside caring.

In April 2022 the ICF was replaced by the Health and Social Care Regional Integration Fund which will run until March 2027 (Welsh Government, 2022a). Taking forward the learning and progress of the ICF, the focus of this new fund moves towards developing and embedding six national models of integrated care. Through amalgamating several short-term funding streams, the fund has streamlined resources, reduced duplication, and targeted investment to deliver long-term sustainable system change. All RPBs must use the Health and Social Care Regional Integration Fund to invest in the development and embedding of the six priority models of care, these being:

- Community based care – prevention and community coordination
- Community based care – complex care closer to home
- Promoting good emotional health and well-being
- Supporting families to stay together safely, and therapeutic support for care experienced children
- Home from hospital services
- Accommodation based solutions

The most successful regional models will be adopted at a national level, so all citizens in Wales can expect to receive the same seamless delivery of care and support. The delivery of these national models must be driven by the core principles of the 2014 Act (Figure 2). The five priority population groups for integrated support are maintained, with the addition of people with emotional and mental health well-being needs. Therefore, in addition to any indirect services because of care provided by carers for those they support, the fund must be invested to ensure carers receive direct support to enable them to realise their personal well-being outcomes.

2.4 Promoting carer well-being throughout the caregiving career through the provision of meaningful short breaks

International policy (e.g., Integrated Carer Support Service in Australia, Lifespan Respite Care Reauthorisation Act of 2020 in America, National Carers Strategy 2022 in Sweden, Carers' Strategy Action Plan 2019–2023, New Zealand), and UK policy (e.g., Care Act (England) 2014 in England, Social Services and Well-being (Wales) Act 2014 in Wales; Carers and Direct Payments (Northern Ireland) Act 2002 in Northern Ireland, Carers (Scotland) Act 2016 in Scotland) recognises the imperative of short breaks to enable carers to balance their caring responsibilities and manage their your own well-being,

to achieve a life alongside caring. In Australia, the Integrated Carer Support Service model is premised on the principle that the best way to support carers is to help them early in their caring role, including through tailored planned short break packages, reflective of needs and circumstances, throughout their career. The Lifespan Respite Care Reauthorisation Act provides $10 million annually to 2024, to support a programme of community-based short breaks services across America. The law approves competitive grants in collaboration with a public or private non-profit state organization to identify, coordinate, and expand upon quality short break services, accessible to all family carers. A central purpose for the fund is to support 'coordinated systems' of services, and eliminate the bureaucratic maze of funding, so carers can more easily access breaks. Likewise, the need to streamline access to breaks through single points of access and funding streams is a priority focus in Wales (National Assembly for Wales, 2019; Rochira, 2018). Echoing the focus of UK strategy for carers, in New Zealand, a key objective is to improve the quality, accessibility, and equity of short breaks services across New Zealand, of which carers for people with dementia are a priority population group. Collectively, these policy aspirations reflect the transition of many economically developed nations towards personalised care and support that promotes independence and well-being. Thus, there should be an inherent element of personalisation in the provision of short breaks to support the preferences, needs, and desired outcomes of carers (i.e., a meaningful short break). Flexibility and choice of short break options are critical to accommodate the evolving needs and circumstances of carers and those they support (Newbronner et al., 2013; Rochira, 2018).

The Welsh Government has reinstated its effort to work collaboratively across sectors to ensure short break options are recognised and embedded as a preventative resource, not just something offered at a point of crisis (Welsh Government, 2021f). The 2014 Act states that 'a local authority should always look to provide preventative services to individuals at every stage of that person's pathway' (Welsh Government, 2015b, p. 40), emphasising the need for short breaks that extend across the caregiving career; in dementia caregiving relationships the likelihood of a career spanning more than five years is high (Alzheimer Association, 2019; Centers for Disease Control and Prevention, 2020). The evidence demonstrates that short breaks are most effective when used consistency (Bangerter et al., 2019; Gaugler, Jarrott, et al., 2003; Gaugler, Zarit, Townsend, et al., 2003; Kosloski & Montgomery, 1995; Liu et al., 2015), and accessed early in the career (Gaugler et al., 2005; Gaugler & Teaster, 2006). To realise the preventative purpose for short breaks, their provision should be flexible and reflect a personalised continuum that runs throughout the caregiving career.

Sustained and substantive spending on short breaks is essential to realising Welsh Government policy

objectives. The Welsh Government commitment to short breaks is reflected in a £9 million investment to support a National Short Breaks fund for carers to increase opportunities to take breaks (Welsh Government, 2022d). This short break scheme, to be delivered over three years, 2022 to 2025, is intended to enable more carers across Wales, including those who may not identify as a 'carer', to have access to breaks that are meaningful to them, at the right time. It aims to do this by increasing the capacity of RPBs and third sector organisations to deliver preventative and responsive short breaks to a diversity of caregiving relationships. An important aim of the fund is to stimulate new and existing provision, this may involve challenging traditional ideas about how breaks can be realised involving separation and services. In the funding years 2023-24 and 2024-25, Carers Trust Wales is responsible for the allocation of funding to a competitive small grants scheme, 'Amser: the flexible breaks fund' for third sector organisations across Wales. This fund is anticipated to build and enhance the range of short break options for carers of all ages across Wales, complementing regional provision. The fund should respond directly to and support the implementation of the 12 central principles for short breaks outlined in the 'What a difference a break makes' report. Collectively, the 12 guiding principles offer a future vision for short breaks for all carers, of all ages, in Wales, that are creative, co-produced, and collaborative. These principles are summarised in Table 2.1.

Table 2.1: The 12 short break principles for a future vision for short breaks in Wales

See individuals and focus on what personal outcomes matter to carers and the people they support	Start with a 'what matters' conversation so that: • Break outcomes that matter most to people are given meaningful consideration. • The exploration of break options with people is mindful of the active offer, of language, culture, and diversity.
Build on strengths in supporting and sustaining caring relationships.	As well as identifying difficulties in caring, explore: • Satisfactions in caring and positive ways of coping. • Ways a break can help to support these, including breaks taken together as well as apart.
Be sensitive to caring relationships and work towards making breaks a positive experience for everyone.	As far as possible, ensure: • The interdependent well-being of carers and the people they support. • Carers do not feel guilty and the people they support do not feel a burden.

Provide accessible and timely information about break options.	Provide information: • On a variety of break options, including breaks taken together and breaks taken apart, scheduled breaks and breaks to cover emergency situations. • At a time when it is needed, in formats that are accessible and engaging, and, for the youngest carers, are age appropriate.
Offer supported choice of breaks and help with decision-making.	Offer relational support to help people think through their break options.
Provide personalised, flexible, and responsive break options, that reflect the diversity of the carer population.	• Ensure people have access to timely, personalised break options, including breaks that can support them to engage in paid employment, reflect the diversity of the carer population education/training and leisure should they wish. • Ensure break options recognise important factors relating to diversity and inclusion, for example, age, disability, language, and culture. • Be responsive to changing needs and preferences.
Identify and promote creative approaches to commissioning and other statutory funded and low cost/no cost breaks options.	Think 'outside the box' about: • Alternative ways to commission and fund breaks, for example, through the development of social enterprises, individual and pooled Direct Payments as well as no cost options • The challenges and opportunities associated with implementing these into practice.
Build links with key sectors that relate to everyday life not just social care and health	• Design breaks through collaborative working, for example, with hospitality, tourism, arts, leisure, and education. • Strengthen collaboration with health services on the provision of short breaks for people with complex needs and their carers. • Work with health services to proactively identify carers whose break opportunities are most likely to be limited because of the complex nature of care they provide.
Promote and support creative break options in the local community and communities of interest.	• Support the development of diverse local community breaks for people, including informal support and micro-enterprises • Embed both creativity and safety in break options moving forward from the pandemic, including in-person and online

	options.
Nurture the development of peer support.	• Ensure opportunities for carers to access/benefit from peer support. • Explore ways to facilitate this, including collective break options, delivered face-to-face or online.
Ensure quality of break options with a particular focus on what matters to carers and the people they support.	Develop approaches to quality assurance that are: • Meaningful • Support learning and further development
Capture outcomes arising from a break for carers and the people they support.	• Identify ways to effectively capture break outcomes- both planned and serendipitous outcomes • Ensure this information informs future policy and practice development

To support the implementation of these principles into practice, much work remains to distil consensus around 'what matters' in short break provision, both from the perspective of identifying, discussing, and capturing short break needs, and in supporting the delivery of outcomes. RPBs must develop a robust understanding of their short break landscape, including the factors that progress or undermine policy ambition for short breaks, and identify the range of organisations with potential to strengthen collaborative approaches to supporting sustainable breaks. Providing flexible and responsive breaks necessitates an understanding of how carer short break needs and preferences change overtime and the circumstances that may propel such change. This is especially important for degenerative chronic conditions, such as dementia, where complex care and support needs may motivate different short break priorities and outcomes. This thesis contributes evidence to advance such knowledge to support the translation of these principles into practice.

2.5.   Conclusion

In this chapter, the policy emphasis on short breaks as a central resource to enable carers to maintain their well-being in ways that are important to them has been highlighted. The policy impetus to support carer well-being has been outlined and demonstrates the need for preventative provision throughout the caregiving career; this includes, as a national priority, opportunities to take short breaks from caregiving routines and responsibilities. In line with Welsh Government policy ambition, short breaks should be personalised, as much as feasible and is practical, to meet the needs, preferences, and desired outcomes for carers, and so provide a meaningful experience and outcomes. The preventative agenda recognises that short breaks should also be continuous and proportionate throughout the caregiving career to support caregiving relationships as circumstances evolve. Having considered the policy context underpinning the provision for short breaks, the next chapter of this thesis introduces the methodological approach that underpins this research inquiry.

Chapter Three: The methodological approach

3.1   Introduction

This chapter presents the rationale for choosing a constructivist research paradigm, where the researcher and participants co-create understanding. First, the philosophical background of constructivism, comprising of the basic ontological, epistemological, and methodological assumptions, is highlighted. Next, the research strategy encompassing the qualitative methods and sampling approaches used in this research are summarised. The study region of north Wales is described and the ethical approval for this research stated. The recruitment of, and contribution of the Project Advisory group is discussed.

In complex and highly contextualised contexts such as short break provision, a range of knowledge is needed to support a fuller appreciation of the topic area. Researching 'what matters' requires engaging with different stakeholders that share a vested interest in the topic, and who may hold convergent or contrasting, but equally valid, accounts of reality. Understanding what matters in short breaks requires insight into the carer's world, to gain an appreciation of their beliefs, values, preferences, and priorities, and the contexts and circumstances that embody them. From a practice perspective, the provision of short breaks occurs within a dynamic political and cultural context. Practitioners' perceptions of the challenges and opportunities to meaningful short break provision are interpreted through the landscape in which they operate and how they chose to navigate it. Thus, the appropriate research methodology for this study must be guided by a research philosophy that embraces an emic epistemology to reconstruct multiple perspectives, unearth the meaning situations and action hold, and embrace the influence of culture, context, and circumstance. For this reason, the constructivist research philosophy was chosen and guided the position the researcher adopted in relation to the generation and interpretation of knowledge.

3.2   Research philosophy and positioning of the research

A philosophical paradigm is a way of looking at the world and studying reality. It encompasses a basic set of beliefs and assumptions that guide what the researcher believes is worth knowing and how it should be studied and understood (Guba & Lincoln, 1989; Hiller, 2016). Within each paradigm, the pursuit for knowledge and 'truth' is governed by fundamental propositions about reality and the

process by which knowledge can be known and validated. These propositions can be distinguished by their ontological, epistemological, and methodological orientations (Moon & Blackman, 2014).

Within the theoretical continuum of philosophical paradigms, the positivist paradigm, also referred to as the scientific or empirical approach, subscribes to a single objective reality (Park et al., 2020). Ontologically, reality exists externally, independent of human activity or consciousness, and is there to be discovered (Moon & Blackman, 2014). Discovery of this reality is based on what can be observed and measured to develop verifiable explanatory knowledge (Petty et al., 2012a). This knowledge is used to refute propositions and confirm causal inferences to generate universal laws that can predict phenomena (Park et al., 2020). Knowledge that is replicable is truth, concurrent with reality, and remains stable over time (Rehman & Alharthi, 2016). Positivism is commonly the underpinning philosophy in quantitative research, where variables can be controlled, and steps are taken to ensure objective free from values and biases (Alharahsheh & Pius, 2020; Crossan, 2003). However, a major criticism of positivism is that it does not allow for proper or appropriate scrutiny of the world of human experience and social interactions (Crossan, 2003). Human experience is incalculably complex, varied, contradictory, and intangible. Inquiry into human experience and social realities cannot be realised using the same methods to observe the physical phenomena of the natural world (Hiller, 2016). Interpretivism was borne out of the response to the critique of the positive paradigm and is concerned with individual meaning imparted on experience (Gray, 2014). Closely aligned to the interpretivist perspective lies constructivism (Adom et al., 2016).

3.2.1   Constructivism

Constructivists ascertain that reality is construed and modified through experience (Guba & Lincoln, 1994). Constructs of reality are assembled from innumerable personal experiences and influences, such as significant events, family, and culture, which reinforce perceptions and understanding of behaviour and phenomena (Denicolo et al., 2021). These constructs are integrated internally to form a set of 'working hypotheses' (Guba, 1981) used to navigate the world and interpret experience. Perceptions of reality are likely to differ because interpretation is based on and mediated through existing knowledge and values. As people experience the world, they 'dance with the continuous negotiation' (Denicolo et al., 2021, p. 7) of their reality. Knowledge is actively built through a continual process of integration, assimilation, and accommodation of new experiences against current constructs of reality. In this sense, meaning is not imposed on experience, but rather is created in response to experimentation and problem solving.

Originally named the 'naturalistic inquiry', Guba and Lincoln propagated the constructivist paradigm and described its fundamental philosophical tenants (Guba & Lincoln, 1989). Constructivist ontology is that of relativism. Guba and Lincoln (1994) argue that constructivist realities are multiple, intangible mental constructions, that are socially and experientially created and contextually specific. Constructions of realities are divergent and 'ungoverned by natural laws, causal, or otherwise' (Guba & Lincoln, 1989, p. 86). These constructions emerge as individuals attempt to make sense of their experiences through interactions and experimentation. While shared perceptions of phenomena may exist or are commonly assented to by similar groups of cultural or moral distinction, realties are individually defined and unique. Constructions of reality are better conceived at any one point in time as more or less informed or sophisticated as opposed to 'true' in any absolute sense (Guba & Lincoln, 1994). Since knowledge is created through engagement with the world and interpretation of experience, meaning is also modified upon experience (Crotty, 1998).

The epistemological position of constructivism is that of transactional subjectivism, the understanding that knowledge can never be 'free' from past experiences, exposure, or information (Poucher et al., 2020). Hence, constructivists reject the objective posture of positivism that knowledge exists independent of the human mind and is there to be discovered (Guba & Lincoln, 1994). Rather truth or meaning come 'into existence in and out of engagement with the realities in our world' (Moon & Blackman, 2014, p. 1172). Truth or meaning, therefore, has no universal or timeless validity and are subject to alteration and change with new experience (Appleton & King, 1997). Interpretations of responses to new experiences infuse with prior knowledge, stemming from an individual's pre-existing construct system, to generate a more complete or contextually astute understanding of an evolving reality (Denicolo et al., 2021). Guba and Lincoln (1989) assert a moral endeavour bestowed upon the constructivist is to 'continuously seek out challenging constructions with which to confront their own' (Guba & Lincoln, 1989, p.87). In the context of this research inquiry, to seek out such constructions, the researcher must interact with participants throughout the research process to reconstruct multiple realities or access perceptions of the phenomena being studied. Together they seek to co-create reality through negotiated interpretation, in which the participant(s) and researcher will influence each other during this process. The researcher's values and preconceptions inextricably shape their inquiry and they themselves become an instrument in data collection (Dodgson, 2019; Pezalla et al., 2012). Therefore, the distinction between the ontological question of 'what can be known' and the epistemological question of 'what is the relationship between the researcher and what can be known' is rendered irrelevant (Guba, 1990). Constructivism as a worldview creates both reality and knowledge (Appleton & King, 2002; Lee, 2012).

Methodologically, constructivists adopt hermeneutic and dialectic approaches to gain an emic perception of reality and clarify the meaning ascribed to experience (Appleton & King, 1997). The hermeneutic-dialectic approach is based on a process of reflection and interpretation (Appleton & King, 2002). It embraces new perspectives and thinking to generate idiographic knowledge, that is culturally or contextually sensitive (Robinson, 2011). For complex or subjective phenomena, it may be difficult to reach agreement between participants. However, the priority is not to elicit what is 'true' but rather coalesce around a consensus construction that offers the 'best fit' to the phenomena under study (Guba, 1981).

The goal of this research was not to prove or dispute hypotheses or knowledge but was concerned with gaining a fuller understanding and appreciation for realities that are constructed, negotiated, debatable, and contextualised. It is for this reason that the constructivist 'lens' was chosen as a paradigm for this research and guided the research strategy. The research strategy is now presented, which outlines how a constructivist approach, utilising qualitative methods of inquiry and collaborative means of engaging with and exploring evidence in context, shaped the different phases of the research.

3.3   Research strategy

The research strategy is the bridge that connects the philosophical standpoint (ontological and epistemological beliefs) with the method (practical tools and techniques) (Denzin & Lincoln, 2011). In this thesis, the research strategy was characterised by four phases of study, that guided how the research was conducted and the appropriate method(s) for data collection and analysis. These phases were culminative in nature and helped inform the direction and priorities for knowledge generation; together they construct a fuller and holistic understanding of meaningful short breaks. The four phases of research are exemplified in Figure 3.1. The knowledge gathered maps onto and answered the following four research questions, which collectively addressed the research objectives (Table 3.1):

Table 3.1: Research questions aligned to the research objectives.

Research Questions	Research Objectives
What are the key challenges and opportunities associated with the planning, commissioning, and delivery of short breaks?	1. To identify ways to effectively develop, commission, and scale up short breaks that reflect 'what matters'. This objective includes developing insight into:

	• The challenges (barriers) and opportunities (facilitators) to take forward new policy ambition for meaningful short break provision. • Future sustainability and local capacity issues and how these might be addressed against a backdrop of rising short break demand and declining public budgets. • The emerging landscape of new providers and models that may offer greater flexibility and choice.
How do spousal carers' short break needs, experiences of accessing breaks, and desired break outcomes change over the caregiving career?	To explore the short break needs and preferences of spousal carers for people with dementia using short breaks, specifically: • How short break needs and preferences are evidenced in assessments following the implementation of the Social Services and Well-being Act (2014) and the degree to which these needs are met. • How carer short break needs, preferences, and desired outcomes might evolve over time in response to the progression of dementia.
What are the defining features of meaningful short break provision? How can these be translated into social care practice recommendations to support the provision of short breaks.	To develop policy and practice recommendations to help to support the delivery of improvements against Welsh Government national priorities for carers and those they support, specifically, a life alongside caring.
How can developmental temporal models of the dementia caregiving experience inform a new understanding of carer short break needs over the caregiving career.	To understand 'what matters' in short break provision. This includes: The hallmarks of impactful provision that support the realisation of carer generated outcomes (Cook & Miller, 2012), including

	health, well-being and sense of resilience, a life of their own, and a positive relationship with the person with dementia.

Figure 3.1: *The four phases of the research strategy.*

- Semi-structured interviews with social care professionals
- Qualitative thematic analysis

Exploring the challenges and opportunities associated with the planning, commissioning, and delivery of short break

Describing spousal carers' break needs, experiences of accessing breaks, and desired break outcomes over the caregiving career

- Narrative interviews with spousal carers
- Narrative analysis

- Knowledge exchange event underpinned by a collaborative and constructivist approach to knowledge mobilisation

Integrating understanding and distilling consensus of 'what matters' to co-create practice recommendations

Identifying developmental models of dementia caregiving to inform a conceptual framework for understanding short breaks needs across the caregiving career

- Scoping review following the framework proposed by Arksey and O'Malley

At this juncture, it is crucial to deliberate on the rationale behind positioning the scoping review towards the latter end of the thesis. First, during the period this PhD project was undertaken, comparable work by Seddon and colleagues, discussed below, identified knowledge gaps in the short break literature. Their work helped shaped focus of the scoping review in Chapter eight. Second, this focus was strengthened by evidence from this project's first three phases, demonstrating the importance of understanding how break needs and outcomes may evolve over time and how these can be supported.

Over the past five years, the work of Seddon and colleagues (Seddon, Miller, et al., 2021; Seddon, Andrews et al., 2021; Seddon & Prendergast, 2019) and O'Shea and colleagues (O'Shea et al., 2017; O'Shea, Timmons, O'Shea, & Irving, 2019; O'Shea, Timmons, O'Shea, Fox, & Irving, 2019; O'Shea et al., 2020) have delved into the short break literature, examined the evidence base, and identified crucial evidence gaps. Together, their work comprehensively documented the current knowledge base, outlining key stakeholders' experiences of short break provision (O'Shea et al., 2017), elucidating issues around access to short breaks (O'Shea, Timmons, O'Shea, & Irving, 2019), conducting a conceptual review of the term 'respite' in dementia care (O'Shea, Timmons, O'Shea, Fox & Irving, , 2019) and capturing the experience of short break services from the perspective of the person with dementia (O'Shea et al., 2020). In tandem, Seddon and colleagues focused on evidencing important carer well-being outcomes realised through short breaks (Seddon & Prendergast, 2019), which contributed to the development of an outcome-focused research agenda on personalised short breaks (Seddon, Miller, et al., 2021).

Consequently, a robust comprehension of short break provision, the barriers and facilitators to access, the nature of experiences for carers and people with dementia, and outcomes was distilled from their collective work, and summarised on page 27 (1.7.1 The evidence base). Crucially, this examination revealed several evidence gaps (1.7.2 The evidence gaps), among which the understanding of the evolving nature of short break needs and how these might change over time emerged as an area of limited knowledge. This evidence gap prompted the argument to explore how a conceptual framework for short breaks across the caregiving career could contribute to informing policy and practice, subsequently becoming the focal point for the scoping review in Chapter Eight.

3.3.1 Research type and methods

The research methods described in the ensuing chapters are qualitative data collection and analysis methods underpinned by an inductive approach. Inductive reasoning is exploratory in nature.

Typically, an inductive approach to data collection, analysis, and interpretation is iterative and allows for flexibility in the refining of the research focus and question(s) in response to the emergence of knowledge, rather than following a stepwise linear sequence (Fossey et al., 2002; Petty et al., 2012b). Inductive reasoning is generally allied with qualitative research (Hesse-Biber, 2011; Yilmaz, 2013).

Qualitative research has its origins in the humanities and social sciences. Denzin and Lincoln (2011) offer a description of qualitative research as a set of complex interpretative activities that privileges no single methodological approach. In qualitative research traditions a diversity of methodologies, strategies, and methods are used, spanning clinical research, life history, case study, ethnography, narrative inquiry, and phenomenology, amongst others (Denzin & Lincoln, 2000). Each of these approaches privilege 'quality' (depth) over 'quantity' (breadth) (Yilmaz, 2013), and generate insight from different emic standpoints (Denzin & Lincoln, 2011). Qualitative methods are advantageous in gaining rich and detailed knowledge from an individual or collective perspective that can help make sense of human experience. They are particularly beneficial to advance knowledge of a topic about which little is known or to understand complex social systems or situations comprised of multiple social actors, processes, and reciprocal interacting components (Cohn et al., 2013; Greenhalgh & Papoutsi, 2018). Broad research questions are addressed that seek to explore, interpret, and describe meaning. This contrasts with quantitative research that seeks to test hypothesises and draw conclusion through deductive logic. When studying the experience dimension of a person's life, understanding must be placed within context to situate their 'life as experienced' and orientate their lived experience to a specific time and place (Fossey et al., 2002). Findings are therefore context bound and may only be generalised to similar situations.

3.3.2 Sampling methods

The sampling methods chosen in this study reflected the research objectives and the characteristics of the study population, such as size and diversity. They also reflected participants' availability, interest, and willingness to engage, and the ability to communicate and articulate experience and perspective in a reflective and open manner. In qualitative research the sampling choices support an idiographic understanding as opposed to a more general nomothetic understanding favoured in quantitative studies (Etikan, 2016). There are several nonprobability samplings methods employed in qualitative research, the most common being purposive sampling (i.e., participants are deliberately chosen by the researcher), convenience sampling (i.e., participants self-select if they wish to participate), and snowball sampling (i.e., participants are referred to the researcher) (Palinkas et al., 2015; Stratton, 2021). The combination of sampling methods is increasingly used in qualitative

research that necessitate an iterative and flexible approach to data saturation (Miles & Huberman, 1994). The sample size in each research phase of this thesis is determined by data saturation, not by statistical power analysis.

To summarise, this research adopted a qualitative inductive approach to inquiry. The researcher had to be agile and proactive in their approach to inquiry, adopting different approaches to engage and interact with participants in response to the COVID-19 pandemic. This necessitated moving between in-person interactions, to online, and to hybrid approaches.

The qualitative research methods are allied to constructivist methodology and chosen based on their suitability to construct and interpret the meaning engendered through experience (Appleton & King, 2002). Purposive and convenience sampling strategies were selected to identify participants prepared to share their realities and lived experience. The data collection methods, involving in-depth interview work and stakeholder engagement, were exploratory in nature and elicited the views, experiences, beliefs, and motivations of participants, and captured important contextual detail.

The breadth and depth of data collected required constant comparative analysis, in which consistencies and contradictions could be inspected, and consensus constructions formed. The interpretation of meaning was supported through the researcher's extensive familiarity with the data, opportunities to sense-check interpretations, and group dialogue to help assimilate new knowledge. The role and the influence of the researcher in the interpretation and co-construction of meaning was acknowledged in this process.

3.3.3   The study region

This study region for this research is north Wales. North Wales has a distinct identity, underpinned by Welsh culture and language, and characterised by diverse topography, spanning rural mountainous regions to more populated coastal towns. North Wales encompasses the local authorities of Conwy, Denbighshire, Flintshire, Gwynedd, Isle of Anglesey, and Wrexham, each characterised by their cultural and working practices, shaped by the diverse characteristics of its people and topography. Gwynedd, the largest yet most sparsely populated county, has the highest percentage of Welsh speakers in Wales. This contrasts with the three smallest Northeast counties (Flintshire, Wrexham, Denbighshire), marked by larger, more concentrated populations and proximity to the English border. In the region, two prominent carers charities operate, with one serving the counties of Flintshire, Denbighshire, and Wrexham, and the other covering Gwynedd, Isle of Anglesey, and Conwy. This

regional distinction in carer support has influenced the commissioning and delivery of short break services.

In Wales, the average age of the population is higher whilst the economic output is lower compared to other UK countries (Carers UK, 2022b), meaning the challenges of caregiving can be more severely felt. The demography of Wales is also changing. In north Wales, the predicted number of people aged 65 years and over living with dementia is expected to rise from 12,530 in 2023 to 16,270 in 2033 (National Social Care Data Portal for Wales, July 2023). The study population for this research, aged 65 years and older, was chosen because dementia is principally a disease experienced in older age, and as mirrored across the UK, Wales has an ageing population. By 2038, 1 in 4 of the population will be over 65 years old. The number of carers in Wales is also increasing and people aged 65 and over are the fastest growing group, making this a key demographic of concern (Welsh Government, 2021c).

3.3.4   Ethical approval and ethical considerations

Ethical approval for this research was granted in August 2019 by the School of Health Sciences Academic Ethics Committee (2019-16563), Bangor University.

This research was guided by a set of tenets designed to ensure the well-being, dignity, and rights of participants, as well as the integrity of the research process.

Voluntary informed participation and consent. Securing voluntary and informed consent was facilitated through a bilingual research pack, comprising a consent form and an information sheet detailing the research's purpose, process, and potential discomforts and benefits, both short and long-term. Participants were given the opportunity for pre, during, and post-participation discussions, underscoring the voluntary nature of their involvement. Clear emphasis was placed on their right to withdraw at any point, with no repercussions. Additionally, participants were informed of their right to pause or stop interviews or decline to answer without providing a reason. Post-interview should participants decide against the use of specific data, the designated information would be promptly deleted from the researcher's M drive, and any hard copy transcripts securely destroyed.

Maximising benefit and minimisation of risk of distress. Throughout this research, the researcher actively sought to maximise the benefits of participants' involvement, offering opportunities for reflective and cathartic discussions, supporting a nuanced understanding of short break provision, facilitating networking and peer support, and contributing to future research capacity. Participants

were invited to a knowledge exchange event, providing a platform for sharing perspectives and fostering collaborative work.

Recognising potential distress, particularly during narrative interviews with carers where personal information was shared, the researcher took precautions to minimise harm. Interviews proceeded at the participant's pace, with the option to spread sessions over different days if narrating their caregiving experience in a single sitting felt overwhelming. In instances of participant upset or distress, the recording device would be turned off, and carers given the choice to terminate the interview or take a rest. The researcher was equipped with a list of national and local support sources, ready to help or referral as needed. Amid the Covid-19 pandemic, interviews with carers were held through phone or online platforms, offering the flexibility for carers to choose a mode of communication. This option aimed to enhance comfort and ease, enabling carers to engage in interviews from the familiarity of their homes. Interviews held over the phone, the most preferred option of carers, may have provided a sense of anonymity, reduced potential anxieties, and contributed to more open and honest responses.

Anonymity and Confidentiality. Prior to the start of the PhD project, the researcher successfully completed GDPR training administered by Bangor University, ensuring compliance with data protection regulations. Throughout the project's lifecycle, stringent measures were implemented to protect participants' identity and maintain the confidentiality of information. Hard copy data was securely stored in a locked filing cabinet within the researcher's office, and once digitised, it was responsibly destroyed using a standard shredder. For online discussions on platforms such as Zoom and Teams, the recording function of the platform was utilised, with recordings safely saved to the researcher's OneDrive. Personal electronic data, including transcripts, electronic consent forms, and Dictaphone recordings, was stored in anonymised form on the researcher's OneDrive, accessible only by the researcher. Files in OneDrive are automatically backed up, further ensuring the security and integrity of the data. Data will be stored on the Bangor University network for a period of five years, in compliance with the Bangor University Research Data Management policy.

It is important to underscore that the commitment to confidentiality is not unconditional and there are situations which may necessitate the disclosure of information to ensure the safety and well-being of all parties involved. If participants were to share information indicating a serious risk of harm to themselves or others, or if they disclosed instances of malpractice, the researcher would be ethically and legally required to report such information to the appropriate authorities. In such cases, the

primary concern would be to address potential risks as quickly as possible, to prevent harm and safeguard individuals affected.

3.4   Project Advisory Group

Critical to the research's integrity and transparency, the study was conducted in close collaboration with a Project Advisory Group. The multisectoral Project Advisory Group comprised of five professional stakeholders. Members were identified and recruited through the supervisor's networks and through the researcher's own exploration of the local organisations supporting short break across north Wales. The aim was to achieve a balance in professionals employed in statutory and third sector organisations across north Wales and in strategic and/or operational positions. The researcher initially aimed to include an unpaid carer in the Project Advisory Group, with the support of professional advisory members aiding in recruitment. However, due to the escalating challenges posed by the COVID-19 pandemic, this recruitment task became increasingly difficult. Consequently, a decision was made to proceed with the project without a carer in the group. Further details regarding this decision are explored in the discussion chapter.

The Project Advisory Group met five times throughout the lifespan of the project that reflected key millstones to ensure timely input. Meetings were originally intended to be held in person. However, apart from the first meeting, in which travel expenses were reimbursed, most of the meetings were held during the COVID-19 pandemic and during subsequent social restrictions, and therefore moved online. The meetings were kept to a one-and-a-half-hour limit.

Harnessing their professional expertise, members contributed to the research in many ways. They shared their practice knowledge, expertise, and opinions to guide decision-making, ensured reasonable and practical objectives, supported the recruitment of carers and professionals, and kept the focus on meeting the needs of intended beneficiaries. Figure 3.2 shows each meeting objective and the Project Advisory Group's contribution. An element of fluidity and flexibility underpinned the meeting format. While every effort was made to ensure a time convenient to meet for all members, if one member couldn't make a meeting, a de-brief of the meeting was shared, and an individual phone call to discuss the topics covered was offered.

Figure 3.2: *Project Advisory Group's contribution to the meeting objectives.*

5th July 2019

Objective: to review interview topic guides and recruitment strategy for phase one

- commented on the wording and structure of the interview schedule.
- checked question relevance to short break policy and practice.
- refined and simplified questions and ensured appropriate use of terminology (e.g., the interchange between the terms respite and short break).
- suggested providers, practitioners, and commissioners to invite to participate in the study.

28th August 2020

Objective: to share and explore prelimary findings from phase one

- remarked on the coherence of findings, offering suggestion to interpretation of meanings that fine-tuned explanations.
- discussed the relevance of the findings and their potential to inform planning and decision-making about meaningful short break provision

16th December 2020

Objective: to discuss the narrative interview approach and recruitment strategy for phase two

- discussed the narrative interview approach and opening question to elicit the carer's story.
- highlighted the sensitivities that may arise during conversations and how best respond to these.
- advised on local organisations and community groups who could promote the opportunity take part in the study to carers.

13th October 2021

Objective: to share and explore preliminary findings from phase two

- considered how the evolving nature of carers' break needs resonated with their practice experience, offering complementary and some contradictory perspectives and examples.
- discussed the capacity of local communities to respond to these needs and development of promising future initiatives to desired short break outcomes.

14th March 2022

Objective: to help plan for and advise on the knowledge exchange event

- helped decide upon the material most useful and thought provoking to share with the intended beneficiaries and stakeholders at the knowledge exchange event.
- considered together the appropriate venue, timing, and delivery approach.
- reflected on draft recommendations for social care policy and practice development.

How the National Standards for Public Involvement in research (National Institute for Health and Care Research, 2019) were implemented during engagements with the Project Advisory Group is shown in Table 3.1

Table 3.2: Implementation of the National Standards for Public Involvement.

NIHR standard	Implementation of standards
Inclusive opportunities	The Project Advisory Group members were consulted about the meeting format and times. Most of the meetings were held during the COVID-19 pandemic, and in accord with Welsh Government and Bangor University guidelines, an online format had to be adopted. All members were invited to the knowledge exchange event (reported in chapter six).
Working together	To promote shared understanding of ways of working together, the responsibilities of the researcher and the *likely* nature of the Project Advisory Group's contribution, building upon individual strengths and areas of expertise, to the research was discussed in the first meeting. The confidentiality of discussions was emphasised. Many members were already acquainted with each other through professional networks and therefore appreciated the variety of perspectives and drew upon the diversity of experience to enrich discussion and understanding.
Support and learning	Time was taken to ascertain what each member wished to gain and learn from their involvement in the study, from both a professional and/or personal perspective. When sharing findings, orientation to the data collection and analysis methods were clearly explained to support understanding and learning. During the life span of the research, the publication of relevant strategies or grey literature was shared between the researcher and the group.
Communications	All stakeholders invited to join the Project Advisory Group were provided with an information sheet which detailed the research aim and objectives. Written consent was obtained. The agenda for each meeting and any material to be discussed during the meeting was circulated at least one week prior.

Impact	The group's contributions were acknowledged in the published papers, thesis, during all presentations of findings, and in the knowledge exchange event.
Governance	Project Advisory Group members had an important role in the oversight of the study to ensure fair and transparent decision-making and that focus remained on meeting the needs of intended beneficiaries. All their opinions were heard, valued, and respected in decision-making.

3.5   Conclusion

In this chapter, the relative ontology and constructionist epistemology of this research has been confirmed. The value of adopting a constructivist lens to this research was in generating a holistic and contextual understanding and consensual agreement, or at least movement towards, 'what matters' in short break provision. The thesis is structured through four phases that seek to explore, describe, accommodate, and assimilate knowledge to deliver consensus, and supplement understanding. The next chapter reports on phase one of this research, and explores the challenges and opportunities associated with the planning, commissioning, and delivery of short breaks.

Chapter Four: Planning, commissioning, and delivering meaningful short breaks for carers and their partner living with dementia: challenges and opportunities

This chapter presents findings from qualitative professional interviews that offer strategic and operational insight of short breaks provision for spousal carers and their partner living with dementia. It proposes a dynamic descriptive model of the short break landscape in north Wales, describing factors shaping local and regional decision-making. The model interprets key challenges (barriers) and opportunities (enablers) that shape the planning, commissioning, and delivery of short breaks. It contributes to the emerging evidence base on the features of meaningful short breaks provision to support carers and people with dementia to achieve personal well-being outcomes. The findings reported in this chapter have been peer reviewed and published in the Journal of Health & Social Care in the Community https://doi.org/10.1111/hsc.13533. The researcher collected, analysed, and interpreted the data and wrote the manuscript. Diane Seddon provided critical revisions to all sections of the manuscript and supported the interpretation of results. Sion Williams refined the design of the descriptive model, and Catrin Hedd Jones provided constructive comments and suggestions to help hone the findings. All authors read and approved the final manuscript. The authors acknowledge the contribution of the multisectoral Project Advisory Group members in shaping the research objective and plan of investigation, supporting the development of the interview topic guides, advising on participant recruitment, and contributing to discussions that supported the refinement of the model presented in this chapter.

4.1   Introduction

In the UK, social care legislation emphasises that care and support should help people achieve the outcomes that matter to them in their life; this includes the opportunity to take short breaks from caregiving routines and responsibilities. In Wales, the 2014 Act is ambitious in the support it promises to carers to enable them to have live a life alongside caring (Clements, 2018). While the duties specified in the 2014 Act aim to provide greater flexibility and scope for collaboration and 'innovation' in short breaks provision, the nature of providing short breaks is inherently complex (Allen et al., 2020; Pierse et al., 2022; Shared Care Scotland, 2016; Welsh Government, 2021b). In each region of Wales, and in each local authority, the duty and challenge are to provide variety and choice of short break options that meet local needs, preferences, and desired outcomes. From a legislative perspective, the

requirements, and principles of the 2014 Act embolden a preventative and sustainable development approach to short breaks and must be flexibly adapted and applied to local dynamic contexts to respond to 'what matters' to carers. At a practice level, how each organisation charged with delivery of short breaks assess, interpret, and respond to carer short break needs in their area will inevitably be shaped by their distinctive histories of preventative work and community engagement, organisational culture and practices, depth and breadth of partnership relationships, and ability to identify the approaches to delivering outcomes for carers that make the best use of limited resources (Verity et al., 2019).

There are several strategies specific to north Wales that evidence the long-standing need for improved short breaks. The 2022 North Wales Population Needs Assessment made several recommendations for improving support for carers, which included increased choice and access to short breaks (North Wales Social Care and Well-being Improvement Collaborative, 2022). This recommendation aligns with the aim of the North Wales Carers Strategy to ensure that there is equity of flexible short breaks for carers across the region (North Wales Social Care and Well-being Improvement Collaborative, 2018). The North Wales Dementia Strategy evidences the need for increased short breaks for carers for people in the later stages of dementia, and further identified the requirement for a variety of break options that can flexibly meet the individual needs of the person with dementia (North Wales Social Care and Well-being Improvement Collaborative, 2020). However, as regional priorities, these are broad in nature and scope, and there is limited detail to illustrate how regional intent for improved short breaks is being operationalised and its effectiveness evaluated at a local level. In an evolving and transforming landscape, to provide for better access, variety, and choice of short breaks necessitates an understanding of the local context in which short breaks are planned, commissioned, and delivered.

4.2   Method

4.2.1   Data collection

Between October 2019 and January 2020, purposive sampling (Palinkas et al., 2015) was used to identify 26 professionals who were knowledgeable or held roles within their organisation that related to the planning, commissioning, or delivery of short break for carers and people with dementia. Staff in both operational and strategic roles were recruited from all six counties to create a balanced sample that reflected a regional perspective. To support the recruitment for potential professional participants, it was emphasised that their involvement was not part of a 'compare and contrast' exercise with other organisations but would contribute to the generation of a more sophisticated understanding of the local short break landscape, and this knowledge would be shared to support

their work. The Project Advisory Group advised on the suitability and supported the identification of participants by virtue of experience, or relevance of role to the area of short break provision.

Participants took part in qualitative individual interviews (N= 10) or small group discussions (N=5). The semi-structured interview format was chosen as it allowed the researcher to ask all participants specific policy and practice relevant questions to short break provision while still extending participants the conversational space and flexibility to explore what is important to them. The aim of these interviews was to engage in discussion that was conversational yet focused, with some degree of predetermined order (Longhurst, 2013).

In this study, the mean size of groups interviews was three people, and the range between two and four (Figure 4.1). The format capitalised on interactions and conversation between people of similar or shared cultural, social, or professional backgrounds, to collectively explore issues (Longhurst, 2013). Here, the researcher's role was to facilitate discussion between participants as opposed to between themselves and the participants (Acocella, 2012). The group dynamics, specifically for the groups of four, meant that the data collected represented the collective view of the group rather than the aggregated views of individuals (Fossey et al., 2002).

Two topic guides, one for strategic staff and one for operational staff, were designed in collaboration with the Project Advisory Group that harnessed the expertise of professional stakeholders and ensured interview relevance to current policy and practice directives. Questions were open-ended and acted as flexible guides to focus the conversation and stimulate discussion. The distinct topics areas that guided the interview questions, for strategic and operational staff, respectively, are summarised in Table 4.1. All participants received a project information sheet (in Welsh and English) (Appendix 1), and formal written consent (Appendix 2) was gained. All interviews were conducted in English, although in accordance with the Active Offer (Welsh Government, 2015a), the option for the interview being held in Welsh was offered. Apart from two interviews conducted over the phone due to geographical distance, all interviews were conducted in person, with ten interviews conducted one-to-one and the remaining five conducted in small groups of up to four persons (Figure 4.1). Interviews were recorded and transcribed verbatim, anonymised, and stored in compliance with General Data Protection Regulations, in a password protected folder on the researcher's University M drive.

Table 4.1: Areas of substantive interest addressed in staff interviews.

Strategic areas of interest
Barriers and facilitators to the scaling up of meaningful short break provision and sustaining over time (including structures, resources, practices, and processes).
Translating the legal duty to promote a variety of providers into practice to respond to the diversity of short break needs, preferences, and desired outcomes.
Vision for the evolution of commissioning and/or delivery arrangements to address local and regional priorities in relation to short breaks provision
Use of resources to support the delivery of Welsh Government national priorities, especially a life alongside caring.
Evidence most compelling in steering future commissioning.
Opportunities to learn and share good practice across the region.
Involvement of carers and people with dementia in the planning and shaping of short breaks provision.
Over the next five years, the greatest challenge and/or opportunity to meet the growing need for break provision.
Operational areas of interest
What matters *most* to carers about breaks provision.
Strengths and weaknesses of current breaks provision.
Barriers and facilitators for carers to access a break.
Ways to empower carers with choice and control in relation to breaks provision.
Extent to which short break needs and preferences are identified, discussed, and evidenced during Carer's Assessments.
Over the next five years, the greatest challenge and/or opportunity to meet the growing need for break provision.

Figure 4.1: *Frequency of staff interviews by group size.*
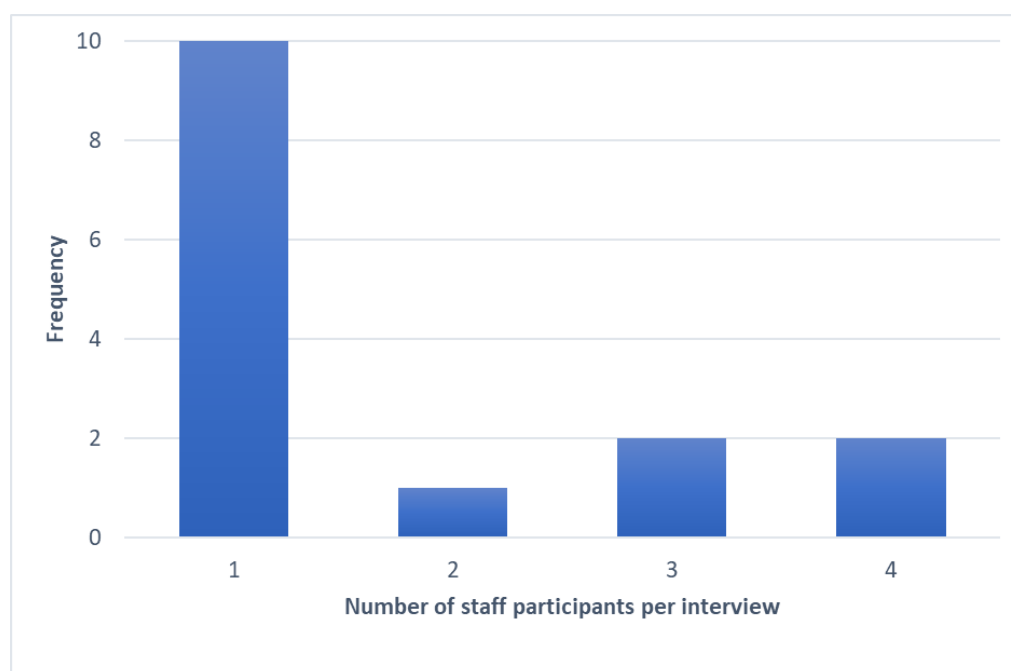
4.2.2 Participant characteristics

The participant demographic consisted of staff working within the field of social care. Participant characteristics by sector (i.e., third or statutory) and by role (i.e., operational or strategic) are shown in Table 4.2. Strategic staff (e.g., Commissioning Officer, CEO) were identified as having responsibility for the commissioning and procurement of support services for carers. Operational staff (e.g., Social Worker, Well-being Manager) conducted Carer's Assessments or were involved in planning and delivering community support services that provided a short break.

Table 4.2: Participant characteristics by sector and by role.

	Role		
Sector	**Strategic**	**Operational**	**Total**
Third	3	6	**9**
Statutory	11	6	**17**
	14	**12**	**26**

4.2.3 Data analysis

Thematic analysis is a flexible approach to qualitative data analysis, designed to identify and describe patterns, connections, or themes across data sets (Kiger & Varpio, 2020). It is an appropriate method to use when seeking to identify common and shared meaning across multiple perspectives, as opposed to the detailed inquiry of a singular case. Meaning is derived inductively from the data and used to develop a descriptive understanding and synthesis of phenomena (Fossey et al., 2002). The analytical approach in this study followed the iterative process for the heuristic coding, exploration, analysis, and conceptualisation of data described by Braun and Clarke (2006), and Miles, Huberman, and Saldana (2014), respectively. Codes were generated through the reading of data, revisiting of data, and revising codes. This allowed the researcher to combine and organise segments of data to build up a granular understanding of the data and to distinguish between descriptive and patterns codes and their potential to inform subsequent semantic and latent meaning (Miles et al., 2014). The software package Atlas.ti 8.2.34. helped organise the data and facilitate data searching (Smit, 2010). Codes were then integrated to begin the active and constructive process of building patterns, themes, and processes of potential significance. The identification of such were supported through processes of writing descriptive summaries and interpretative coding (i.e., making interpretations) (Sullivan & Forrester, 2018). To determine the validity of themes, it was important that themes independently resonated with the data set, but also, worked together to form a coherent whole story interpretation (Braun & Clarke, 2006). While alluding to some local county-level context to illustrate regional differences, it is crucial to note that the findings predominantly centre on the shared challenges and opportunities across all counties in the North Wales region. The analysis and interpretation of findings adopt a comprehensive regional perspective.

Candidate themes were then graphically mapped to conceptualise the relationships and distinctions between them, identify the different conceptual levels of data (e.g., overarching process and sub processes) and emerging contexts (Miles et al., 2014). The mapping of data to form a descriptive model of the short break landscape was an iterative process; key processes, contexts and contingencies were reviewed, refined, and defined to determine the hierarchy amongst them and to generate a visual display. This process supported the credibility of drawing 'accurate' and valid interpretations from the data. There was an inherent aspect of interpretation in the process of constructing the model, that involved the researcher's own reflection and intuition, which incorporated an understanding of the policy landscape and regional characteristics. The verification

of the model was supported through the Project Advisory Group members who commented on its cohesion and potential to inform planning and decision-making about short breaks.

4.3   Findings

The descriptive model of the short break landscape is an interpretation of how professionals describe the processes and contingencies involved in shaping the direction of short breaks provision in north Wales (Figure 4.2). The model centres on a series of interlinked levels represented as

1) the core process
2) the local contexts
3) focal contingencies
4) wider contingences

A description of the models' levels is provided in Table 4.3

Figure 4.2: *A descriptive model of the north Wales short break landscape.*

Wider contingencies

Policy directive
to innovate breaks provision

Funding cycles
and structures

1. **Developing equity of short breaks provision
    across the region**

- Regional collaboration
- Effective coordination and communication

Focal contingencies

3. **Understanding 'What Matters' in short breaks
   provision**

- A meaningful short break
- The merit in the 'traditional'

The carer

Person with
dementia

Core process

**Local cultural, and care and
support contexts**

2. **Building resilient and inclusive communities**

- Choice and diversity
- Information, advice, and assistance
- Normalising short break culture

Focal contingencies

Determining eligibility for short
breaks

Involving carers and people with
dementia in shaping breaks provision

Wider contingencies

Table 4.3: Description of the model's levels.

1. The core process
Represents the dyadic nature of caregiving and interdependencies that typify the caregiving relationship, the couples' values and preferences, and the stage of dementia in shaping what matters in short breaks provision.
2. The local contexts
2.1 Cultural context
The perceptions, morals, and beliefs that influence carer's engagement with support provision, sense of duty to care for their partner with dementia, and self-identification as a 'carer'.
2.2 Care and support context
Th local circumstances that shape short breaks provision (e.g., the adult social care workforce, rurality, and local authority operational and commissioning arrangements).
3. Focal contingences
Characterised by three key interlinked processes occurring at a local and regional level;   1. developing equity of short breaks across the region,   2. building resilient and inclusive communities,   3. understanding 'what matters' in short breaks provision.   These processes illustrate the direction of the region to transform short breaks provision. They also play a part in facilitating the steps needed for effective collaboration between sectors and supporting the vision for inclusive communities to reduce social isolation, loneliness, and stigma of living, or caring for someone, with dementia.
4. Wider contingences
Represent the extent to which policy ambition and legislative requirements exert influence on local and regional decision-making in relation to short breaks provision.

A full description of the data and illustrative quotes substantiate the model. Quotes are coded as 'S' for strategic and 'O' for operational staff perspectives. A unique identifier is attributed to each participant.

1. The core process

Operational staff spoke of the mutuality and reciprocity that imbued many spousal caregiving relationships and emphasised that often carers require a break from their caring role and responsibilities rather than a break from their spouse. What constituted a meaningful break varied

considerably, from a carer "*who wants to go for a pint with his friends*" (O1), to a couple who "*don't want to be split up but they want a break from being at home"* (O6)*.* Staff acknowledged that carer short break needs and preferences tended to evolve over time to reflect changes in the caring role associated with the progression of the dementia. For example, a preference for breaks taken together in the early stages of the dementia that support engagement in community-based activities, and during the later stages of dementia, breaks that may involve temporary separation of varying duration through the provision of in-home or residential care.

Staff conducting Carer's Assessments underlined the need for diplomacy to support compromise where the couple diverged in their perspective of the caring situation or in break preferences:

> *"A carer's needs might be able to be met by a service but that relies on the person they care for either paying for that service or to consenting to go into that service. I think that professional engagement with a family is quite important to navigating both sets of needs"*
> (S13).

2. The local contexts

2.1 The cultural context

Staff recognised that the generational distrust of social services held by some older carers (aged 65 years and over) fuelled anxiety and influenced carer willingness to engage with statutory support, *"you do get people who initially will say, 'I do not want the local authority knowing my business'"* (O9).

Local authority staff were therefore eager to "*re-educate what social services are about now"* (O3) to reflect how needs for a break are supported under the 2014 Act, i.e., meeting support needs should involve 'building on people's resources, including people's strengths, abilities, families, and communities' (Welsh Government, 2015a, p. 13). Building carer independence from service engagement set the precedent for commissioned breaks provision, *"[Carer's charity] are here to help and support the carers' transition into the community…they are the support mechanism rather than the hand holder"* (S11).

Operational staff were mindful that the term 'Carer's Assessments' implied an assessment of ability to care, which many carers found intrusive. Considering this perception, the What Matters (Wales) approach to guiding and crafting the assessment process was welcomed for its humanistic and holistic method to co-producing short break solutions:

"From a professional point of view, it's much more satisfying. It has given more flexibility for carers to think of different ways that might work for them and there are opportunities there" (O6).

Some staff reflected that the What Matters approach was emblematic of the wider cultural change in social care provision, with a greater focus on mobilising people's strengths, potential, resources, family, and community support, and this required skill and agility on behalf of practitioners engaged in the assessment and support planning process:

"It's more of an equal partnership. It's challenging for carers receiving the service because they're used to going to their local council for advice and What Matters is more of a collaborative conversation, about what your strengths are, how can you help yourself within the community, what are your links? I think people are still expecting a list of services and 'what can I have?'" (S9).

Operational staff discussed how caregiving was internalised by many spousal carers as a natural extension of their martial role. This moral duty to care explained, in part, why carers did not intuitively identify as a 'carer' in need of a break and would often *"struggle along, in that 'we have to make this work', the carer has this expectation of that 'I am the husband or wife and I have to look after them'"* (O1). Loyalty to their identity and duty as a spouse meant the concept of a short break was perceived as failure in their ability and dedication to care, *"[A short break] has to be under the radar to except, I think, because [carers] are so guilt ridden"* (O9).

2.2. Care and support context

As well as the pronounced differences between communities across north Wales in terms of language and culture, staff remarked on variations between local authorities' historic *modus operandi* that shaped the local outlay of breaks provision:

"In each local authority the areas are different, and the people they are working with are very different. In [local authority], they have many little services for carers, and they have their own Carers Officers, [local authority] and [local authority] do not" (S14).

One local authority employed an Internal Carers Team who focused on supporting those facing particularly complex and challenging circumstances, *"We are the only authority in Wales to have such a set up with our Carers Officers. It is unique"* (O5).

Local authorities with a dedicated Commissioning Manager for carer services were juxtaposed to those with Commissioning Officers who oversaw service provision for carers of all ages *as well as* people living with complex health conditions, including dementia. This enabled for a more coordinated approach to commissioning breaks provision, where the effects of services for people with dementia on carers and vice versa could be considered, *"we have to be extremely careful in how we put all our services together and mesh them, so people don't fall through the cracks"* (S11).

The adult social care workforce was described as in *"major crisis"* (S9); high staff attrition was identified as a barrier to continuity of care and the cultivation of carers' trust in staff to deliver quality person centred care and thus support a meaningful short break for their partner living with dementia:

> *"Carers worry while their partner is away because they are not satisfied and confident in the quality and it is not as good as being at home"* (S6).

Strategic staff reflected on the challenges of commissioning for short breaks in rural communities, where such provision was often deemed financially unviable. Rurality also affected the frequency of public transport which determined whether some carers could attend community activities that afforded them a short break from caring.

3. Focal contingences

3.1. Developing equity of short breaks provision across the region

Regional collaboration and use of the Integrated Care Fund. Staff who were part of the regional Carers Strategy Group expressed interest and intent to develop a Short Break Toolkit that defined parameters for eligibility of entitlement to short breaks across the region and supported more equitable decision-making:

> *"There is fresh talk about developing a tool to assess eligibility for short breaks and having some sort of equity across the board on that…it's something we are going to look at regionally"* (S4).

However, the degree to which regional intentions translated into practice was debated amongst staff. Local authority staff in a commissioning role recognised working closer on a regional basis was required because *"we haven't got the staffing capacity to do what is required and sharing resources would support that"* (S1)*.* Where local priorities and circumstances aligned, there was agreement in *"amalgamating and joining forces"* (S1) with neighbouring authorities. In such a context, the Integrated Care Fund supported a sub-regional contract to test a new model of delivering meaningful short breaks:

"[Local authority] have done it ten times better than we have, hence why we have gone for a collaborative approach" (S8)*.*

However, staff reflected on the lack of impetus to use the Integrated Care Fund to embed longer-term change in how the region responds to the identified need to improve planning and commissioning for choice and flexibility of short breaks:

"We have missed a trick… Integrated Care Funding is available for carers, but we have all gone back and had our discussion on a local basis rather than having that regional discussion…we haven't had that regional dialogue" (S1).

The 2014 Act repealed The Carers Strategies (Wales) Measure 2010, which placed the local health board as the lead agency in producing local Carers Information and Consultation Strategies. There was agreement from local authority and third sector staff that since the repeal of the 2010 Measure there was a diluted sense of responsibility from the local health board for carers' well-being and little systematic effort to ensure integration with short breaks provision:

"In the 2010 measure, there was a clear expectation of what local health board had to deliver…some local health boards do some really great work, but it isn't necessarily that connected to local authorities" (S13).

For people with dementia living with complex care or high-level personal care needs, third sector staff emphasised the importance of the collaboration with health services to ensure that the health needs of the person with dementia can be safely met during break provision:

"*Because we are a regulated provider, our staff can help them in the bathroom and do personal care, so the carer can leave them. If the person with dementia goes to other groups, if they need any support at all, the carer must stay because they aren't regulated*" (O8).

Effective coordination between local authorities and carers charities. The carers charities in the region work with and alongside the local authorities to support carer well-being and short breaks. Third sector staff observed that where there was effective coordination and communication with a local authority (i.e., team working, data sharing agreements, and commissioning strategies that harnessed the local knowledge of charities), short breaks were supported in a more efficient and resourceful way:

"The Carer Officer can go straight to the carer's house and phone me from there and say, 'I'm with this carer now, what can you offer' and can we be there tomorrow or next week. Everywhere else it must go through different stages before you can get there, the carer might be waiting six weeks for a break" (O8).

Strategic staff within local authorities commented that commissioning a carers charity to conduct Carer's Assessments established a clear process to access a short break and afforded greater confidence and assurance for carers to know they had an independent assessment. Similarly, the commissioning of short breaks provision to a single carers charity was premised on their capacity to "*do more with less money*" (S12), and ability *"to continue to be creative about providing services and giving [carers]a short break"* (S14) tailored to their personal circumstances.

3.2 Building resilient and inclusive communities

Supporting choice and diversity of breaks. A notable gap regionally in the provision of short breaks was for carers supporting people living with moderate to advanced dementia, who needed support to enable them to maintain their independence and connections to their community:

"I think health and social services need to think, right, there are a whole raft of people in the intermediate stage who have got nothing…I've got five or six couples and the only thing they have got for a break is day care in an institution" (08).

To promote variety and choice of break options, staff spoke of the need to facilitate breaks through capitalising on the abundance of outdoor spaces and natural environments, as well as collaboration with the arts, sports, leisure, tourism, and hospitality:

"We are looking at a woodland project, rather than traditional day care…we are hoping people can use their support budgets to pay for something like that. A lot of people say they want fresh air, they want to be outside" (O6).

There was strategic interest from local authority staff in community break activities (e.g., peer support groups, coffee mornings, luncheon clubs, exercise groups etc.) that could become more sufficient in terms of governance and funding with minimal reliance on statutory social care funding or provision:

"The community itself is really coming behind that project and they're getting legacies from wills…it's that balance between something that was started by the local authority but is taking momentum within the community" (S9).

Carers charities were eager to scale up their respitality offer (i.e., partnering with hospitality, tourism and leisure businesses willing to donate a **break** free of charge or at a discounted rate). Local respitality provision included hotel breaks, spa weekends, and caravan holidays, and presented a choice for the couple to experience a break together or apart. Where the carers charity organised a group hotel or spa break, staff would accompany, organise transport, and be there *"if they need to talk to somebody"* (O7). Group breaks also encouraged social interaction and peer support between those in similar caring circumstances:

"Carers are so grateful they have had two nights away, but they have also met other people…some have set up Facebook groups and have met up" (O7).

Connecting carers to information, advice, and assistance. To empower carers with the information to make an informed decision about the break options available to them, strategic staff in local authorities emphasised having *"more information locally, down there on the ground…this is what we need our communities to be like"* (S11). Within each local authority there was praise for the work of staff (e.g., Community Connectors; Local Asset Coordinators) embedded within the community who provided relevant and timely information, advice, and assistance, and crucially, helped carers make sense of the information and signpost to short break opportunities:

"If things get tough, [carers] have that contact with the Local Asset Coordinator who works closely with our Social Workers here…it brings everything together and I think that early intervention, having information at the right time, and in the right place, is key" (S1).

Local authority staff mentioned developments to their online information, advice, and assistance services, including carer information packs and essential guides, detailing who to contact to request a Carer's Assessment, different ways a break may be achieved and a list of organisations that may support breaks:

"We have made available on your website all the different things that people with dementia and their carers can access" (S3).

Normalising short breaks through carer friendly communities. Alongside momentum to develop dementia friendly communities, staff articulated the importance of cultivating carer friendly communities, where local communities and their residents of all ages and cultures would legitimately recognise carers' rights and needs for a break:

"We need to work with communities better, so the community can be there as a wider support network for that carer, so the carers know that if their loved one wants to go to the pub somebody is there and if they are having difficulties the carer will get a phone call" (O6).

In addition to peer support groups exclusive to carers and/or people with dementia, staff articulated a vision for community activities that were "*more inclusive of everybody who wants more support*" (S9), and therefore appealed to those "*reluctant to label themselves as carers*" (S9).

Volunteers were central to galvanising change and championing people with dementia to be supported to remain active and visible within their community, which could allow carers to have a break (jointly or separately from their spouse).

3.3 Understanding 'what matters' in breaks provision
Features that contribute towards a meaningful short break. Staff identified features of provision that supported a meaningful short break experience and outcomes for the carer and the person with dementia:

- choice in breaks to align with personal preferences (e.g., the couple can experience a break together or separately);

- flexible provision (i.e., regular provision balanced with a break 'as and when needed');

- consistency of short break provider/care staff to establish a trusting triadic caring partnership;

- appropriateness of the break to the person's stage of dementia and tailored to their interests, to support meaningful engagement;

- sustainability of provision so the benefit is cumulative.

Across the region, new models of short break provision embedded some of these features and were being piloted. Examples included Care Co-operatives (pooling support packages for caring dyads with similar needs and interests), personalised support schemes, such as Shared Lives, volunteer-led services, and micro-care enterprises (i.e., small businesses of up to five people who offer flexible and personalised care and support services):

> *"The [personalised support scheme] is a great idea if it will take off. I have loads of people in my case load who need that one-to-one support, who are still quite active and want to go for walks and to do gardening, and to be taken places of their interest… it will help so much with reducing carer breakdown"* (O2).

Acknowledging the merit in the 'traditional'. The consensus amongst staff was that traditional services (i.e., day care, residential care, and in-home break provision) maintained a valuable place within the spectrum of short breaks options. These models were considered important for those living with dementia whose mobility was poor, were living with complex care needs, and needed a safe and comfortable environment to rest:

> *"There are times when actually what you want is 'traditional'. One of the ladies whose husband would come to [residential care home] every year just before Christmas, she would get the house sorted out and get her head straight and it made all the difference to them… I remember saying we're going to close… both of their faces just dropped"* (S7).

Day and residential care homes which provided meaningful occupation for people with dementia (e.g., intergenerational programmes, links to community activities) and had invested in dementia training for its staff were considered an asset; *"We have got the formal day care centre in [Town] which I think is an invaluable service"* (S1).

Staff emphasised that the preference of people with advanced dementia to remain within a familiar environment meant in-home services were essential for carers to realise a break, *"People with dementia tend to like routine and their surroundings, if they go somewhere totally new, it will compound confusion possibly"* (O10).

4. Wider contingencies

4.1. The Integrated Care Fund directive to 'innovate'

Staff reflected that the Integrated Care Fund's directive to 'innovate' risked the consistency of support that was providing breaks in favour of new projects that evidenced 'additionality'*:*

> *"I'm always writing bids and you must tick the innovation box, but what I want to say is 'we want to continue with this effective project, it has been working well'. You can't do that; it must be blooming innovative"* (S7).

Staff reported that carers value reliability and continuity of breaks provision. What 'works' and what is meaningful does not always equate to something new and innovative:

> "*A lot of the things that carers tell us they need, they're not innovative. They are known and they are simple services that don't need to be changed every year or two. That is a difficult thing in an environment where something like the Integrated Care Fund is focused on innovation"* (S13).

4.2. Funding cycles and structures underpinning the 2014 Act

All staff expressed concern over reducing public funds and the pressure to make efficiency savings:

> *"We are having to look at all contracts and assessing where potential saving can be made…the savings we have to make this year are bigger than ever"* (S4).

The need to be "*rational and careful*" (S5) with available resources meant difficult commissioning decisions:

> *"It's half the money they used to give… It's hard…sometimes you must make the decision whether to give fewer people a real meaningful break or give more people less"* (O12).

Local authority strategic-level staff agreed that the 'short-termism' of funding cycles made it difficult to invest in stable and effective partnerships with third or private sector short break providers:

"It takes trust, it takes investment…the funding practices don't encourage sustainability. They don't encourage the retention of a specialist workforce" (S13).

Third sector perception of gaining access to the Integrated Care Fund was described as *"an old boys club…we can't get in"* (S7) and the tendering process as disheartening and overly bureaucratic.

A third sector Chief Executive discussed the challenge of utilising small amounts of funding, awarded through various streams, so all carers within the authorities that they operate, had equity of short break opportunities:

"[Local authority] will give us a set amount, and [Local authority] a different amount from [Local authority] and yet we want to be able to offer the same services to all the carers in the area which means I have to apply for funding from different places to make sure there is equity of service provision for all the carers" (S14).

4.3. The 2014 Act's requirement to involve carers and people with dementia in shaping short breaks provision

Different methods were used to involve carers and people with dementia in the shaping of short break services and supports. Locally, the mechanisms in which information or feedback from carers was gathered included carer forums, viewpoint meetings, case studies of Carer's Assessments (process and outcomes), questionnaires, and surveys.

Voluntary councils and third sector organisations were considered *"better placed to talk to people about their growing needs, as they know the people within their community"* (S9).

At a regional level, a formal requirement was to conduct a Population Assessment which includes the assessment of carer support needs. However, concern was expressed by third sector staff, that it was often the voices of the same demographic of carers, active in their community and 'easy to access' which were captured in this assessment. Yet, the voices of carers in most need of a break, but who could rarely leave their house because of their intensive caring responsibilities, and therefore less visible in their community, were absent.

4.4. Determining eligibility for short breaks

Strategic staff reflected that whilst the 2014 Act recognises the importance of Carer's Assessments to identify, understand, and evidence short break needs, stringent eligibility criteria means that, "*lots of people are getting an assessment and nothing happens anyway…it's just an exercise and they may or may not get services*" (S4).

This meant staff conducting Carer's Assessments needed to be more creative in employing people's resources, families, and communities in supporting a short break:

"*Unless someone is really in crisis, I'm quite often asked to look at community things, can the cared for go to a group that is community based so we don't fund it…I've a gentleman who doesn't want to leave the house, so it makes it difficult… it's hard when you have met the carer and know how much they are struggling*" (O1).

4.5   Discussion

The findings reported in this chapter offer a descriptive model of the short break landscape in north Wales depicting the multilevel contexts, processes, and contingencies involved in shaping short breaks provision. It exemplifies the focus of the region to improve the strategic collaboration across sectors, a broad approach in thinking around how short breaks can be delivered with stronger links to different activities, and the vision for communities where there is a strong sense of civic and corporate responsibility for the care and support of carers and for people living with dementia. However, transforming the ways in which communities and formal care and support services work together to improve access to and choice of short breaks is a long-term programme of work and transformation is likely to be incremental and an iterative process. Much of the work reported in this study was in the initial stages of development. Progress will depend on the long-term investment and securing leadership to build effective partnerships, and the capacity to maximise co-productive ways of working with local communities to make the best use of resources.

The Welsh Government has stated their commitment to reduce inequality in provision of support for carers across Wales through supporting a more regional and integrated approach to service delivery (Welsh Government, 2021a). As a region, while there were strong expressions of future intent to work more collaboratively with neighbouring authorities to offer consistency and parity of short breaks, there was evidence of the legacy of a silo mentality in how local authorities commission support for carers. This was reflected in the current varied offer of short breaks across the region, and the

variation in the robustness and quality of partnerships with carers charities; in the more established strategic partnerships between local authorities and carers charities, these charities took greater ownership, autonomy, and direction for the provision of short breaks in their county(s), buttressed by more sustainable funding arrangements, which enabled them to provide a comprehensive service from conducting Carer's Assessment through to supporting flexible short breaks. However, in some measure, the distinct characteristics of each county, as briefly noted in this study, justifies the rationale for using resources to meet local priorities and that complement local ecosystems of support, rather than pooling budgets. This view has been reflected in the evaluation of the 2014 Act which acknowledged that a regional 'one size fits all' approach can be problematic in responding to sub-regional and locality issues (Welsh Government, 2021b). This highlights the need for further discussions at a strategic level to establish the short break needs and priorities addressed most effectively at a local county level, and those better supported in term of sustainability, availability, and accessibility through a sub-regional or regional approach.

While equitable provision does not have to equate to an identical service offer, it is important that as a region that there are clear mechanisms to share good practice, particularly to improve the sustainability for short breaks in rural communities, which characterise much of the region, and in supporting greater choice for people with moderate to advanced dementia where the provision of breaks requires greater collaboration with health services. At a regional level, these findings demonstrate the need to ensure the meaningful involvement of the third sector and health services in the planning of provision and fundings decisions, specifically to support a greater diversity of social value and third sector organisations in the process of applying for grant monies that encourage collaboration rather than competition (National Assembly for Wales, 2019; Shared Care Scotland, 2021). To support a shared regional expectation and understanding of short breaks provision, Seddon, Andrews, et al., (2021) recommend that each Regional Partnership Board in Wales publish a Short Breaks Services Statement, outlining carers' rights to short breaks, their vision for local breaks options and intended outcomes, and their work to realise this in practice. Shared Care Scotland have developed a template and guidance to develop a Short Breaks Services Statement that is clear and understandable for carers and reflects the region's strategic choices and decisions about short breaks (Shared Care Scotland, 2018).

These findings illustrate the intent of the region to widen opportunities for short break through links with nature, the environment, and outdoor activities. Capitalising on the opportunity to improve social infrastructure through reconnecting rural areas and society, the development of an alternative model

of nature-based day care called 'care farms' has been pioneered by the Netherlands and Norway. Care farms are farms that combine agricultural activities or small-scale commercial farming activities with health, educational, and social services for a range of populations, including for people with dementia. The proliferation of these models is underpinned by a strong evidence base that demonstrates the enhanced holistic well-being and quality of life benefits for people with dementia and their carers compared to regular care facility environments (de Bruin et al., 2012, 2020, 2021; Ellingsen-Dalskau et al., 2021; Finnanger-Garshol et al., 2022; Garshol et al., 2020). With support from volunteers and trained care staff, they offer people with dementia a connection to health prompting and social activities, such as time spent outside helping with animals, gardening, crafts, woodwork, physical activity, preparing food, and provide important structure and a sense of contribution, community, and self-esteem (de Bruin et al., 2021; Pedersen et al., 2022). It is because of these purposeful, active, and engaging activities that carers experience less guilt in having a break, and the care farm model is more likely to support a meaningful break experience and outcomes for both the carer and person with dementia (de Bruin et al., 2015; Sudmann & Børsheim, 2017). Family carers reported that their relative with dementia slept better after attending the care farm, and as a corollary, resulted in a more restful night sleep for themselves (Taranrød et al., 2021). In rural and agriculture regions like north Wales, there may be some transferable lessons in applying the principles of care farm short break provision to local contexts that have easy access to outdoor environments and nature-based activities, and that can help preserve local activities, Welsh traditions, and Welsh culture and heritage (de Bruin et al., 2020).

4.5.1   Future research directions

The challenges associated with scarce funding and resources underlies the need for evidence informed commissioning to ensure model/service effectiveness in releasing meaningful outcomes for carers, people with dementia, and society. However, research on the efficacy of short breaks is stifled by methodological and conceptual inconsistency, notably, the lack of a cogent and consistent definition, inadequate or loosely defined service models and their operationalisation, lack of theoretical underpinning, and the application of overly rigorous evaluative design (Arksey et al., 2004; Chappell et al., 2001; Maayan et al., 2014; Zarit et al., 2017). Given the complex and intersectoral nature of short break provision and model heterogeneity, a range of methodological approaches are likely to be needed (Mason et al., 2007). To determine the change outcomes attributed to short breaks services or support, Kirk et al., (2015) offer a useful continuum of methodological approaches that reflect the stage of model development. Although the degree to which outcomes can be absolutely attributed to a particular short break service or activity will always remain limited (Barrie & Miller, 2015), the matching of methodological rigour to level of short break model development is an attempt to ensure

the prudent use of resources and appropriate methods to deliver as reliable findings as possible. Kirk et al., (2015) argue that the carer should be regarded as the primary beneficiary of short breaks, and all short break research should include, as a priority, at least one measurable outcome for carers relating to their quality of life, well-being, caregiving competence, or self-efficacy. Where feasible, additional outcomes for the person with care needs, family system, and society should be measured.

Quality of life and well-being outcomes valued by carers have been identified in a range of toolkits and frameworks including the Carers Outcomes Agreement Tool (Hanson et al., 2008), the Adults Social Care Outcomes Toolkit for carers (ASCOT-Carer) (Rand et al., 2015), and the Talking Points Framework (Cook & Miller, 2012). These toolkits identify broad areas for support (e.g., enough time away from caring to have a life of their own outside of the caring role), that can help demonstrate the contribution of services and supports on carer quality of life (Cook & Miller, 2012; Rand et al., 2015) or negotiate for better outcomes (Hanson et al., 2008). Specific outcomes stemming from short breaks have also been recognised. In Scotland, the Shared Care Short Breaks Evaluation Toolkit groups outcomes contributed by short breaks into three categories. Those that arise from 'Taking the Break', including improved morale and confidence as a carer, outcomes experienced 'After the Break', such as more able to maintain the caregiving relationship, and 'Long-term' outcomes, namely, a reduced likelihood of breakdown and crisis in the caring role. In Wales, Rochira (2018) proposes a short break outcomes framework for people with dementia and carers, which promotes connectedness and coherence with the National Outcomes Framework, that describe the fundamental outcomes that people who need care and support and carers should expect to lead fulfilled lives (Welsh Government, 2016). In turn, this short break outcomes framework is hoped to promote the development of more meaningful models and promotion of evaluation measures that reflect the core well-being outcomes for both carers and people with dementia. Over time, short break providers can expand upon this core set of outcomes to include specific additional or unexpected outcomes acknowledged by carers and/or people with dementia arising from their short break experience (Barrie & Miller, 2015).

Although methodological challenges pertain in how to conceptualise and capture dyadic outcomes (Zhang et al., 2022), the relational impact arising from short breaks is relevant to guide care planning and service delivery in line with a whole family approach to care and support that recognises the reciprocal impact and nature of caregiving (Carers Trust, 2023a; Kirk et al., 2015; Mason et al., 2007; Rand, Zhang, et al., 2022). Further, while the focus on proximal outcomes (i.e., immediately observable) is well established, longitudinal research is needed to capture distal outcomes (i.e., that emerge over time) that reflect trajectory changes in carer well-being following sustained short break

engagement (Gaugler et al., 2005). This evidence may help delineate the efficacy of different types of short breaks over time and their suitability for carers at different points along their caregiving career (Seddon, Miller, et al., 2021). Alongside contribution to well-being outcomes, the demonstration of cost effectiveness or Social Return on Investment (SROI) provide compelling economic evidence for policy makers and commissioners surrounding the costs and benefits of short break provision (Kirk et al., 2015; Mason et al., 2007; van Exel et al., 2006; Vandepitte et al., 2020). In Wales, new research is establishing the utility of SROI analysis, a form of cost-benefit analysis, as a method to evaluate an alternative to day centre support for people with dementia and their families (Toms et al., 2020).

4.5.2 Study limitations

Many different methods for data collection and consultation with carers were alluded to by the staff participants, but a weakness of this study was that it did not question participants more thoroughly around how this data on carers' short break needs, desired, or realised short break outcomes were being collated and operationalised (i.e., aggregated at a service level or triangulated with other data sources) to guide planning, commissioning, and improvements decisions about short breaks. The coordination of data from carers is essential to guide improvements in how short breaks are supported, both at an individual and service level. This may relate to how data captured and recorded during individual Carer's Assessment is analysed and feed through to supporting service level improvements. Arguably, difficulties in how data is managed can be attributed to the many different organisations involved in supporting short breaks, several local data systems, and variation in who conducts Carer's Assessment, raising issues around data sharing and confidentiality.

Considering the diversity of organisations (i.e., local authorities, carers charities, and dementia charities) involved in the assessment and delivery of short breaks evidenced through this study, these findings strengthen the recommendation of the National Assembly for Wales for there to be stronger leadership in how data on carers from across *all* sectors is coordinated and utilised (National Assembly for Wales, 2019). This includes the development of National Guidelines to determine what data needs to be collected, how it is to be collected, and how it will be used. Helpful insight, particularly in relation to recording information during the assessment and support planning process, can be gained from the Meaningful and Measurable project (Miller & Barrie, 2016). The Meaningful and Measurable project was developed in recognition of the difficulties associated with the recording, analysis, and use of personal outcomes data at all levels of health and social care organisations. In collaboration with seven social care organisations in Scotland, and one local authority in Wales, the project examined the difference made by focusing on outcomes in health and social care practice, including how best to capture and use personal outcomes data. Amongst important themes generated through this project,

there was consensus around the need to elevate the status of and clarify the purpose of recording and measuring personal outcomes. This meant shifting the focus from viewing recording outcomes as a transactional exercise, conducted primarily for bureaucratic or accountability purposes, to be understood and valued as a relational practice, central to generating personalised outcome data of sufficient quality to inform decision-making. Noteworthy, project partners reported that the more insightful and most useful outcomes focused data tended to be recorded outside of formal documentation such as support plans, limiting the potential for this data to be harnessed in constructive ways. Practitioners also emphasised the value of recording carer's words and reflecting these back, which supported carers to feel heard and listened to, and encouraged reflection and accuracy of recording. The main area of collated outcomes used by practice partners related to practice improvement and service development in the form of IT adaptations, tool development, and staff support and development initiatives. This necessitated the creation of a feedback loop for the sharing of information and, more importantly, the ability to makes sense of individual experiences and mobilise this knowledge to support service or organisational improvement. Only as a secondary concern was outcome data used to demonstrate service performance to external audiences. Notably, this demonstrated the distinction between using personal outcomes information to 'improve' or 'prove' and refocused the importance of capturing outcomes at an individual level, and the quality of this process to ensure credibility of information, which in turn can be used to inform whole systems change (Cook & Miller, 2012).

While purposive sampling has many advantages, namely, the flexibility to concentrate on those best suited to contribute to the research objective, the external validity of findings is low, limiting the transferability of these findings to other service settings. A limitation of this study is the absence of health professionals and representatives from private short break providers. Improved integration across sectors, especially with health, is a priority for new models of community-based care and support (Welsh Government, 2022a). The perspective of these sectors would have enriched the robustness of these findings. There was also a lack of insight in how, or if, third sector organisations work together to support short breaks. Exploring the depth and breadth of collaboration, or competition, in supporting short break provision between local dementia charities and carers charities would provide for interesting comment.

Focus groups (N = 8 to 10) that brought together professionals from the different local authorities, health services, third sector charities, and private providers, may have stimulated more energetic interaction and discussion, and expanded on the differences in perspective or experience, and how

this guided thinking around short break provision. This may have supported a more coherent and shared construct of what 'innovation' means in short break provision, as the term was often used in different ways. This view corroborates the conclusion of the evaluation of the Integrated Care Fund that greater clarity on what 'true innovation' means in practice is required to avoid synthetic interpretation (Welsh Government, 2022b).

The differences between the local authorities' organisational structure and hierarchy meant recruiting equivalent professional counterparts, to enable comparison, was difficult. The sample's lack of diversity in staff conducting Carer's Assessments amongst local authorities and third sector organisations meant detail gathered on how assessments were navigated, the prominence given to understanding and identifying carer short break outcomes, and how the strengths-based approach to supporting short breaks was enacted, was minimal. Nevertheless, a strength of this research was that most interviews were conducted in person, and this supported high-level engagement from participants. Open ended questions allowed for depth and vitality of response. Topics often arose organically as the conversation evolved; this natural ebb and flow of conversation would have been difficult to achieve over the phone or online. In person meetings strengthened the researcher's professional network building capacity, which subsequently encouraged participant engagement in the knowledge exchange event (reported in Chapter Six).

4.6   Conclusion

The model of the short break landscape presented in this chapter is a useful construct to help visualize current factors influencing efforts to improve access to a sustainable choice of short break options across north Wales. The model supports the interpretation of challenges and opportunities associated with the planning, commissioning, and delivery of short breaks to increase local practice wisdom. Through highlighting complex context-specific processes and contingencies, the model reaffirms the understanding of a short break as a complex intervention, both in terms of the intervention itself and in the systems which it is implemented (Evans, 2013). The model contributes towards preliminary theory development of 'what works and under what circumstances' in short breaks provision (Pawson et al., 2005). It also helps identify topics that warrant a more focused investigation, for example the identifying and evidencing of short break needs and outcomes during assessment and support planning. The next chapter of this thesis presents spousal carers' experiences of accessing short breaks over the caregiving career. Carers' evolving short break needs are explored and what they ascribe as a meaningful short break experience and outcomes are described.

Chapter Five: Understanding break needs, break experiences, and break outcomes over the caregiving career: a narrative approach

5.1   Introduction

The experience of becoming a carer for someone with dementia, although diverse and varied for many reasons, is typically marked by the introduction to a terrain of uncertainty and unpredictability (Lee et al., 2019; Lin et al., 2012; Macdonald et al., 2020). During the years in which carers provide support, they will inevitably experience change across many dimensions of their life (Cooper et al., 2022; Miller-Ott et al., 2022). The international literature emphasises caregiving as a developmental process, far from static in nature, but dynamic in which identity and relationships evolve, and demands and stressors change over time, superseding or compelling a carer's ability to adapt to and cope with their caring role (Clemmensen et al., 2019; Gaugler & Teaster, 2006; Pearlin et al., 1990). Correspondingly, in response to these changes, carers' needs and preferences for support will fluctuate over the disease trajectory (Hodgson et al., 2014; Kinchin et al., 2022; Kokorelias et al., 2020).

It has long been argued that a critical organising principle within the typology for carer support should be the temporal dimension (Aneshensel et al., 1995; Gallagher-Thompson et al., 2020; Nolan et al., 1996, 2002). Understanding carers' changing experience and needs over time is identified as a global priority for developing support or interventions across the caregiving career (Harvath et al., 2020). Short breaks have historically been positioned as a preventative intervention as their consistent use over the caregiving career contributes towards their efficacy (Bangerter et al., 2019; Gaugler, Jarrott, et al., 2003; Gaugler, Zarit, Townsend, et al., 2003; Kosloski & Montgomery, 1995; Y. Liu et al., 2015). However, there is limited understanding of how carers' break needs evolve in response to the degenerative course of dementia. While the heterogeneity of short break services accounts for considerable variation in experience and outcomes supported (Arksey et al., 2004; Maffioletti et al., 2019), a better understanding of the temporal dimension to short break needs can help inform the planning processes, commissioning, or improvement of services to enable carers to have a life alongside caring. This knowledge is pertinent to advance significant gaps in knowledge in caregiving intervention research (Harvath et al., 2020), but is also central to realising improvements against Welsh Government priorities for carers: throughout their career, carers should have equal and timely access to a choice of short breaks that reflect their needs and outcomes (Welsh Government, 2021e).

In response to this knowledge priority, this chapter is an attempt to contribute a temporal understanding of how carers' short break needs evolve in response to the degenerative course of dementia, and how they are supported. This is an area of knowledge that is currently poorly understood and under researched (Seddon, Andrews, et al., 2021; Seddon & Prendergast, 2019). The research reported in this chapter aggregates the short breaks stories of spousal carers for people with dementia. This study adopts the career perspective of caregiving to orientate attention to the temporal sequence of events. Whilst it was not the aim of this study to identify and define the precise stages that carers progressed through, the intent was to construct an experiential temporal description of the caregiving career. The scaffold of the caregiving career enabled spousal carers' evolving break needs, experience of accessing breaks, including the provision of information, advice and assistance, and the availability and choice of break options, to be explored.

Using a narrative approach to data collection and analysis, the stories of thirteen spousal carers were used to construct a collective narrative of the caregiving career. This career was marked by the continual adaptation and acceptance of acute and gradual changes to the caregiving relationship which influenced short breaks needs. Desired short break outcomes were considered within the

context of dementia spousal relationships. Irrespective of when in the career, the process of deciding upon a meaningful short break was relational and emotive, emphasising the relevance of practitioner guidance and skill to negotiate options, balance priorities, and aid transitions to breaks of mutual value. Outcome focused conversations are needed to provide carers the psychological space and chance to reflect on their lives and identify their short break priorities. Practitioners who undertake Carer's Assessments have a vantage, yet complex task, to guide such conversations, and to utilise the understanding gained from genuine dialogue and discussion to help carers to realise their short break outcomes. With the deepening cognitive and physical impairment of the person with dementia, spousal carers encountered difficulties in achieving breaks due to relational and service factors. The conceptualisation of caregiving as a series of shifting configurations underlines the necessity for ongoing practitioner engagement to help carers consider what matters to them, and proactively anticipate and respond to changes in what matters, within the context of changing situations.

5.2   Method

To explore how spousal carers' short break needs evolve over their caregiving career, the stories of spousal carers were sought. Narrative research is the study of stories. Across cultures and ethnicities, stories are familiar patterns, and in those patterns, meaning is constructed through experience, and preserved through plot, settings, characters, and actions. Polkinghorne espouses the narrative is 'the primary form by which human existence is rendered meaningful' (Polkinghorne, 1998, p. 11).

The narrative interview is a method to encourage and stimulate storytelling (Jovchelovitch & Bauer, 2000). Specifically, the meaning brought to experience, and the stories told about that meaning (Polkinghorne, 2007). Harnessing the natural propensity for humans to compose, structure, and make sense of their reality through storytelling, a narrative approach allows for an emic perspective of individual or collective lived experience across time within a particular social milieu (Connelly & Clandinin, 1990; Squire et al., 2015). A narrative approach has been used to understand the experience of carers for people with dementia, how carers articulate their support needs, negotiate identities, and endow their caring role with meaning (Tretteteig et al., 2017a; Varik et al., 2020; Witham et al., 2018). The Biographic Narrative Interpretive Method proposed by Wengraf (2011) was adopted in this study and supported a holistic psychosocial inquiry of lived experience.

5.2.1   Data collection

Convenience sampling was used to identify spousal carers willing to articulate their short break experience(s). Convenience sampling is considered a time and cost-efficient method (Stratton, 2021).

Recruitment was supported through members of the Project Advisory Group and local third sector carer organisations and networks, who promoted the opportunity for carers to share their short break experiences. This helped ensure that those who were motivated to share, had an interest in the topic, and were available to participate responded to the invitation. Although this method did introduce an element of motivation bias, through advertising the research opportunity through diverse channels (e.g., carers' newsletters, support groups, carers' forums, social media etc) it was envisioned that a reasonable and varied sample would be achieved. It was anticipated that challenges to recruitment may be the belief that involvement will be demanding and time consuming. For carers, in addition to their caregiving responsibilities, this may have deterred their participation. However, because this study was undertaken when COVID-19 guidelines applied, conversation and interaction with carers was restricted to online or over phone. In some cases, this may have encouraged carer participation as it meant that in-person conversation, as originally proposed as an option, was not permissible. The researcher could not conduct the interview in the carer's home, which some carers may have found intrusive and distracting. Likewise, it negated the effort on behalf of the carer to travel to a place of convenience outside of their home to be interviewed, which could have required arranging replacement care for their partner.

Participants (n=13) received a bilingual project information sheet (Appendix 3), and formal consent was gained (Appendix 4). Interviews were conducted between March and September 2021. They were conducted remotely, in line with COVID-19 regulations, either by telephone (n=9) or using the online platforms Zoom or Microsoft Teams (n= 4). Interviews were recorded to allow the researcher to engage in active listening and avoid having to take notes continuously. Data was securely stored, in a password protected folder on the researcher's University M drive, in compliance with General Data Protection Regulations.

Personal narratives were elicited via the Biographic Narrative Interpretive Method (Wengraf, 2011). This method is an unstructured in-depth interview that does not follow the typical 'question and answer' format, rather the elicitation of the story is based on a single question, broad enough to prompt a substantial story. Compared to the semi-structured interview format, this method permits participants the psychological space for reflection and devoting time to what *they* deem meaningful to their story. The generative single question, inviting participants to tell their story, was:

"Please tell me about your story of caregiving, taking me through the support you have received that has helped you in your caregiving role, and the ways you have been able to experience short breaks

from your caring responsibilities and routines. You may start at any point in time that feels right for you."

During the storytelling the role of the researcher was minimal and discrete; they did not interrupt or disturb the flow of storytelling, until there was a clear coda which signalled the natural end of the story. Once the participant reached a natural conclusion to their story, specific questions, based on individual narratives, were asked to help clarify the narrative and gain greater understanding of how (or if) short breaks were supported. During this phase, 'why' questions were avoided as to minimise the perception of cross-examination that may have caused the participant to feel uncomfortable or to have to justify their reality or actions. The duration of interviews ranged from 60 to 90 minutes. Potential benefits for carers of sharing their story was the cathartic effect, and the opportunity to voice their reality and have it heard and to be listened to, without judgment or the conversation being part of a formal assessment of need. However, there was a risk that the revisiting of stressful events, or worry and apprehension for the future, could cause emotional distress. To minimise any potential distress, carers were reminded that they could stop or pause the conversation at any time and a list of organisations offering professional support was made available. Mindful of the Active Offer (Welsh Government, 2015a) interviews were offered in English and Welsh. A translator was arranged for one interview, to give the carer the option to speak in both English and Welsh, however, they predominantly spoke in English. All remaining interviews, at the preference of carers, were conducted in English.

5.2.2   Participant characteristics

Eleven narratives were from spousal carers whose relationship with their partner predated the onset of dementia and continued to evolve as the dementia progressed; the longest marriage was 67 years. Two narratives were provided on behalf of spousal carers by their adult daughters who were involved in supporting their parents and shared their parents' story. Spousal carers' age ranged from 69 years to 87 years; the mean age was 76 years. People with dementia ranged from 66 years to 94 years of age; the mean age was 80 years. Eleven spousal carers were female, and two were male. Three people living with dementia were diagnosed with an additional neurological disease, and one person with dementia had long-term physical disabilities. Three people were bed ridden and being cared for at home. Within the last two years (from date of interview), three people with dementia had moved into nursing or residential care home and one person with dementia had died, however their death was preceded by a move to a residential care home.

5.2.3 Data analysis

The interpretative and analytical process reflected a holistic-content approach as described by Lieblich et al., (1998). This approach preserves and embraces the narrative as a whole, allowing for the sequencing and progression of events distinctive to the caregiving career (Andrews et al., 2013). As such, this approach is well suited to Wengraf's (2011) recommendation for interpreting data elicited via the Biographic Narrative Interpretive Method, in which the lived experiences of participants are chronologically structured, and the dynamics of whole cases can be compared and used to lay the basis for theorisation.

Transforming interviews into a storied description started with the transcription of interviews. Immersion and familiarisation with the content was supported through several readings. Next, the storyline was crafted by attending to two flows of decision-making (Wengraf, 2011). Firstly, the flow of decisions about carer's lived experience (i.e., objective life events revealed through their narrative), and secondly, the flow of decisions in the *telling* of how breaks were experienced, and the meaning and emotional responses ascribed to those experiences. Forming a coherent textual narrative involved an element of narrative smoothing (Kim, 2015) and the judicious selection of aspects of multiple individual stories that best illustrated shared experience. The software package Atlas.ti 8.2.34. (Smit, 2010) helped organise the data and facilitate data searching. Carers were assigned a pseudonym to protect their anonymity.

5.3   Findings

5.3.1   An experiential description of the caregiving career

In this study, the caregiving career is based on the stories of 13 spousal carers and begins from formal diagnosis. While there were periods of stability of varying length, the degenerative course of dementia meant that over time the intensity and range of caregiving responsibilities for all carers gradually increased. For some people with dementia, the presence of comorbidities exacerbated the progression of dementia and increased the complexity of their care and support needs. Acute functional decline of the person with dementia was often the result of a fall or infection that required hospitalisation, and difficulties were reported in adjusting to caring at home following a stay in hospital. The changing nature of the spousal relationship influenced carer's sense of identity and sense of couple hood. Over time, the range of activities that couples enjoyed together, such as walking, cultural activities, debate and conversation, and travel, became less frequent and, practically and emotionally, more tiresome to arrange. Caregiving in older age (65 years and over) exacerbated

emotional vulnerabilities, such as lack of self-confidence and assertiveness, which made navigating the health and social care system to access timely and appropriate breaks difficult without guidance from practitioners. Carers reflected on their limited physical strength and capability to support the person with dementia, who in this study were mostly male, with personal care tasks and required support from professional carers to help them at home. With career progression, a multitude of interrelated factors, namely the escalation in caregiving and household responsibilities, increasing care dependency and distress shown by the person with dementia, and wearisomeness and monotony of caregiving routines, left carers feeling overwhelmed and exhausted by their caregiving role. Sleep disturbances affected the quality of life for the couple and the distress shown by the person with dementia posed new challenges for carers who had to adapt home environments and daily routines and learn new ways to communicate and comfort their partner during periods of confusion or upset. For the five people with dementia who did transition to a care home, one move was precipitated by a breakdown in the caregiving relationship and was an emergency care home placement. For the other four, this was a deliberate but difficult decision, based on the person with dementia needing more care and support than the carer could provide by themselves. One carer refused an initial residential care home placement based on concerns over the quality of care. With the move to a new home for the person with dementia, the balance of carers' responsibilities shifted from physical care tasks towards providing emotional reassurance, so their partner felt comfortable in their new home and retained a sense of purpose and agency. Throughout their career, carers demonstrated dedication and commitment to caring for their partner, despite experiencing a depletion in their own well-being and resilience. Carers grieved for the diminishing loss of connection to their partner who they could once reflect on their shared history together and discuss their hopes for their future. Carers shouldered the responsibility for both their well-being and the weight of these responsibilities was compounded by the loss of support, security, and reassurance that their partner used to provide as a husband or wife. Daily, carers oscillated between and grappled with a conflict of emotion and feelings, such as sadness, frustration, regret, longing, guilt, and loneliness. Many carers, although acknowledging a shift in their self-perceived identity from a spouse to a carer, reflected on the moments that they could connect and relate to their partner, find joy and purpose in their caring role, and emphasised the importance of appreciating and treasuring these moments, however fleeting they may be.

5.3.2   Carers' changing short break needs

Following the formal diagnosis of dementia, there was a period, varying from a few months to several years depending on how advanced the dementia was at the time of diagnosis, where couples' needs for breaks emulated their pre-existing routines and preferences. For Mark and his wife, they continued

to take breaks away together through their local tour company. During these breaks, Mark had minimal responsibility and could relax in the company of his wife:

"We have been all over the country with [tour company] …going on these tours, we've met a lot of people over the years, and everything's laid out. You get different attractions… It's all arranged for you, so you know what you're doing. Because it's a lot of stress, if we went somewhere on our own you've got to find something to do… You get a full cooked breakfast in the morning, and you get a three-course meal at night…I don't have to drive."

Over time, the cognitive and physical functioning of the person with dementia deteriorated. Catherine acknowledged that, due to her husband's deterioration, the time for going abroad on holiday, which provided a break for them as a couple, had passed:

"[Husband] has been dying to go on holiday, we always go to [country], but to entertain that with him how he is, if he gets any worse, that would be difficult".

The declining self-care capabilities of the person with dementia meant that the caring role intensified, and carers recalled feeling more consumed by responsibilities with less time for themselves and to do the things that brought them meaning and enjoyment:

"I see from everything from his clothes to his tablets and making sure he has a shower; he wouldn't want somebody coming in to help him shower or do anything like that. My time has virtually disappeared…I have so many phone calls and things to deal with, my time isn't my own. I am just tired all the time; I wake up in the morning and I think I don't want to get up"
(Catherine).

Carers reminisced about the former aspects of their relationship that they missed. Louise remarked on her mother's sadness at the fading of activities that her parents previously enjoyed together and that provided her mum with regular short breaks:
"Breaks were going to pubs for lunches and going for nice walks...But he, as time went on, just got less confident about walking very far, even going to see films, everything just felt a bit of a big deal for him, he would rather just sit in his comfortable chair where he felt safe and secure. And that was really frustrating for Mum."

Reflecting these transitions in the relationship, carers' needs for breaks were so they could continue to nurture their well-being through activities, friendship, and reciprocal support. They relied more on their community, friends, and family, to achieve a break:

"Conversation is limited…he is often confused…I think twice before I say anything, which doesn't make for spontaneous conversation…I go on a Monday morning to the leisure centre, they have just started this, it's free from 10am to 12pm, you can go to the gym or play table tennis or a bit of aerobics, I really enjoy it, and it's so nice to see different people" (Molly).

Community groups or clubs, designed for carers and/or people with dementia, were identified by five carers as providing a short break from their caring responsibilities, and as a source of reciprocal support and learning:

"The most important thing in my month was the day at [carers charity's club], because you got to share your problems and find out information and know you are not alone.…You would be doing things for half the session, and then have some lunch, the people with dementia would be entertained and we (carers) would go off and have a talk about things that were available and that kind of thing. Just having a day with other people in a similar situation that was the best part" (Bianca).

However, for others, as Catherine articulated, these groups reinforced her preoccupation with dementia and caregiving in a way that wasn't helpful for her and did not provide a break, at that point in her career:

"They suggested I could talk to people who have similar problems…I just wanted time to relax and not to go deeper into the problems. I felt I was being drawn deeper and deeper into the Alzheimer's, rather than adapting to things in my own time".

Carers conceded that their own health concerns made their caring role harder. Coupled with the increasing dependency of their partner and intensity of caring responsibilities, break needs were for sufficient time to disengage and recuperate from their caring role and demands, psychologically and physically. Carers spoke of needing longer and more consistent breaks that helped them relax and revive their energy levels. In-home break provision, where replacement care was provided by a paid

carer or support worker, commonly once or twice a week, for two hours, was deemed insufficient to meet carers break needs as their career progressed:

"It did help but I still needed a lot more than that…It was only two hours once a week, that is not a lot out of 24 hours, when you have the other 22 hours to do…it would have been nice if I could have just gone on holiday for a week" (Caroline).

For five carers, after many years of caregiving at home, they acknowledged that the physical care or behavioural support needs of their partner were beyond what they could confidently and sustainably meet. On balance, it was in both of their interests for the person with dementia to permanently move to a nursing or residential home. However, following the move to a new home for the person with dementia, the caring role continued, and carers' needs for breaks remained high. Geraldine described how she relaxed and restored her energy so she could continue to support her partner in his new home:

"Even though he's in care, I'll never stop caring. I find it difficult because I worry about him emotionally…He's got a phone, he phones me a thousand times a day…and I just say the same, "Yes, it's fine"…in the night my head nearly splits…Since he's been in care, I go every three weeks to have a facial, body massage, pedicure, manicure, and I do feel an immense physical relief from that".

5.3.3   Carers' experiences of accessing short breaks

In the beginning of the career, community activities, that were either dementia specific or inclusive groups that welcomed people irrelevant of diagnosis, were perceived by many carers as an accessible, inexpensive, and consistent way of supporting regular breaks, with the added value of peer support. Jane explained how these community groups supported her parents to preserve their sense of couple hood and social connections and brought structure and routine to their week:

"They were attending local community groups, boules, and art and walking with friends, and with these regular activities, my dad was getting enough respite…they were doing activities with an older age group, citizens who were more worldly-wise…I think there might have been one or two other people who had early stage dementia, at least one person with Parkinson's and one person with multiple sclerosis…They knew that my mum was showing some of these

behaviours, but they just accepted it, and patiently answered the same question every few

minutes."

The availability of inclusive or dementia friendly activities were dependent on where the couple lived. Following the diagnosis of her husband, Francesca proactively decided to move to a town with a better variety of activities for people with dementia which would also enable her to have regular breaks:

"I decided because we were rural, nothing going on, nothing to do, in the winter its dead and it

can be quite depressing, so I said, 'shall we move to [town], we have friends up there…I looked

into the kind of dementia activities, and there were loads, places I could take him and leave

him for a morning which would help me."

As time went by and carers grew uncomfortable leaving their partner by themselves at home, or their partner exhibited distress in the absence of the carer, achieving a break became more difficult and required more planning and organisation. If the couple had children, they enabled their parent to have a weekend break. In some instances, adult children worked abroad, or due to their own family and work commitments, the support they could provide was temporary, and not a regular option:

"I was really having a hard time and so my children then gave me some respite…it wasn't

sustainable, they both have hard jobs…my daughter has a family, my son has a full-time job in

London…they both had to take annual leave from work" (Caroline).

Carers tried to seek more practical support and guidance from health or social care professionals to experience a break. The immediacy of this support was paramount to ensure access to a timely break. However, the prevailing perception around accessing timely support from local authorities to support breaks was one of difficulty:

"The local authority will say, 'we have this service and this service' but, when you dig into it, they aren't available either through lack of staff, lack of money, or the ridiculous high criteria…There was volunteer buddy system that [husband] was on the waiting list for over a year for, when I chased that up, they said the waiting list is so long, realistically, you aren't going to have anybody." (Caroline).

Catherine recalled that despite being given information about break options, the lack of guidance to help her make sense of the information and talk through options meant she struggled to think about how her break needs and outcomes could be met:

"I feel sometimes I get bogged down with all the information and trying to take it all in… People seem to link you all together as though you are the same, but dementia doesn't affect everybody the same, and in practical terms things don't always work… the things that they are telling us to take part in don't suit our needs. I do feel overwhelmed with everything that has been pushed in front of me."

Bianca expressed her uncertainty in knowing where to look and who to ask for support in accessing a break and understanding her break options as circumstances changed:

"Some people, including myself, need a helping hand through these things, rather than being left to do it by yourself…clarity, on 'this is the person you ring if you want respite care' …and to give a roadmap of where you are on it and when you get to this point, we can do this, that and the other".

The value of a practitioner who offered supported choice was relayed by Geraldine who spoke of the succour received from her local Carers Champion who listened and discussed with her the ways she could experience a break that would balance her and her partner's needs. Day care was chosen as it was a steppingstone to eventual residential care:

"It was not leaflets I needed…I needed a person one-to-one, and the Carers Champion was on hand for me all the time…Without her I wouldn't have been able to help [husband]…she advised me, listened to me, helped me, she told me about day-care…If he hadn't gone to day care, he would never have settled in a care home".

By contrast, despite acknowledging Molly's urgency for a break, Molly expressed her disappointment at the lack of communication and engagement shown by her Social Worker, when she was trying to arrange a residential break for her husband:

> *"She said I would be put at the top of the list for respite and she would ring me weekly to see how I was coping, and she would keep in touch...I don't hear from her unless I ring her... she said she would come and visit me one week, she didn't come...I just think, what is the point, I am getting no support."*

Communicative tensions were present between some couples which made some carers feel guilty about articulating their break needs and taking a break. With the increase in caregiving responsibilities, Catherine described the sensitivities of explaining to her husband that she needed a break and some time for herself:

> *"We were discussing whether it would be a good idea for me to get away for a while and his answer was 'why would you want to do that', and I said ' to recharge my batteries because am I so tired', and his response was 'why are you so tired, I know you do a lot and you look after me, but you won't let me do things and you won't let me drive' and then it goes on or we end up in an argument."*

A typical arrangement to facilitate weekly short breaks for a few hours was through in-home break provision. For some couples, this break option worked well and the rapport between the person with dementia and the support worker was strong and instant, easing the ability for carers to have some time to themselves knowing their partner was content and safe. There was flexibility for the care worker to go out with the person with dementia or stay at home, depending on their ability and preference on the day; "*From day one, he checked on what [Husband] hobbies were. [Husband] likes steam trains and the first thing he did was take him up to train station and they had a coffee*" (Lucy).

In contrast, however, this arrangement proved more difficult for Jane and her parents, who as a couple were used to doing things together:

"We did try getting a support worker, which we were paying for, to come in. The idea was that she came in a couple of times a week for an afternoon and that would provide a break for Dad. She was a lovely lady, but it just didn't work out. It's a problem with a lot of couples that they don't particularly want somebody else in their home, and they don't want to do anything without their partner. We were trying to create jobs for this lady to do, which wasn't achieving the outcome, nobody was getting a break…we gave up on that idea."

Edward described his experience of using Direct Payments to employ a small team of carers to help him care for his wife and allow him to take a break for a couple of hours each week to go for a walk. Although the Direct Payments did offer control and flexibility over who he employed, the support provided by the local authority to help manage the Direct Payments was unreliable:

"If I didn't have the ability to be as proactive as I have been and find things out for myself, then it wouldn't have been easy…they haven't got one person who the Social Workers can contact, or anyone can contact who knows what happening with Direct Payments".

Edward further described the pressures he faced in finding highly skilled and dedicated care staff to become part of his caring team, "*We have been struggling to get the amount of care that [wife] should be having, it's so difficult to get a good carer…that is one of the main difficulties, finding suitable carers who you know and trust.*"

As their partner become less physically mobile, carers conveyed their concern and frustration that there were limited activities that provided meaningful engagement for the person with dementia, and this was a barrier for the carer to achieve a break as they could not find any suitable activities that would relieve them of their caring role:

"Up until 18 months ago, he was going to indoor bowls on a Friday afternoon, and he loved it, and it was keeping him active. I would leave him with all the other bowlers, and I would go next door and have a coffee with my friend…but now he won't do anything, he doesn't even watch the television; there is nothing for him anymore, no stimulation".

As caregiving demands escalated, a sufficient day and/or night rest was crucial for carers. Carers frustratingly reflected upon the limited choice and availability of break options for them to experience a full day for themselves. Day care or residential care were the only two options referenced and both

options were caveated by contingencies and reservations pertaining to service factors (e.g., long waiting lists, care quality) and personal factors (e.g., reluctance of the person with dementia to attend, carer guilt). Felicity described her husband's preference to stay at home, which meant that day care and residential care were not deemed appropriate break options for their situation:

"We tried to get him to go to this day centre…a couple of times when [husband] was more in the mood of getting in the wheelchair and a car, we almost got him to go, and then he'd back off at the last minute and he wouldn't go…we did also look at one stage at [husband] going into a respite home placement for a short break so that that would give me a break, and it just felt like it was not going to work for him".

5.3.4 Carers' short break outcomes

Regardless of when in the caregiving career, a break supported meaningful outcomes for carers when it enabled them to nurture the aspects of their well-being that mattered most, whether this be solitude or time with their partner but in a new environment that offered a pleasant change from caregiving routines. Carers often chose ordinary and modest things to do with their time. The simplicity of her mother's choice of how to spend her short break was noted by Louise:

"Her plan was to walk around and see the birds because she hadn't seen them for ages, but she just ended up going and sitting on a bench and reading the newspaper and enjoying the sun and just sitting… those just still things, just calm things is what she mostly wanted".

Catherine used her short break to enjoy time socialising with friends which reminded her of a life outside of her caring role:

"I went and stayed at a friend's house. It was social, we went out to eat, we had a bottle of wine, we went for walks, it was just lovely, it was like being plucked out of one world and put into another nice world".

Following a break, carers commented on their increased compassion within the caregiving relationship, energy to be in the present moment with their partner, and patience to communicate with empathy; *"Because you've had a break, you've got more patience"* (Rebecca).

An important short break outcome for Francesca was that it helped her and her husband to relax and feel rested, which in turn supported a more positive caregiving relationship:

> *"We stayed at this beautiful hotel, we went to dinner together, we sat on the balcony, it was lovely and sunny…and [Husband] thoroughly enjoyed it and one night was enough… I felt the benefit of it, not having to cook and not having to drive".*

For breaks taken apart, it was important that carers perceived the experience as being of mutual value for their partner and that supported their personal well-being. Caroline wished her husband had had access to activities that utilised his skills and capacities, instilled a sense of worth and bestowed a sense of achievement:

> *"[Husband] was an active man who did a lot of sports, windsurfing, skiing, cycling. Sitting around in a group doing chair aerobics, was not good…somebody like him needs that one-to-one or a group of similar people who would take him out and do activities but could manage his toileting and food to enable him to enjoy life."*

Felicity shared how the affection and support that was once mutual in their relationship had gradually become unilateral, and this relational shift influenced her desired break outcomes:

> *"The thing that's difficult to acknowledge is that I've become very unrelated to him…the more I've become a carer, the less I'm a partner, so the less I'm relating as somebody whose company I enjoy…there are times when I've been really upset about something, and he will momentarily be able to be there for me, but it will be gone the next time we have a conversation …the thing that I want more of now is solitude.*

Edward's desired break outcome was simply having time to do as he pleased without expectation or pressure. He illustrated the impact of having a full day break:

> *"I can go for a walk now without having to look at my watch during the respite week…It just gives me the chance to breathe and switch off a little bit, it takes three days at least for me to acknowledge that she isn't in the house, and I don't have to check on her."*

Where replacement care was needed to facilitate a break, person-centred care was central to delivering meaningful break outcomes for the people with dementia and for carers. Edward described the reassurance he gained from knowing that the care staff caring for his wife were compassionate and highly trained to meet her complex needs. This assuaged any worries and guilt about experiencing a break:

"[Wife] went for a week there, and because of staffing they have got there, they have obviously got doctors, they have qualified nurses, they have got support workers, and physios they could look after her needs because of the nature of their work. I wouldn't let her go anywhere else…it's the only place I feel happy letting her stay".

The quality of the relationship between the paid, professional carer, Lucy, and her husband with dementia, was integral to a meaningful break experience and outcome. Lucy appreciated the consistency, compassion, and the professional carer's natural ability to support her husband's personhood and interests with empathy and respect. Together, as a triadic caregiving partnership, they cultivated a relationship of trust and friendship, and this sense of security and confidence underpinned a meaningful break experience and outcomes for lucy and her husband:

"I enjoy having [paid carer] in the house, I can go out during that time, but I love [carer's] company too much I often stay in, it's also company for me…he has a tremendous amount of patience, is compassionate and caring. We have good rapport, all three of us laugh together, and that is good therapy for me".

5.4 Discussion

This research offers a descriptive narrative of the caregiving career in which carers' break needs, experience of accessing breaks, and breaks outcomes were explored. A range of short breaks of varying lengths, activities, and appropriate supports were sought throughout the caregiving career to promote personal and relational well-being and help sustain the caregiving relationship. Each relationship had pre-existing strengths and vulnerabilities to the challenge of dementia that influenced the couple's ability to adjust, and by extension of carers' short break needs and preferences, and desired outcomes. The career trajectory was marked by the gradual transition from informal community activities, characterised by health promoting activities and social engagement, that provided a break, to formal break services with increasing support from health and social care professionals. It was in these transitions where delay spawned through lack of accessible and relevant

information, supported choice from practitioners, and lack of choice of break options, caused difficulties for carers to access timely breaks and achieve meaningful outcomes. Noteworthy, the need for breaks continued after the person with dementia moved to a care home.

Cook and Miller (2012) identified meaningful carer generated outcomes as improved satisfaction and choices in caregiving, a positive caregiving relationship, maintaining health and well-being, and the ability to have a life of their own. These finding demonstrate the contribution of short breaks towards these important outcomes, however, provide limited evidence to demonstrate the contribution of short breaks to facilitating choice and satisfaction in caregiving. Many carers expressed that short breaks were not securely embedded into their caring routine to enable them options and choice around how and when they cared, and as the caregiving career progressed and break needs increased, the options became more limited. For one couple, this sense of confinement, for both the carer and the person with dementia, contributed to a breakdown in the relationship. This is concerning as having genuine choice and gaining satisfaction from the caring role is associated with willingness and ability to care and can support a better quality of life for the carer and person with dementia (Quinn et al., 2020; Seddon & Prendergast, 2019).

The process of deciding upon a break was typified by many deliberations and the balancing and negotiation of personal and relational priorities, needs, preferences, and opportunities, including the opportunity to take a break together. These deliberations were shaped by the shifting relational dynamics between the couple over the course of the career. The relational aspect inherent in planning for short breaks endorses literature that advocates for a relational approach to the assessment of support needs and understanding of outcomes (Hanson et al., 2008; Kokorelias et al., 2019; MacBride et al., 2020; Rand, Zhang, et al., 2022). Adopting such an approach invites a holistic and contextualised view of the caregiving situation and may help expose the interwoven nature, or divergence, in individual short break related needs and so support a more effective way to balance personal outcomes with relationship outcomes (Larkin et al., 2022). The relational approach to assessment is strengthened by research that has shown that uncoordinated need assessments have contributed to carer's needs, wishes, and preferences being marginalised, overshadowed, or poorly integrated with the person with care and support needs (Glendinning et al., 2015; Larkin & Mitchell, 2016; W. Mitchell et al., 2015; Seddon & Robinson, 2015). However, adopting a relational approach foregrounds the skill and agility needed on behalf of the practitioner to tactfully navigate incongruence between needs and balance and assimilate individual and relational strengths, and capabilities, as well as vulnerabilities to inform short break priorities and outcomes. Rand, Zhang, and colleagues (2022) explored the

feasibility of applying a dyadic approach to the needs assessment process and although the approach was recognised by social care practitioners as beneficial in building trust and partnership with families, exposed inherent difficulties stemming from the lack of resources and time of staff, and the ongoing support staff would need to learn how to skilfully combine complex information and weigh different perspectives. Embedded systems-level tensions, such as the fragmented nature of the adult social care system and tendency for funding to be allocated for either adults with care needs or for carers, makes it difficult to commission and deliver for improved dyadic outcomes (Rand, Zhang et al., 2022).

The importance of a relational approach further extends to how information about short breaks is presented, shared, and discussed (Hargreaves et al., 2023). Phillipson et al., (2019) explored the short break information seeking behaviours of carers for people with dementia and found that compared to a helpline or online, carer preference was for interpersonal information sources. It was through interpersonal interactions with GPs, practitioners, support groups, or family and friends, that carers benefited from active support, encouragement, and guidance to access and make sense of information to support decisions around short breaks. Peterson et al., (2016) reported that carers for people with dementia conferred strong trust in their GP to endorse sources of support and information, and valued this validation, even when their GP's response was limited or brief, over online sources of information. These findings highlight the significance of a relationship with a trusted professional to support carers to meaningful engage with the information and to access appropriate support. Barnes et al., (2016) caution against viewing information as a 'neutral or cognitive resource' used to enable better choices and inform decision-making for carers. Rather, the receipt of information is profoundly interwound with emotion and has an emotional impact (Hargreaves et al., 2023). For information to be a positive and empowering resource, how it is communicated needs to be sensitive to the nature of the care context and dynamics of the caregiving relationship (Barnes et al., 2016; National Assembly for Wales, 2019; Steenfeldt et al., 2021).

It is often the case, as demonstrated in this study, that carers are not in a position of stability or clarity to feel empowered to, or indeed have the solutions or resources, to identify their own needs or realise important outcomes without support and guidance (National Assembly for Wales, 2019). The agility, therefore, of the practitioner to consciously move between the role of the 'expert' and the 'enabler' in needed (Miller & Barrie, 2016). There may be some circumstances, where one role is more exaggerated, for example, in a crisis, where the expertise of the practitioner is needed in arranging services, and in others, where the practitioner adopts the role of enabler in supporting carers to recognise their strengths, abilities, and possibilities to support short breaks (Miller & Barrie, 2016). To

support the careful negotiation of outcomes, the practitioner must be equipped with a wealth of information and knowledge about local services and support and skilfully explore resourceful options that can support short break outcomes; this is creative and complex interpersonal work and requires confidence to talk and think about breaks, in their broadest sense. In the current climate of economic constraint, it is necessary to acknowledge that conversations may require the managing of expectations and being honest about the availability and limitation of short break services (Miller et al., 2011).

These findings further augment the need for impartial relational support offered by practitioners to legitimise carer's need for and right to breaks, and ease associated anxieties. Such may be the case when discussing breaks taken apart where carers can experience guilt or anxiety or where the person with dementia expresses hesitancy to enter unfamiliar environments (Huang et al., 2017; Leocadie et al., 2018; O'Shea et al., 2017; Robinson et al., 2012). A phased introduction may be beneficial in these circumstances. Previous research has shown initial hesitancy on behalf of the person with dementia to attend day care can be temporary and soon overcome (O'Shea, Timmons, O'Shea, & Irving, 2019; Rokstad et al., 2019). Initial ambivalence on behalf of the carer and person with dementia is offset by the skills and trust in staff, in creating environments of safety and security, and providing social and culturally appropriate activities (Brataas et al., 2010; Strandenæs et al., 2018; Weir & Fouche, 2017). This knowledge could be heartening for carers in knowing that the person with dementia could come to enjoy the new structure, meaning, and rhythm of life that day care can provide (Strandenæs et al., 2018).

The temporal and changing nature of carer short break needs and preferences underlines the cruciality of the assessment review process to ensure continued relevance of support, including the outcomes supported through short breaks (Allen et al., 2020). In Wales, carer support plans should have a review date, that is agreed between the practitioner and the carer, and must not exceed 12 months (Welsh Government, 2015d). Unfortunately, in the latest State of Caring Wales report (2022) only 19% of carers in Wales reported that they had an assessment, or a review of their assessment, in the last 12 months. The review process should be primarily understood to monitor progress against personal outcomes and ensure the resourceful and effective use of services and support (Social Care Wales, 2019a). As demonstrated through these findings, unpredictability and change in the caregiving career are to be expected. Thus, review of the caregiving circumstances should be an ongoing process throughout the career, to identify where changing circumstances might pre-empt fluctuations in break needs and desired break outcomes and to be proactive in planning for likely changes. Information

gathered from an assessment, and recorded in the care and support plans, can be a rich source of information to ensure improvements in services and practice are being driven by the short break priorities of carers and people with dementia (Welsh Government, 2015b).

Based on the findings from this study, Figure 5.1 represents the principles identified as central to the assessment and support planning and the commissioning process to support meaningful short break outcomes.

Figure 5.*1*: *Principles identified as central to the assessment and support planning and the commissioning process to deliver meaningful short break outcomes.*

- Support needs and priority outcomes are considered holistically. Achievable individual and relational break outcomes are coproduced based on what matters most.

- Carers are guided through their decision-making process. Confidence in carers choice of break is supported through the meaningful and creative exploration of intersectoral break options.

Understanding **what matters**

Timely and relevant information

Relational support

Integrated support

Supported choice

Choice and flexibility

Review of break needs, preferences, and outcomes

- Diverse forms of evidence on carers' break needs and desired outcomes are collated to guide local planning, commissioning, and improvement decisions.

- There is regular review of the caregiving circumstance and relationship to identify, or pre-empt, fluctuations in break needs and desired outcomes, and to plan accordingly.

Substantiated in this narrative is the complexity of caring for someone living with dementia. Carers' multi-layered and interdependent support needs necessitate involvement and input from a multi-disciplinary team of health and social care professionals (Atoyebi et al., 2022; Zwingmann et al., 2019). Findings from this study emphasise the need for a consistent professional contact, introduced to carers from the point of diagnosis, with responsibility for coordinating carer's support needs, including short breaks, throughout their caregiving career. This view corroborates previous research that recognises the importance of a named expert contact for carers, who can offer bespoke and curated support throughout their career (Bergmann et al., 2022; Britton & Zimmermann, 2022; Glasby & Thomas, 2018; Kerpershoek et al., 2019; MacBride et al., 2020; MacLeod et al., 2017; Stephan et al., 2018). Such roles in north Wales have been identified as a 'Carers Well-being Officer' or 'Carers Champion' and, in the context of dementia caregiving relationships, 'Dementia Connectors'. As the vision for the delivery of community care and support in Wales is founded on integrated and multidisciplinary teams (Welsh Government, 2022a), the role of such a designated practitioner for the carer, and how they work alongside other professionals (e.g., Dementia Support Worker, Social Worker, Community Navigator) requires further attention and thought to avoid role duplication or confusion.

Similar challenges to accessing short breaks, as reflected in this study are reported by parent carers (Graaf et al., 2022). Parents for children with autism, described the 'relentless journey', of accessing short breaks typified by lack of information, not 'knowing the questions' to ask health professionals to access short break services, and concerns regarding replacement care quality for their child (Cooke et al., 2020). Interestingly, the temporal progression in needs for short breaks was illustrated. Concurrent with children with autism entering adolescence is an increase in their physical size and strength and behaviours perceived as more difficult to manage, and thus parents expressed increased needs for breaks over time. Analogy can be drawn here between people with dementia who may express greater symptoms of distress and behaviours that challenge as the disease advances. This research reinforces the notion that short break provision must be sensitive to the temporal and developmental changes in the disease or disability trajectory, but also stage of life.

5.4.1   Study limitations and future research directions

The 'trustworthiness' of narrative studies is an important methodological consideration (Guba, 1981). In narrative epistemology, knowledge and experience of the world is malleable and propels an ever developing and evolving narrative. Carer's perspective on past experiences were told from the vantage of a particular moment in the present, as such these were retrospective accounts, subject to conscious and unconscious selectivity (Spector-Mersel, 2010). The passage of time will have most likely affected

carer's perspective of past events. Future research could adopt a longitudinal approach and capture insights in real time. While it was not the focus of this study to verify the accuracy of carers' stories, their verisimilitude was supported through questions that qualified and clarified events, as to learn of their transformation and resolution over time, and the meaning ascribed to them. Multiple stories were compared to look for commonalities in lived experience and the meaning accrued to those experiences. The narrative presented in this chapter is not an exclusive nor perfect or 'true' construction that can claim to fully capture and reveal the complexities and nuanced experiences of its multiple authors, rather it is a partial interpretation of realities experienced and retold through the constructivist and perspectival lens of the researcher.

While efforts were made during the interview to ensure clarity around the sequencing of events and through reflecting carers' thoughts and feelings back to them, a limitation of this research was that member checking was not performed. In narrative work, member checking is an important technique to ensure the story sequence and meaning ascribed to experience is accurately reflected, as to support the credibility and dependability of findings (Creswell & Miller, 2000; Nasheeda et al., 2019). The main reason this technique was not utilised was the time constraint upon which this phase of the research had to be completed, and the delay already experienced due to difficulties in recruiting participants during the COVID-19 restrictions. However, the collective narrative of the caregiving career was presented in a knowledge exchange event (reported in chapter 6) which carers from this study attended, and thus provided an opportunity to sense-check the narrative. In future, lessons can be learnt from Kokorelias et al., (2020) who performed member checking with a purposeful selection of carer participants.

The concept of a caregiving career can be criticised for mispresenting caregiving as a formal 'occupation', overlooking the reciprocity of many interdependent caregiving relationships. Indeed, for many spousal carers, caregiving is a natural extension of their martial role and they do not identify with the term 'carer' (Larkin et al., 2019). It is also common that the caregiving career can start years before the formal diagnosis, which is an important and often invisible phase of caregiving (Nolan et al., 1996). The objective point at which caregiving begins, denoted by the shift from reciprocal to more unilateral support, has been shown to differ from the subjective point at which carers start to recognise and identify with their role as a carer (Aneshensel et al., 1995; Seltzer & Li, 1996). However, for the purpose of this research the focus was on provision of short breaks after diagnosis to avoid any issues around eligibility for formal short break services.

Eleven out of the 13 carer participants were female, and this figure is representative of the broader caregiving population in Wales and England; as of Census Day 2021 (21st March 2021) in Wales the percentage of people providing unpaid care was higher in females (12%) than males (9%) (Office for National Statistics, 2023). The samples lack of ethnic diversity, although representative of the north Wales population, of which 97.5% of the population describe their ethnic group as white (Welsh Government, 2022c) , limits the transferability of findings. Different ethnicities and cultures have shown to influence ways of coping and engagement with formal support services (Brown et al., 2014; Johl et al., 2016). Parker and Fabius (2020) found that black carers for people with dementia were 69% less likely to use short break services compared to white carers. This was speculated to be in part due to the lack culturally appropriate options which caused black carers to rely heavily on informal support from family and friends.

5.5   Conclusion

In this chapter, a representation of the caregiving career was constructed from the stories of 13 spousal careers and used to explore the temporal nature of carers' short break needs, allied to the progression of dementia. The unpredictable and dynamic trajectory of dementia caregiving was punctuated by periods of stability and uncertainty, but ultimate change and decline in physical and cognitive health and function of the person with dementia. As such, the short break needs and preferences of the carer, and the person with dementia, fluctuated over the disease trajectory. This finding reinforces the view that short breaks, as a distinct form of preventive support, must adapt to support the evolving nature of the dementia caregiving relationships. In this sense, the construct of a career trajectory was helpful to appreciate the commonalities in experience of realising short breaks by carers drawn down a dementia caregiving path.

Having gathered the perspectives of both professionals and carers in the provision of, and experience of short breaks, respectively, the next chapter of the thesis describes how this knowledge was shared and discussed and used to enrich understanding of meaningful short breaks and co-create social care recommendations.

Chapter Six: Integrating knowledge to construct mutual understanding about meaningful short breaks

6.1   Introduction

This chapter describes the process and outcomes of a knowledge exchange event that brought together academics, carers, and social care professionals from the third and statutory sectors in north Wales. The aim of the event was to share, discuss, and construct knowledge to enrich understanding about meaningful short break provision. Guided by a collaborative and constructivist approach to knowledge mobilisation (Andrews et al., 2015), the objectives for the event were to:

- value and empower participants to contribute their perspectives and knowledge about meaningful short breaks.
- sense-check research findings to enhance the credibility and trustworthiness of evidence.
- reach consensus surrounding the features that contribute towards a meaningful short break.
- offer a structure through which tacit knowledge could be explored to support continued learning.
- guide the development of recommendations to support the realisation of Welsh Government priorities for carers, specifically, the commitment to support a life alongside caring.

The event integrated evidence gathered from phases one and two of this research, as well as the new perspectives of seven social care professionals who had not taken part in the prior phases of the research. Supported through a dialogic storytelling approach to learning, participants explored the narrative of the caregiving career developed in phase two of the research (Caulfield et al., 2022b), and reflected on the distinct challenges, considerations, and decisions of carers to realise meaningful short breaks over time. These discussions helped generate recommendations that build upon good practice to improve access to short breaks throughout the caregiving career. Features identified as important to the provision of a meaningful short break were offered for joint consideration to support conceptual clarity and reach mutual consensus. Importantly, the event was a chance to say thank-you to all those who had been involved in or supported the research, and to celebrate areas of positive practice across north Wales to support improved short break outcomes.

Private recorded conversations with two social care professionals and one carer, in English and in Welsh, were recorded on the day. These conversations captured professional and personal accounts, reflections, and experiences of short break provision in north Wales. The researcher's supervisor,

whose first language is Welsh, conducted two of the conversations with participants in Welsh on the researcher's behalf, so the participants could speak in their language of choice. Consent was gained for these conversations to be used for future teaching and learning purposes. It is the intention of the researcher to explore the potential for these conversations to form a short podcast series, to provide stimulus for teaching and practice discussions. There are several degrees programmes at Bangor University for which this material could be relevant, including the Professional Doctorates, and relevant Masters degrees, for example, the MA in Social Work and MSc in Dementia Studies, as well as within courses that will form part of the new North Wales Medicine programme which is due to commence in September 2024. More work is needed to consider how to best to present these conversations and decide upon the key learning outcomes that would be beneficial for future teaching and development.

6.1.1 Knowledge exchange as a process

Improving short break outcomes for carers is an essential component of sustainable care (Welsh Government, 2021e). In Wales, the vision for sustainable social care is driven by core principles that guide ways of thinking and working together (Social Services and Well-being (Wales) Act 2014; Well-being of Future Generations (Wales) Act 2015). One of these principles is co-production. Co-production is a strengths-based approach to learning and development. It intends to build the local core economy of people by sharing knowledge and strengthening relationships and can be explained as; 'A way of working whereby citizens and decision makers, or people who use services, family carers, and service providers, work together to create a decision or service which works for them all' (Social Care Institute for Excellence, 2022, p. 6).

Throughout Welsh Government policies, co-production is widely encouraged to empower people to meaningfully engage in the planning, delivery, and evaluation of support. In doing so, it recognises people as assets, each having a unique contribution to make towards improving the quality of care and support. In valuing and including different people in this process, it also values and includes their knowledge as evidence (Andrews et al., 2015; Social Care Institute for Excellence, 2022). However, how knowledge is constructed, shared, and discussed influences how it is perceived, its capacity to stimulate learning, engender consensus and action, and the likelihood that it will deliver demonstrable and sustainable societal impact (Andrews & Beer, 2019; Greenhalgh et al., 2016; Kagan, 2022; Langley et al., 2018). In health and social care, there is a strong tradition of using collaborative approaches to mobilise knowledge and its use to generate impact (Fleming et al., 2014; Jull et al., 2017; Nguyen et al., 2020; Rycroft-Malone et al., 2016). These are variously referred to as, co-creation (Greenhalgh et

al., 2016), integrated knowledge translation (Graham et al., 2018) participatory research (Jagosh et al., 2012), knowledge exchange (Ward et al., 2012), and Mode 2 knowledge production (Nowotny et al., 2003). This suite of collaborative approaches developed out of the need to bridge the 'evidence-practice' gap more effectively by softening the hierarchy and division between two communities and cultures: those that produce knowledge (e.g., researchers), and those that use it (e.g., health and social care practitioners) (Evans & Scarbrough, 2014; Graham & Tetroe, 2009; Rycroft-Malone, 2014). Collectively, they represent a transition from linear models of knowledge transfer, where evidence is produced in isolation and recommendations are imposed, to more iterative, context sensitive, and interactive ways of generating and mobilising knowledge (Andrews & Beer, 2019; Graham et al., 2018; Langley et al., 2018; Nowotny et al., 2003). While these approaches purport different mechanisms of knowledge mobilisation (Nguyen et al., 2020), they share a commitment to relational co-productive ways of working that foster reciprocity, trust, collaboration, and the democratisation of knowledge to support shared decision-making (Nguyen et al., 2020; Rycroft-Malone et al., 2016). Their epistemological orientations accommodate pluralistic ways of knowing that are sensitive to differences in what is perceived as evidence and whose evidence counts (Gerrish et al., 2011; Nguyen et al., 2020; Rycroft-Malone et al., 2004).

Knowledge exchange is one approach to support the cross-fertilization of perspectives in aid of mutual learning. It can be broadly defined as 'a process of generating, sharing, and/or using knowledge through various methods appropriate to the context, purpose, and participants involved' (Fazey et al., 2014, p. 205). While the exchange of knowledge in applied research can be claimed to occur organically and informally through the various interactions and activities of the researcher(s), to enhance and make explicit the pathway to impact there is increasing emphasis on how exchange and engagement occurs to best facilitate learning and support a context for co-production (Andrews & Beer, 2019; Fazey et al., 2013, 2014).

6.1.2 Developing Evidence Enriched Practice methodology

Developing Evidence Enriched Practice (DEEP) is a collaborative approach to exploring and using diverse types of evidence in policy and practice development (Andrews et al., 2015). DEEP incorporates and utilises a range of principles and methods and places emphasis on the use of storytelling to facilitate relational and reflective ways of working and learning together.

DEEP methodology is underpinned by several research-informed methods in learning and organisational development that guide how knowledge is collected, understood, and mobilised. These methods are summarised in Table 6.1

Table 6.1: Research-informed methods in learning and organisational development that support the DEEP approach to knowledge mobilisation.

Appreciative Inquiry **(Whitney & Cooperrider, 2000)**	the act of valuing the best in people and their organisations to discover new potential and possibility. It represents a departure from the deficit-based approach to change to a strengths-based approach to change. It is driven by a collaborative and appreciative approach to leveraging an organisation's positive core strengths through four stages, i.e., discover, dream, design, and destiny.
Experience based co-design **(Bate & Robert, 2006)**	an approach to improve support, services, or care pathways through partnership working between staff and people with care and support needs. It is based on in-depth gathering of experience to identify key 'touch points' (emotionally significant points) and the highs and lows of service experience. Together, staff and people with care and support needs discuss these experiences to identify and implement activities that will improve the service or the care pathway.
Exploratory talk **(Mercer & Littleton, 2007)**	based on reasoned discussion where people engage critically but constructively with each other's ideas. It is guided by ways of inclusively talking and thinking together, for example, statements and suggestions may be disputed, but challenges are justified, and alternative views offered. All opinions are sought before a decision is made.
Community of inquiry **(Garrison, 2016)**	a group of individuals (i.e., the community) who collaboratively engage in purposeful discourse, construct personal meaning, and confirm mutual understanding. The process of creating a meaningful (collaborative-constructivist) learning experience is based on the interactions between three interdependent presences: social presence, cognitive presence, and teaching presence.
Most significant change **(R. Davies & Dart, 2005)**	a participatory form of evaluation and learning based on the collection and systematic selection of stories. These stories focus on the most significant change occurred as the result of an initiative, and why that change occurred.

In the context of this event, the DEEP approach does not seek to effect immediate change by the linear transfer or implementation of research recommendations into action, but rather, through the cross-fertilization of knowledge and perspectives of key stakeholders and intended beneficiaries, support a more informed and sophisticated understanding, and consensus around, meaningful short break

provision. In preparation for this event, the researcher attended the DEEP Catalyst training provided by Swansea University in collaboration with Health and Care Research Wales. This training offered an introduction to the DEEP approach to exploring and using evidence in policy and practice development.

6.2 Method

6.2.1 Conceptualising the knowledge exchange event

To foster a meaningful and collaborative learning experience, it was important that those attending were intrinsically motivated by the topic and open to sharing and learning (Andrews et al., 2015). A purposive sample (Palinkas et al., 2015) were invited that included people from various professional backgrounds and those with experience of caring for people with dementia, who could offer distinct but complementary forms of explicit and tacit knowledge.

The Knowledge Exchange Event took place in May 2022, gathering participants from phases one and two of the research. These original participants extended invitations to individuals keenly interested in short break provision but who did not partake in the earlier interview phases. The group consisted of 13 individuals, excluding the researcher. Six participants, including two spousal carers, two academics, and two social care practitioners, had taken part in phases one or two, or Project Advisory group meetings. Additionally, there were six new participants, amongst them a trustee from a carer's charity, a professional from the North Wales Regional Partnership Board, two staff members from a local authority, and two third-sector staff – one employed by a dementia charity and the other by a carers charity. Notably, two of the social care practitioners had first-hand experience in caring for a parent with dementia in North Wales.

To support event planning, the Project Advisory Group meet with the researcher to offer their opinion on the findings from phase one and two of the research they considered most pertinent, thought provoking, and relatable to the invited participants. The structure for the event was discussed and how evidence would be presented to maximise engagement and critical reflection. One and a half hours was dedicated for group discussion, and 40 minutes for lunch and informal conversation and networking. In registering for the event, participants gave their consent for the discussions to be audio recorded. These recording were used to help the researcher summarise the discussions and were not shared publicly. In reporting quotations, participants were assigned a participant number to protect their anonymity and any personal or sensitive information was removed or anonymised.

The approach for the event was guided by the five underpinning elements to knowledge mobilisation identified by Andrew and colleagues (2015). Collectively, these elements support engagement with evidence in a way that maintains an openness to new knowledge. How these elements were embedded into the event are now discussed.

6.2.2 The five elements for Developing Evidence Enriched Practice

Valuing and using a range of evidence

A democratic and inclusive approach to learning recognises the value and contribution of different forms of knowledge in shaping thinking and actions (Andrews et al., 2020). There are important ethical and policy imperatives for valuing diverse evidence. Ascribing prominence to a particular form of evidence, for example, intellectual knowledge, as often produced by academics (Miller, 2019), can neglect other sources and systems of knowledge (e.g., local, traditional, spiritual, or indigenous knowledge) (Hall & Tandon, 2017) in shaping how care and support is delivered leading to inequity of provision (Rycroft-Malone et al., 2004). In social care, exploring broader ways of knowing and doing, guided by practitioner intuition, lived experience, values, understanding of culture, and contexts, can help support the melding of different sources of knowledge (Andrews & Beer, 2019; Rycroft-Malone et al., 2004) and promote knowledge democracy for a fairer, and more inclusive and equitable way of using evidence in practice. The political incentive for the use of diverse evidence in policy, practice, and service development is that it builds upon the ethos of co-production, a key concept in the development of more effective and sustainable public services through promoting equal partnerships between people who use services, carers, and professionals (Boyle & Harris, 2009; Social Care Institute for Excellence, 2022). Diversity and inclusion are important values in co-production. This is to ensure that a greater proportion of people who use services are more likely to realise the outcomes that matter to them, and so develop stronger communities and a sense of citizenship.

The event drew upon evidence in the form of academic findings, the tacit and operational knowledge of practitioners, lived experience of carers, the strategic and organisational knowledge of commissioners, including underpinning legislation and guidance for short break provision. The purpose of using a range of evidence in the event was to enrich understanding by building upon existing knowledge so to co-construct new meaning. In this sense, it adopted a strengths-based approach that valued and encouraged the voicing of multiple perspectives.

Creating an enriched environment of care and learning

The vitality and authenticity of the event was premised on people feeling valued, safe, and welcome to share their genuine thoughts and feelings. Following the COVID-19 pandemic lockdowns, it was important to consider people's preferences for interaction. Some older carers, who self-identified as physically vulnerable and were caring for their spouse with dementia at home, expressed caution about meeting in a group inside. Difficulties also arose for carers in arranging replacement care for their partner so they could attend in person. Online communication was favoured by many professionals as it supported better time management, and many were now used to attending events online. Mindful of these preferences, and to support choice and flexibility, a hybrid approach to delivery was adopted. Five participants joined online via Zoom and nine participants, including the researcher, attended in person. Consideration was also given to where the event was held. Following consultation with the Project Advisory Group, a neutral environment, outside of Bangor University, but central to north Wales, was chosen. This was to deter possible 'ivory -tower' connotations of holding the event at an academic institution. The location chosen was a small but welcoming community business centre, with open meeting spaces, accessible parking, and access, that catered for lunch and provided excellent conference facilities to allow for hybrid attendance and conversation.

Imposing knowledge in a way that does not first connect with or build upon people's existing constructs of reality can lead to disengagement and resistance to learning (Andrews et al., 2015). To support an environment where people are open to learning and curious to engage with evidence that is new to them, DEEP draws upon principles of social pedagogy (Kirkwood et al., 2019), a values-led approach to relationship-centred practice that aims to holistically support people's well-being and learning. To help set the tone for the event, the researcher welcomed everyone and emphasised everyone here was united by a shared commitment to improve short breaks provision, and that their time, interest, and unique contribution was greatly appreciated. This event was a shared space to reflect and critically engage with knowledge to foster understanding. As part of this process, this may mean sharing the personal and the professional, however, everyone's contribution was respected.

Gathering and presenting evidence in meaningful formats

The creation of knowledge in social care, as in other people and relational professions, is an inherently social and dynamic process where knowledge is constructed and continuously revised through the interactions and dialogue with others (Nevo & Slonim-Nevo, 2011). A powerful way to inquire into experience and the meaning that it embodies is through the narrative form (Squire et al., 2019). The human life is a 'storied life' (Riessman, 1993), and humans are 'narrative beings' (Rodriguez, 2002)

who narrate stories to make sense out of, organise, and structure their experience (Connelly & Clandinin, 1990; Gonçalves et al., 2004). It is the narrative derived from stories that becomes the primary meaning making tool (Lyle, 2000), an instrument to construct, interpret, and understand how a person experiences their sense of the world from their own perspective (Mitchell & Egudo, 2003). Andrews et al., (2015) places storytelling at the heart of helping people to engage with and use evidence through igniting both an intellectual and an emotional response. In this event, the stories and anecdotes of carers' short break experiences were the centrepiece for discussion and an effective catalyse for thinking, dialogue, and invoking empathy and understanding.

Effectively talking and thinking together about diverse types of evidence, which may conflict

Research across fields such as education, social psychology, and organisational psychology and leadership have shown that when people are supported to communicate and think creatively and productively together their collective intelligence and problem-solving abilities are enhanced (Hill et al., 2015; Littleton & Mercer, 2013; Woolley et al., 2015). To support ways in which people can effectively talk and think well together, Andrews et al., (2015) encourages the use of dialogue-learning techniques. The term 'dialogue' is a kind of relational activity, in which every answer given engenders another question. Mindful of the need to facilitate and stimulate dialogue between 13 individuals, the researcher prompted exploratory talk (Mercer & Littleton, 2007). Exploratory talk is a social mode of collective thinking, founded on reasoned discussion where people engage critically and constructively with each other's ideas. This type of talk promotes a form of shared thinking and allows for the equitable exploration of different perspectives and evidence. Statements or propositions are offered for joint consideration (Mercer & Wegerif, 2021). Responses may be challenged, and clarification and justification sought, but in seeking to better understand responses demonstrates that other people's ideas and perspectives matter and there is value to their exploration. Putting exploratory talk into practice, the researcher encouraged participants to build upon responses by making connections to what has been said, reflect on any assumptions behind what they are saying and, where feasible, identify the implications of what had been discussed. In this way, knowledge was collectively and constructively built upon to promote shared understanding.

Recognising and addressing structural barriers to using diverse evidence and operating within complex adaptive systems

In highly contextualised and adaptive systems such as health and social care, there are multilevel influences that can enable or undermine the use of evidence in practice (Damschroder et al., 2009; Davies et al., 2012; Kagan, 2022)**.** The importance of context surrounding efforts to embed knowledge

in practice is widely recognised within the implementation literature (Beckett et al., 2018; Dryden-Palmer et al., 2020; Nilsen & Bernhardsson, 2019). Findings from phase one of this research were helpful in elucidating some of the local interrelated contexts that may enable or frustrate meaningful short break provision (Caulfield et al., 2022a), and these were acknowledged to support contextualised discussion. Recognising that knowledge about 'what matters' in short break provision is inherently personal and context sensitive, it is unlikely this knowledge would be applied instrumentally in practice but rather used conceptually to grow thinking around the features and mechanisms that support meaningful short breaks (Andrews & Beer, 2019; Gabbay & le May, 2004). The features that contribute towards a meaningful short break were broad and flexible enough for participants to adapt and reflect upon them within their context and understanding of local circumstances and systems.

6.3   Findings

The knowledge exchange event was structured around two principal activities. Firstly, the performance of the caregiving career was narrated by the researcher. Developed in phase two of the research, the caregiving career is an experiential narrative (Caulfield et al., 2022b). To facilitate its discussion, a heuristic visual representation of the caregiving career, built from the quotes of carers who participated in phase two was presented (Figure 6.1), and used to support and stimulate reflection on carers' evolving break needs and experience of accessing breaks. The discussion centred around four themes; the early recognition of carers to support meaningful short breaks; promoting choice of short break options; the seamless provision of support throughout the caregiving career; and the importance of supportive communities in facilitating short breaks. These discussions helped shape thinking around recommendations to improve access to short breaks throughout the caregiving career. Secondly, features that emerged during phase one and two of the research associated with the provision and experience of meaningful short breaks, respectively, were offered to the group for shared consideration, and their significance and applicability to local practice were sense checked to support mutual consensus.

Figure 6.1: *A heuristic representation of the caregiving career, constructed between the researcher and 13 spousal carers.*

"The Alzheimer's was getting worse, but we led a normal life"

"His behaviour was becoming more challenging for me to manage"

"I was losing control of the situation... not being able to move it on and to help"

"I would love him to be involved, it would be something in his life for him. It's not just about me"

"The things they are telling us to take part in, don't really suit our needs"

"Some people need a helping hand through these things, rather than being left to do it by yourself"

"I do know that I have to accept the fact that he needs more care than I can give"

The early recognition of carers to support meaningful short breaks

The description of the caregiving career illustrated that, as the dementia progressed, carers' breaks needs evolved; carers were more likely to need more frequent and longer breaks to sustain their caring role (Caulfield et al., 2022b). Underpinning the couples' successful transition to different formats or types of breaks were conversations with practitioners who could offer supported choice. While many of the participants recognised the cruciality of ensuring these conversations were had, and were skilfully and tactfully conducted, in practice however, it was emphasised that practitioners were regularly arranging breaks as part of crisis management, and therefore, the capacity for these breaks to be meaningful were drastically reduced:

"In reality, by the time short break needs are discussed, carers are at a crisis point and it is too late, and it cannot be a meaningful break, it is break but only because it is really needed"
(P11).

This impact of carers receiving support late on in their career was exemplified by a carer who conveyed the experiences of carers he knew:

"Many carers who are part of the support group I was in got in touch with social services far too late, and by the time they had got in touch, their partners had to go into a care home straight away" (P8).

In response to these observations, the discussion moved onto the local efforts to raise awareness of the support available. In particular to encourage carers to recognise their caring role and the value of exploring, from as early a stage as possible, the support that could help them to care and to look after themselves:

"One of the big things that has stood out to me is the lack of awareness of the support out there, and given the increase in digital platforms and social media outlets, why is there still a lack of understanding of what support is available? How do we get the message out there?"
(P4).

Recalling his personal experience, a carer shared that himself and many older carers (aged 65 years and over) are not active on social media. His contact with social services was a fortunate coincidence, and it would not have occurred to him, at that point in his career, to get in touch with social services.

"I tried to cope on my own initially. It was only until one day, a senior social worker who lived close by passed our front garden and spoke to my wife, and after speaking to my wife, she said to me 'You need to get in touch with us now, I didn't realise your wife had changed so much in the last few years'. Without that conversation I really wouldn't have known anything about social services" (P8).

A third sector professional added that for a break to be meaningful it must be at the right time. Introducing the concept of short breaks early may prepare the ground for carers to think about their preferences and options and reinforce its preventative purpose. For some carers, however, considerable time may pass before they need, or are eligible for, formal support or services to realise a break. Until that point, practitioners must continue to maintain a relationship with carers to be able to proactively assess and plan for breaks before the need becomes critical:

"People need time to adjust to a diagnosis, people with dementia and the carer, their roles don't change overnight, especially for carers, they are a husband or a wife first. To ask for help or realise they need help is a huge thing, and it is about that timeliness, it is not offloading all the information once people get the diagnosis, it's about that constant check in and that follow up" (P6).

The importance of supportive communities in facilitating short breaks
Reflecting on the shared difficulties across the region in identifying carers, dementia/carer friendly communities was conjectured as a promising approach to support the osmosis of knowledge around local support for carers, alongside support for the person with dementia; *"It's a slow burn, I don't know how far it has taken off across the region, but here in [county] I believe dementia friendly communities are the way forward"* (P10).

Cultivating these inclusive and supportive communities involves supporting continued access to the physical and social aspects of community vital to the everyday lives of older citizens (Shannon et al., 2019). Often these are places grounded in routine, such as local cafés, outdoor spaces, shops, libraries, community centres, including GP surgeries and pharmacists. The group acknowledged that GPs are critical in supporting carers in the pre-diagnostic stage, not only to encourage them to recognise their caring role, but in ensuring the timely referral of the person with dementia to a Memory Assessment Clinic. A third sector employee stated that the average waiting time for a diagnosis in Wales is over a

year, in which people are missing out on vital support, *"You don't just become a carer when you have a diagnosis, it is more often a crisis point triggers you to go and get a diagnosis"* (P11).

One carer shared her disappointment over the initial conversations with her GP, who failed to recognise the worrying behaviours of her husband, which ultimately delayed access to care and support for them both:

> *"I had been to see at least four GPs. The GP had no idea. He told me there is nothing wrong with him, and that he needs to pull himself together and told him that…the damage done in those early years is irreparable"* (P9).

In relating the implication of this to short break provision, it was recognised by the group that formal short break services, in the form of replacement care at home, day care or residential care, would not be statutory funded without a diagnosis and the subsequent assessment of eligible care and support needs. This circled the discussion back to the importance of grass roots developments within communities, where short breaks are not necessarily delivered by statutory services, and support is not dependent or distinguished by a label or diagnosis. Short break activities within communities were broadly recognised as being more appropriate for carers of people experiencing early or moderate symptoms of dementia, as engagement in activities typically requires the person with dementia to be physically able to attend and cognizant of their surrounding and of others:

> *"[Support group] has recently moved to a community in [town], it is very rural, and we opened it up to older people and its inclusive of people with dementia, and it's also telling people it's okay to include people with dementia, they have a right to be here, it's part of life. Things are moving because people are telling us to move in that way…but it's not as easy as it sounds, its word of mouth, its persuasion, its perseverance, and local contact"* (P3).

The stigma around dementia was anecdotally perceived to exist more prominently in Welsh speaking communities and was recognised as a cultural barrier to carers being open and seeking support early in their career for themselves and their partner:

> *"Welsh Wales is worse than any other part of Wales, in saying 'my husband has got dementia', because we don't want anybody to know and for them to lose their status within their community, we want to keep his dignity"* (P9).

In 2023, the Alzheimer's Society announced the Dementia Friendly Communities recognition scheme will come to an end in December 2023. The recognition scheme promoted awareness and celebrated the work of dementia-friendly communities across the UK. While many communities and organisations may continue to take proactive steps to help carers and people with dementia to feel respected and involved in community life, the lack of public recognition of these efforts by a reputable charity may undermine the momentum and development of good and creative practices to continue to nurture dementia friendly communities.

The seamless provision of support throughout the caregiving career

In reflecting upon the caregiving career, the group identified the challenges experienced by carers in needing to constantly adapt to the ever-changing disease progression, navigate the health and social care system, and know who to ask for the appropriate support and advice related to short breaks. In recognition of these challenges, a professional from the North Wales Regional Partnership Board offered a regional perspective and explained current thinking was focused on ensuring a whole system pathway approach to care and support for people with dementia and their carers. This vision is enacted by the All-Wales Dementia Pathway of Standards (Improvement Cymru, 2021). The aim of the Dementia Pathway of Standards is to improve dementia care for individuals and support for their carers, by providing a clear pathway towards implementing 20 effective standards within dementia care by 2023. The pathway is emblematic of the Welsh Government drive to reduce inequality in provision of support through supporting a regional integrated approach to service delivery (Welsh Government, 2021a). A central theme of the Dementia Pathway of Standards is the theme of 'journey' and the smooth and facilitative navigation of that journey to ensure that all care, support, and learning is provided **at the right time and stage**. It is envisioned the integration of support and services along the journey for the carer and person with dementia would offer a more holistic and seamless way of delivering short breaks for carers and people with dementia:

"There is always the need to increase provision, but we have recently tried to smooth the pathway in line with the journey as people progress from diagnosis to post diagnosis support, and there are more posts to fill in the existing gaps" (P2).

Lending support for better integrated support, a carer recalled that joint working between health and social services cultivated a positive and constructive relationship between him, his wife, and the professionals, which resulted in the efficient and timely organisation of a short break. However, the co-ordination between services was something the carer had to request:

"To begin with the social worker used to call every seven to eight weeks, then the Community Psychiatric Nurse (CPN) used to call every seven to eight weeks. I had a chat and said is there any chance that you could come together, and every meeting after, this was pre-covid, they both worked in tandem, they came to have a chat with me and my wife at the same time, and it was through the CPN that the day care centre was organised" (P8).

Promoting choice of short break options throughout the caregiving career

The narration of the caregiving career accentuated the need for real choice and flexibility in how couples could experience short breaks to support their well-being. The group acknowledged that having flexible support takes on greater importance as the dementia progresses and needs become more personalised, and additional planning may be required to accommodate for mobility issues, additional health conditions, and personal care needs etc.

In recognition of the ways local authorities were trying to promote greater choice and control around short break options, Direct Payments was enthusiastically raised. Promoting the use of Direct Payments was a priority for all counties and local authority staff remarked on the need to improve how Direct Payments are offered to make them a genuine and attractive choice for carers:

"I think we can all hold our hands up and say we haven't made it as simple as it could be, and they are not used nearly enough as they should be. In [County] we have just employed two people to promote them and try and make it simpler" (P7).

A discussion ensued that addressed some of the systemic issues that had a direct effect on the uptake of the Direct Payments method, and the overall capacity and sustainability of the social care sector at large. The dominant issues were the substantial challenges in relation to the recruitment and retention of paid care and domiciliary staff. This is a longstanding challenge and has been made worse by the COVID-19 pandemic:

"The availability of people who carers can personally employ, that is a huge challenge, it is about making it a much more attractive profession, it is going to take time to recruit more people" (P3).

One carer in the group confirmed this reality by sharing the difficulties he encountered "*finding good carers, who you can rely on and trust*" (P8). He further added that on a day-to-day basis, managing the

carers he employed through Direct Payments took a considerable amount of administration, organisation, and forward planning for which he was solely responsible and needed to constantly keep upstream of*:*

> *"I was very fortunate that I could manage all the paperwork, all the monitoring, but many people can't do that. No one showed me how to do it, no one came over to discuss practical ideas on how to set up payments and keep a filing system etc, I was fortunate that I could work out a system that worked for me"* (P8).

6.3.1   The defining features of a meaningful short break

In the previous two phases of this research (Caulfield et al., 2022b, 2022a) several distinctive features emerged as contributing to the experience of a meaningful short break, and in doing so the likelihood of realising important well-being outcomes. The knowledge exchange event was an opportunity to offer these features for shared consideration and elaborate on how each feature, individually and collectively, might support a meaningful short break (Figure 6.2).

No one feature took precedence over the other, and it was noted that in practice it is challenging to ensure all features are simultaneously embedded into the provision of a break because of limited resources. These features interact to provide a critical sense of trust, security, and confidence for carers in knowing their short break needs and outcomes can be supported over time in ways that are meaningful for them. For breaks to be meaningful all features must be considered within the relevant history and context of the caregiving relationship. There was accord amongst the group that the appropriateness of a break is linked to its timeliness; what is deemed 'appropriate' will differ depending on the couple's interests, needs, strengths, and capabilities, at that point in time.

It was further acknowledged that underpinning any type of short break provision is the application of relational-centred support. A relational-centred approach recognises the importance of supporting the interdependent well-being and recognises the 'mutually constructed subjectivities' (Morhardt & Spira, 2013) of everyone involved in the caring relationship (Nolan et al., 2006). During the assessment and support planning process, supportive and trusting practitioner-carer relationships can help to prompt meaningful outcome focused conversation and planning for short breaks (Shared Care Scotland, 2022b). During breaks supported by paid care staff, the nature and quality of interactions and relationships between care staff and the person with dementia are essential to a positive experience and to realising meaningful outcomes for everyone involved:

"It's the [professional] carers as well, and if that person it right for the job…I am finding that now with the care home, it's not so much the home, it's the people and their heart" (P9).

In the planning and commissioning for short breaks, the evolving commissioning landscape was emphasised:

"We will always be able to, out of what we develop, identify gaps, because provision is limited. It's part of an ever-changing landscape…with population trends and changes, for example, what people in their 70's and 80's may want now, the next generation will be different, I don't think we ever be able to achieve 'perfection' but we always to adding to, changing, and tweaking" (P2).

Regardless of trends in short break activities the relevance of these features to support a meaningful short break were mutually recognised. Having the empirical evidence base to substantiate the importance of these features, as reflected by one third sector manager, was useful for them as an organisation when applying for funding and in justification of resources needed:

"Everything that has been presented today rings true from what we have heard back from our carers. We try to feed up to Welsh Government, and this work will really help when we are applying for funding in terms of what works and what we need to be thinking about" (P10).

Figure 6.2: *Features that support a meaning short break experience and outcomes.*

"I went with my husband to the day care centre because he wouldn't go by himself, but I learnt a lot about people with dementia through watching other people as well, it was good training for me too" (P9).

"I started off with one carer, and as my wife' condition changed, each of my carers found someone else who they knew. In the end we had seven carers on the books, and that enabled me to have two hour breaks every day" (P8).

"For my mum, respite care through the medium of Welsh and it being local was so important. The day care was in her own community, there were people from her school days and the care staff spoke Welsh. If she had to move to away from her community into a placement where only English was spoken, it wouldn't have been suitable" (P3).
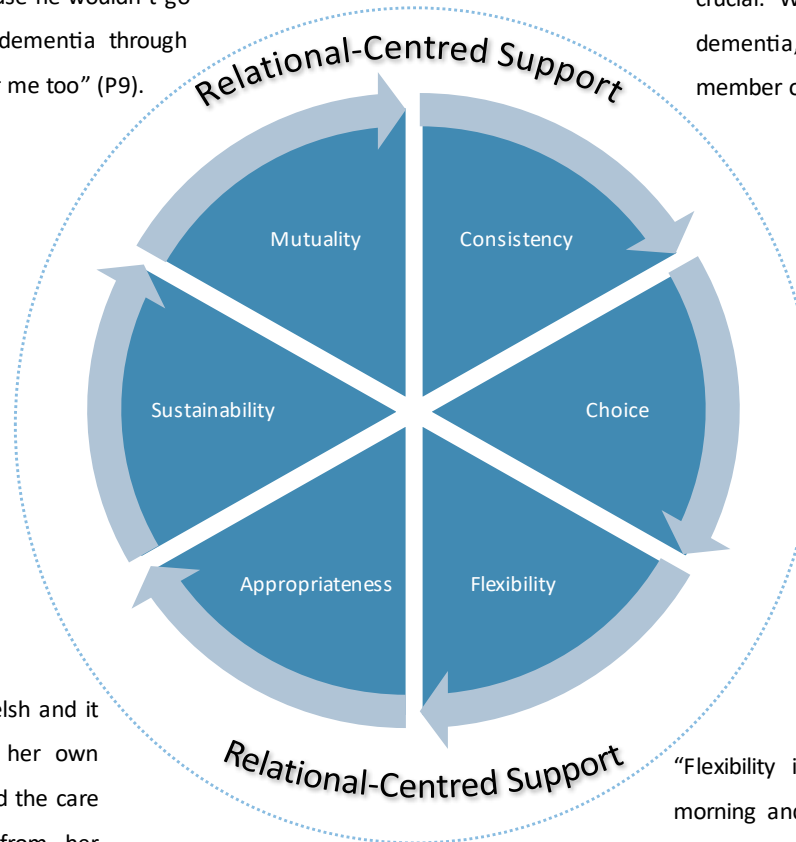
"Consistency of care staff when talking about dementia is crucial. When my sister was looking after her partner with dementia, she could only take a break when a particular member of staff was available" (P1).

"Social services were great at facilitating a short break for my wife, two days a week at a day care centre. Then my wife would be able to go for a week's respite at the same care centre, every seven or eight weeks, and that gave a longer break for me" (P8).

"Flexibility is key. If the person with dementia gets up in the morning and doesn't want to go, or isn't in a good place, all the preparation for that short break must be moved or changed, and that experience can be traumatic. Flexibility needs to be embedded into any plan" (P10).

Relational-Centred Support

Mutuality · Consistency · Choice · Flexibility · Appropriateness · Sustainability

6.4　Co-constructed practice recommendations

Discussions supported the democratisation of knowledge and aided the development of six recommendations to support the delivery of national aspirations for carers, specifically, to embed short breaks as a sustainable and preventative resource throughout the caregiving career. Recommendations evidence the leadership needed by the Welsh Government to address systemic barriers to sustainable provision such as ensuring the long-term investment for the third sector as they take a leading role in enabling community-based short breaks. Illustrative national and international good practice examples are highlighted in yellow boxes.

1.　**Strong leadership from Regional Partnership Boards, supported by the Welsh Government, to advance regional approaches to support the identification of carers across health and social care settings and within local communities, and improve signposting to appropriate information, advice, and assistance.**
The early identification of carers is a priority for the Welsh Government (Welsh Government, 2021e). This is crucial to ensure that breaks are not experienced in a moment of crisis but there is sufficient time for practitioners to understand the caregiving circumstance and plan accordingly so breaks can be as meaningful as possible. However, there are challenges to the identification of carers. The latest State of Caring Wales report (2022) revealed that 52% of all carers took over a year to recognise their caring role, with over a third (39%) taking over three years to recognise themselves as a carer (Carers Wales, 2022). Similar findings are echoed across all UK countries (Carers UK, 2022a). Research by Carers Wales found that the caring role in dementia caregiving relationships is poorly recognised and not clearly defined due to the evolving and insidious nature of the disease (Banks, 2022). Carers Wales have set out their priorities for the next Welsh Government to support carers in Wales. This includes a new duty on the NHS to identify carers and promote their health and well-being and a requirement that all health and social care staff likely to interact with carers undertake a proportionate level of Carer Awareness training (Carers Wales, 2021). A series of useful resources have been developed by Carers Trust Wales to help GPs and primary care staff to identify and support older carers in doctor surgeries across Wales (Carers Trust Wales, 2022). In developing and executing awareness campaigns it is important that the social fabric, culture, and language of the many rural north Wales communities is understood and used to tailor how information about what may constitute a caring role and the various responsibilities, and the support that is available, is presented and shared in a sensitive and appropriate

way. This is even more important in dementia caregiving, as anecdotally reflected in this event, there is evidence to suggest that stigma associated with dementia is prominent in rural communities (Bauer et al., 2019; Roberts et al., 2023).

Closely related to the identification of carers is the availability of accessible information, advice, and assistance. This is crucial to carer knowledge of and timely access to break options. Based on the discussion during the knowledge exchange event, it was encouraging that across the region emphasis was focused on developing different ways to promote information, advice, and assistance related to short breaks. However, there is always the risk that the provision of information becomes an 'overcrowded market' (National Assembly for Wales, 2019) and there is duplication or inconsistency of information. A single support and information hub within every local authority area or region could provide a clear focal point for carers, and health and social professionals, to get up to date information. Seddon and colleagues (2021) recognise that the development of a hub would necessitate the building of strong links with a broad range of organisations, not just those with a health and social care remit.

In Scotland, Shared Care Scotland have advocated the bureau model of delivery. A Short Breaks Bureau brings together, in one place, the information, expertise, and resources to connect people to short breaks that best meet their needs and situation (Shared Care Scotland, 2015). Benefits of the Short Break Bureau Model is the specialist help and guidance people can receive in navigating assessments and fundings to organise a tailored package of support. Shared Care Scotland hosts an online directory and interactive map where you can search for short breaks across the whole of Scotland, by area, type of break, break needs, and accessibility.

2. **It is critical that the Welsh Government, statutory, and private providers of social care take the urgent steps to improve the pay and employment conditions in social care to raise the status of social care as a skilled, valued, and rewarding profession.**

The availability of suitably qualified and skilled care staff is central for carers and people with dementia to realise meaningful short breaks outcomes. Across the UK, the long-term failure to invest in the social care sector has given rise to considerable challenge in the recruitment and retention of the adult social care workforce (Trickey & Siôn, 2020). This increases the difficulty of commissioning because the market and availability of short breaks is inextricably affected by the broader state of health and social care (Shared Care Scotland, 2021). The Rebalancing Care and Support (Welsh Government, 2021d) report acknowledges high staff turnover, costly recruitment and training of new staff, and increased use of agency staff as systemic barriers to workforce quality and sustainability. At a national level there has been recent action to address these barriers. The Welsh Government has provided local authorities and health boards with £43 million so they can implement the real living wage. Ongoing work is being delivered under the Workforce Strategy for Health and Social Care which outlines the strategic framework, ambitions, and actions to develop a more engaged, agile, skilled, and sustainable workforce by 2030 (Social Care Wales, 2020)**.** While the building of the workforce is a long-term ambition, the effects of which will not be realised for many years, it is paramount for the future capacity for short breaks to be built around long-term evolving relationship with skilled professionals.

In 2022, Gwynedd local authority, the largest county in north Wales, and the Betsi Cadwaladr University Health Board collaborated to remodel how its home care service is delivered to provide more flexible support and opportunities for short breaks (Cyngor Gwynedd Council, 2022). To ensure consistency of care staff, as to build better long-term partnerships with families, the authority has been divided into different patches, and only one or two home care providers now work within each patch, which is anticipated to make it easier to arrange and manage care and support. The local authority and health board are working with local home care providers to develop consistent standards and guidelines relating to pay and terms and conditions for staff, including access to training and improved working practices. They have taken steps to reduce the amount of paperwork so more time is available for care staff to spend with families to get to know what is important for them to live well in their community. Changes in working practices should mean care staff have greater flexibility from week-to-week for when they visit a home to accommodate the care and support needs of the person with dementia, including opportunities to support more regular short breaks (Cyngor Gwynedd Council, 2022).

3. **Carers, who are eligible for Direct Payments, should be offered information about their potential to provide flexible short breaks, and offered support to help confidently set up and manage their Direct Payments.**

The latest 'Track the Act' (2020) report demonstrates the variation in number of carers across north Wales who received Direct Payments in 2020. This discussion during the knowledge exchange event demonstrated, that as a region, the renewed focus on promoting uptake of Direct Payments to provide real choice and tailored support for carers. This recommendation extends the recommendation of the National Assembly for Wales (National Assembly for Wales, 2019) (i.e., that a minimum standard of advice is provided across Wales to those carers wishing to make use of Direct Payments), by including varied examples of the flexible use of Direct Payments to support short breaks, such as the option to pool payments (Seddon, Andrews, et al., 2021), and that support is offered to manage Direct Payments, if needed, or if their use changes over time. A local authority in north Wales has produced guidance on pooling Direct Payments with others to meet shared short break needs and aspirations more efficiently and effectively (Flintshire County Council, 2019).

My Virtual Wallet is an online platform designed to help individuals to manage their personal care funding or Direct Payment in a secure online environment. My Virtual Wallet is currently available to all Direct Payment recipients in Powys, Wales, and in eight local authorities in England. The platform brings together individuals, their personalised care funding or Direct Payments, and care providers in a secure web-based system. The Virtual Wallet support team works with the carer and their funding authority to ensure that all care arrangements are 'set-up' in Virtual Wallet. All payments for care and support services are managed through the Virtual Wallet and can be tailored to support the most simple or complex of arrangements. The platform offers a full and transparent record of all bookings, invoices, and payments, and negates the need for the carers to manage a bank account.

4. **As part of any integrated provision or teams, it is important that there is a designated practitioner with responsibility for coordinating carers support needs, including short breaks. Their role may include communicating and liaising between health and social care services, offering tailored information and advice, and proactively assessing the carer's needs alongside the needs of the person with dementia.**
The All-Wales Dementia Care Pathway of Standards states that people with dementia and their carers should have a named contact (i.e., Journey Connector) to offer support, advice, and signposting, throughout their journey from diagnosis to end-of-life care (Improvement Cymru, 2021). This perspective closely aligns with findings from the European Actifcare study (Access to timely formal care) (Kerpershoek et al., 2019). A key recommendation was that people with dementia and their carers have a named contact person who continuously maintains contact, cooperates closely with primary, secondary, and social care services, offers individualised information, advice, and support, and regularly assesses the needs of the person with dementia and their carer/family. Research by Glasby and Thomas (2018) acknowledges that while there are different health and social care professionals with potential to occupy this role, what is most important is that the professional is highly trained, skilled, and well-funded, with specialised knowledge in gerontology or dementia, who can remain with the family over the course of the dementia. Reflecting the considerable regional diversity in assessment and delivery arrangements for short breaks (Caulfield et al., 2022), there needs to be local and, where feasible, regional agreement on the professional(s) responsible, and how they form part of an integrated post-diagnostic support team for carers and people with dementia; this is key to simplifying the pathway to timely breaks as part of a holistic and integrated approach to supporting carer well-being (Improvement Cymru, 2021). In Norway, at the point of diagnosis, people with dementia and their families are allocated a Dementia Coordinator to act as the primary contact person to follow and support the person with dementia and their family members from the time of diagnosis until they need long-term care (Norwegian Ministry of Health and Care Services, 2022). These are professionals with specialist knowledge of dementia. They are embedded within local interdisciplinary teams and provide and guidance and education on dementia to other health practitioners and can participate in assessment work in cooperation with general practitioners. In the 2018 national survey, 90% of the municipalities in Norway stated that they had interdisciplinary teams with competency in dementia.

5. To fully realise the envisioned role for the third sector as a cost-effective delivery partner, a strategic approach to funding and working with the third sector is required. This approach should be outcomes focused and informed by a thorough understanding of the diversity, capacity, assets, and skills of the third sector

Third sector organisations have an increasing prominent role in the provision of community lead short break activities for carers and people with dementia. Research has evidenced that where there is the right partnership infrastructure in place, this can help ensure joint working is effective in delivering timely short breaks (Auditor General for Wales, 2017; Caulfield et al., 2022a; Rochira, 2018; Seddon, Andrews, et al., 2021). Working proactively to genuinely grow and build third sector skills and capacity must be underpinned by a strategic plan that sets out how the local authority will engage, work with, fund, and assess the impact of partnership arrangements to meet the national priorities for carers (Auditor General for Wales, 2017).

The Promoting Variety Guide is designed to help local authorities to systematically work through the challenges of offering a viable and financially sustainable marketplace of short break opportunities through a collaborative, outcome-led approach to commissioning (Shared Care Scotland, 2021). It promotes a strategic approach to gathering intelligence about current short breaks provision, including gaps, and local short break needs and aspirations to develop a short-break-specific market shaping plan. Engagement with providers or partners from a range of sectors is important to help explore and identify all possible solutions and options to sustainably supporting short breaks. This understanding is important to help commissioners make effective decisions about how to deploy resources so that communities can become a fertile source for the development of short break activities.

6. Continue to support the local momentum to nurture dementia/carer friendly communities, to encourage citizens of all ages and cultures to legitimately recognise carers' right and needs for short breaks.

For carers who may not have the support of close friends of family members their community can be their main source of support and connection to others. In rural north Wales communities, the sense of community is often strong, supported by a shared cultural heritage, language, and history (Welsh Government, 2019). Many of the new models of short breaks provision being piloted across the region (e.g., community-based support groups, Shared Lives, micro-care enterprises) are predicated on small caring networks, embedded within communities, that enable carers and people with dementia to maintain active roles and connections to their community (Caulfield et al., 2022a; Prendergast et al., 2022). The development of such community models of support aligns with the ambitions of the Welsh Government strategy for Connected Communities (Welsh Government, 2020) and the Welsh Government Strategy for an Ageing Society (Welsh Government, 2021c). Both strategies are a response to modern ways of living and population ageing that bring new challenges to Governments, communities, and individuals. These strategies set out the priorities for action intended to foster environments where social links are broadened and deepened to support individual and community resilience and where people with dementia and their carers and are not limited to segregated social support. Much research has been conducted on developing the foundations for such social links and networks to thrive and has exemplified the interconnection between supportive communities and understanding and awareness of dementia and an enabling ethos of dementia 'inclusivity' (Hung et al., 2021; Quinn et al., 2021; Robertson et al., 2020; Shannon et al., 2019). This interconnection needs to be considered when customizing local plans and approaches that genuinely seek to build sustainable short breaks that depend on informal community support. The interdependence between inclusive communities that can support carers to realise breaks and the vitality and capacity of the third sector is further demonstrated.

In Taiwan, the Carer Cafés model is a community-based initiative of the Taiwan Association of Family Caregivers to improve the identification of carers and help cultivate social responsibility in supporting carers throughout Taiwan communities. Developed in 2017, Carer Cafés are locally operated cafés that offer carers a safe space to take a short break and enjoy up to ten free coffees a year. Carer Cafés employ a range of methods to help carers recognise their own well-being needs, increase awareness of, and referral to, long-term care resources and support services in the community. There are now over 100 Carers Cafés in Taiwan. In 2018, the Carer Cafés model were identified as a global innovative carer practice by the International Alliance of Carer Organizations (International Alliance of Carer Organizations, 2018)

6.5   Discussion

The knowledge exchange event aimed to integrate knowledge gathered in the phase one and two of this research to augment understanding of meaningful short break provision. The event brought together a small but varied and dynamic group of stakeholders and intended beneficiaries, with diverse knowledge and lived experience. While areas of interests around short breaks differed, consensus was achieved on the features that contribute towards a meaningful short break experience and outcomes. A unique observation of this event was the understanding that sustainable and meaningful short break provision is only achievable when the well-being, reciprocities, and interdependencies of all those involved in the provision of care and support, across all sectors and settings, are meaningfully considered (Andrews et al., 2009; Keating et al., 2021; Nolan et al., 2006). This means adopting a whole system approach in which to better appreciate how carers' evolving short break needs are supported; in this event, the caregiving career was an aid to facilitate this holistic, developmental, and experiential inquiry.

Supported through a dialectic approach, it emerged that meaningful short break provision is about much more than having a choice of break options, it is supported through a culture that values carers, including paid care staff, a health and social care system that is designed and orientated to recognise carers early in their career, and a workforce that is provided with the skills and knowledge to intentionally nurture supportive and enabling relationships with carers and people with dementia, to help them prioritise and realise their short breaks outcomes, together with other forms of preventative support, when they need it. This perspective aligns with research that urges that the notion of a short break and the role they can have in supporting personal and relational well-being, is discussed early in the caregiving career to orientate carers to the different types of breaks that are possible, and appropriate, depending on their needs and preferences (Bayly et al., 2021; Gaugler et al., 2005; Kirk et al., 2015; Kosloski & Montgomery, 1995; Rose et al., 2015; Shared Care Scotland, 2012).

During the discussion, the temporal alignment of breaks was emphasised, and there was greater cognizance in thinking of short breaks as existing and evolving along a pathway of post-diagnostic support, concomitant with changes in support needs, as well as well-being outcomes, as the dementia progresses. If short breaks are not available, appropriate, or known about at the right time carers may prematurely consider permanent care home placement because the preventative role of short breaks are lost, and as a resource they are 'too little too late' (Gaugler et al., 2005; Kosloski & Montgomery, 1995; Montgomery & Kosloski, 2000). Montgomery and Kosloski (2000) allude to 'severable moments'

based on 'markers' within the caregiving career, where short breaks can be expected to have their greatest impact. For example, carers first must identify and recognise their role as a carer and must be providing a certain intensity of care before they reach the point of receptivity to certain break options (e.g., in-home provision or day care). To appreciate and act upon these 'severable moments', breaks must be understood as existing along a continuum, with certain breaks being more appropriate, and potentially serving different purposes, at different points on that continuum.

The knowledge exchange event was helpful in drawing attention to the increased urgency and reliance on the third sector to foster diversity of community short break options. The elevated focus on third sector involvement has arisen because of their distinct position within the community, being more sensitive to local circumstances, particularly those of hard-to-reach demographics, such as carers and people with dementia, and having the flexibility to deliver responsive support. Encouragingly, greater third sector influence of how short breaks are designed and delivered is reflected through the Amser programme. Grants are available for one or two years, between £5,000 and £100,000 per annum. The Amser programme intends to offer third sector organisations support to help them evaluate their short break models and capture the outcomes supported. This knowledge is critical to gather evidence needed for future funding applications and for organisations to consider the effectiveness of their service and supports to inform strategic decision-making. The variety of applications received demonstrating the local short break needs of the different demographics and communities, and how short breaks intend to be supported, is in and of itself valuable information to demonstrate the diversity in thinking around short break provision across Wales.

While the attractiveness of two years of funding through the Amser programme is a positive example of dedicated funding and commitment to improving access to short breaks across Wales, historically, the appeal of applying for funding for many small third sector organisations has been undermined by the challenges brought by insecure annual grant-based schemes (Wales Council for Voluntary Action, 2021). These challenges threaten the sustainability and resilience of organisations to provide consistent preventative support for carers through restricting their ability to plan and deliver services and attract and retain suitably qualified and experienced staff (Caulfield et al., 2022a; National Assembly for Wales, 2019). The five-year life span (2022 – 2027) of the Health and Social Care Regional Integration Fund (Welsh Government, 2022a) is designed to ensure the sustainable long-term resourcing needed to embed and mainstream new models of integrated care. Under this fund, all service delivery partners are encouraged to find match resources to help develop and embed integrated models of delivery across the health and social care system. Match resources may be made

up from direct financial contributions from core funds or other non-Welsh Government grant sources, income generation, staff and volunteer time, and use of facilities and buildings (Welsh Government, 2022a). Recognising the limited access of the third sector to core funding, third sector providers and partners are encouraged to contribute the use of community facilities and access to charitable funds and grants. While this longer-term funding is welcomed, there is a risk perhaps that this new model of match funding will favour the larger more established third sector organisations who have greater capacity to cover their core running costs, at the neglect of supporting a greater diversity and building the capacity across the third sector to deliver short breaks.

Highlighted in the knowledge exchange event was the benefit of health and social care professionals working together to holistically consider the support needs of the couple which resulted in the efficient and timely organisation a short break. Community Resource Teams are already in operation across north Wales to provide integrated health and social care services. However, as these models aim to scale up across the region, one of the main barriers to their success is the lack of a suitable system to share information between team members (North Wales Social Care and Well-being Improvement Collaborative, 2021). The Welsh Community Care Information System (WCCIS) is a new and ambitious system being introduced across Wales to enable local authorities and health boards to record, share, and update information on a single electronic record. This is essential infrastructure to support integrated, local, and efficient care and support closer to home for people with dementia and their carers (Welsh Government, 2022a). The third sector is a major provider of services to carers across north Wales (three out of the six local authorities in north Wales commission a local carer's charity to conduct Carer's Assessments and organise and oversee short break provision). Therefore, to ensure the true integration with the third sector, consideration must be given to how third sector practitioners can access the WCCIS or at least share in the knowledge.

There were challenges to implementing the DEEP approach in practice. Given the limited time frame, it was difficult to find balance between the depth and breadth of discussions. The researcher had to adopt the role of 'knowledge broker' (Lightowler & Knight, 2013) and thread the research evidence into the discussions in ways that blended with rather than took prominence over other forms of participant knowledge. To share and highlight all the main research findings, a lot of information was delivered in a short time. All participants were presented with a research pack, which included a summary of the main research findings, produced by the researcher, however, greater attention on behalf of the researcher could have been dedicated to inviting participants to close or summarise their interpretation of the discussion by inviting 'last words'. In DEEP practice, 'last words' presents the

opportunity for participants to say what they think is most important in what has been discussed, how they felt about the process, or what they think the most important implications are for practice. This knowledge could have potentially helped produce a summary of shared learning or take-home messages which could have been distributed to all participants and considered as a key output from the event.

A limitation of the knowledge exchange event was that no formal feedback was gathered from participants to try and measure the impact of the event, rather feedback was mostly anecdotal. While accepting the limitations of the event to effect demonstrable influence at an organisational level, it can be postulated that it had a more subtle impact at an individual level through encouraging participants to be heard, feel valued, gain confidence, enhance their networking skills and communication, and build future research capacity.

Inevitably, delivering and managing the hybrid event did present a challenge in giving voice to all perspectives and ensuring that the discussion was not dominated by a few individuals. Encouraging meaningful engagement from those who attended online and from those the researcher had not met before and therefore lacked personal acquaintance, was challenging. The hybrid event also meant that information was predominantly presented over PowerPoint and slides were talked through. This method, on reflection, was not the most captivating way of engaging participants and creating an enriched environment of learning. An alternative way to facilitate a meaningful and constructivist learning experience would have been to follow the structure for a Community of Enquiry (Muirhead, 2018). This would have involved the presentation of a 'thinking prompt' or stimulus, which participants would initially discuss in pairs and then come together to work in small groups to generate a conceptual question that they want to propose to the group. The group would then engage in an enquiry to gain an enriched understanding of the concepts embedded in the question(s). While this approach may have encouraged a more focused discussion, it was important that time was preserved to allow participants to contribute and exchange their stories. The centre staging of participates stories was important to construct shared values, understanding, and vision for supporting meaningful short breaks, built from multiple voices and perspectives. The telling of stories was central to communicate values and experience and socially construct knowledge in practice 'mindlines', the collectively reinforced, tactic, and internalised guidelines (Gabbay & le May, 2004) that could help guide meaningful short break in different contexts.

6.6   Conclusion

This chapter reported on a knowledge exchange event that integrated different forms of knowledge to augment understanding and enable a holistic inquiry of supporting meaningful short breaks. The interdependence between, and the important contribution of government, local authorities, third sector, and communities, in supporting meaningful short breaks provision was recognised. Short breaks are a source of support that have the potential to span and support carers over their career (Zarit, 2018). However, to truly realise their preventative purpose, breaks need to be timely and appropriate to the **stage** in the caregiving career. Thus, drawing on other developmental temporal models of dementia caregiving is needed for future short breaks research. It is prudent to begin work to develop a new conceptual framework to understand the needs for short breaks based on career stages, as experienced, or identified by carers. For planning and commissioning practitioners, this knowledge is critical to effectively ensure there is equity of choice of short breaks appropriate to stage and as a guide for proportionate resource allocation.

Chapter Seven: Towards a conceptual framework for short breaks

7.1   Introduction

Over the last three decades, the international literature on dementia caregiving has grown substantially in sophistication and depth (Britton & Zimmermann, 2022; Cheng et al., 2019; Maslow et al., 2021). Research has evidenced the extent of change in the lives of the person with dementia and the carer, and how couples attempt to navigate these trajectories of change, practically, socially, and emotionally (Daley et al., 2017; Merrick et al., 2016; Miller-Ott et al., 2022). This fertile effort has helped to delineate the support needs and experience of carers at different points along their career, for example, prior to, and at the point of receiving a diagnosis of dementia, and recognition of their caregiving role (Adams, 2006; Boots et al., 2015; Ducharme et al., 2011; Hodgson et al., 2014; Zwaanswijk et al., 2013), through to the latter stages of caregiving, which may be characterised by decisions relating to the permanent transition to a care home (Gaugler et al., 2001; Sutcliffe et al., 2017), end-of-life care (Kinchin et al., 2022; Lewis, 2015; Thompson & Roger, 2014), and the caregiver bereavement experience (Peacock et al., 2018; Supiano et al., 2022). However, a notable absence in the caregiving literature is that of a temporal developmental understanding of dementia caregiving, distinguished by discernible stages of caregiving, and the transitions that link them (Bangerter et al., 2019; Gallagher-Thompson et al., 2020; Harvath et al., 2020; Nolan et al., 1996). Understanding caregiving as a dynamic and developmental process encourages thinking around how interventions and support can be tailored to, or intervene at specific stages, so the career trajectory is not splintered by uncoordinated or fragmented support (Gaugler & Teaster, 2006; Keady & Nolan, 1995; Lethin et al., 2016; Pearlin et al., 1990). This is important for short break provision, the purpose of which is to support carers over their caregiving career.

Short breaks are a unique preventative intervention with the potential to extend across the whole course of the caregiving career, so their benefit is cumulative and sustained (Bangerter et al., 2019; Gaugler, Zarit, Townsend, et al., 2003; Liu et al., 2015; Måvall & Malmberg, 2007; Zarit, 2018). For the UK policy and practice vision for timely personalised short breaks to be realised, the development of short breaks must be guided not only by outcomes that are important to carers, but by a developmental understanding of the caregiving experience, and crucially the transitions in the caregiving experience that intersperse and connect the trajectory (Gallagher-Thompson et al., 2020; Liu et al., 2015; Newbronner et al., 2013). In the context of the dementia caregiving career, Gallagher-

Thompson et al., (2020) describe transition points as 'noticeable shifts in the need for resources, to accommodate the changing care needs of the person with dementia' (Gallagher-Thompson et al., (2020, p. 32). For example, a transition may encompass the move from one care setting to another in which there is greater dependence on the carer and increased responsibility for decision-making. Transitions during the caregiving career are denoted by changes in social engagement, family support, and in the psychological well-being of the carer and the person they support (Gallagher-Thompson et al., 2020; Seltzer & Li, 1996, 2000), which are likely to influence the need and preference for short breaks. Examining the experiences of transitions between care settings for people with dementia (e.g., from home to hospital, from home to nursing home) have been used to understand how meaningful activities, that reflect the current and past interests, routines, habits, and roles of the person with dementia, are adjusted to abilities, and maintained (Groenendaal et al., 2022). It is the intention of this chapter to consider how transitions between stages have potential to serve as indictive 'markers' (Montgomery & Kosloski, 2000) for short breaks that may be acceptable and beneficial at a particular point in the career.

Carer-identified phases across the Alzheimer's disease trajectory have been operationalised to explore carers' health and social care decision-making over time and highlight the complexity of navigating health and social care systems and accessing services as caregiving goals change (Kokorelias et al., 2022). Caregiving goals early in the career related to wanting to maintain a sense of normalcy following the dementia diagnosis (e.g., the wish to resume life, as much as possible, to how it was before the diagnosis), to latter stages of the career, where caregiving goals shifted to finding a suitable care home where the person with dementia could receive a better consistency of care (Kokorelias et al., 2022).

This chapter is an initial step to develop a new conceptual framework to understand the temporal nature of carer short break needs. It does this by firstly scoping the international literature for developmental models of dementia caregiving, in which the career is furnished by discernible stages, as observed, experienced, or identified by carers.

The rationale for positioning the scoping review within this section of the thesis has been discussed in the research strategy (Chapter Three, Page 56). To reiterate, the aim and justification for undertaking this scoping review stemmed from a crucial gap in evidence identified by Seddon and Prendergast's 2019 work titled 'Short breaks for carers: a scoping review'. In substantiating this identified knowledge gap, the first three phases of data collection in this research not only validated this gap but strengthened the focus for this scoping review. For instance, Chapter Four underscored that

practitioners acknowledged the evolving nature of short break needs and preferences over time, reflecting changes in the caregiving role associated with dementia progression. Additionally, it was noted that while there was a regional intent to broaden short break choices, there were limited strategic tools to guide this endeavour (Caulfield et al., 2022a). Chapter Five revealed that during transitions in the caregiving career, delays and limited choices in short break options posed challenges for carers in accessing timely breaks and achieving meaningful outcomes (Caulfield et al., 2022b). In Chapter Six, the potential value of a new framework for short break development emerged during a knowledge exchange event and discussions on the national initiative to plan and implement support for carers and individuals with dementia along a pathway (Improvement Cymru, 2021). The All-Wales Dementia Pathway of Standards, structured around the 'journey,' aims to ensure a seamless trajectory from diagnosis to end-of-life, offering stage-appropriate learning, information, supports, and services. However, it is noteworthy that the Pathway makes no reference to the number of stages in a journey, the defining characteristics of each stage, and the transitions between them. This knowledge is pivotal for effectively targeting preventive interventions, such as short breaks. In summary, to augment the transferability and practical applicability of these findings, this research constructs a compelling argument to contemplate how a conceptual framework for short breaks provision can facilitate a more nuanced and developmental understanding of break needs. Certain breaks may be more suitable and potentially serve different purposes at different junctures along the caregiving career. This chapter contributes to refining this understanding and explores potential solutions and opportunities to support it.

7.2 Aim

The **aim** for this scoping review was to provide a synthesis of developmental models of dementia caregiving and explore how these can inform a conceptual framework for understanding short breaks needs across the caregiving career.

Two exploratory objectives were addressed:

1. To scope and chart the range of developmental dementia caregiving models and to delineate the key characteristics and stages that define the models.
2. To explore how these models can offer insight into short breaks most appropriate to stage and how short breaks might support carers as they transition through stages.

7.3   Method

As an approach for knowledge synthesis, scoping reviews are commonly used for a 'reconnaissance' of the published literature, to map the available evidence (or lack thereof), to clarify concepts, and identify the coverage and sources of evidence that can help guide policy, practice, and research development (Daudt et al., 2013). Scoping reviews are often a precursor to determine the value and likely scope of conducting a systematic review (Daudt et al., 2013). The aim for this review was not to address the feasibility, quality, or efficacy of selected models but to provide an overview of an area that has not been exhaustively explored, thus, a scoping review was deemed the most appropriate method.

There is considerable variability in definition, methodology, and reporting criteria for scoping reviews (Colquhoun et al., 2014). This scoping review was guided by Arksey and O'Malley's (2005) five-step process to the systematic identification, searching, selecting, charting, and synthesizing of existing knowledge. The PRISMA Extension for Scoping Reviews (PRISMA-ScR) was followed to ensure clarity and strengthen the rigor of reporting (Tricco et al., 2018).

7.3.1   Study identification

A comprehensive search of the literature was conducted in the following four health sciences and social care databases in January 2023: Applied Social Sciences Index and Abstracts (ASSIA)(ProQuest); CINAHLPlus (Cumulative Index to Nursing and Allied Health Literature: EBSCO); MEDLINE (EBSCO), and PsycInfo (ProQuest). Lateral forward (i.e., citation search in Google Scholar) and backwards searches (i.e., checking references) of selected papers were performed. In developing the search terms, an academic librarian was consulted. Titles and abstracts were searched using the following terms: "caregiving process" or "caregiving trajectory" or "caregiving model" or "caregiving stages" or "caregiving phases" or "caregiving career" or "multidimensional model of caregiving" or "changes in caregiving over time" or "longitudinal changes" or "temporal models of caregiving" AND Dementia. The publication date was set between 1986 and 2023. This period reflects the earliest publication by Chenoweth and Spencer (1986) identifying stages in a caregiving career to the present year of 2023.

7.3.2   Study screening

Inclusion and exclusion criteria

All sources were published in the English language in a peer-reviewed journal or published book. In this study, developmental models of dementia caregiving were defined by their explicit identification and naming of specific stages along the caregiving career. To determine a 'stage' Aneshensel et al.'s, (1995) definition was used: a stage in caregiving is a 'heuristic device, that helps detect the threads

connecting each part of caregiving to its other parts and identify conditions that move caregivers along their career trajectories at different rates and at different psychological and material cost to themselves' (Aneshensel et al., 1995, p. 23).

To avoid the subjective interpretation of stage or transition between stages on behalf of the researcher, studies that presented a temporal description, for example, of health-related outcomes or appraisal (Connors et al., 2020; Perren et al., 2006), changes in experience, needs, and preferences for support (Caulfield et al., 2022b; Lin et al., 2012) or interaction with formal services over time (Lethin et al., 2016), but did not delineate the specific stages of the caregiving career were excluded.

7.3.3 Study selection

Searches of academic databases generated a total of 556 papers. Two seminal books by Aneshensel et al., (1995) and Nolan et al., (1996) were included as additional sources. The search results were saved to Mendeley Reference Manager and duplicates were removed. Titles and abstracts were screened for relevance.

7.3.4 Knowledge charting process

A Microsoft excel spreadsheet was developed and the data was extracted in relation to reference and research location (authors, year, and country), study population, study aim(s), methods, and number of identified stages. While it is recognised that not assessing the methodological quality of the papers limits the interpretability of findings (Levac et al., 2010), in this review, and as generally accepted in scoping review methodology (Munn et al., 2018), the methodological quality was not critically apprised because the primary aim was to offer a preliminary assessment of the potential size and scope of literature.

7.3.5 Synthesis of model stages

The synthesis of the eleven models was guided by the reflexive approach to qualitative data analysis outlined by Braun and Clarke (2019). The aim was to identify similarities in the stages outlined in the models, bringing to the fore shared features of the dementia caregiving experience and to summarise the movement between stages. Following familiarisation with the textual description of each model, the visual organisation of model stages was a beneficial exercise to understand how stages were structured and described (Figure 7.2). The inspection and comparing of stages, broadly grouped at the

start, middle, and at the end of each model informed a broad linear pattern of career progression. The models shared several similarities in their progression, starting with the recognition of symptoms of dementia, receiving a diagnosis, coming to terms with the caring role and taking it on, dealing with how the dementia presented and the balancing of the many responsibilities and changes, to eventual care home placement. Differences were apparent in the particular emphasis of each model. To illustrate, Kobayashi et al.'s, (1993) stages paid attention to how the carers' understanding and perception of the person with dementia evolved with disease progression. Cooper et al.'s, (2022) stages focused on changes to the spousal relationship and communication over time, and Tu et al.'s, (2022) stages drew attention to the impact of caregiving on the carers' health and well-being. Refining of the narrative synthesis required the continual revisiting and reflection on stages to accentuate the experiences and observations shared between models and highlight their novel and unique insights, relating to transitions in relational, practical, or intrapersonal experiences.

Figure 7.1: *PRISMA flow diagram.*

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Identification

    Papers identified through electronic        Papers identified through additional
          database searches:                      sources searches and referrals
             Total = 556                                      (5)
    ASSIA (20); CINHAL (137); Medline
          (367); PsycINFO (32)


                           Papers after duplications removed
                                        (387)

Screening
                           Title and abstracts screened (387)


                                                 Irrelevant papers excluded (367)


                           Full text assessed for eligibility (20)

Eligibility
                                                 Papers excluded (13)
                                                 Did not specify or expand on
                                                 caregiving career stages

                           Papers selected for synthesis (7)


Included
                           New papers included following reference
                               and citation searches (4)


                           Total papers included in knowledge
                                   synthesis (11)
```
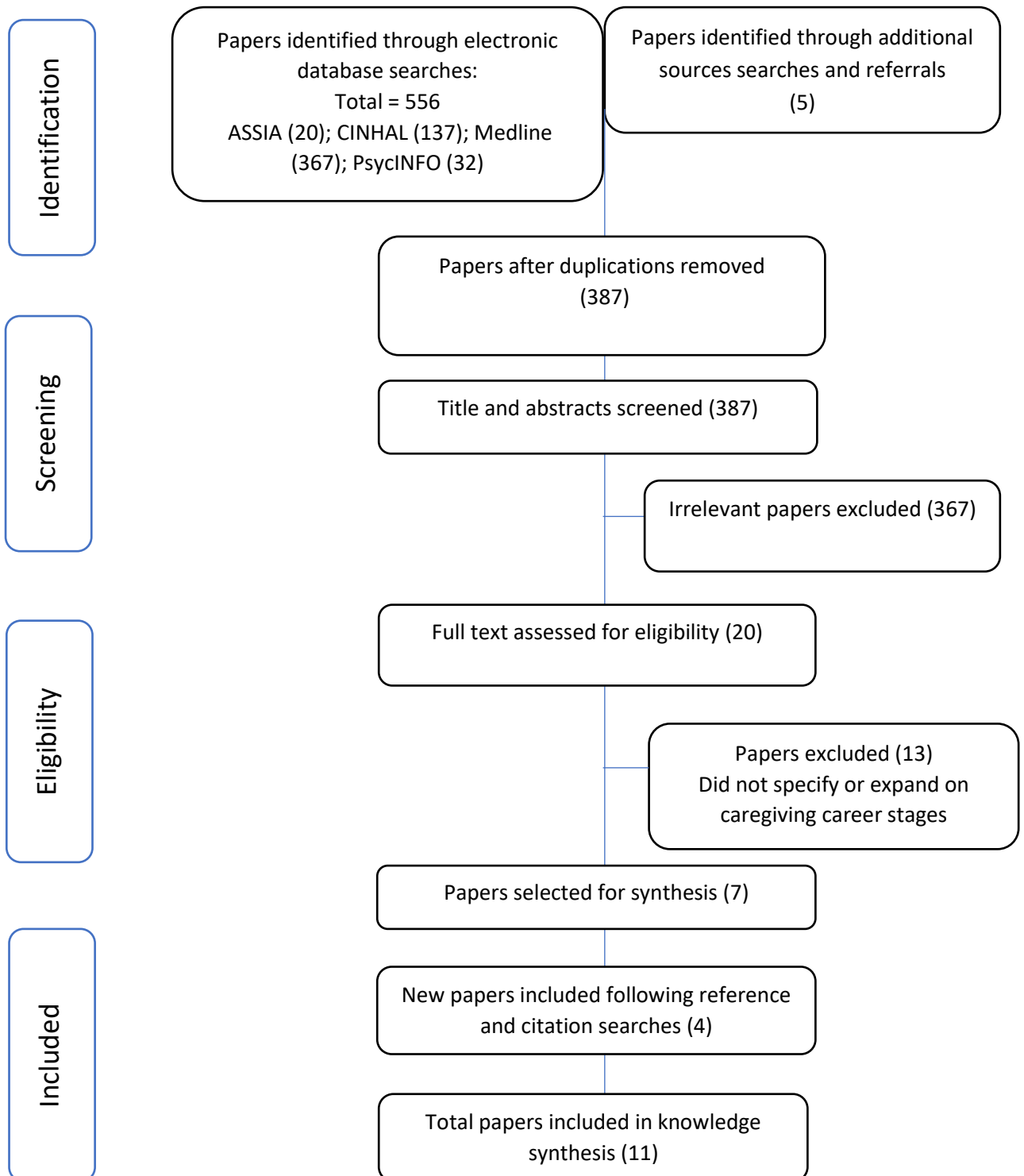
Table 7.1: Studies identifying stages in the dementia caregiver career

References and research location	Study population	Aim(s)	Method(s)	Number of identified stages
Tu et al., (2022) China The trajectory of family caregiving for older adults with dementia: difficulties and challenges *Age and Ageing, 51* (12)	**13 family carers:** 5 spouses (4 wives and 1 husband) 8 adult children (6 daughters and 2 sons) Mean age: 63 years. Duration of providing care < 1 month to 5 years. Ethnicity: Chinese	To investigate the trajectory of family carers struggles from home care to *long-term institutional care. To identify the common 'tipping points' leading to institutional care.	Ethnographic study. The researcher stayed in the care institution full time for 14 months, observed and recorded all aspect of interactions among staff, people with dementia, and their family. Family members were interviewed when they visited the care institution. Semi-structured retrospective interviews focused on the long-term experiences of caring at home and in the institution.	2 overarching stages, each with 3 subthemes. 4 tipping points, triggering the decision for institution placement.
Cooper et al., (2022) USA "That's when the relationship shifted": Relational and communicative turning points in Alzheimer's disease and related dementias.	**18 spousal carers** (10 wives and 8 husbands). 3 participants' spouses had died prior to interview. Mean age: 69 years. Mean years married: 38 years.	To investigate the specific relational turning points experienced by spousal carers across the trajectory of Alzheimer's disease and related dementias.	In-depth retrospective interviews to gain insight into spousal carers' relational experiences across the disease trajectory. To help identify turning points across the disease trajectory, the participants created turning point timelines of their relationships from the onset of symptoms to the present.	3 overarching stages containing 9 discrete relational turning points.

Personal Relationships, *29*(1), 217-235.	Mean disease length: 5 years. Race: White: 13 Black: 2 Multiracial: 2 Hispanic: 1			
Kokorelias et al., (2020) Canada A grounded theory study to identify caregiving phases and support needs across the Alzheimer's disease trajectory. *Disability and rehabilitation*, *44*(7), 1050-1059	**40 family carers:** 20 spouses (10 wives) 20 adult children (10 daughters and 10 sons) Age range: 45 years to 88 years.	To develop a conceptual framework of caregiving phases across the Alzheimer's disease and caregiving trajectories and the corresponding carer support needs.	Grounded theory guided by Charmaz (2006) methodology. Semi-structed interviews collected data on the overall experience and responsibilities of carers across the disease trajectory. Member checking interviews were conducted with 10 participants.	5 carer-identified phases across the Alzheimer's disease trajectory.
Pfeiffer (1999) USA Stages of caregiving	Not given	To describe the stages of caregiving as experienced by carers, the issues they faced, the services most appropriate for that stage, and the possible adverse outcomes for each stage.	Years of observation of family carers as they continued their varied caregiver careers for persons with Alzheimer's disease.	7 caregiving stages.

American Journal of Alzheimer's Disease, 14(2), 125-127.				
Nolan et al., (1996) UK Understanding Family Care: A Multidimensional Model of Caring and Coping Open University Press, Buckingham	**58 family carers:** A mixture of carers new to their role; experienced carers who had been providing care for many years; carers who had placed the person with dementia in care/nursing home or the person with dementia had died.	To outline a temporal model of the caregiving process based on the study of dementia carers.	In depth interviews from a collection of research over 3 years. Cross sectional design. No information given to determine if interviews prompted carers to retrospectively reflect on caring experiences.	6 caregiving stages.
Aneshensel et al., (1995) USA Profiles in caregiving. The unexpected Career. Academic Press	**555 family carers** (at baseline) Relationship to person with dementia (%): Wife: 34.2 Husband: 24.5 Daughter: 31.2 Daughter in Law: 3.2 Son: 6.7 Son in Law: 0.2 Spousal carers age (%): Less than 65: 22.8	To highlight the long-term and varied course of caregiving for persons with Alzheimer's disease or related dementias. To capture the transitions and changing conditions that carers experience during the extended trajectories of their activities.	Multi-wave panel study. Four-in person semi-structured interviews conducted at 1-year intervals. Interviews were conducted at baseline, caregiving at home, institutional care, and bereavement.	3 caregiving stages denote a 'typical' career.

	65-74: 45.5 75 and older: 31.7 Race (%): Non-Hispanic white: 83.8 African American: 10.6 Hispanic: 3.1. Asian American and other: 2.5			
Wuest et al., (1994) Canada Becoming strangers: the changing family caregiving relationship in Alzheimer's disease. *Journal of advanced* *nursing, 20(3),* 437- 443.	**15 family carers:** 8 spouses (5 wives) 5 daughters 1 son 1 sister Age range: 28 years to 83 years.	To explore the reciprocal process of becoming strangers in which carers and people with dementia interact on a continuum from intimacy to alienation.	Grounded theory. Commonalities and relationships in the data focused observation and interviews to clarify emerging theme. Data collection, analysis, and development of hypothesis occurred concurrently.	A continuum of 'becoming strangers' made up of 3 stages (dimensions)
Kobayashi et al., **(1993)** Japan Developmental process: family	**49 family carers:** 19 daughters-in-law 11 wives 10 daughters 8 husbands 1 son	To identify how carers: a) perceived the person with dementia and attitudes held towards them. b) changes in perceptions and attitudes over time.	Semi-structed interviews. Questions focused on the carers understanding and perception of the person with dementia from the time they notice symptoms to the present.	7 stages during which the carer demonstrated certain characteristic perceptions and attitudes toward the

caregivers of demented Japanese *Journal of Gerontological Nursing, 19(10),* 7-9	Mean age: 57.9 years. Ethnicity: Japanese	c) when, and in what manner their perception and attitudes changed. d) what specific changes did they display.		person with dementia.
Willoughby and Keating (1991) UK Being in control: the process of caring for a relative with Alzheimer's disease *Qualitative Health Research, 1(1)*, 27-50	**10 family carers** (from 7 families): 3 wives 4 daughters 3 sons Range of years providing care: 1.5 years to 15 years.	To understand the process of dementia caregiving from the perspective of family carers.	Grounded theory. In-depth unstructured interviews. Each participant was interviewed twice, with the second interview focusing on the development of hypotheses about stages. The first interviews focused on early changes in the person with dementia, how and when the disease was diagnosed, decisions about care placement, relationship with paid carers and useful support. The second interview encouraged participants to identify the beginning of caregiving, to anticipate the end of the process, and to discuss differences in caregiving over time. The researcher also observed some carers when they visited their relative with dementia in the care home.	5 caregiving stages of gaining and relinquishing control of caregiving.

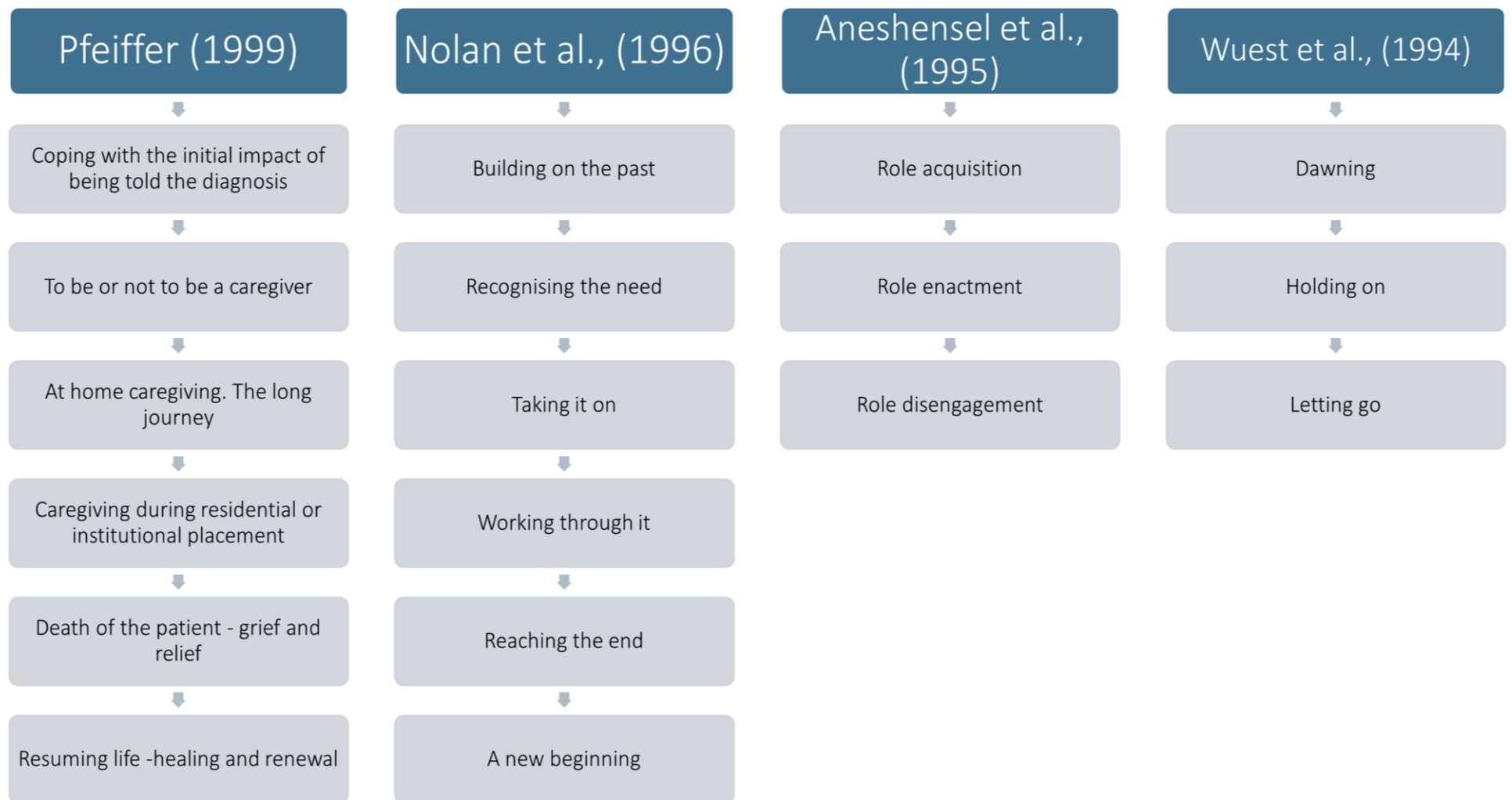| Wilson (1989) UK Family caregivers: the experience of Alzheimer's disease. *Applied Nursing Research, 2(1)*, 40-45.	20 spousal carers (14 wives and 6 husbands). Marital status: 18 married 2 widowed Age range: 29 years to 85 years Mean age: 62 years. Ethnicity: Asian: 1 Native American: 2 White: 17	To conceptualise the progressive course of Alzheimer's disease as experienced by family carers in the process of daily living with a relative with dementia.	Semi-structured in-person interviews. These addressed the cues that first indicated a problem, the diagnostic process, and the progressive decline. Thematic data analysis identified common patterns and themes that captured the lived experience of the course of dementia from the perspective of the carer.	8 caregiving stages.
Chenoweth & Spencer (1986) USA Dementia: The experience of family caregivers. *The Gerontologist, 26(3),* 267-272.	289 family carers (%): Wives: 41 Husbands: 14 Not specified: 45 Race (%): White: 99 Other: 1 Age (years) (%): 24 to 40: 24 41 to 60: 39 61 to 82: 37	To explore the experience of family carers from the time of the earliest recognition of symptoms of dementia throughout the course of the disease.	Data was collected via a 24-page questionnaire (not validated) combining open-ended and closed questions and checklists. Questionnaires were accompanied by photographs, medical records, and letters with additional information. 13 telephone interviews were conducted with carers willing to share their experiences in greater detail.	4 caregiving stages

	Religious preference (%): Protestant: 60 Catholic: 26 Jewish:4 None or other: 10			

Note. *Long-term Institutional care is the wording used by Tu et al., (2022) to refer to a residential or nursing home.

Figure 7.2: *Visual schematic of the titles given to each caregiving stage*

Tu et al., (2022)	Cooper et al., (2022)	Kokorelias et al., (2020)
Caregiving at home	My spouse has dementia	Monitoring initial symptoms
Mental stress	From spouse to caregiver	Navigating diagnosis
Physical burden	My spouse is gone	Assisting with Instrumental Activities of Daily Living
Social and emotional pressure	Transcending dementia through love	Assisting with Basic Activities of Daily Living
Caregiving following long-term care placement		Preparing for the future
Moral pressure and emotional torment		
Financial burden		
Worries		

Kobayashi et al., (1993)	Willoughby & Keating (1991)	Wilson (1989)	Chenoweth & Spencer (1986)
First notice of elder's dementia and confrontational approach	Emerging recognition	Noticing	Recognising early symptoms
Caregiver recognises dementia and ceases criticism of elder	Taking control	Discounting anti-normalising	Problems with diagnosis and information
Hope that elder's conditions will return to normal	Losing control	Suspecting	Impact of providing care at home
Resignation to the fact of dementia and adoption of hands-off care policy	Adjusting to psychiatric institution	Searching for explanations	Family reactions to institutionalisation
Recognition that interaction with demented elder is taking place	Moving on	Recasting	
Early efforts to understand demented elder's nonverbal signs and feel empathy for elder's condition		Taking it on	
Recognising qualities of elder that transcend disabilities caused by dementia		Going through it	
		Turning it over	

7.4 Findings

7.4.1 Model characteristics

The fundamental idea that these eleven models are advancing is that caregiving and the interpersonal relationships that underpin it move through stages and this process is dynamic, in which a trajectory of decline and growth is simultaneously played out (Cooper et al., 2021). Although travelling down the same chronic care trajectory, in which the passage through stages is chiefly driven by the progressive nature of dementia, it is not a clear-cut sequence. Dimensions from each stage can overlap, and within stages tremendous variation can exist. Aneshensel et al., (1995) assert that within-stage variation is the confluence of several interrelated conditions: the progressive deterioration of the health of the person with dementia, the proliferation of stress in domains of life outside of caring, and the diminished personal and social resources of the carer. The more progressive the advance of the dementia, the quicker carers move through their career (Kobayashi et al., 1993). Interestingly, Aneshensel et al., (1995) note that there is not necessarily a correlation between the progression of dementia impairment and the experience of carer stress. To illustrate, the receipt of a diagnosis can be an extremely stressful time, but it is usually when caregiving tasks and responsibilities are minimal. In Ansehensel at al.'s (1995) study, typically, the average time at which caregiving 'begins' is marked at seven months following a diagnosis.

The transition between stages were commonly defined by an event, such as a diagnosis, a care-related decision, such as the decision to take on the caring role or to accept or request formal support, or the physical movement of the person with dementia to a care home. In Willoughby and Keating's (1991) study, movement between stages was determined by a cognitive shift, defined as 'a change in thinking, a new understanding, and new insights about an experience' (Willoughby & Keating, 1991, p. 35).

In some models, stages are pronounced by their orientation towards caregiving tasks and responsibilities (Chenoweth & Spencer, 1986; Kokorelias et al., 2020; Pfeiffer, 1999; Tu et al., 2022), described as the 'activities, tasks, and focus of care contributed by carers to assist the person with dementia' (Kokorelias et al., 2020, p. 1053). In three models, attention is given to the relational and emotional changes over time (Cooper et al., 2022; Kobayashi et al., 1993; Wuest et al., 1994). However, stages within most models capture the varying challenges that confront carers, involving practical caring tasks, stressors, cognitive processes, and emotional states, which are not always in harmony; for example, conflict between emotion and reason is prominent when carers deliberate the transition to care home placement for the person with dementia.

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Most models were developed in western countries (USA (4), UK (3), Canada (2), China (1), and Japan (1)) in which care home placement is a common phenomenon and there is not as strong a familial or cultural expectation for adult children to provide care as in undeveloped economies (Escandón, 2006). Interestingly, despite the inclusion of models developed in China and Japan, both being collectivistic cultures that value family obligations to care, care home placement was nevertheless an embedded stage in the dementia caregiving career, which is indicative of the distinct challenges of caring long-term for a person with dementia at home. However, Tu et al., (2022) did acknowledge that this stage was stigmatised in Chinese society, and Chinese spousal and adult children carers feared social criticism.

Six studies explicitly reported the ethnic or racial characteristics of carers and only Chenoweth and Spencer (1986) reported carers' religious preference.

7.4.2 Overview of progression through stages

The beginning stage for many studies described the 'dawning' (Pfeiffer, 1999) or 'emerging' (Willoughby & Keating, 1991) realisation that something is wrong and the worry and ambiguity that accompanied this period. Aneshensel et al., (1995) describes entry into this stage as having a nebulous quality, owing to the insidious nature of dementia. Carers had dificultly pinpointing the initial changes, as symptoms often manifested in employment-related problems or subtle personality changes; only retrospectively did they see the signs (Chenoweth & Spencer, 1986). Carers oscillated between convincing themselves symptoms such as forgetfulness or changes in personality and behaviour were part of *normal* ageing and suspecting something more serious was underlying these symptoms (Cooper et al., 2022; Kokorelias et al., 2020). Rational explanation may be sought to normalise behaviour until discounting is no longer persuadable (Wilson, 1989). Wuest et al., (1994) elaborated on this phase by suggesting three noticeable strategies that the carer and the person with dementia may use pertaining to 'explaining' (e.g., finding meaning or excuses for unusual behaviours), 'covering' (e.g., conspiring to maintain a façade of normality), and 'confirming' (e.g., prominent changes can no longer be ignored). Naivety to causes of behaviour change and early symptoms were often a source of frustration and conflict, and strained spousal relationships (Cooper et al., 2022; Kobayashi et al., 1993; Willoughby & Keating, 1991). The delayed recognition of symptoms was cause for carer retrospective self-blame and guilt in not seeking professional inquiry sooner and in potentially receiving medication that could delay disease progression (Kokorelias et al., 2020; Tu et al., 2022). As symptoms persisted, this was the point at which there were subtle and intricate shifts in the relationship and the carer began to conceive a changing dynamic and emotional dissonance

(Cooper et al., 2022; Nolan et al., 1996; Willoughby & Keating, 1991). Nolan et al., (1996) offer an antecedent stage to the suspicion of symptoms. 'Building upon the past' is a nod to the salience of the nature of kinship relationships and the fact that the caregiving role does not spontaneously manifest but evolves from a prior familial or relational role. The history of the caregiving relationship is an integral component in shaping the entirety of the caregiving process. For, in some circumstances, prior strong and devoted relationships may overcome periods of challenge and reaffirm bonds of loyalty and love (Fauth et al., 2012; Quinn et al., 2009), in contrast, where there is a fractured or poor relationship history, the experience of stress, burden, and family conflict is more likely (Ablitt et al., 2009; Carpentier et al., 2008).

When symptoms did not resolve or indeed worsened, carers embarked on a 'diagnostic quest', described by Kokorelias et al., (2020) as 'navigating diagnosis', by Wilson (1989) as 'searching for explanations', and by Chenoweth and Spencer (1986) as 'problems with diagnosis and information'. Chenoweth and Spencer (1986) reported that carers struggled to convince the person with dementia to see a physician, and it was rare the person with dementia initiated an appointment. A prolonged diagnosis can accentuate the anxiety and unpredictability of the situation for carers (Chenoweth & Spencer, 1986; Nolan et al., 1996). Confirmation of a diagnosis was a significant juncture in the caregiving relationship. Some spousal carers experienced relief in knowing the cause of changed behaviour, and this provided an opportunity for more honest and open communication, and renewed closeness (Cooper et al., 2022). Others, knowing their family member was embarking on a path towards dependence and impairment, were faced with the internal dilemma and dialogue around their commitment, willingness, and ability to 'take it on' (Nolan et al., 1996) or 'to be or not to be…. a caregiver' (Pfeiffer, 1999).

Considerable variation of experience persisted within the longest and most demanding phase of caregiving, described as 'working through it' (Nolan et al., 1996), 'going through it' (Wilson, 1989), 'holding on' (Wuest et al., 1994), and the 'long journey' (Pfeiffer, 1999). This stage represents the experience of caregiving at home and the carer's progression from assisting with instrumental activities of daily living (e.g., meal preparation, household tasks, medication, and financial management) to more personal activities of daily living (e.g., bathing, toileting, and dressing) and the **likely** corresponding increase in physical and emotional exhaustion and financial strain. Kobayashi et al., (1993) and Wilson (1989) noted that at this stage, while carers' understanding of dementia may have improved, they were still responding to emergent problems and situations on a trial-and-error basis, with one source of stress replacing another (Aneshensel et al., 1995). The disturbed sleep

'changed the lives of carers' (Tu et al., 2022), leaving them demoralised. Families varied in their acceptance and adjustment to the consequences of dementia, while some families were drawn closer together and provided some support for the primary carer, mounting tension and family conflict was common (Chenoweth & Spencer, 1986). Even in Chinese culture where there is a strong affinity to filial piety, the dementia threatened the family equilibrium and sparked relational conflicts (Tu et al., 2022). Despite changes to routines, to varying degrees, and alterations to family life, attempts were made by carers to maintain normality, find purpose in their caring role, and maximise the positive elements of their new reality (Kokorelias et al., 2020; Nolan et al., 1996).

This was a 'juggling operation' (Wuest et al., 1994). Family friends and neighbours were generally not asked to support caregiving tasks, this was speculated to be because their role was to remind the carer that there was a life alongside caregiving (Willoughby & Keating, 1991). At this stage the primary concern for carers was to maintain mutual quality of life, dignity for the person with dementia, and protect other family members, such as children and grandchildren, from emotional distress (Willoughby & Keating, 1991). Carers sought to find balance in their life, but as the caregiving demands grew more pervasive, other relationships were jeopardised, and social networks narrowed leaving carers feeling isolated (Chenoweth & Spencer, 1986; Tu et al., 2022; Wuest et al., 1994). By this stage carers were acutely aware of the impending deterioration in the person with dementia (Kobayashi et al., 1993; Kokorelias et al., 2020). It is here where there was a tangible cognitive and practical shift from 'spouse to carer' (Cooper et al., 2022) denoted by feelings of loss and fading reciprocity and intimacy. Carers looked towards 'preparing for the future' (Kokorelias et al., 2020; Wuest et al., 1994).

Considering the continuing decline of the person with dementia, the next transition in the career was carers realisation and acceptance of their ability to continue caregiving. Time to 'let go' (Wuest et al., 1994) signalled the transition to care placement, which was the next stage in all models, and this decision was eased when there was agreement from family or health professionals (Chenoweth & Spencer, 1986; Willoughby & Keating, 1991). Tu et al., (2022) identified discernible 'tipping points', that triggered this decision, these included the marked deterioration in mental and cognitive status of the person with dementia, a diagnosis of compound diseases in addition to dementia, one or more falls, or the overall physical deterioration of the person with dementia. These tipping points influenced the carer's health status and resilience to care. Changes in carer willingness to continue to care can be speculated, although this was not explicitly discussed in any studies. Willoughby and Keating (1991) propose that the cognitive shift towards care home placement was the accumulation of many events over time as opposed to a singular event, which catalysed the carer to acknowledge it was not in either

their best interests or the person with dementia to continue caregiving at home. From an emotional perspective, this stage was reached when carers reported the person with dementia did not recognise them, their behaviour was perceived as troublesome or aggressive, or that the relationship dynamics had changed so radically that they had become strangers (Cooper et al., 2022; Tu et al., 2022; Wuest et al., 1994). Aneshensel et al., (1995) also note secondary stressors (i.e., stressors anchored in domains of life outside of the caring role) as having an influence on the length of time between the beginning of caregiving and care home placement, amongst them the extent to which the carer felt they were 'captive' in their role. Aneshensel et al., (1995) found that in addition to the many other factors that contributed towards care home placement, the carer or family's ability to afford the cost was significant. For families who were financially fortunate and in possession of more financial resources, the greater the likelihood of care home placement (Aneshensel et al., 1995).

As the person with dementia's capacity to articulate their needs became strained, it was at this stage where Kobayashi et al., (1993) marked that communication started to shift towards nonverbal, and the quality of life for the person with dementia hinged to some extent on the degree to which the carer was aware of and could perceive and respond to these nonverbal signs. Moreover, it was at this stage that a pervasive sense of psychological loss in the spousal relationship was reported, coalescing in the perception that 'my spouse is gone' (Cooper et al., 2022). The decisions surrounding the transition to care home placement was vexed and conflicted and met with feeling of sadness and anxiety. This was a stressful and, on occasions, a protracted transition, involving a lengthy process of searching for a home, waiting lists, financial arrangements, overshadowed by pervading concerns for how the person with dementia will adjust to their new surroundings (Aneshensel et al., 1995; Chenoweth & Spencer, 1986; Tu et al., 2022). Nolan et al., (1996) disaggregates this stage by suggesting three substages: making the decision, finding a home, and living with the consequences.

Following admission to a care home, the locus of caregiving responsibilities shifted. Carers renegotiated their caring role, with many still choosing to assist in substantial care tasks which supplemented those of the care staff, providing home cooked meals, spending time being present and entertaining the person with dementia (Aneshensel et al., 1995). While physical burden decreased, some carers encountered new 'moral and emotional torment' (Tu et al., 2022), and financial difficulties in affording the considerable cost of accommodation and care (Aneshensel et al., 1995; Pfeiffer, 1999). Worries persisted over the quality of personalised care, which was a reason for frequent visits by carers, where logistically possible (Tu et al., 2022). Aneshensel et al., (1995) remarked that where there was a residue of the carer's experience or perception of 'role captivity',

such as feeling consumed, overwhelmed, or restricted because of their caring role, the carer's adaptation to the care home placement was likely to be poor. However, despite carers' continuing investment, on balance, carers benefited from the alleviation of stressors that were determinantal to their well-being (Aneshensel et al., 1995). It is at this stage, Kobayashi et al., (1993) and Cooper et al., (2022) both referred to an 'awakening process' in which it is possible for the carer to 'transcend dementia through love' and still appreciate and treasure aspects of the person. It is here that carers became cognizant that interaction and closeness is still possible, mostly aided through nonverbal communication and the senses, and that there remained opportunity for warmth and compassionate care; the quality of the relationship prior to caregiving maybe a significant factor in the carer's ability to experience this awakening (Wuest et al., 1994).

The final stage, reported in four models (Aneshensel et al., 1995; Nolan et al., 1996; Pfeiffer, 1999; Willoughby & Keating, 1991) relates to the rebuilding of life following the physical death of the person with dementia. While physical death is a discrete event, disengagement from the caring role is far more gradual and complex (Aneshensel et al., 1995). This stage does not mean forgetting of the past but starting the process of healing 'the wounds and many scars' (Pfeiffer, 1999, p. 127) caused from what can be years of traumatic personal upheaval and immense cost, emotionally and financially. The financial strain may not be so easily recovered or regenerated. Anticipatory grief may have already occurred with progression through the career, but following physical death, carers work through the stage of 'role disengagement', a process of bereavement, recovery, and social reintegration (Aneshensel et al., 1995). It is now time for carers to heal and renew their own life, re-establishing social networks that have been dormant or waned during their caring career. Part of this process may mean closure of good relationships with paid care professionals (Willoughby & Keating, 1991). As part of their healing process, some carers may choose to be active in supporting other carers through their career, volunteering, and mentoring (Aneshensel et al., 1995; Pfeiffer, 1999).

7.4.3   How do these models offer insight into the short breaks most appropriate to stage?

Following a dementia diagnosis, carers reflected a desire to have a practitioner to discuss and talk through the diagnosis, both to help them process the news and to ensure appropriate and relevant information (Kokorelias et al., 2020; Pfeiffer, 1999). These early stages in the career are fertile ground for introducing the idea of short breaks, but this must be done with sensitivity and understanding of the caregiving relationship, history, and context. As many models reflected the overwhelm and conflict that carers internally deliberated at this time, an initial understanding of the ways breaks could help support a life alongside caring, the caring relationship, and the well-being for the person with

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dementia, may be helpful to focus discussion and decision-making. It is at the stage, thus, that the presence of a single expert practitioner with responsibility for helping carers to recognise their caregiving role and to establish a foundation to explore their needs, as and when they arise, should be introduced (Britton & Zimmermann, 2022; Hanson et al., 2008; Improvement Cymru, 2021; Lethin et al., 2016). This is important as later in the career, carers may need encouragement to recognise or accept the need for a break (Huang et al., 2017; O'Shea, Timmons, O'Shea, & Irving, 2019) and support to start planning for short breaks (Lethin et al., 2016; Seddon, Andrews, et al., 2021). The presence of a practitioner with whom they have developed trust and familiarity may help facilitate this process (Carpentier & Grenier, 2012; Shared Care Scotland, 2022b). Proactive and personalised support early in the career is significant as carers initial perception of support from care practitioners influences their decision-making for health and social care utilisation throughout their career Willoughby and Keating (1991) contend that it is with the onset of symptoms of dementia that carers experience the most disruption to their expectations and hopes for the future. To moderate this effect, it is thus pertinent at this stage that practitioners encourage the couple to continue to nurture and embrace activities they enjoy together, or individually, as many people with dementia, have opportunity to live a life of meaning and purpose, with appropriate support (de Bruin et al., 2021). Encouraging breaks at this stage is important for the couple to maintain a sense of 'normalcy' and the continuation and maintenance of their skills, interests, and capacities (Pfeiffer, 1999).

For some time, following diagnosis, carers may still be able to leave the person with dementia unaccompanied to enable them physical time for other pursuits, but require formal (e.g., counselling) or informal (e.g., peer support) emotional support to help them come to terms with and adjust to changes in their relationship (Kokorelias et al., 2020). Short breaks that incorporate an element of peer support are needed here and can provide both a psychological and/or physical break (Caulfield et al., 2022b; Willis et al., 2018). Research consistently demonstrates the value of peer support in supporting carers' learning, knowledge of services, developing new friendships, and the reciprocal sharing and supporting of others in similar situations and with comparable challenges (Dam et al., 2016; Lauritzen et al., 2022; Smith et al., 2018). Peer support may also promote carers in similar circumstances to establish smaller circles of support (Carpentier & Grenier, 2012), or to pool Direct Payments to organise joint activities or services that can resourcefully facilitate short breaks (Seddon, Miller, et al., 2021).

It can be contended that the need for short breaks is most localised to the prolonged stage of caregiving at home in which the carer progresses in their intensity of provision of instrumental and

personal care. As a corollary, the carer's emotional, physical, and social well-being can deteriorate. It is during this stage where needs and preferences for short breaks become more personalised, and where it is most likely that some form of professional intervention is needed to support the realisation of more regular breaks, with appropriate levels of support and care (Nolan et al., 1996). Nolan et al., (1996) stated that the primary aim at this stage is to 'maintain relationships and mutual quality of life for as long as possible'. Couple based short breaks, that take the form of various activities, may be advantageous to help sustain caregiving relationships (Moon & Adams, 2013; Rausch et al., 2017; Zhang et al., 2022). Bielsten and Hellström (2019a, 2019b) reviewed couple-centred psychosocial interventions in dementia, amongst them included music therapy, couple counselling, goal attainment, exercise programmes, and reminiscence activities. However, these interventions were shown to differ widely in terms of attention to interpersonal issues and lacked a fundamental relational approach, often neglecting the history and dynamics, strengths, and weakness of the dyadic relationship. The absence of a holistic approach reduced the potential for these activities to sustain a sense of couple hood. In a recent scoping review by Cheung et al., (2021) exploring the strategies to engage carers and people with dementia in dyadic interventions, the authors stressed the importance of tailoring the intervention content to the preferences and abilities of the couple, to personalise the support as much as possible, even if in a group environment (Barrado-Martín et al., 2019). The tailoring or personalisation of short breaks to individual or/and relational needs and preferences is an important mechanism to support better outcomes for carers and those they support (Seddon, Miller et al., 2021).

Day care is a community care service intended to provide carers with a break, and support the therapeutic, social, and recreational needs of people with dementia (Hamilton et al., 2022). Day care, as a specialised day programme for people with care and support needs, vary in size, social environment, structure and organisation of activities, and overall provision of care (i.e., transport to and from the day centre, lunch etc) and support for carers (Ellingsen-Dalskau et al., 2021; Gitlin et al., 2019; Ibsen et al., 2018; Strandenæs et al., 2019; Weir & Fouche, 2017). In general, it is considered a service most appropriate for people with dementia who do not require constant vigilance or complex personal care and are content in the company of others (Måvall & Malmberg, 2007). This is so there is some flexibility for the carer to attend, should they wish. Research demonstrates the efficacy of day care programmes to support the carer to find balance in their lives (Maffioletti et al., 2019; K. H. Thompson & Fletcher, 2019; Tretteteig et al., 2017a), and is thus most appropriate for carers during the prolonged period of caregiving at home where more regular breaks are needed to bring equilibrium and counter increasing caregiving responsibilities. Throughout the extended period of

caregiving at home, the models infer an increased risk that carers become more disconnected from social domains of life. The greater the extent to which ties to social networks and friendships are frayed, the more apt a carer is to experience loss of self and identity (Pearlin & Aneshensel, 1994). Short breaks facilitated through day care usually provide a half or a full day break, and on a regular basis, this may be one avenue for carers to sustain vital social connections. During the sustained period of caregiving at home, the models brought attention to the range of skills that carers needed to acquire, some of these akin to those provided by professional trained carers. In addition to practical care tasks, this may also mean learning new ways or strategies to communicate and respond to behaviour. This is where day care, as well as facilitating short breaks, has potential to serve as a conduit of valuable knowledge for carers. Boafo et al., (2022) recognises that day care programmes, where care staff are knowledgeable and well trained in person-centred approaches, provide flexible social environments with 'under recognised expertise' in responding and respectfully managing behavioural and psychological symptoms of dementia. Day care programmes are underutilised channels for the strategies and knowledge used by the professional care staff to be shared with family carers and reinforced at home or in other care settings (Laird et al., 2017; Symonds-Brown et al., 2021). Likewise, a chance for carers to share or discuss their expertise and experience with other families and professional carers.

There may come a time when day care is no longer perceived, or never was deemed appropriate by care staff, the person with dementia, or the carer (Carer Respite Alliance, 2021; A. Robinson et al., 2012). Research has shown that people with dementia whose behaviour is perceived to be challenging, and who need greater assistance with personal activities of daily living (e.g., dressing and continence), are those most likely to discontinue with day care (Måvall & Malmberg, 2007; Tretteteig et al., 2016). Aneshensel et al., (1995) and Chenoweth and Spencer (1986) suggest that the most powerful primary stressors (i.e., directly related to the person with dementia) that confront carers arise where close vigilance of the person with dementia is necessitated, leading to feelings of role entrapment and confinement. This is where in-home break provision may be most beneficial, if provided on an intensive basis (Liao et al., 2022). The preference for in-home breaks by carers and people with dementia is evidenced in the literature (Arksey et al., 2004; Hogan et al., 2022; O'Shea et al., 2020; Walsh et al., 2020; Wang et al., 2021), particularly for persons whose health is poor, dementia is more advanced, or personal preference is to stay at home in environments of comfort and familiarity (Caulfield et al., 2022b; Holm & Ziguras, 2003; Kampanellou et al., 2019). However, for in-home breaks to be effective, they need to be built upon strong care partnerships and triadic relationships between the carer, person with dementia, and paid carer/professional, that can

potentially span and evolve over many years (Caulfield et al., 2022b; Lethin et al., 2016; O'Shea et al., 2017; Prendergast et al., 2022). Shared Lives is an example of one community care service founded on building sustainable relationships to offer flexible short breaks in the home and community of the family (Jane & Rachael, 2010). These breaks are highly individualised based on a matching process between the paid Shared Lives carer and the person with care and support needs. Recent iterations of service models have expanded to include two or three people with dementia with similar interests and dispositions. While the scheme is implemented in the north Wales region, its expansion requires specific investment in Shared Lives carer knowledge and capacity within the scheme to cultivate meaningful and sustainable relationships (Jane & Rachael, 2010; Prendergast et al., 2022).

During stages of intensive caregiving at home, sleep deprivation is common and can leave carers debilitated to deal with their daily responsibilities (Chenoweth & Spencer, 1986; Johansson et al., 2021). This is where overnight short breaks provision may be needed. Unless a paid carer, or other family or friends can stay overnight in the family home, short-term residential care is often the only option for the carer to have more than a full day and nights rest (Brandão et al., 2016; Moholt et al., 2020). However, carers have raised concern around the quality of residential care, citing lack of personalised support and activities, inadequate staff training in specialised dementia care, long waiting lists, and fear that the person with dementia will return home in a more distressed state (Leocadie et al., 2018; Phillipson et al., 2013; Upton & Reed, 2005). Alternative models of overnight provision have been reported in the published literature. One such example is a cottage model, developed in Australia (Harkin et al., 2020). The cottage models are suburban homes that have been repurposed for overnight short breaks and retain important domestic aspects that promote a homely, intimate, and flexible experience compared to larger residential care facilitates (Harkin et al., 2020). The preference of carers and persons with dementia for the cottage model, as opposed to residential care facilities, was accredited to personalised care and attention, high staff ratio, efforts to create and ensure a familiar relaxing atmosphere. A unique advantage was that it offered a gradual and sensitive transition to the use of overnight short break, in which carers also have the option to stay. This is in contrast with the fixed minimum period in residential facilities and where the separation is expected.

All models supported the notion that the transition to a care home was an emotionally complex and practically tiresome process. During this transition, rarely could the person with dementia actively participate in discussion, and carers felt a tremendous pressure to make the 'right' choice. Carers needed help, information, and advice to find the right care home, in terms of quality of care and medical attention, and support to enable the person with dementia to settle in their new home

(Kokorelias et al., 2020; Tu et al., 2022). Prior to the permanent transition, short breaks can act as a gradual steppingstone to support the person with dementia slowly and sensitively to a new home (Caulfield et al., 2022b; Greene et al., 2017; Taranrød et al., 2021). This may help soften what can be a drastic and abrupt transition (Saragosa et al., 2022). It may also be an opportunity to support a positive adjustment for the carer through getting to know care staff and how the home operates before a final decision is made (Hoek et al., 2021; Pritty et al., 2020; Saragosa et al., 2022). This option is caveated by the person's health status and capacity to spend increasingly longer periods within a care home, without it causing too much distress, and the care home's capacity to support this graduated process, which in practice can be argued to be too idealistic. Unfortunately, it is too often the case that the transition to a care home is in haste, in a moment of crisis or in an emergency (Cole et al., 2018).

As highlighted in chapter five (Caulfield et al., 2022b) and supported through this scoping work, the need for short breaks extends into care home placement. During this stage of caregiving, the locus of caregiving responsibilities shift, and although some stressors may be alleviated, significant consequences of caregiving persist. These models recognise and acknowledge this crucial stage in a caregiving career, in which carers can have a vital role in helping with care task, relieving the workload for professional carers, and supporting the dignity and quality of life of the person with dementia, especially during their end stages of life. Vick et al., (2019) found that the odds of high caregiving strain was nearly twice as high for dementia carers compared to those who were caring for older adults nearing end of life. During this stage, carers will still need short breaks to help them sustain their resilience to provide care and support, albeit within a new context.

Recognising post-caregiving as a stage of the career has garnered increased attention, notably because carers can experience a complicated bereavement process and support is needed to help carers adjust, rebuild their identity, and revitalise their purpose (Larkin & Milne, 2017; Orzeck & Silverman, 2008). It is apparent at this stage why short breaks throughout the career are crucial for maintaining social connections and preserving a sense of identity and purpose outside of the caring role. The healthy adjustment for the carer following the death of the person with dementia, to some extent, may depend on their capacity to preserve their life alongside caring through short breaks during the most demanding stages of their career; this is an area for potential future research.

7.5   Discussion

This aim of this chapter was to provide a synthesis of developmental models of dementia caregiving depicting identifiable stages of caregiving as experienced by dementia carers. While not purporting to provide a time correlated trajectory, indeed many models caution against the linear correlation of time and stage, these models do help to identify 'threads of continuity' (Aneshensel et al., 1995, p.349) weaved throughout the career, which offer a useful framework for recognising markers associated with carer's 'status movements across career lines' (Pearlin & Aneshensei, 1994, p. 375) and consequently an indication of likely support needs, including the appropriate types of short breaks (Montgomery & Kosloski, 2000; Nolan, Ryan, et al., 2002).

The primary purpose for developing a new conceptual framework for short breaks is to serve as guide to demonstrate how short break needs are **likely** to progress, within the context of dementia caregiving relationships, and the short breaks options that may support them. While acknowledging that further substantive work is needed to develop a practical, versatile, and engaging framework that broadly tailors short break options and services to specific stages within a typical career, having such a framework that portrays the evolution of short break needs and the potential solutions and opportunities to support them, may aid the commissioning process. The Promoting Variety in Short Breaks Toolkit (Shared Care Scotland, 2021) considers the market shaping process to increase the choice and suitability of breaks, and to support the 'right balance' of short breaks provision. A developmental understanding of evolving short break needs could supplement the market shaping process by helping commissioners to make better decisions about how to proportionately deploy resources against evidence-informed career stages. Exploration of the equity and choice of short options in their locality against career stage, could support a better overall balance between traditional offers and contemporary innovative solutions in how breaks can be supported.

Findings illuminated short breaks underpinned support for carers at all stages of the career, but their intensity of need was most localised to stages of caregiving at home, where personal activities of care was provided, and care demands were described as numerous and pervasive. This stage represented the period of greatest variation in experience and outcomes. Aneshensel et al., (1995) attributed the differences between caregiving experience, in what may appear to be similar caregiving situations, to the extent to which the demands imposed by the person with dementia are in discord with the carer's subjective ability to respond to these demands. This reinforces the understanding that a stage is not necessarily a period of stability and some transitions (e.g., moving to a care home) may be welcomed to restore a sense of equilibrium. A subtle shift in the priority of short breaks can be discerned, from

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earlier in the career where supporting relational well-being and couple hood is a priority, to the middle or later stages, where greater emphasis is placed on breaks to enable carers to rest and recuperate from their consuming caregiving demands. The bridging function of short breaks was highlighted, where short breaks could help smooth career junctions, for example, if the person with dementia starts to spend more time at home, and a shift from activities in the community to activities at home is needed, or when longer stays in a care home are required to support the process of a permanent transition. How health and social care practitioners facilitate these transitions is an area that warrants further investigation.

During the prolonged period of caregiving at home, day care programmes emerge as having the most possibility for variation in activities and flexibility in design and implementation to support carers to balance varying levels and intensity of caring responsibilities with a life alongside caring. Symonds-Brown et al., (2021) reflect on the historical conceptualisation of day care programmes as 'background spaces in which care happens', in a benign and passive manner. The authors postulate that this ingrained and narrow notion of day care as an isolated unit of substitute care, limits progression in thinking about what day care is and how it may evolve. In practice, there is considerable scope to re-think the nature of day care programmes, beyond a single building-based unit of intervention, to cultivate culturally appropriate activities, spaces, and practices that reflect 'real life', as opposed to a 'constructed institutional life' (Liou & Jarrott, 2013; Symonds-Brown et al., 2021; Taranrød et al., 2021). In recent years, online internet-based interventions have grown increasingly popular and have demonstrated their value in supporting carers in various domains of caregiving (Etxeberria et al., 2021). During the first year of the COVID-19 pandemic, Maffioletti et al., (2021) explored the feasibility of virtual day care for 26 people with dementia and their families and demonstrated through the careful adaption of daily virtual activities, people with dementia remained physically, socially, and cognitively active, and the maintenance of the carers' bond with their peers and with the team was enabled, minimising their socioemotional isolation.

To maximise the break experience and outcomes, providing supportive services for carers as an ancillary to the provision of day care for people with dementia has received increased attention for its added service value, potential cost effectiveness, and in improving the sustainability and quality of caring relationships (Anderson et al., 2015; Logsdon et al., 2016; van Haeften-Van Dijk et al., 2016). Gitlin et al., (2019) describes a protocol for a pragmatic trial designed to augment standard day care for people with dementia to deliver a Day Care Plus programmes across 50 different day care centres for over 300 carers. Day Care Plus is a tailored and evidenced based programme that as well as offering

a short break, provides carers with "disease education, referral/linkages, emotional support, self-care strategies, and skills to manage care-identified challenges including functional decline, behavioural symptoms, and care coordination" (Gitlin et al., 2006). The authors aim to evaluate the effectiveness of Day Care Plus to improve carer well-being and reduce depressive symptoms compared to routine day care provision at two time points, 6 months, and 12 months, respectively. As part of the trial, initial assessments are undertaken with carers to understand their caregiving routines, daily care challenges, and knowledge about dementia. Over a 12-month period, the carer will work with trained and experienced existing day care staff, to learn different management and coping strategies. Support components related to carer self-care, education, validation and support, referral and linkage, skill building, and strategies are tailored to carer's self-identified unmet needs and challenges associate with providing care at home. While the results from this trial are yet to be reported, the authors anticipate key challenges in design pertaining to ensuring standard delivery across the 50 sites with varying resource capacities, staff turnover, and implementation fidelity.

Although there may be overlap between stages, the models identified in this study all portray a unidirectional sequence, with minimal discursion between stages. However, recent research has alluded to the bi-directional possibility of the caregiving career: caring for someone in the community post care home placement (Toles et al., 2022; Robison et al., 2021). This newly identified stage of the caregiving career has largely unknown consequences for carers. Robison et al., (2021) reflected that in the USA, this unexpected stage of the caregiving career emerged with the advent of state funded transition programmes (i.e., The Money Follows the Person), that assist individuals returning to community living after care home placement through improved access to home and community-based services. Toles et al., (2022) describe the unique care needs of people with dementia and their carers during transitions from skilled nursing facilities to home, demonstrating the unpreparedness of carers to manage some symptoms of dementia at home, and their difficulties connecting to community supports, or having their own well-being needs met.

A limitation of these models is that they all presume a gradual entry into the caregiving career. This is rarely the reality in dementia caregiving. A delayed diagnosis means that carers may be caring for significant periods without adequate support or understanding of dementia. The National Audit of Memory Assessment Services in England and Wales, conducted between January and August 2021, reported that average waiting time from referral to dementia diagnosis increased to 17.7 weeks, up from 13 weeks in 2021 (Essel et al., 2021). The report further documented a decrease in early-stage drug prescriptions in 2021, implying more people are receiving their diagnosis later and missing early

access to drug treatments to help relieve symptoms. Gaugler et al.'s, (2003) study revealed how carers assumed their caring role had long-term consequences for their well-being. Carers who experienced a gradual entry into caregiving were less likely to place their relative with dementia into a care home or experience poor adaptation over time. This was postulated to be because the coping resources and responses of these carers were more established before a crisis arose, which moderated the potential distress. This perspective is endorsed by research which demonstrates the benefits of an early dementia diagnosis in offering carers the chance to advance the process of adaptation to the caring role and understanding of the changes that characterise dementia (de Vugt & Verhey, 2013; Dubois et al., 2016).

Across the models, carer participants were predominantly spousal (wives) or adult daughters. Noting an interesting cultural observation, most carers in Kobayashi et al.'s, (1993) study, conducted in Japan, were daughters-in-law. These different kinship relationships may condition the effects of career transitions (Montgomery et al., 2000). Seltzer and Li (2000) found that adult daughter carers experienced comparatively few changes in their social, familial, or psychological well-being following entry into, or disengagement from, their caring role. In contrast, spousal (wives) carers demonstrated a more pronounced decrease in their well-being when entering their caregiving career, but following bereavement, an increase in social engagement and personal growth. The profound effect on spousal carers is attributed mainly to the salience and intensity of the relationship, and thus the martial relationship is more likely to be negatively afflicted, compared to the parent–adult child relationship. It also foregrounds the importance of stage in the life course when caregiving begins. A richer assortment of personal and social resources is likely to be present in middle age, compared to older age caregiving, in which the carers own health fragilities may impede their resilience to care and there tends to be fewer social resources to buffer the stressors of caregiving (Keating et al., 2003; Seltzer & Li, 1996, 2000). Montgomery et al., (2000) infer differences in the caring careers of adult children compared to spousal carers. The onset of the caring career can be imperceptible for spousal carers because many caring responsibilities and inclinations are assumed as part of their martial life. The caregiving tasks, however, that adult children may assume, such as assisting in shopping, transport, and managing finances, can represent a significant shift in the family dynamic. Therefore, adult children tend to identify their caring role sooner, and seek out information and support earlier. They also abdicate their caring role in earlier stages, as it is more likely to interfere with other familial and employment obligations making their caregiving role a seemingly impossible proposition, compared to spousal carers who are more likely to cohabit with their partner with dementia and to be in retirement. Although it should be noted that with the rise in the UK state pension age, and ongoing

pension reform across Europe, many people are in employment for longer, late into their 60's (Broese van Groenou & De Boer, 2016).

It is important to acknowledge the time span of 36 years in which that these models were developed. During this time, late 1980's until present day, the UK and international policy context underpinning support for carers has changed substantially and therefore findings should be interpreted with this caveat. Noteworthy also is how the use of language has changed, and reference to 'institutionalised', and 'demented' are no longer deemed acceptable, as they undermine the personhood of the people living with dementia (Alzheimer's Society, 2018). Conspicuous is the significant time gap in publication of studies. In part, this may be due to a search strategy that obviated longitudinal studies that did not explicitly identify stages in the career. However, longitudinal research has brought attention to the changes in caregiver burden (Connors et al., 2020), subjective stressors (Bangerter et al., 2019) appraisal of the caregiving role (Kajiwara et al., 2018) and carer well-being outcomes (Lethin et al., 2017; Pertl et al., 2019; Skaff et al., 1996), over time. Thus, the closer inspection of longitudinal research in dementia caregiving may enrich understanding of the types of short breaks most appropriate as circumstances change. Although not specific to dementia, developmental models of older adult caregiving, such as those by Cavaye (2008) exploring the careers of adult carers for frail parents, and by Montgomery et al., (2000) offering a seven-marker model, with each marker linked to significant changes in the caregiving career, may have relevance to this work. As Wales continues to work towards its vision for an age friendly Wales that supports people of all ages and conditions to live and age well, inclusivity is a central theme (Welsh Government, 2021c). Comparison of older age caregiving with dementia caregiving models may help elucidate the differences or compatibilities in stages and needs for support over time, and so support more inclusive ways of supporting all people through ageing and ill health to live well in the community.

Acknowledging that more work is needed to develop and test the acceptability of a new conceptual framework for short breaks, there is substance to take forward this work. This could involve exploratory focus groups and workshops with carers, commissioners, and practitioners to discuss the strategic and practice feasibility and practicality of a conceptual framework from different perspectives. Taking inspiration from Shared Care Scotland's short break toolkits, there is scope to think about how a new toolkit could be developed around developmental changes in short break needs and preferences. This toolkit could help carers in their thinking around breaks as circumstances change, as well as serve as an indicative guide for practitioners to aid the proactive planning for breaks, with a better understanding of how to skilfully support transitions between different break types and

formats. For commissioners, a toolkit may offer a new perspective to guide the deployment of resources and monies to ensure an appropriate range and balance of short breaks throughout the caregiving career.

7.6   Conclusion

This scoping review is preliminary work in the development of a new conceptual framework of short breaks across the caregiving career based on identified career stages and transitions between stages as experienced by dementia carers. A developmental understanding of short break needs, illustrating the typical considerations and challenges that carers may face when seeking short breaks at different stages in their career, could help minimise 'career gaps' in short break options and choice.

The models identified in this review were advantageous in bringing attention to the time preceding the dementia diagnosis, such as the experience of 'diagnostic limbo' (Nolan et al., 1996) to the recalibration of carer tasks following the move of the person with dementia to a care home, and beyond the physical death of the person with dementia, where carers sought healing and a new beginning. Short breaks throughout the career, that are regular and help preserve relational and/or a personal identity and purpose, are an essential resource to support well-being and ease adjustment post-caregiving, once more emphasising their preventative role in supporting a life *alongside*, and *beyond* caregiving.

The final chapter in this thesis is the discussion and conclusion chapter. This chapter reflects on the contribution of this research to enhancing understanding of meaningful short break provision, the most salient findings to inform policy and practice development around short breaks, and important areas for future research.

Chapter Eight: Discussion and conclusion

8.1   Introduction

This chapter reflects on the key findings from this research, the unique contribution of this research and how it adds to the existing evidence base on short breaks. Based on key findings and observations, reflections for policy and practice are made, addressing the assessment and support planning process, the broader state of the adult social care sector, and the objective and subjective understanding of a short break. These reflections are intended to advance how short breaks are conceptualised and supported. Areas for future research inquiry are offered. Methodological limitations relating to the constructivist approach, and alternative methods for the generation of evidence and sharing of knowledge are considered. To offer a reflexive perspective on this work, the strengths of this research, as well as the limitations, are acknowledged.

The **aim** of this research was to provide evidence that enhances the development, commissioning, and delivery of meaningful short breaks provision for spousal carers for persons living with dementia (aged 65 years and over). This thesis met this aim by addressing four research objectives, realised through four phases of inquiry.

The first objective was concerned with identifying ways to effectively develop, commission, and scale up short breaks that reflect 'what matters. This research offered a regional perspective on the challenges and opportunities related to the planning, commissioning, and delivery of short breaks, shedding light on the evolving landscape of new providers and models that could enhance flexibility and choice (see Chapter 4).

The second objective was to explore the short break needs and preferences of spousal carers for people with dementia who utilise short breaks. By constructing a collective narrative of the caregiving journey, the study revealed the dynamic dimensions of short break requirements and preferences. This illustrated the variety of break types and support mechanisms that carers sought to achieve well-being outcomes as their circumstances evolved (see Chapter 5). The research also provided insights into how short break needs and preferences were addressed in assessments following the implementation of the 2014 Act and the degree to which these needs were met.

The third objective aimed to develop policy and practice recommendations supporting improvements aligned with Welsh Government national priorities for carers and their beneficiaries. This objective was met through a knowledge exchange event, fostering the sharing and integration of knowledge

and perspectives. This collaborative effort resulted in a consensus on features that underpin meaningful short breaks, leading to the development of six practice recommendations. These recommendations contribute to envisioning a more equitable, sustainable, and diverse short breaks landscape (see Chapter 6).

Finally, the study's last objective sought to understand the key elements of impactful provision that contribute to the realisation of important carer-generated outcomes (Cook & Miller, 2012). Preliminary work considered the feasibility of a new conceptual framework to explore how different formats and types of short breaks support outcomes such as health, well-being, resilience, and positive relationships across the caregiving career (see Chapter 7).

Collectively, this research has provided robust evidence to advance international ambition to improve access to and the outcomes supported through short breaks for carers (International Alliance of Carer Organizations, 2018). On a national level, this research supports the delivery of improvements against the Welsh Government priority to enable a life alongside caring through access to meaningful short breaks. Findings have potential to support innovations in policy and practice development to help ensure the well-being and short break outcomes of all those affected by the caring situation are purposely considered.

8.2   The contribution to knowledge and the existing evidence base

The findings from this research offer an original, contemporary perspective to enrich understanding of short breaks options and support. Through significant stakeholder engagement, employing a collaborative approach to knowledge generation, this research complements the existing literature that reflects on critical factors in promoting and impeding access to short breaks (Arksey et al., 2004; Carer Respite Alliance, 2021; Carers UK, 2019b; Leocadie et al., 2018; Neville et al., 2015; O'Shea et al., 2017; O'Shea, Timmons, O'Shea, & Irving, 2019). This research, however, has brought forth a more nuanced and detailed exploration of some of the tensions at the forefront of a complex commissioning landscape. It has offered a unique strategic and operational perspective of how the north Wales region is responding to the need to improve access to short breaks. In doing so it has shown that supporting short breaks is truly a multi-agency and multi-sector response and responsibility, and the need to support robust and sustainable partnerships, coordination, and collaboration between organisations and sectors is vital to minimise fragmentation and to reduce inequity in access and opportunities for breaks. The need to adopt a macro-level systemic approach is evident, to recognise the interconnectivities of different people, processes, and systems, across sectors, that help promote and sustain partnerships and opportunities for short breaks. It is only when there is comprehensive

workable understanding of the ways that *all* sectors of communities and formal health and social care and support services can work in synergy, leveraging each other's strengths and resources, that short breaks can be embedded into the structural bedrock of a community. If this was realised in practice, carers and people with dementia would likely feel supported through genuine choice and flexibility of sustainable short break options.

The six features identified through this research as contributing towards a meaningful short break, relating to consistency, flexibility, choice, sustainability, appropriateness, and mutuality, have relevance to guiding the planning, commissioning, and delivery of short breaks at a strategic and operational level. Taking mutuality, for instance, regardless of if breaks are experienced together or apart, mutuality in experience and outcomes is a fundamental feature of a meaningful break and can be a determinant factor in the carer's acceptance of a break (Caulfield et al., 2022b; Harkin et al., 2020; O' Shea et al., 2020; O'Shea et al., 2017; Rokstad et al., 2019; Taranrød et al., 2021). Acknowledging the importance of this feature, future practice could consider how mutuality is better embedded into the delivery for short breaks. Reflecting the emerging interest in relationship-centred short breaks through respitality, important lessons for the scale up, governance, and quality assurance of respitality models can be learnt from Shared Care Scotland. The respitality scheme brings the hospitality, leisure, entertainment, and the tourism industry together with carer organizations to offer free breaks to carers. Respitality breaks are not means-tested. In Scotland, respitality operates as a social franchise; models of respitality are managed by local carer organisations, coordinated, and supported nationally by Shared Care Scotland. Through the respitality scheme in Scotland, the type of breaks reported to be taken in 2022 by carers and those they support included football matches, accommodation, dining, theatre and music, leisure, and visitor attractions (Shared Care Scotland, 2022a). There is compelling evidence of the effectiveness of these more personalised breaks to support mutual outcomes for the carer and the person they support (Shared Care Scotland, 2022a).

The need for a break away from routine and responsibility is not a new nor surprising dimension of human life. All people, at all stages in life, need time away from the responsibilities that shape their life, paid or otherwise, to do the things that matter to them. The relational context in which this research was conducted was that of an older spousal relationship, however, many of the features of meaningful short breaks identified as pertinent to dementia spousal carers such as positive relationships with staff and having the inbuilt flexibility to meet their changing needs and circumstances, reflect the experience of carers for adults with intellectual disabilities (Gadd, 2020), children with autism spectrum disorder (Cooke et al., 2020; Hartrey & Wells, 2003), and children with life-limiting conditions (Remedios et al., 2015). It can be argued that the inherent complexity and

interdependencies of caregiving relationships, regardless of whether these are parental or spousal, mean that short breaks are often an emotional and morally charged issue eliciting deeply personal and relational responses. This research has evidenced the impactful difference of relational support, made possible through the presence of reliable and trusted health and social care practitioners, to how carers navigate their short breaks expectations and reservations, and the outcomes realised. One of the most visible observations derived from this research is that relational-centred care, support, and guidance is sacrosanct to all carers and those they support in achieving a meaningful short break of mutual value and benefit. The time and effort required to establish these relationships, with the carer and with the person with dementia, must be understood as an essential investment in creating a sense of trust, security, and genuine partnership in realising short breaks. This has the effect of substantially increasing the possibility that carers can derive the most benefit from their break because their needs, preferences and values have been embedded in how a short break is supported (Caulfield et al., 2022b; Kelly & McSweeney, 2009; Ryan et al., 2008; Shared Care Scotland, 2022b).

The necessity for short breaks to evolve in their format and function is relevant for all caring relationships where degenerative chronic conditions are present. The relevance of stage and the transitions that bridge them is important to understand the nature of degenerative conditions and to guide intervention research and development and inform strategy design (Gallagher-Thompson et al., 2020; Gitlin & Wolff, 2011; Wyman et al., 2022). For instance, Fortinsky and Downs' (2014) typology of six transitions in the dementia journey, from symptom recognition to end-of-life care, has been used to critically evaluate how national dementia strategies of seven countries addressed each transition, demonstrating the need for greater care coordination and workforce training to support later transitions (i.e., home, or residential care to palliative or end-of-life care). This research has demonstrated the potential of developing a new conceptual framework of potential widespread applicability to advance the field of short break research, policy, and practice development. By signifying the carers' progression through typical stages and transitions in the caregiving career, findings exemplified how short break needs and preferences change over time and the supports and resources required to respond to these changes. This has contributed a more informed and nuanced understanding of the ways in which short breaks must adapt to support transitions and transformations in the caregiving relationship, and why these adaptations are vital to help sustain caregiving relationships. In doing so, this research has taken forward a global research priority in family caregiving to develop a more cohesive means of organising support for family carers for people with dementia based on a developmental temporal understanding of dementia caregiving (Gitlin & Maslow, 2018; Harvath et al., 2020); this understanding is distinguished by discernible stages in

caregiving and the transitions that link them (Gallagher-Thompson et al., 2020; Gaugler & Teaster, 2006; Kokorelias et al., 2020; Liu et al., 2015). This research augments O'Shea et al.'s, (2017) work about the importance of supporting the transition to the use of break services, and it offers new insights that highlight the imperative of supporting transitions to different break lengths, break activities, and break providers over time. Having a practitioner who can offer supported choice, guidance, and help balance individual and relational short breaks needs and outcomes is essential to navigate what can be difficult or tentative transitions to different break options.

The research reported in this thesis strongly affirms the contention that short breaks cannot exist in isolation from other services to support carers and people with dementia (Arksey et al., 2004; Brimblecombe et al., 2018; Gitlin et al., 2019; Heinrich et al., 2019). Throughout the phases of this research, short breaks were recognised and discussed as needing to be part of a wider, integrated offer of support, comprised of complementary services and resources that work together to maintain the well-being of carers and people with dementia. It is incumbent therefore to consider the added value of short breaks (Prendergast et al., 2022), especially in combination with other support services (Kirk et al., 2015). There is considerable evidence for the efficiency of multi-component interventions (Abrahams et al., 2018; Brimblecombe et al., 2018; He et al., 2022). Combining short breaks with skills training, psychoeducation, counselling, or peer support, is a natural progression in supporting the holistic needs of families affected by dementia and represents a promising approach to supporting the multidimensional needs of the family or couple (Derence, 2005; Maffioletti et al., 2019). In the published literature, there are several examples of short breaks combined with another support component, including residential breaks combined with dementia skill-based training (Gresham et al., 2018), residential breaks that offer counselling sessions for carers (Heinrich et al., 2019), activities for people with dementia combined with peer support for the carer (Willis et al., 2018), and short breaks combined with a psychoeducational programme (Tompkins & Bell, 2009). Multi-component interventions may offer more flexibility and scope to support a psychological and/or physical break, in ways that acknowledge the heterogeneity of caregiving relationships, variation in preferences and needs for breaks, and address specific aspects of the caregiving relationship that other breaks may not.

8.3 Implications for policy and practice

8.3.1 The assessment and support planning process

The research findings have relevance to assessment and support planning processes. Finding a suitable break option can take time and consideration and this research speaks to the centrality of investing

time to understand what matters to the carer, and the difference they would like a short break to contribute towards. Due to intensity of the caregiving situation and varying degrees of co-dependency, carers can find it difficult to spontaneously express or willingly identify their own needs or translate their thoughts and feeling into outcomes (Feeley, 2021; Miller & Barrie, 2020; Shared Care Scotland, 2022). Acknowledging this, this research strongly advocates for a conversational approach to the assessment and support planning process, founded on genuine dialogue involving the sharing of views, opinions, and expertise (Hanson et al., 2008; MacBride et al., 2020; Miller & Barrie, 2016; Phillipson et al., 2019).

There are several good practice conversational approaches to the Carer's Assessment process that merit attention because they are designed to recognise the expertise and wishes of everyone involved in the caregiving situation. An early example is the Carers Outcomes Agreement Tool (COAT) (Hanson et al., 2008). The COAT is premised on several domains of questioning, including what a good quality of life for the carer and for the person with care and support needs looks like. The central aim of the COAT is to enable carers and practitioners to exchange knowledge and insight as 'co-experts'. Feasibility findings demonstrated its capacity to be a gratifying and fulfilling process, for both the carer and the practitioner, in which delicate and nuanced issues could be discussed, which resulted in a fuller and more explicit understanding of the carer's situation. The COAT was viewed by practitioners as a systematic approach to work proactively rather than reactively with carers, to identify key areas for support and to negotiate potential solutions through thoughtful and inquisitive conversation. Information gathered through the COAT provided an evaluation system for local carer support and as an evidence base to guide future strategic decisions about priorities for support.

This research has highlighted that much work is needed to proactively educate carers about the necessity for short breaks early in their career and to include short breaks as a key component of the assessment process (Welsh Government, 2021f). The acceptability of a counselling-based care and support-planning intervention for care dyads in early-stage dementia, SHARE (Support, Health, Activities, Resources, and Education) has been tested in practice. The SHARE approach is proactive in establishing mutual understanding of care values and preferences early in the caregiving career as a foundation for a plan of care that can be adapted as needs change. Through seven sessions, each focusing on a distinct aspect of care and support (e.g., taking care of yourself/taking care of each other) the practitioner's role is to scaffold a process by which the carer and person with dementia work together, at their own level of readiness, to strengthen communication skills, increase knowledge about dementia and available services, resources, and support in the community. The

purpose of these sessions is to build a more a balanced and holistic understanding of the couple's life and support transparent and open conversation about values and preferences for support.

In summary, the above examples demonstrate the importance of investing time and resources into important relationship building conversations with carers. The process of such conversation, that gives time and attention to enabling the carer and/or person with dementia to reflect on their situation in a more considered way, has been shown to have therapeutic purpose in and of itself cultivating a greater sense of security for the carer and helping them recognise and clarify their own needs (Hanson et al., 2008; Larkin et al., 2022; Miller & Barrie, 2016). This can be considered an essential first step in the preventative approach to ensuring that support, and in the context of this research short breaks, are meaningful discussed and supported.

This research has illustrated that due to a multiplicity of reasons (e.g., lack of community support, high eligibility criteria for statutory support), available resources and options for short breaks can be limited. An interesting practice implication arising from this research is the potential for social network mapping to help identify the mechanisms that may support a short break. Given the many difficulties reported by carers in accessing sustainable and flexible breaks, looking beyond the caring dyad's capacity to consider the architecture of carers' social and support networks (e.g., the ties between different actors that aid or impede the organisation of different resources) may offer a creative way to facilitate short breaks.

Several studies have explored the application of a social network approach to map the composition, coherence, function, and strength of different kinship and social connections and processes involved in the caregiving situation, and how they support, or hinder, the carer in their ability to provide care and maintain their well-being (Carpentier & Ducharme, 2003, 2005; Carpentier & Grenier, 2012; Keating et al., 2003; Koehly et al., 2015; Spillman et al., 2020). A distinctive feature of the social network approach is that it prioritises relational information over individual attributes. Campbell et al., (2019) demonstrated that a participatory social network mapping method supported carers for people with dementia to articulate and reflect on their relationships with others and their contribution in supporting care practices. This was a reflective sense-making process in which carers structured their daily and weekly routines and the frequency in which they would engage with individuals. The support carers received was categorised with regards to the type of help or care received and by whom (e.g., informal, or formal, practical, or emotional), and how these supports complemented or overlapped with each other. In consequence, it provided a method for understanding the multi-

dimensionality and complexity of support systems and processual properties within a carers' network. All network maps were accompanied by a developing narrative which provided an opportunity for reflectivity, and for revisions to be made to the maps and for the reappraisal of relationships. The reflective process of engaging with the emotion of relationships, infused the map with affective qualities, evidencing the strength of emotion and meaning associated with certain relationships. In this sense, maps went beyond the graphic representation of relationships to generate an 'affective artifact', emblematic of the emotional context in which relationships exist. Although only offering a temporary glimpse of a network in a moment in time, the method proved an effective co-productive exercise to reveal the fluidity and intricacy of support and care within a web of relationships and it captured the dynamic nature of 'lived networks.'

Keating (2003) makes an important distinction between the 'social', 'support' and 'caregiving' networks of older people with long-term chronic conditions, noting conceptual differences relating to size, composition, normative expectations to provide care and support (emotion and instrumental), sustainability, and proximity. With the transition from social through to support and then to caregiving, the number of members who are willing to provide support, and the resources that they can mobilise, tends to contract. Understanding the capacity of the informal networks of carers and people with dementia to adapt as care or support needs intensify is important for the proactive future planning, organisation, and deployment of resources. Accordingly, in recognition of the degenerative nature of dementia, Carpentier & Ducharme (2003) argue that in dementia caregiving relationships, more attention is needed to transformations in the carer's network over time, to understand how networks cope and adjust to the continuously changing situation. The authors contend that an integrated approach combining the caregiving career perspective and the social network analysis perspective could promote a more precise configuration of formal and informal support interaction, and communication between different actors, over time. The career perspective evokes the description of proliferation of stressors and care related responsibilities across time, whereas the network analysis is helpful to examine the relationship amongst different social actors, revealing the strengths or weaknesses of connections and resources that are available. The integration of the two approaches is postulated to promote a 'better understanding of the formation, maintenance, and discontinuation of supportive ties in both formal and informal care networks' (Carpentier & Ducharme, 2003, p. 517).

There are several ways that social network approach may contribute to the planning for and realisation of short break outcomes. Firstly, during the assessment and support planning process, the

network map could act as 'sounding board' to aid the creative and holistic exploration of how short breaks could be supported. An understanding of the robustness or fragility of relationships and connections within a network, could reveal the capacity for short breaks to be maintained as circumstances change. Pertaining to the development of short breaks activities or models, it may be constructive to think how different short breaks models can contribute to the strengthening, maintenance of existing, or formation of new supportive ties as network configurations change and evolve. Viewing short breaks as one way to sustain important social networks and social relationships over time aligns with current policy momentum that seeks to broaden and deepen social links within communities to support the independence and well-being of carers and people with dementia (Rochira, 2018; Welsh Government, 2020, 2021d).

8.3.2   A whole systems approach to supporting interdependent well-being

Caregiving is a global issue of growing political, economic, cultural, and moral magnitude (International Alliance of Carer Organizations, 2021). Despite decades of gradual policy progression in the rights and supports for carers, the evidence is compelling that carers still feel, and remain, invisible and undervalued (Carers UK, 2020, 2022a). At the crux of this matter lies a deeply flawed social care system and the urgent need to reform this system has blighted successive UK governments for decades (Needham & Hall, 2022). Inadequate coordination and integration between services, insufficient funding to meet the needs of an ageing population, and a resource and workforce crisis are well rehearsed factors at the heart of the debate on social care reform (Adult Social Care Committee, 2022; Trickey & Siôn, 2020). Many of these challenges are echoed internationally, as countries continue to debate how best to meet the unprecedent demands posed by population ageing and shifting the provision of long-term support and care into the community (Cahill et al., 2022; Courtin et al., 2014; Spasova et al., 2018). Recent research by Carers UK showed that 86% of the public in Wales believe that the Welsh Government should provide additional support for carers such as increased financial support, increased investment in social services and in care and support services to enable carers to take a break (Carers UK, 2022b). Despite strong public support for social care reform, reinforced because of the role both paid and unpaid carers undertook during the COVID-19 pandemic, the lack of UK political imperative has beset progress and contributed to the bourgeoning complexity and expense of the reform needed (Adult Social Care Committee, 2022; Needham & Hall, 2022). In April 2023, the decision of the UK Government to cut £250m from the social care workforce funding in England has been widely criticised and evidenced the stagnation in progression of attitude and in the recognition of the urgent action needed to begin the process of reform (Beal, 2023) .

As the research in this thesis has demonstrated, short breaks provision is inextricably connected to the wider effectiveness and agility of the health and social care system, and until the complex and interconnected issues that destabilise the system are radically addressed, there will remain a handicap in how much short break provision can progress in the ways which are needed to improve the well-being of carers and people with dementia. An example that this research has brought into focus is the political oxymoron between the drive for early intervention and preventative support and high eligibility criteria for health and social care funding. Research by Carers Wales (2022) found that of those carers who believe they should be eligible for services, the majority reported that they had never had access to one or more services (Carers Wales, 2022). Two-thirds of carers had never had access to care homes for short breaks (66%) or residential care (64%). This research corroborates literature that shows that in many circumstances, supporting sustainable and positive short breaks necessitates the building of trusting relationships with others, especially the care staff providing replacement care and support (Caulfield et al., 2022b; Jane & Rachael, 2010; Prendergast et al., 2022; Rodrigues, 2020; Ryan et al., 2008; Shared Care Scotland, 2022b). However, the high eligibility criteria for formal support threatens the potential for the gradual and receptive nurturing of these relationships early in the caring career and undermines the purpose for short break as a proactive preventative support. This research spotlights the criticality for a more drastic shift in the cultural orientation and structural underpinnings of the social care system, to reassert what best supports adult social care to deliver sustainable and effective care and support. Ultimately, required is a fundamental move away from transactional support, premised on time limited-service use based on 'eligible' needs, towards care and support that is spawned from and rewards the nurturing of long-term continually evolving relationships (Adult Social Care Committee, 2022; de Witt & Fortune, 2019; Rand, Collins, et al., 2022). It is against this backdrop that the findings from this thesis advocate for progression in practice and policies that recognise and support the interdependent and reciprocal well-being of everyone involved in the caregiving endeavour (Andrews et al., 2009; Keating et al., 2021; Moholt et al., 2021; Nolan et al., 2004, 2006; Watson, 2019).

Nolan and colleagues made a significant contribution to understanding how relational-centred care can be generated and sustained in health and social care setting. The Senses Framework, proposed by Nolan et al., (2006) eloquently captures the interdependencies between the carer, older adults needing care, and health and social care professionals, by describing six senses that are preconditions for good relationships to evolve. The best caring environments were characterised by the achievement of the senses of security, belonging, continuity, purpose, achievement, and significance. When everyone involved in the caregiving endeavour, whether they are delivering or needing care and

support, is nurtured to experience these six senses, an 'enriched environment of care and learning' is manifested. Interestingly, it was postulated, that achieving the senses for one group (e.g., carers) depended on the people within the other groups (e.g., care staff and people with dementia) achieving the same, and so demonstrating the reciprocity inherent to the realisation of well-being and sustainable care. The framework subscribes to the proposition that living, or caring for someone, with dementia is about supporting quality of 'lives' rather than quality of 'life' (Post, 2001b). Nolan et al.'s, (2006) work around creating the conditions for enriched environments of care and learning has been embedded into the Good Work Framework: A Dementia Learning and Development Framework for Wales (Work & Theresa, 2016). Recognition of the interdependence of well-being and everyone's right to experience well-being forms the cornerstone of the framework to support compassionate practice in dementia care. The Sense Framework has relevance to the design, delivery, and evaluation of short breaks through recognition of the interconnectivities between all those involved in supporting a short break (Laird et al., 2017; Prendergast et al., 2022; Ryan et al., 2008). Emphasised through this research, access to and the positive experience of short breaks was often founded on the success of triadic caregiving partnerships, characterized by the continuity of caring relationships between the carer, professional(s), and person with dementia, in which their respective needs, perspectives, and responsibilities were equally valued. The process of deciding upon and accessing a short break often required 'negotiating the balance' (Quinn et al., 2013) within the context of a trusted and collaborative triadic caregiving relationship. How all care partners are supported to experience the 'senses' and derive belonging, purpose, and self-fulfilment from short breaks is essential to the capacity of care partnerships to support the evolution of short break needs and preferences.

8.3.3 The objective and subjective experience of a short break

A unique focus of this research has been to advance understanding of short break provision through exploration of what a meaningful short break is, and can look like, for spousal carers of people with dementia. Throughout this work, a diversity of break options, activities, formats, and types have been identified, each proposing a different mechanism to how a break, whether this is a physical and/or psychological break, is realised. This demonstrates the positive expansion in what a break can mean and warrants discussion around how time away from caregiving that offers a restorative experience for carers is objectively or subjectively defined, recognised, and supported. Few studies have explicitly explored this distinction or the impact of objective or subjective short break experiences on carer well-being (Bangerter et al., 2019; Chappell et al., 2001; Wylie et al., 2021). Wylie et al., (2021) define a subjective break as the perceived experience of a break, whereas an objective break as the amount of measurable time spent away from caregiving. Analogy here can be drawn to the experience of caregiver burden; the subjective experience determined by the carer's personal appraisal of the caring

situation and the extent to which they perceive the burden of caring, and the objective experience by observable care tasks and activities, and their tangible impact on the carer's physical, psychological, social, and financial well-being (Jones, 1996).

Bangerter et al., (2017) indicated the difference in value gained through adult day care use, which supported an objective break, and carers' appraisal of their ability and capacity to 'step away' from caregiving, which aided a subjective break. Day care use was associated with overall lower levels of role captivity and, in contrast, subjective breaks with lower levels of role overload. Wylie et al., (2021) found that objective and subjective break experiences affected well-being in different ways. Objective break experiences supported through adult day care services provided a physical break and were an objective time resource associated with greater daily positive affect. However, while objective break experiences created opportunity for carers to engage in mood boosting activities, they did not reduce negative affect suggesting that the perceived stressors of the caring role persisted. Subjective break experiences were related to lower levels of negative affect but did not have any consequence on the experience of positive affect. Subjective break experiences have previously been alluded to by Chappell and colleagues (2001) as 'stolen moments', the fleeting periods of time away from practical caregiving tasks within the confines of ongoing caregiving responsibilities and routine. These moments may be time spent walking the dog, watching television, or having a bath, that provide a change of pace, scenery, or task unrelated to caregiving. These findings demonstrate the importance of personal-level resources and the subjective appraisal of the caregiving role in influencing the degree to which carers feel that they can experience a break. The distinction between an objective and subjective break is important for practitioners to recognise while discussing short break needs, preferences, and outcomes. For countries like Wales, where rurality characterises much of the region and presents challenges in sustaining formal short break services, a greater awareness for subjective time resources that facilitate 'stolen moments' may be one approach to support how a short break can be realised.

8.4   Implications for research

This research has underlined the importance conferred upon the Carer's Assessment process to the identification and discussion of short breaks needs and outcomes. In this research, the Carer's Assessment emerged as being the main route for carers to access a short break (Caulfield et al., 2022a). Concerning, however, is the well documented barriers to accessing a Carer's Assessment in Wales, including not being routinely offered an assessment, and the experience of considerable delay in accessing assessment and reviews (Social Care Institute for Excellence, 2021b). A mismatch between

carer expectation and outcomes of the assessment process is prevalent, with carers reporting that there is little point in having an assessment because no support is offered (Carers UK, 2022a). This reflects a broader loss of confidence in the system to proactively provide preventative support. The latest State of Caring Wales report (Carers Wales, 2022) reported that a third of carers (33%) who had received an assessment in 2022 felt that the need to have regular breaks from caregiving responsibilities were not meaningful or diligently considered in their assessment or through the support they received. Collectively, these findings reinforce significant concern around the prominence given to short breaks, and how they are identified and discussed.

The process of a Carer's Assessment holds considerable potential to be an empowering and facilitative process for carers to meaningfully and creatively consider their short breaks options (Seddon, Miller, et al., 2021; Shared Care Scotland, 2020). However, this is a complex process and variation between practitioner knowledge, skill, and interpretation of shaping collaborative outcome focused assessments can result in the inconsistent implementation of policy intentions (National Assembly for Wales, 2019). The lack of merit and value attributed to the Carer's Assessment process, and as a therapeutic process in and of itself was reflected by staff in this research (Caulfield et al., 2022a), and aligns with broader findings in Wales, evidencing that the attitudes of staff have significant bearing on access to Carer's Assessments and how the assessment is conducted (National Assembly for Wales, 2019; Seddon & Robinson, 2015). Examination of how short breaks needs and outcomes are discussed and supported during Carers' Assessments is vital, as facilitating carers to access appropriate support at the right time is a policy priority (Welsh Government, 2021f).

To develop a more sophisticated understanding of the practice landscape, future research could explore current practice, including the methods and approaches (e.g., toolkits, templates, measures, or conversational aids) that practitioners currently use to understand carer short break needs and outcomes. This exploratory work could help ascertain the extent of variation across practice, and the method or approaches that are perceived to work well and why. Moreover, it could help evidence the extent to which practitioners are able to harness a carer's personal resources and capacities, and whether this strengths-based approach is considered proficient in supporting carers to experience breaks that better reflect their needs, preferences, and desired outcomes. Inquiry into the Carer's Assessment process builds upon an identified area for future practice development identified in this research; the regional interest to develop a short break toolkit to help assess eligibility and support decision-making (Caulfield et al., 2022a).

An initial step in this pursuit could be to scope the published literature for emerging evidence on the utility of decision aids or tools used to support and empower carers to take a more proactive role in discussing short breaks. For example, Stirling et al., (2012) reported on the development and piloting of a decision aid to assist carers for people with dementia to make informed decisions about short break services. Using a randomised control trial design, the intervention group who utilised the decision aid showed a greater decrease in decisional conflict. Although the results did not reach significance, the aid evidenced its potential to help carers feel more informed and knowledgeable, better supported, and less dubious, and that they made effective decisions about their choice of short break.

In New Zealand, the Time Out Toolkit has been developed to help carers proactively think through and take the steps to plan and organise short breaks (Carers New Zealand, 2015). The toolkit acknowledges the individuality of a short break, and that rest and rejuvenation from caregiving can be supported in a variety of ways. However, to realise a break requires a well thought out plan, or at least the ability to 'to take the opportunity when it arises'. A positive short break plan requires three things: motivation, inspiration, and calculation. These three strategic steps are designed to help overcome barriers to access and recognise where support from others is needed. The Weekly Short Break Calendar is a method to help carers conceptualise how they can experience regular short breaks, ranging from a few minutes to an hour, throughout their week, embedding regular activities with 'something different'.

Similarly, the Inspiring Break Toolkit developed by Shared Care Scotland (Shared Care Scotland, 2020) is based on a process of empowering carers to identify the best break for them at their point in life. It recognises there may be limitations on choice, such as time, finances, and availability of replacement care, but aims to overcome challenges by going back to basics and thinking about the 'key ingredients' that make up a break for the carer. These ingredients are then used to identify and clarify the different types of breaks and realistic possibilities that may work for them. Future research could build upon the development of a short break toolkit for north Wales, with the potential to be used as part of the assessment process, drawing upon regional expertise and knowledge of how breaks are accessed and supported. This area of development aligns closely with the Welsh Government delivery plan to support the strategy for unpaid carers in Wales (Welsh Government, 2021f). The plan acknowledges that across Wales there are differences in the interpretations of legislation when making decisions on allocating short breaks. A toolkit for practitioners could help clarify guidance and approaches to the

assessment of short break needs and how outcomes are negotiated, driving improvements in the delivery of the strategy for unpaid carers in Wales.

This research has predominantly focused on the exploration of short breaks from the perspective of the carer, developing an account of how carers' short break needs and preferences evolve paralleled to the progression of dementia. In doing so, it drew attention to the various individual, role, and relational transformations over time. As emphasised through this research, and reflected in growing number of contemporary reports, is the endorsement of short breaks as an inherent relational resource and support (Glasby & Thomas, 2018; Rochira, 2018; Seddon, Andrews, et al., 2021; Shared Care Scotland, 2022b). To advance research, there could be merit in the construction of a dyadic career, illustrating the patterned trajectory of caring dyads' short break needs and preferences. The development of a joint career could better account for the shared and reciprocal nature of experiences and the ways that short breaks are amenable to transformations in relational role and boundaries over time. While recognising that there can be considerable difficulties in actively involving people with dementia in research, especially people living with moderate to later stage dementia, the perspective of the person with dementia should be more prominent in short breaks research.

The conceptualisation of a joint career honours the significance of the dyad to the experience of dementia and recognises that dementia propagates changes within trajectories that are interrelated and symbiotic (Bannon et al., 2022; Evans, 2013; Fletcher, 2020; Wadham et al., 2016). Gallagher-Thompson et al., (2020) argue that the dyad or family should be the unit of study because of the significant cross over effects. Studies from different patient demographics, including breast cancer caregiving dyads (Ferraris et al., 2022; Katapodi et al., 2018) and heart failure caregiving dyads (Bouldin et al., 2019; Trivedi et al., 2012), demonstrate the ways that dyad members influence each other's well-being while providing and receiving care. The notion of supporting a joint career further complements the Welsh Government commitment to implement the All-Wales Dementia Care Pathway of Standards to smooth the interconnected journey for both the person with dementia and the carer (Improvement Cymru, 2021).

8.5   Methodological considerations

This research was grounded in a constructivist epistemology, in which meaning, and learning is constructed through experience. The constructivist perspective was chosen to develop contextual knowledge about an inherently complex yet specific topic area, to produce relevant evidence with real world applicability. The endeavour to inquire into participants' subjective truth and perceptions was

truly a co-operative and reciprocal process, in which knowledge was brought into being and coloured through the predispositions, agendas, and the belief systems of the researcher and the participants (Hewitt, 2007). There must, therefore, be an explicit acknowledgement that these research findings do not represent a stable objective perspective, that can exist in various contextual constellations. Although this research was undertaken in response to international consensus of the myriad of challenges encountered by carers and people with dementia when accessing and taking short breaks, findings need to be interpreted with discretion if considered in countries with differences in ownership structures of health and social care delivery systems, health, and social care infrastructure, and legislative and policy approaches to unpaid caregiving. The commissioning landscape is rarely a static terrain and is subject to change in strategic priorities and funding mechanisms. Thus, the findings from phase one of the research (Caulfield et al., 2022a), offer a description of an interpretation of the current short break landscape, and the present contingencies, at a moment in time. Nevertheless, a strength of this research was that it was able to transcend some of the constraints associated with qualitative contextually derived findings. Throughout the reporting of this research, care was taken as to not 'prescribe' or 'impose' what constitutes a meaningful short break, but to look for commonalities and consensus in the broad features that contribute towards a meaningful experience and outcomes. In this sense, the findings have greater potential to be translated to similar caregiving contexts and cultures.

The four phases that this research inquiry followed was what was deemed practicable and achievable in the time frame and resources allocated for this research. However, alternative methods of inquiry could have been adopted. In phase two of the research, the aim was to gain a temporal understanding of how carers' short break needs and preferences change over time. A cross sectional design was adopted, and carers were interviewed at one point in time and asked to reflect retrospectively on their experiences. As an alternative, a longitudinal design could have been considered, where a smaller sample of carers were observed over a period and interviewed at several different time points. A longitudinal design would have permitted an examination of changes in needs and preferences for short breaks over a designated period (i.e., one year), the subtlety of change in needs experienced, and insight into what 'regular' and 'sufficient' short breaks mean in different caregiving contexts. This method would have been advantageous to the development of case studies which present a more detailed and nuanced curation of carers' short break experiences. Furthermore, it could have enabled a way of exploring how often carers engaged in conversation with professionals about their well-being and short break needs, and who instigated those conversations. However, given the unprecedented challenges for carers in accessing services and support during the pandemic, including the closure of

some short break services such as day care centres and restricted access to residential care, there was a need to be pragmatic in approach, and retrospective narrative interviews were deemed a more appropriate method to explore changing break needs over time rather than focusing on the needs and experience of breaks during the COVID-19 pandemic, even though researching the impact of the COVID-19 pandemic on carer well-being and access to support is an important research area (Carers UK, 2020).

While the knowledge exchange event was helpful to share learning and knowledge, discussion predominately centred around areas of weakness and deficits within short break provision. Limited attention or time was given to the promising or motivating examples of good practice and optimistic stories. Consequently, this could have contributed to participants feeling disempowered and disillusioned about their work and the future for meaningful short breaks. An alternative constructivist method that could have been applied to support the sharing of learning and knowledge is Appreciative Inquiry. Appreciative inquiry is the art and practice of inquiring into a person, an organisation, or a system's existing strengths, successes, and values to engender change and transform relationships (Whitney & Cooperrider, 2000). Simply, it is about focusing on what is working as opposed to what is not and using this knowledge to amplify a shift in perspective to marshal possibilities for positive change. It is premised on the experience of key freedoms (e.g., the freedom to be heard, to be positive, to dream). The experience of these key freedoms is postulated to significantly alter the perception of an individual's power within an organisational context and the capacity for an organisation 'to become more capable of innovation, learning, and contributing to the greater good' (Whitney & Trosten-Bloom, 2010, p. 268). Key freedoms are elicited through a cycle of discovery, dream, design, and destiny. Taking the topic of short breaks, the discovery phase could seek to explore what is best about an organisation in supporting short breaks, and exploration of the unique factors, such as the values, partnerships, technologies, processes, that make 'the best' possible. The dream phase channels these strengths and potential to create a collective vision for the future hopes and aspirations of stakeholders for meaningful short breaks provision. In doing so it seeks to grow an organisation's true potential. The fundamental social architecture for this vision is crafted in the design phase. Provocative propositions are composed that bring together the 'best of past and possibility' to refocus and reaffirm daily actions that help support the vision for short breaks. The destiny phase confirms and aligns the commitment of individuals and the group based on what they realistically can and will do to help bring the vision into fruition. These commitments then serve as a basis for subsequent activity. Despite the many challenges that dominate the social care sector and compromise meaningful short breaks provision, the merit of Appreciate Inquiry is that is refocuses energy and gives

momentum to examples of effective practice, demonstrating that positive change and growth is possible through existing resources and attitudes. Reflecting the current policy and practice preoccupation with 'innovation in short breaks provision' (Rochira, 2018; Welsh Government, 2021f), Appreciative Inquiry is a method that can help boost innovation and scalability of change by inquiring into and leveraging the core strengths of an organisation and its people.

8.6   Trustworthiness of qualitative research

What constitutes good robust research is important. In qualitative, quantitative, or mixed method studies, the trustworthiness of the research depends on the adequacy and transparency of the methods used to collect and analyse data (Creswell & Miller, 2000). In quantitative research, confounding or extraneous factors can be reasonably controlled for, variables manipulated and objectively measured, and experiments replicated to independently verify the reliability and validity of the results (Yilmaz, 2013). In qualitative research, the procedures for assessing the trustworthiness of the findings include strategies that can help establish the credibility, transferability, dependability, and confirmability of findings (Creswell & Miller, 2000; Lincoln & Guba, 1985; Rose & Johnson, 2020). Throughout this research several strategies were taken to support the trustworthiness of interpretation. The triangulation of multiple perspectives incorporating the lived and practice experiences alongside influential policy and strategy, supported the development of a comprehensive understanding of short breaks provision, and the pivotal factors mediating its future development. The accurate and authentic representation of the participants' realities and perspective was supported through collecting rich and detailed descriptive data, and use of participants own words, so their accounts could be juxtaposed with the researcher's interpretation. Effort was made to ensure there was sufficient contextual information about the local environment and settings that the research was conducted to support evaluation regarding the transferability and applicability of findings to other settings. The coherence of complex interpretations was supported, where possible, through visual models to help illustrate interrelated and multi-layered principles, e.g., Figure 5.5: principles identified as central to the assessment and support planning and the commissioning process to deliver meaningful short break outcomes.

The knowledge exchange event was an opportunity to enhance the confirmability of the findings through dialogue and scrutiny of interpretation of meaning by key stakeholders and intended beneficiaries. The co-creation of practice recommendations was a shared and collaborative process in which the researcher purposefully adopted a facilitative rather than a directive role, so recommendations were developed based on priorities of mutual and shared importance. The Project

Advisory group supported the dependability of findings through examining the process of inquiry and the use of methods. Throughout all phases of the research, the refining of consensual constructions was an iterative process, and each phase of the study brought new knowledge which influenced and informed the next phase of investigation. Findings were also subject to peer review to attest the quality, originality, and relevance to the field, and as a source of critical feedback and professional development for the researcher.

As this research involved interaction with different stakeholders, the varying interpersonal dynamics between the researcher and participants and how this may have shaped the data collection process, warrants consideration. Throughout the research phases, subtle power imbalances in the researcher-participant relationships and shifts in vulnerability are likely to have influenced the nature and conviction in which questions were asked, and the insights and information shared (Råheim et al., 2016). Considering the interviews with carers in the first instance, the researcher, working within an academic institution, is often perceived as being in a position of authority. They decide the agenda, ask the questions, and are the final arbiter in what is considered important to report (Dodgson, 2019; Råheim et al., 2016). The carers in this research were being asked to share personal information to someone they had not met before, and in the instances where conversations were conducted over the telephone, could not see. For apprehension of judgment or pressure to share or to conform to cultural and societal expectations of spousal caregiving, this may have influenced, unconsciously, or consciously, the extent to which they disclosed and the detail they chose to include (Polkinghorne, 2007). Interestingly, it was perceived by the researcher that having a conversation over the phone appeared to provide an extra layer of anonymity and security for the carer, helping them feel more at ease and unguarded while talking. Attempts on the behalf of the researcher were made to diffuse any power differentials and establish a shared rapport to generate understanding. During introductions, the researcher shared with the carer their professional interest in the topic, emphasising that they were not an 'expert' in this area, but they were interested in their personal experience. The use of the word 'story' and the innocence and uncomplicatedness of being asked to tell their story, in their own way and at their own pace, was a natural way to elicit the meaning ascribed to events and experience without probing into 'why' carers thought or acted in certain ways, which could have undermined their moral compass.

In contrast, when interviewing staff participants, the researcher experienced a different dynamic. Staff participants where often in a position of seniority and authority and were the gatekeepers of knowledge about how their organisation worked. Possessing relatively limited knowledge about the

inner workings and operational structure of each local authority, combined with a strict time window to ask questions, contributed to the researcher's perception of being in an 'inferior' knowledge position. Questions had to be diplomatically proposed so as not to threaten professionals' competence or performance as an organisation. This contributed to some questions been asked with less intention and conviction, and not following through on some of the responses given by staff, e.g., the professional(s) responsible for supporting carer well-being and access to short breaks, and the timeframes for carers to access a Carer's Assessment. In consequence, what materialised from this discussion were rather broad factors and considerations, and a more detailed examination of some of the mechanisms in which short break were supported would have been insightful. Future research could address some of the short comings of these interviews by asking more focused questions around co-productive activities with carers and people with dementia, the assessment process, and short break evaluative approaches.

8.7   Stakeholder engagement

The purpose of the Project Advisory Group (PAG) was to support the quality and transparency of how this research was executed by incorporating multiple perspectives to maximise the interpretability, relevance, and impact of findings. Overall, the PAG's contribution was noteworthy in supporting the development of study documentation and interview topic guides, facilitating recruitment, interpreting findings, and in the planning for the knowledge exchange event. The inherent complexity of the short break landscape necessitated the involvement of professionals with experience of the local practice and commissioning environment. Five professionals from multisectoral backgrounds were approached and agreed to join the project in an advisory capacity. A strength of the group was their range and balance in perspectives and experience, and collectively the group represented every county in north Wales which ensured a fair overview of the region. Conspicuous, however, is the lack of a carer from the group. This was not a deliberate decision. The recruitment of professional stakeholders was a more straightforward process as there were initial links and contacts to build from. The researcher, however, had no prior connection to local carer groups or knowledge of carers with experience of accessing short breaks. Professional stakeholders were asked if they knew of any carers who had relevant experience and capacity to advise on this research project. However, eight months after commencing this research, the COVID-19 virus reached north Wales, and this brought new challenges to recruiting new PAG members, as well as maintaining momentum and structure in how and when the PAG met.

Due to the unprecedented demands on many social care organisations and professionals during the first year of the COVID-19 pandemic, there was a delay in convening the second PAG. As meetings moved online, considerable efforts were made to present material in an engaging format online, and any documentation was circulated via email to all members at least one week prior to the meeting. However, this format of engagement was not as interactive or discursive as an in-person meeting may have offered. As the researcher had not worked with members before, in-person meetings may have supported the building of stronger personal rapport with the group and affiliation to the research over time. Although efforts were made at the start of the project to share what their *likely* commitment may be, on reflection however, to help ensure clarity around commitment to attend regular meetings, a schedule of engagement highlighting prospective dates could have been set in advance, to help keep structure. Despite gaps between meetings in which the researcher was collecting and analysing data, update emails were circulated to keep the PAG informed of progress, and to share news e.g., publications from the research.

The last PAG meeting was held before the knowledge exchange event, and this also marked the end of the three years of active research and the contribution of the PAG. Four out of the five PAG members attended the knowledge exchange event. However, on reflection, it would have been helpful to have convened a final sixth meeting, in-person, to have had a more personalised conversation with the PAG about the relevance of the findings within the context of their own work and priorities. A final meeting would have also been an opportunity to evaluate stakeholder engagement, to revisit expectations, gather information on the positive aspect of the process, and areas for improvement. However, during the duration of the project, the group composition changed. One member left her role in as a CEO of a carer's charity and, although efforts were made to establish a connection with the new interim CEO, the temporary nature of their position meant they did not have capacity to commit. Another member was taken ill for the best part of one year, and a third member moved jobs, although continued to offer their support and guidance but in a different capacity. The extent of these changes meant reconvening as a group proved difficult.

In future projects, more intentional steps will be taken to ensure better planning and evaluation of the process and outcomes of stakeholder involvement. To support this endeavour, the researcher could draw upon the evidence informed reporting framework for stakeholder involvement. For example, Ray and Miller (2017) propose a comprehensive framework, identifying contexts, processes, and outcomes, to foster improved rigor and transparency in the planning, reporting, and evaluating of stakeholder engagement. Six core values, important to stakeholder engagement but often difficult

to objectively measure, are mapped onto specific processes to help guide how stakeholder engagement processes are managed to support the integrity and quality of experience and process.

8.8   Dissemination

In addition to the two published papers, the findings of this research have been widely disseminated on both national and international platforms. Locally, they were presented at the Bangor University Health Sciences Summer School (2021) and The Centre for Ageing and Dementia Research (CADR) Conference (2021). Internationally, the research was shared through two webinars hosted by the International BREAK (Building Respite Evidence and Knowledge) Exchange group in 2020 and 2023. Furthermore, in October 2023, a poster titled 'Planning, commissioning, and delivering meaningful short breaks for carers and their partners living with dementia: challenges and opportunities' was showcased at the Alzheimer's Europe Conference in Finland.

The researcher, along with her supervisors, aims to further enhance and test the feasibility of a conceptual framework for short breaks throughout the caregiving career. They plan to conduct a hybrid event in spring 2024, hosted by Shared Care Scotland. The aims of this event are to share insights into evolving carer needs and preferences for breaks across their caregiving career and to gather input from practitioners and commissioners on the practicality of applying this knowledge to support decision-making in practice and commissioning. This collaborative approach ensures that stakeholders are actively involved, aligning with the steps of scoping review methodology (Arksey & O'Malley 2005), and their invaluable perspectives contribute to shaping the feasibility of a potential framework.

8.9   Summary of recommendations

The recommendations co-created with a range of stakeholders have implications for policy, practice, and future research.

Policy recommendations

This research has consistently highlighted a key policy insight, emphasising the imperative adoption of a whole systems approach for fostering effective and sustainable short breaks. In health and social care, a holistic perspective is crucial for establishing robust support systems that can dynamically respond to the evolving needs and preferences of individuals and families affected by dementia. At the national level, policy implications underscore the vital need for a designated professional point of contact for carers. This individual would be responsible for coordinating the comprehensive range of carers' support requirements, including the facilitation of short breaks. Recognising the centrality of

quality short break provision, there is a need to invest significantly in the recruitment, training, and retention of social care staff. This strategic focus on developing the social care workforce is paramount in ensuring the planning and delivery of trustworthy and high-quality short break services alongside other forms of social care support and requires a comprehensive and sustained commitment from policymakers. Policy plays a pivotal role in enhancing and fortifying the capacity of the third sector, positioning it as an indispensable partner in the provision of short breaks. A strategic funding approach and collaboration with the third sector are essential, aiming to complement and address gaps in both local council and private sector initiatives. This concerted effort will not only support the third sector's operational needs but also empower it to explore innovative approaches to delivering short breaks.

Practice recommendations

The research findings hold significant practice implications, particularly in the realms of assessment and support planning. The research strongly advocates for adopting a conversational outcome focused approach within the assessment and support planning process. This process should involve genuine dialogue that encourages the sharing of perspectives and expertise to help identify short break needs, preferences, and desired outcomes. This research underscores the value of consistent communication to understand the nuanced and changing needs of carers and people with dementia and to tailor support plans accordingly, prioritising outcomes, and regularly assessing progress toward their achievement.

On a regional and local scale, sustained, long-term efforts are essential to identify carers within health and social care settings and communities, which is one of the four national Welsh Government priorities for carers (Welsh Government, 2021e). Effectively signposting carers to pertinent information, advice, and assistance emerged as one of the most impactful strategies to ensure their access to or proactive planning for appropriate short breaks. Additionally, the findings underscore the significance of dementia/carer-friendly communities in naturally facilitating short breaks through enhanced peer support and social networks. Consequently, local councils must continue supporting the momentum to cultivate dementia/carer-friendly communities, fostering an environment where citizens of all ages and cultures legitimately recognise the rights and needs of carers for short breaks.

Research recommendations

There are several research recommendations stemming from this project. Notably, much work remains to be done to better understand the practice landscape of carers' assessment and the legitimacy given to discussing, identifying short break needs, and planning for appropriate solutions. Future research might explore current practices, examining the methods and approaches employed

by practitioners (such as toolkits, templates, measures, or conversational aids) to comprehend the needs, preferences, and outcomes of carer short breaks.

Underscored in this research is the strong endorsement of short breaks as an intrinsic relational resource and support. To advance research in this area, there may be value in creating a dyadic framework that depicts the structured trajectory of short break needs and preferences for caring dyads. Constructing a joint framework could enhance the understanding of the shared and reciprocal nature of experiences, illustrating how short breaks undergo transformations in relational roles and boundaries over time.

As mentioned earlier in the section on Dissemination (8.8), there are plans for stakeholder engagement in 2024. The objective is to evaluate the usefulness and acceptability of a conceptual framework for short breaks throughout the caregiving career and its potential to inform decision-making in both practice and commissioning.

8.10   Conclusion

Globally, as more people, aged 65 years and over, embark on a dementia caregiving career, this research, providing evidence to enrich the development, commissioning, and delivery of meaningful short breaks for spousal carers for persons with dementia, has come at an apt time.

This research has helped address critical knowledge gaps in understanding how meaningful short breaks can be supported. Findings from this research have contributed towards the development of an Economic and Social Research Council (ESRC) grant proposal, to co-design and explore the acceptability and feasibility of a novel Images for Dialogue aid that will use pictures to support short break conversations.

The features identified as contributing towards a meaningful short break corroborate important reflections reported in 'Rethinking Respite for People Affected by Dementia' (Rochira, 2018), Seddon, Miller, and colleagues (2021) 'Future Vision for Short Breaks in Wales', and 'Rethinking Personalised Short Breaks' (Shared Care Scotland, 2022b). Together with these reports, this research demonstrates the importance of having a choice of short break options, with some elements of flexibility, tailored to interests and abilities, and where there is mutuality of benefit (Figure 6.2). Above all, short breaks must be underpinned by consistent and evolving professional support and guidance. The imminent task now turns to how to embed this knowledge in practice. This requires a contextual understanding of regional and local short break landscapes, and of the potential cross-sector partnerships and collaborations that could help sustain a range of break options within communities. Chapter four

presented finding from such an inquiry of the north Wales short break landscape, underscoring the need to evaluate the outcomes supported by different types of short breaks to guide evidence informed commissioning, and drive improvements in how data collected about carer short break needs and desired outcomes is collated and operationalised.

Throughout this thesis, attention has been given to providing sensible practice and policy recommendations and highlighting illuminative international good practice examples. A unique contribution of this research to the evidence base is thinking around the evolution of short break needs and options throughout the caregiving career. This knowledge is critical if breaks are to achieve their purpose to support a life alongside caring. There is exciting potential for this work to be developed through co-productive activities.

The challenges of identifying carers early in their career and being able to provide proactive preventative support as needs and circumstances change cannot not be underestimated. This task is made harder by the current turbulence of the NHS and social care sector. However, this research has evidenced the simple effective practices that can make an immediate difference to carers' lives. These include recognising the importance of the assessment and review processes, and the necessity for genuine dialogue, listening, and supported choice to navigate decisions of emotional and moral conflict. Expansion in the conception of a short break, incorporating both subjective and objective definitions, offers greater latitude and freedom to think creatively about how breaks can be supported. Ideas for future research have been presented.

To end, while great challenge and opportunity remains to enable more carers in Wales to access meaningful breaks, the findings borne from this research are a timely and important contribution to advance the delivery of Welsh Government policy ambition for unpaid carers. These finding hold depth and substance to improve possibilities for more carers to experience a life alongside caring.

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Appendices

Appendix 1: Staff interview information sheet
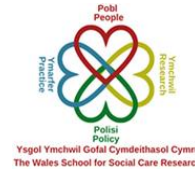
Participant Interview Information

Co-creating meaningful short breaks: Integrating research, policy, and practice

Funded by The Wales School for Social Care Research this research explores how short breaks can support positive caregiving relationships and promote well-being for spousal carers (aged 65+) whose partner is living with dementia.

The aim of this research is to provide evidence that informs the development, commissioning, and delivery of short breaks for spousal carers (aged 65+) and their partner living with dementia.

We would like to invite you to participate in an interview to share your perspective and/or experience in supporting short breaks for carers and their partner living with dementia.

We would like to hear the perspectives of operational staff (e.g., social care practitioners, carer support officers) and strategic staff (e.g., commissioning managers, local authority carer leads) within the statutory, third, or independent sector.

Interview topics with operational staff are likely to include:	Interview topics with strategic staff are likely to include:
• Ways individual needs and preferences for short breaks are identified, discussed, and evidenced in Carer's assessments following the Social Services and Well-being (Wales) 2014 Act. • Strengths and weaknesses of current short breaks provision. • Barriers and enablers to supporting a diverse population to access meaningful short break activities. • Evaluation of short breaks provision, capturing and reporting on short break well-being outcomes.	• Funding opportunities to enable better carer service planning and sustainability. • Use of resources, including Welsh Government monies, to commission and/or deliver short breaks. • Evolution of commissioning and procurement arrangements required to support innovation and scaling up of short break activities. • Evidence most compelling in steering future commissioning decisions.

Interviews shall take approximately 45 minutes and will be conducted at a date and time convenient for you, over the phone, through skype/zoom, or in person.

If you would like to take part in an interview, please return your completed consent form via email to Maria Caulfield at m.caulfield@bangor.ac.uk

What are the possible benefits and risks to taking part?

There are no immediate benefits from taking part in this research. Recommendations shall support improvements to the quality of short breaks across north Wales for carers and their partner living with dementia. We do not anticipate any disadvantages or risks.

Will my taking part in the study be kept confidential?

Yes. We will follow General Data Protection Regulation (2018) guidelines to ensure confidentiality and data protection. Participation is confidential, however, if risk to personal health and safety or professional malpractice is disclosed, the researcher (Maria Caulfield), will have a duty to escalate this information to her supervisors. Interview transcripts will be anonymized. All data is handled in confidence and personal data shall be securely kept in anonymized form on Maria's password protected encrypted computer at Bangor University.

What happens if I start the interview and then decide I don't want to continue?

You can stop at any time if you feel uncomfortable. You are free to not provide an answer to a question without giving a reason and this will not have any repercussions. If you would like to withdraw from the study you can let Maria know via **email:** m.caulfield@bangor.ac.uk, **Tel**: 01248 382596, or **Post**: Bangor University, Ardudwy, Normal Site, Bangor, Gwynedd, LL57 2PZ

How will my data be used?

Data obtained from the interviews may be used to inform interview topic guides for carers and their partner living with dementia. Anonymised quotes from the interview maybe included in the research thesis and in journal publications; no identifying, recognisable or sensitive information disclosed will be used in outputs arising from this study. Where relevant, data will be used to highlight good practice and support organisations across North Wales to commission and/or deliver meaningful short breaks for carers and those they support.

Who has approved this research?

This research has been approved by Bangor University School of Healthcare and Medical Sciences Academic Ethics Committee. Application Reference number: 16563
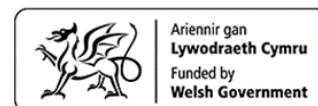
What if I would like to make a complaint?

If you are unhappy about the way you have been approached or treated, please tell Maria about this in the first instance, so that she can try to resolve any concerns and find a solution. If you remain unhappy and wish to formally complain, you can do this by contacting Dr Diane Seddon at Bangor University: **Tel:** 01248 388220 **Email:** d.seddon@bangor.ac.uk

Who is supervising this PhD research?

The research is conducted by Maria Caulfield, PhD student, under the supervision of Dr Diane Seddon (**Tel:** 01248 388220; **Email:** d.seddon@bangor.ac.uk) and Dr Sion Williams (**Tel**: 01248 388451; **Email**: sion.williams@bangor.ac.uk) at the School of Health Sciences, Bangor University.

Appendix 2: Staff consent form

Co-creating, delivering meaningful short breaks

Consent Form

I confirm that I have read and understand the Project Information Sheet dated 08.08.19 for the above study. I have had the opportunity to ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving any reason and this will not have any repercussions. Should I decide to withdraw, all information collected about me will be securely destroyed.	
I understand and give my consent for the interview to be audio recorded.	
I understand that data collected from me during the interview will be anonymised. No identifying, recognisable or sensitive information disclosed will be used in outputs arising from this study, including reports or journal publications.	
I understand that all information given by me or about me will be treated as confidential by the researcher unless there is risk of serious harm.	
I agree to take part in the interview.	

_____   _____   _____

Name of Participant   Signature   Date

Creating meaningful breaks for carers and people living with dementia

What does a break from your caregiving routines and responsibilities mean for you?

What is the aim of this study?

The aim of this study is to explore how you experience a break from your caregiving role, together with or apart from your family member with dementia, to help maintain your health and well-being.

Taking part in this study would mean having an informal conversation about your caring experience, over the telephone or online (e.g., Zoom). Questions may explore:

What would taking part involve?

- How you describe a break from your caregiving routine and responsibilities?
- Support or activities that enable you to have a positive caring relationship with your family member with dementia.
- Is there anything that stops you from having a break? (e.g., cost, transport, lack of suitable care for your family member with dementia)
- The choice and availability of replacement care services (e.g., day centre, sitting service)

Who will I be having a conversation with?

If you decide to take part, Maria Caulfield, PhD student at Bangor University will be talking to you about your caregiving experience.

If you would like to take part in a conversation, please let Maria know via email or telephone. You can ask Maria any questions before you decide whether you want to take part.

- **Telephone**: 01248 382596
- **Email**: m.caulfield@bangor.ac.uk

How do I take part?

Maria will then email or post you a consent form. Please initial the consent form and return via email or post using the free post envelope.

The conversation will be audio recorded so that Maria can listen to you without having to write everything down. The conversation can be held across several days to fit around your commitments.

What are the possible benefits and risks to taking part?

There are no immediate benefits from taking part in this study. Findings are intended to improve the quality and range of short breaks across north Wales for unpaid carers and those they support. We do not anticipate any disadvantages or risks from participation in this research.

Who has approved this research?

This research has been approved by Bangor University School of Healthcare and Medical Sciences Academic Ethics Committee. Application Reference number: 16563

Will my taking part in the study be kept confidential?

Yes. We follow General Data Protection Regulation guidelines to ensure confidentiality and protection of your data. The conversation will be transcribed and made anonymous; this means any personal or identifiable information will be removed. Participation is also confidential, however, if risk to personal health, safety or professional malpractice is disclosed Maria will have a duty to escalate this information to her academic supervisors. All data shall be kept securely in anonymised format on Maria's password protected encrypted computer.

How will my data be used?

Anonymised quotes from the conversation may be included in the research thesis and in journal publications.

What happens if I start the conversation and then decide I don't want to continue?

You can stop at any time if you feel uncomfortable, without giving a reason and this will not affect your health care, social care, or legal rights. You can also choose not to answer a question without giving a reason. If you would like to withdraw from the study you can let Maria know via **email:** m.caulfield@bangor.ac.uk, **Tel:** 01248 382596

What do I do if I would like to make a complaint?

If you are unhappy about any aspect of the way you have been approached or treated, please tell Maria about this in the first instance, so that she can try to resolve any concerns and find a solution. If you remain unhappy and wish to complain formally, you can do so by contacting Dr Diane Seddon at Bangor University: **Tel:** 01248 388220 **Email:** d.seddon@bangor.ac.uk

Who is supervising this PhD research?

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Appendix 4: Carer's consent form

Consent form

I confirm that I have read and understand the Study Information Sheet	
I understand that my participation is voluntary and that I am free to withdraw from the study without giving a reason and that my health care, social care, or legal rights will not be affected.	
Should I withdraw from the study all data collected about me will be securely destroyed.	
I understand that what I say during the conversation will be anonymised. No identifying, recognisable, or sensitive information about me will be used in the study's outputs.	
I understand that all information given by me or about me will be treated as confidential unless there is risk of serious harm.	
I give my consent for the conversation to be audio recorded.	
I understand that should I (the participant) prefer, the conversation can take place across several days to fit around my routine or commitments.	

1. To consent to take part in this study, please print your name and date below:

Name of participant: _____

Date:_____

2. Please provide a telephone number and/or email address so that Maria Caulfield (researcher) can contact you to arrange a time to talk.

Telephone number: _____

Email: _____

3. Please email, or use the free post envelope, to return the consent form back to Maria

Thank-you for your interest and time in taking part in this study.